The psychological effects of mesothelioma in the UK military context from the carer's perspective: an Interpretative Phenomenological Analysis

Virginia Sherborne

A thesis submitted in partial fulfilment of the requirements for the degree
of
Doctor of Philosophy

The University of Sheffield
Faculty of Medicine, Dentistry and Health
Division of Nursing and Midwifery

December 2021

Abstract

Mesothelioma is an incurable asbestos-related cancer with a high symptom burden and poor prognosis. Risk of asbestos exposure to Armed Forces personnel has been identified, e.g., from ships' boiler rooms and damaged buildings. Mesothelioma's long lead time means cases in the military context tend to be amongst veterans. Research shows British veterans and their carers are likely to have particular needs regarding accessing health services and support.

A scoping review showed research into the lived experience of mesothelioma patients was sparse, with a resulting lack of awareness of the disease's unique psychosocial impact. This applied to carers as well as patients. This study therefore aimed to explore the psychological effects of mesothelioma in the UK military context from the carer's perspective.

The study was designed in two stages. Stage One was a secondary data analysis (SDA) of existing interview data from the Military Mesothelioma Experience Study (MiMES). Stage Two comprised semi-structured interviews conducted September 2020 to March 2021 with six family carers of UK veterans diagnosed with mesothelioma. Interpretative phenomenological analysis (IPA) methodology was used for both.

From the SDA, three super-ordinate themes were developed: '*Control and responsibility'*; '*Openness: is it safe?'*; and '*Human connections: getting support'*. Three super-ordinate themes were then developed from the main interview study: '*Going the extra mile'; 'Staying the same person';* and '*Needing to know'.*

The findings of Stages One and Two are discussed in combination. The thesis's original contributions in terms of knowledge and methodology are considered, along with strengths and limitations of the study. The findings are discussed in relation to existing published research, including the literature on hyper-masculine military culture; moral injury; survivor guilt; and relationship-centred care. Implications for practice in the care and support of UK veterans and carers living with mesothelioma are suggested, and recommendations made for future research.

Acknowledgements

To my participants, who candidly opened up about their experiences in the service of others.

To my supervisors Professor Angela Tod, Dr Bethany Taylor and Professor Jane Seymour for their expert, responsive and kind supervision throughout my PhD.

To Dr Stephanie Ejegi-Memeh for her generous mentoring and friendship.

To Liz Darlison, Anne Moylan and all at Mesothelioma UK and in the Supporting Our Armed Forces team for their expert input, encouragement and faith in me.

To all the Asbestos Support Groups, particularly HASAG, who have a national remit to work with veterans, for supporting my study with recruitment.

To the members of the military community who informed and supported my work, with particular thanks to Brian Wallis, Hannah West and the Defence Research Network.

To my PGR community, especially Sarah Varga, for keeping up my morale and providing invaluable advice and technical support.

To my parents, B. K. and J. M. Stephenson, who placed the highest value on academic excellence and paved the way for me.

To Ray Cheung and Matthew Hunt who kindly helped me understand my own intersectionality.

To my children, Sidney and Dora, who shared the highs and lows of postgraduate study alongside me during the pandemic.

To Sam, ever-patient, who has been beside me all the way on this journey, “in sickness and in health.”

Table of Contents

List of Tables

List of Figures

List of Illustrations

List of Abbreviations

A&E	Accident and Emergency Department
AF	Armed Forces
ASG	Asbestos Support Group
BACP	British Association for Counselling and Psychotherapy
BiPAP	Bilevel Positive Airway Pressure machine
BBN	Breaking Bad News
BTW	By the way
CNS	Clinical Nurse Specialist
CR	Critical Realism
CXR	Chest X-ray
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
GP	General Practitioner
GRR	Generalised Resistance Resource
HCP	Health Care Professional
IPA	Interpretative Phenomenological Analysis
MDT	Multi-disciplinary Team
Meso	Mesothelioma
Meso UK	Mesothelioma UK Charity
MOD	Ministry of Defence
MPM	Malignant Pleural Mesothelioma
MURC	Mesothelioma UK Research Centre – Sheffield
PGQR	Phenomenologically Grounded Qualitative Research
PM	Peritoneal Mesothelioma
PTG	Posttraumatic Growth
PTSD	Posttraumatic Stress Disorder
QDA	Qualitative Data Analysis

QDAS	Qualitative Data Analysis Software
QOL	Quality of Life
RTA	Reflexive Thematic Analysis
SDA	Secondary Data Analysis
SOAF	Saving Our Armed Forces Project
SoC	Sense of Coherence
TA	Thematic Analysis
UoS	University of Sheffield

Declaration

I, the author, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not previously been presented for an award at this, or any other, university.

A version of the scoping review presented in Chapter Two was published in *Psycho-oncology* (Sherborne *et al.*, 2020). This is reproduced in Appendix B with the publisher's permission, under a Creative Commons open access licence.

Chapter 1: Introduction

1.1 Introduction

The first chapter of this thesis presents its context. Firstly, information is given to explain how the study originated. The following two sections provide the study's context at the time I was developing and designing it in terms of the key literature on mesothelioma and British military veterans, with key terms explained. The extensive literature on caregivers is not considered here, as the experience of this group was not identified as my PhD's focus until the scoping review was completed. New relevant literature since 2019 will be picked up in the Discussion chapter. A short reflective statement then sets out how I chose to begin this PhD, covering relevant aspects of my personal experience and interests. The final section gives an overview of the thesis's structure.

1.2 The origins of the study

In 2018, the Military Mesothelioma Experience Study (MiMES) was begun at the University of Sheffield in partnership with Mesothelioma UK, a charity dedicated to supporting people diagnosed with mesothelioma and their families. MiMES' purpose was "to generate insights into the experience and health/support needs of British Armed Forces veterans with mesothelioma and identify how best health professionals and support agencies could support them" (Ejegi-Memeh, Taylor, *et al.*, 2020, p. 4). MiMES was funded as part of Mesothelioma UK's Supporting Our Armed Services (SOAF) initiative. This was funded via a UK government scheme to redistribute fines levied on banks for manipulating the London Interbank Lending Rate. SOAF aimed to provide a specialist national service for patients with mesothelioma and their families in the British military community. This was in the context of Great Britain having the highest incidence of mesothelioma in the world (Reynolds *et al.*, 2019). A PhD study was planned as part of the MiMES work package, with MiMES providing a platform for a separate, independent piece of research. I was recruited to begin this PhD study in October 2018. My remit was to develop and conduct a doctoral study that would inform the SOAF work but was separate from MiMES. My PhD commenced just before interviews started for MiMES in December 2018. Work on MiMES was completed in 2020, with the PhD running into late 2021.[1]

---

[1] The COVID-19 pandemic began in the UK on March 2020, coinciding with the second half of my PhD.

1.3 Mesothelioma

1.3.1 Mesothelioma – the illness

Malignant mesothelioma (MM) is an incurable disease usually linked to asbestos exposure (Royal College of Physicians, 2018). There are two main types: the most common form, malignant pleural mesothelioma (MPM), affecting the membrane lining the lungs and chest wall, and peritoneal mesothelioma (PM), affecting the abdominal lining (Hai *et al.*, 2012). Symptoms appear after a long latency period (20-50 years), with the disease often progressing very quickly (Nuyts *et al.*, 2018). Mesothelioma is usually diagnosed in older people, with mesothelioma incidence starting to rise from around the age of 50-54 (Royal College of Physicians, 2018; Cancer Research UK, 2021). Survival rates are poor: for 2014-2016 the percentage of patients in England and Wales surviving 1 year after diagnosis was 38%, and 3 years after diagnosis was 7% (Royal College of Physicians, 2018). Within these figures, there is a significant difference in survival times for different subtypes. In mesothelioma's initial stages, symptoms tend to be non-specific, meaning it is often diagnosed at a late stage (Health and Safety Executive, 2018). However, advances in medical imaging may be leading to more incidental findings at an asymptomatic stage (Mann *et al.*, 2019). Once the disease is advanced, the symptom burden becomes severe, including breathlessness, chest-wall pain, weight loss, sweating and fatigue; symptom severity increases and sometimes proves difficult to palliate (Ball, Moore and Leary, 2016). Although mesothelioma remains incurable, recent advances in clinical research are providing more treatment options, such as immunotherapy (Colarusso *et al.*, 2019). However, research into the lived experience of mesothelioma patients remains sparse, with a resulting lack of awareness of this disease's unique psychosocial impact (Bonafede *et al.*, 2018). Further research into the psychological aspects of mesothelioma is required to map any potential impact that might be occurring alongside developments in medical treatment and prognosis. This applies to carers as well as patients, as their wellbeing is an important part of the picture (Colarusso *et al.*, 2019; Lee and Lyons, 2019). The experience of carers has not been a particular focus of mesothelioma research to date (Guglielmucci, Franzoi, *et al.*, 2018).

1.3.2 Asbestos

Asbestos, a naturally occurring mineral, is a very good fire retardant and thermal insulator, increasingly used from World War II onwards (D'Agostino and Wilson, 1999). Products commonly manufactured using asbestos included insulation for buildings, boilers and pipes;

car brakes; floor tiles; insulating board to protect buildings and ships from fire; and asbestos cement for roofing and pipes (Public Health England, 2017). The dangers of asbestos have been known since at least the beginning of the 20th century (National Rural Bioethics Project University of Montana, 2007). Asbestos's strong carcinogenicity was identified in the 1930s (Furuya *et al.*, 2018). As well as mesothelioma, asbestos exposure can cause lung cancer, asbestosis (debilitating scarring of the lungs) and diffuse pleural thickening (Health and Safety Executive, 2021). There are two types of asbestos, serpentine (white) and amphibole (blue and brown); the latter, being the more dangerous, was banned in the UK in 1985 (Public Health England, 2017). From 1999, importing, supplying and using any asbestos was prohibited in the UK (Public Health England, 2017). The Control of Asbestos Regulations came into force in the UK in 2012, stating that "if existing asbestos containing materials are in good condition and are not likely to be damaged, they may be left in place; their condition monitored and managed to ensure they are not disturbed" (Health and Safety Executive, 2012).

Most of the mesothelioma deaths in the UK at the end of the 20th century were due to exposure that had happened because asbestos was widely used in industry between 1950 and 1980 (Health and Safety Executive, 2018). Evidence suggests that about 85% of mesothelioma cases in men are caused by occupational asbestos exposure, while most in women are caused by indirect exposure, i.e., not by handling it directly (Health and Safety Executive, 2018). Such indirect exposure could occur for example from washing contaminated work clothing (Goswami *et al.*, 2013), or because asbestos was used extensively to construct commercial buildings, homes and machinery (Health and Safety Executive, 2021).

Despite increasing awareness worldwide of public health risks such as smoking, the risks of asbestos exposure are not well known; possible reasons for this are the asbestos industry downplaying the risks, the disease mainly affecting those least politically powerful, and the long latency period (Douglas and Van Den Borre, 2019). Calls have been made for the banning of new asbestos use globally and tighter management of asbestos in situ (Furuya *et al.*, 2018).

1.3.3 Mesothelioma and veterans

Due to the very long lead time between asbestos exposure and diagnosis, with mesothelioma usually diagnosed in older people, cases in the UK military context tend to be amongst veterans rather than serving personnel. When I commenced my doctorate, there was no published research literature available looking specifically at the lived experience of British military veterans with a diagnosis of mesothelioma. US veterans were thought to be disproportionately affected by mesothelioma, comprising around a third of patients (Mesothelioma Applied Research Foundation, 2015), but no data had been collected on the numbers of British military personnel and veterans receiving a diagnosis of mesothelioma. The risk of asbestos exposure was known to be particularly high for naval personnel working in boiler rooms and shipyards (Harries, 1971; Strand *et al.*, 2010). Risk of exposure had also been identified for Armed Forces personnel helping deliver aid or deployed in conflicts where buildings containing asbestos may have been damaged (Brims, 2009). Public interest in the MOD’s handling of asbestos risk increased from 2018 when asbestos components were identified in Sea King helicopters and a vehicle depot was evacuated because of widespread contamination (Ministry of Defence, 2019a). The MOD accepted that although many surveys of military infrastructure and equipment had been carried out, some asbestos might remain unidentified and could have become degraded, presenting an on-going risk of exposure (Ministry of Defence, 2019a).

British veterans diagnosed after 16th December 2015 with mesothelioma caused by exposure during military service are entitled to a war pension, with a choice of a lump sum or regular enhanced pension payments, and with the claim needing to be made during life (Ministry of Defence, 2016b). For veterans who might also have been exposed in a civil occupation, decisions about how to make a claim can be complex (Action on Asbestos, 2021), adding to the stress of the diagnosis and prognosis.

1.4 British military veterans

1.4.1 The definition of ‘veteran’

Different countries apply different definitions of the term ‘veteran’. The UK has a very broad definition compared to other countries: “anyone who has served for at least one day in Her Majesty’s Armed Forces (Regular or Reserve) or Merchant Mariners who have seen duty on legally defined military operations” (Ministry of Defence, 2016a). The government estimated that in 2015 there were 2.56 million veterans living in households across Great Britain (Ministry of Defence, 2016c). The veteran community is heterogeneous, including females, Gurkhas and those from the Commonwealth (Pearson and Caddick, 2018; Dodds and Kiernan, 2019).

Despite the clear UK definition, Burdett et al. (2013) found that of 202 people who had left the British Armed Forces, only half considered themselves to be veterans. There was no association between age or time since leaving and self-identification as a veteran. Only two factors were independently significant: serving as a regular rather than a reservist, and level of education. The study suggested that women are possibly less likely to identify as a veteran, and amongst the public, 'veteran' is understood most often as referring to people who have served in either world war.

1.4.2 The Armed Forces Covenant

In the UK, veterans were given special status under the Armed Forces Covenant. This set out the obligations of the British nation to its veterans and their families in return for their contribution and sacrifice (Ministry of Defence, 2016a). Historically an uncodified understanding, the Covenant was not widely known until 2007, when the Prime Minister announced it would be renewed. The Covenant was enshrined in law in 2011 under the Armed Forces Act, with a report being signed off every year across government departments to ensure accountability (Dannatt, 2016).

Criticisms had been raised about the status of the Covenant, including in terms of a perceived shift of responsibility for veterans towards the voluntary sector (Mumford, 2012), and loss of specialist medical treatment (Stewart, 2017). A new 'Ministerial and Covenant Veterans Board' was created, which published *The Strategy for Our Veterans,* aiming for them to feel more valued, supported and empowered (Ministry of Defence, 2018).

1.4.3 The military mind set and transition

One way military service impacts individuals is through the inculcation of the military mind set, training recruits in a unique cultural ethos and skill set (Cooper *et al.*, 2018; Wood, 2019). Wood (2019) highlighted that the culture aims to separate them from the civilian world, and to provide an environment where 'grey areas' are minimized. All new recruits are immersed in military customs and culture from the start, with initial training inculcating discipline, control and focus (Halvorson, 2010, p. 10):

> "Service members are expected to be disciplined in their actions and words and to maintain control of their emotions and their physical selves at all times…Focus is important to mission success, and the services teach young recruits how to focus in challenging situations – situations where they are lacking sleep, are physically exhausted, or are under unaccustomed and extreme stress."

The strict regime enforces orderliness, cleanliness and obedience, reinforcing a selfless team spirit, bound with loyalty; this ethos bonds all members together in the 'Military Family', where they can rely on each other for support and safety, in practical and emotional ways (Wood, 2019). See Table 1 for a summary of the values and standards in different branches of the British Armed Forces (Mileham, 2016, p. 52)[2].

Table 1: *Values and Standards, British Armed Forces*

Royal Navy	*Royal Marines*	*Army*	*Royal Air Force*
		Integrity	Integrity – courage, honesty, responsibility, justice
Mutual respect	Humility	Respect for others	Respect, mutual
Loyalty	Unity	Loyalty	
Courage in adversity	Courage [personal] Fortitude	Courage	
Discipline		Discipline	
Teamwork	Unselfishness [personal]	Selfless commitment	Service before self – loyalty commitment, teamwork self-discipline and control pride
High professional standards	Professional standards		Excellence – personal excellence excellence in the use of resources
Leadership			
Determination	Determination [personal]		
'Can do' attitude	Adaptability		
Sense of humour	Commando humour Cheerfulness [personal]		
		* Additional themes are: voluntary professionalism; and regimental spirit	

Note: The Army has an acronym for its list, 'SOLID C', and the Royal Air Force uses the acronym 'RISE'.

---

[2] Permission to reproduce this table was granted via RightsLink® - Copyright Clearance Center.

A feeling of pride in having a ‘can do’ attitude is encouraged (see Table 1). Personnel are expected to be self-reliant and to “improvise, adapt and overcome” rather than show weakness, which might mean letting down the team or oneself (Smith, 2014, p. 123). ‘Stoicism’ is a term often used in the military context; Sherman (2004, p. 105) calls it “a philosophy of defence, of ‘sucking it up’”, explaining that the term in popular parlance means “‘controlled’, ‘disciplined’, ‘not easily agitated or disturbed.’” In the military context, the concepts of stoicism and self-reliance may relate to expectations of military partners as well as of personnel (Gray, 2017, p. 234). Wood (2019, p. 22) argues that, because of the risk to life, “military standards, values and ethos appear to have a heightened and very intense level of importance”, with the building of trust being key.

The transition into the Armed Forces generally occurs during adolescence, an important developmental stage, when identity issues are worked through in a process of searching for values, beliefs and goals (Erikson, 1994). Recruits internalise a “robust and ingrained value system” (Wood, 2019, p. 29). The second transition occurs when service members leave, causing a reverse culture shock (Cooper *et al.*, 2017), with the military culture of fortitude influencing veterans’ help-seeking behaviour (Wood, 2019). They leave behind a safe but constrained masculine space for sharing emotional experiences (McAllister, Callaghan and Fellin, 2019). Those British veterans with a heightened sense of military identity have more difficult transition experiences (Binks and Cambridge, 2018). Veterans typically feel that ‘civvies just don’t understand’, so service providers need to have an awareness of possible issues when engaging with them (Wood, Cotterill and Cronin-Davis, 2017). As a result, British service leavers transitioning can struggle with finding employment, accessing health provision, finding accommodation, managing their finances, and social isolation (Ashcroft, 2014). The legacy of the habits and memories formed during military service often lasts a life-time (Cooper *et al.*, 2017).

1.4.4 Public perception of British military veterans

One of the factors identified as causing difficulties for personnel transitioning to civilian life is public perception. Veterans are generally seen as damaged, institutionalised and hard to work with (Ashcroft, 2014; Bergman, Burdett and Greenberg, 2014), a view fed by the proliferation of veterans’ charities (Charity Commission for England and Wales, 2017). Perceptions are also influenced by popular fiction and memoirs. These could, for example, emphasise the role of partners as supplements for military support (Kitchen, 2018), or present narratives around bodily failure (Woodward and Jenkings, 2012). Media images also have an impact. Despite recruitment drives stressing education and training opportunities, media images of the ‘warrior hero’ provide an influential blueprint (Swain, 2016). Reservists (volunteers or ex-regulars) also present an image of the military. In civilian workplaces, reservists may be physically included but socially distanced or stigmatized (Higate *et al.*, 2019). So, a rather contradictory and unrealistic public picture of military veterans is apparent (Bulmer and Jackson, 2016).

1.4.5 Military veterans and access to health care

British veterans and their families are likely to have particular needs in relation to accessing health services, care and support (Hynes and Thomas, 2016). Thanks to the Military Covenant, serving personnel, veterans and families should face no disadvantage in service provision, with special consideration appropriate for some (Ministry of Defence, 2016a). The Ministry of Defence (MOD) provides serving personnel’s healthcare, with families and veterans looked after by the National Health Service (NHS) (NHS Health Education for England, 2019). The Covenant covers the wider veterans’ community of around 6.2 million (Pike, 2016). Nearly 10% of adult UK males are veterans, and female veterans comprise about 10% of the total (Ministry of Defence, 2019b).

Many veterans are unaware of their entitlement under the Covenant, as are many healthcare staff (Finnegan, Jackson and Simpson, 2018). Some veterans do not consider themselves ‘worthy’ of veteran-specific support, e.g. if they have a non-combat injury (Engward, Fleuty and Fossey, 2018). Also, many veterans do not self-identify, and practical issues of transitioning between the two systems can cause problems. To help, an e-learning course was created for health professionals (NHS Health Education for England, 2019), and a Veterans’ Gateway one-stop information website and ID card were launched (Veterans’ Gateway, 2019).

Older veterans may experience more difficulty in accessing services. For example, those over 50 make up the majority of UK homeless veterans (Doherty, Cole and Robson, 2019), and in the context of mental health, older UK veterans are misunderstood and overlooked (Walker and Collier, 2016). The Covenant, alongside the Care Act 2014 (Department of Health, 2016), assumes veterans will self-identify and will have adaptive support networks (Burnell, Crossland and Greenberg, 2017). Veterans may prefer accessing support from volunteers, which feels more like military ‘mateship’ (O’Connor *et al.*, 2014; McAllister, Callaghan and Fellin, 2019). Social isolation is commonly experience by a significant proportion of UK veterans (Albertson, Taylor and Murray, 2019).

1.4.6 Older military veterans' health and wellbeing

British veterans in general are physically robust, though they have an increased tendency for particular health issues, such as hearing loss and musculoskeletal problems (Hynes and Thomas, 2016). Early service leavers are the most vulnerable, with a higher risk of depression than posttraumatic stress disorder (PTSD) (Hynes and Thomas, 2016). Reservists are more likely to suffer mental health problems than regulars, as they do not have the same level of military networking or integration (Hynes and Thomas, 2016). Delayed onset PTSD is more likely if there are contributory factors, and alcohol use and traumatic injuries have a major impact (Hynes and Thomas, 2016).

The focus of research and policy has recently started to move beyond younger veterans (London and Wilmoth, 2016). British veterans over 65 report better physical health thanks to physical training while serving, but they have particular problems, e.g. from lack of protective equipment, and from greater reluctance to seek medical treatment due to a sense of self-sufficiency (Williamson *et al.*, 2019). Reminiscence can help successful ageing, and older veterans may need support to handle avoidance, with PTSD possibly worsening due to age-related changes (Davison *et al.*, 2016; Burnell, Needs and Gordon, 2017). The needs of older ex-forces in terms of social support networks may be different from civilians (Burnell, Needs and Gordon, 2017). A US life-span model suggests the effects of military service can lead to a range of positive, neutral or negative effects accumulating over time, generating inequality in later life (Spiro, Settersten and Aldwin, 2016).

1.4.7 Posttraumatic psychological effects in veterans - links to healthcare

Since 2001, there has been increased research on the negative health effects of wartime trauma, both in the UK and USA (Larner and Blow, 2011). With major differences between the US and UK military experience (e.g., the different conflicts fought; different levels of mental health-related stigma), transferability of research outcomes may be affected (Hunt *et al.*, 2014; Murphy *et al.*, 2019).

Posttraumatic stress disorder (PTSD) in British veterans has been associated with a negative change in relationship to the world, and with a changed perception of self, either positive or negative (Brewin, Garnett and Andrews, 2011). Also, PTSD and suicidal behaviours seem to be linked to more alienation from civilian life, with implications for engagement with NHS services (Brewin, Garnett and Andrews, 2011). US veterans with cancer who are older find the illness less traumatic, though for those with current combat

PTSD it is especially traumatic (Mulligan *et al.*, 2011). Medical procedures themselves can trigger veterans' trauma symptoms (Woods, 2003; Feldman and Periyakoil, 2006; Moye and Rouse, 2015), as can bodily sensations such as sweating, breathlessness and being hyper-alert (Hockey, 2012; Williams and Carel, 2018). The use of 'battle' imagery could also potentially be triggering (Stibbe, 1997).

Positive growth, known as posttraumatic growth (PTG), can also occur after trauma, though there has been less focus on this in veterans' research. Habib et al.'s (2018) review of qualitative PTG research in (ex) military personnel found PTG relates to appreciation for life, bonding with others, re-evaluating one's sense of purpose and improvement in personal traits. US veteran cancer-survivors were found to commonly experience distress but also strengths from previous coping and resilience, showing a life-long military effect (Jahn *et al.*, 2012). Israeli veterans experience simultaneously higher rates of PTG and loneliness (Stein *et al.*, 2018). This possibly happens because they have had a positive shift in world-view but feel out-of-sync with civilians, which could impact on their connection with health services (Stein *et al.*, 2018).

1.5 Reflexive statement

My own presence as part of the research process undoubtedly influenced the decisions I made about methodology and methods and the knowledge I created (Leavy and Harris, 2018). It was therefore vital for me to be transparent and consider how this might have played out at all stages of the research from the beginning. Being reflexive in a systematic way allowed me to be accountable for my role in the study. This reflexive statement is included here for that reason.

When the PhD opportunity to explore the lived experience of mesothelioma in the UK military context was advertised, I was an experienced counsellor with a special interest in trauma and bereavement. My roles had included providing bereavement support and training for a national bereavement charity in the UK, including piloting a pre-bereavement course. I had completed volunteer placements at two local psychological trauma services, and I was currently lecturing on a counselling diploma course. I had recently finished a master's degree in Trauma Studies, during which I had looked at trauma and posttraumatic growth in the military context. On the Trauma Studies course I had studied alongside nurses and paramedics as well as counsellors, an experience which I found highly rewarding. I was therefore interested in beginning research within my local university's Division of Nursing and Midwifery, on a topic where I hoped to contribute to greater understanding of the psychological aspect of this incurable, terminal illness.

Having lived since 2000 in the South Yorkshire region of the UK, I was familiar with its local history which encompassed endemic industrial injury, for example from coal mining and steel production. This made research into the effects of this asbestos-related disease seem worthwhile to me personally.

As an older woman, aged 55 when I began the PhD, I had gathered some life experience of the cancer journey as my father had survived kidney cancer a decade previously, and some close friends had been diagnosed and/or had lost relatives to cancer. I had also counselled clients who had been affected by life-limiting illness, and I was interested in doing research that might help others similarly affected. Unexpectedly, however, I myself was diagnosed with lung cancer in Autumn 2018, shortly after starting my PhD. My husband had also been investigated surgically for a lung nodule six weeks earlier and was subsequently diagnosed with prostate cancer at the end of 2019. My personal experience of cancer as a patient and a carer had implications for me as a researcher. I consider this issue in the Methodology chapter (3.7.3), Methods chapter (sections 4.3.6, 4.5.4 and 4.6.5), Discussion chapter (section 7.7.1) and Appendix Z.

In terms of the military context, I had limited personal experience. An older cousin, who had been British Army gymnastics champion, sadly died after contracting Weils' disease from canoeing whilst in service. Also, after my undergraduate studies in the 1980s, I wasn't sure what career I wanted. I enquired at the local Army recruitment office, attracted by the idea of continuing with high-level sport and having a structure around me. I was immediately interviewed and offered a next-level interview at a military base. Two factors led me to turn this down: firstly, my conscience would not allow me to choose employment where I might have to kill another human being; and secondly, the interview revealed the army had a surprisingly old-fashioned attitude to women in terms of equality.

There were other aspects of myself which could be presented here as relevant to this field of research, since "being reflexive requires the researcher to situate her personal, political, intellectual, theoretical and autobiographical selves" (Carroll, 2013, pp. 550–551). Whilst such transparency made sense in the research arena, it created tension for me in terms of my counsellor persona. Self-disclosure of experiences from a therapist's life has potential advantages and disadvantages (Feltham and Horton, 2006, p. 84), and should therefore be weighed up by considering the appropriateness for each individual client. The personal data

I had previously revealed in the public domain was always carefully guarded for this reason, and the minimum amount that seemed necessary was therefore included in this thesis. Reflexivity is discussed again in Chapters 3 and 4 with respect to ethics, data collection and analysis, and further consideration of my intersectional identities is included in Appendix A.

1.6 The structure of this thesis

Chapter Two: literature review

In Chapter Two, I present a review of the published research literature on the psychological effects of mesothelioma on patients and carers. My choice of using a scoping review approach is justified, and my methods, results and discussion are provided. This chapter also shows how my review informed my research aims, objectives and questions.

Chapter Three: methodology

In Chapter Three I consider the conceptual framework within which I addressed my research aims, objectives and questions. I justify my use of the qualitative paradigm, critical realist epistemology, and a feminist perspective. Various qualitative research approaches are considered, with reasons given as to why I did not consider them appropriate for my project. I outline different phenomenological approaches and show that Interpretative Phenomenological Analysis methodology was a good fit for my project in methodological and personal terms.

Chapter Four: methods

In Chapter Four I set out the protocol I designed to answer my research questions. The study was designed in two stages: Stage One, a secondary data analysis (SDA) of existing interview data from the Military Mesothelioma Experience Study (MiMES), and Stage Two, my main empirical interview study. I describe in detail how I carried out the SDA, and how I conducted individual semi-structured audio-recorded interviews via videoconferencing with carers of UK military veterans who had a diagnosis of mesothelioma. I justify my choice of these methods, showing how they were appropriate for answering my research questions and were aligned with my chosen methodology, interpretative phenomenological interpretation. Finally, I consider my chosen methods in terms of ethics and the quality of my study.

Chapter Five: the findings of the Stage One secondary data analysis

Chapter Five presents the findings of the secondary data analysis (SDA) conducted on the four transcripts from the MiMES study where carers were interviewed on their own. The participants' and patients' characteristics are presented in a table. Three super-ordinate themes, which were developed by looking for patterns across all four participants' data, are presented with supporting quotations from participants. The presentation of the themes is developed as a full narrative. These findings are then summarised in the form of seven key findings, which supported and informed my main study.

Chapter Six: the findings of the Stage Two main interview study

In Chapter Six I present the findings of the main study, in which six participants were interviewed. The participants' and patients' characteristics are provided in a demographic table and a set of pen pictures. Three super-ordinate themes, which were developed by looking for patterns across all six participants' data, are developed as a full narrative. Each theme is presented with supporting participant quotations. At the end of the chapter, a summary is provided of the key findings.

Chapter Seven: discussion

Chapter Seven provides an overview of the study, with a summary of the findings from the SDA and the main interview study. These findings are discussed in combination in relation to the relevant existing literature. Original contributions to knowledge are explained in terms of methodology and results. The strengths and limitations of the study are considered. A closing reflexive overview is then presented. Finally, implications for practice are suggested and recommendations made for future research.

1.7 Conclusion

In this chapter I contextualised my research study. Firstly, I explained how the study originated. Next, I provided the context of my study at the time I was developing and designing it, in terms of the key literature on mesothelioma and British military veterans. I then considered how British veterans and their families could have particular issues in relation to experiencing illness and in accessing healthcare and other support, due to the psychological influence of military culture, the social context, and possible effects from previous trauma. Then I explained how I chose to become involved, describing some relevant aspects of my personal experience and interests. Finally, the overall structure of the thesis was presented. In the following chapter, I present my scoping review where I review the existing research literature on the psychological effects of mesothelioma across patients and carers in general. This provides the first component of my study and sets the context. This wider focus of mesothelioma patients and carers was chosen for reviewing the literature as there was no published academic literature specifically exploring the experience of British military veterans with mesothelioma.

Chapter 2: Literature Review

2.1 Introduction

In this chapter I review the published research on the psychological effects of mesothelioma on patients and carers.[3] Reviewing the literature was important so I could begin to understand my topic; find out what research had already been done and how it was conducted; and get to know the key issues (Hart, 2018). It was also important for me as a 'research apprentice' (Hart, 2018, p. 12) to learn good practice in research methods, as recommended by the Researcher Development Framework (Careers Research and Advisory Centre, 2011). Initially, I read very widely around the topics of illness, cancer, mesothelioma, and military veterans. After I had read widely around these topics, it was clear that no existing published research focused on mesothelioma in military veterans. The scope of my review therefore needed to be widened to cover the broader population.

There has been a growth in the number of different types of evidence review over recent decades, and it was important to choose the one which had most potential for a good fit with the review's purpose (Grant and Booth, 2009; Hart, 2018). Booth et al. (2016) suggest there are five factors which impact on the choice of review type: time/time frame, resources, expertise, audience and purpose, and data. I used Grant and Booth's (2009) analysis of review types and associated methodologies to help me choose. Systematic reviews are suitable when the review's intention is to inform decision-making in a clinical context, whereas scoping reviews are useful for understanding and assessing the extent and characteristics of knowledge in a particular field (Tricco *et al.*, 2018; Peters *et al.*, 2020). As I was constrained in terms of time and resources, a full systematic review was not an option. The most appropriate choice seemed to be a scoping review, with its exploratory aim of identifying the nature and extent of the available evidence, and the potential to be "systematic, transparent and replicable" (Grant and Booth, 2009, p. 101).

---

[3] A version of my scoping review was published in *Psycho-oncology* (Sherborne *et al.*, 2020). This is reproduced in Appendix B with the publisher's permission, under a Creative Commons open access licence. The authors contributed to the published scoping review as follows: study conception and design: VS. Data collection: VS. Validation: AT, JS. Analysis and interpretation of results: VS. Writing – original draft: VS. Review & editing: VS, AT, BT & JS. Draft manuscript preparation: VS. Supervision: AT, BT & JS. All authors reviewed the results and approved the final version of the manuscript.

2.2 Methods

2.2.1 Objectives and search question

The objectives of this scoping review were to examine the extent, range and nature of the existing research on the psychological effects of mesothelioma; summarise and disseminate findings; and identify gaps in the literature (Arksey and O’Malley, 2005). In line with scoping review methodology, the search question was suitably broad, but had clarity regarding the scope of inquiry (Levac, Colquhoun and O’Brien, 2010): what is the current state of the evidence on the psychological effects of mesothelioma on patients and their carers? Using a PICO framework is suggested by Huang et al. (2006) as useful for making an efficient search. The acronym is explained as follows (Booth, Sutton and Papaioannou, 2016, p. 86):

> P = Population (who or what are the problem or situation)
> I = Intervention (option for tackling a problem, or exposure to an unintentional occurrence)
> C= Comparison (looking at an alternative)
> O= Outcome(s) (what is measured and how).

For my review, the population was ‘patients and carers’, the intervention was ‘mesothelioma’ (covering all disease types), and the outcome was ‘psychological effects’ (both positive and negative). There was no comparison in my question, so this optional element was omitted (Booth, Sutton and Papaioannou, 2016).

2.2.2 Scope and reporting strategy

A scoping review does not aim to be exhaustive, but to give an initial assessment of the available literature (Booth, Sutton and Papaioannou, 2016). Therefore, any potentially relevant articles identified from the reference lists of the retrieved articles or from Google Scholar were included, but grey literature was not, nor were attempts made to locate on-going, unpublished research in the field. This decision, made for feasibility reasons, provided a limitation to comprehensiveness.

As I aimed to have a systematic approach to the conduct and presentation of my review (Booth, Sutton and Papaioannou, 2016), it was conducted using the staged method described by Arksey and O'Malley (2005) and Levac et al. (Levac, Colquhoun and O’Brien, 2010):

> Stage 1: identifying the research question
> Stage 2: identifying relevant studies
> Stage 3: study selection

Stage 4: charting the data
Stage 5: collating, summarising and reporting results.

The review was reported following the PRISMA Extension for Scoping Reviews Checklist (Tricco *et al.*, 2018). I chose to follow this checklist as the use of reporting guidelines can aid methodological transparency and make it more likely for research findings to have impact (Moher *et al.*, 2010).

2.2.3 Search strategy

A choice needed to be made of search terms, and reflexivity was relevant here. My use of the term ‘psychological’ was influenced by my own experience and theoretical orientation. As a counsellor, I was from the start interested in the aspects of the mesothelioma experience which went beyond the medical. I have been influenced by Johnstone and Boyle’s (2018) ‘Power Threat Meaning Framework’ as an alternative to the medical, diagnostic model of human distress. Their conceptual system asks, “What has happened to you?” rather than “What’s wrong with you?” It is interested in the *meaning* of experiences for each individual. Because it places power first and foremost, and applies principles across time and across different cultures, the framework aligns with my feminist perspective, with its interest in power relations and injustice. As I did not train as a psychologist, but as a humanistic counsellor, I wondered how to define ‘psychological’ in a way that was not too narrowly scientific but was more holistic and would be understood by the mesothelioma community, including patients, family members and nurses. I found *Psycho-oncology* journal’s (2021) statement about the breadth of their scope helpful:

> *Psycho-Oncology* is concerned with the psychological, social, behavioural, and ethical aspects of cancer. This subspeciality addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease, and that of their families and caretakers; and the psychological, behavioural and social factors that may influence the disease process.

I also paid attention to key words in articles which I had found useful in my preliminary reading about the mesothelioma experience. In addition, my experience as a therapist rooted in the theory of Carl Rogers (Rogers, 1978) and my interest in posttraumatic growth (Casellas-Grau, Ochoa and Ruini, 2017) influenced me to consider positive as well as negative effects. My final definition of psychological effects became ‘psychological symptoms, emotional responses, and coping strategies/mechanisms'. To further inform the process of choosing search terms, key words from published relevant articles were reviewed, and a specialist librarian was consulted on search terms and database selection, as recommended by Booth et al. (2016). The final choice of key terms is shown in Figure 1.

Figure 1: *Relevant key terms identified*

Population (all fields)	patients/carers	patient* families family caregiver* carer*
Intervention (title/abstract)	mesothelioma	mesothelioma
Outcome (all fields)	psychological effects	psychological psychoncology psychooncology psycho-oncology psychosocial support* social uncertainty hope* anxiety depression coping

Searches took place in May 2019 of these bibliographic databases: PubMed, PsychINFO via OvidSP, CINAHL, the Cochrane Library and Web of Science. Search parameters were adjusted to match individual database requirements.

An example search strategy (CINAHL) is given in Appendix C. The results for each database search were exported into EndNote and duplicates removed. A flowchart of the search strategy is given in Figure 2.

2.2.4 Inclusion and exclusion criteria

For inclusion, articles had to be peer-reviewed research articles (reporting empirical qualitative, quantitative, or mixed methods studies and literature reviews). Other inclusion criteria were:

- in English (for practical reasons)
- involving adult humans (mesothelioma is extremely rare in children)

- dating from 1981 (when the seminal article was published (Lebovits *et al.*, 1981)) to May 2019
- focussing on psychological effects (not physical aspects of symptoms or treatment)
- focussing on mesothelioma (mentioned in the title or abstract).

Exclusion criteria applied were:

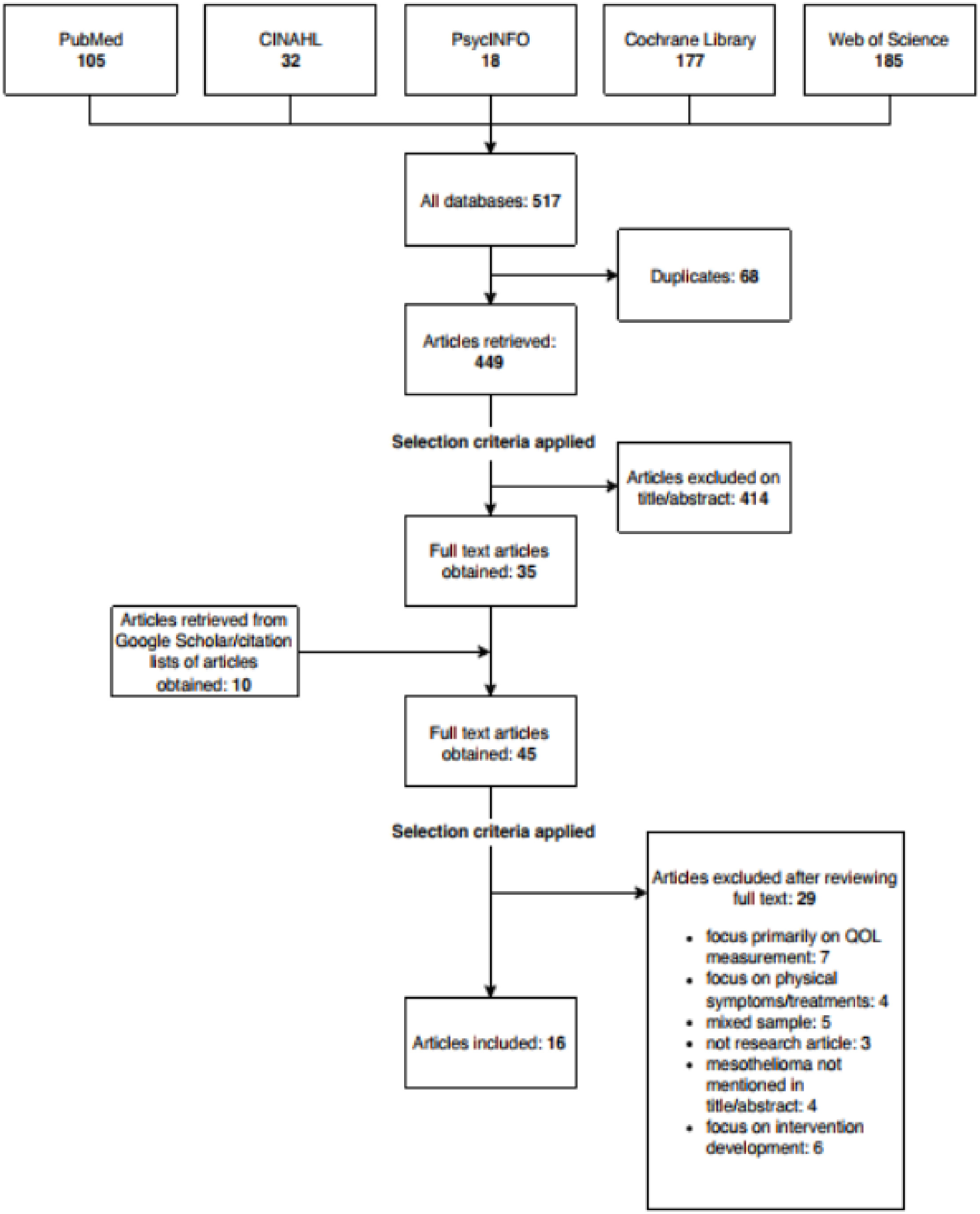
- not in English
- not involving adults
- focussing on the clinician's perspective, rather than patient's or carer's
- about questionnaire development or focussing primarily on QOL measurement (e.g., part of a clinical trial or QOL tool development), as these would not focus on content but on the tool's validity and reliability
- about physical symptoms, treatments or epidemiology
- focussing on intervention development
- conference abstracts, dissertations, editorials, book reviews, or individual case reports
- concerning lung and pleural cancers (i.e., a mixed sample).

I applied the inclusion and exclusion criteria to the retrieved articles after duplicate removal. Titles and abstracts were screened for relevance and irrelevant articles excluded. The remaining articles were obtained in full text and exclusion criteria were applied. Broadly following the team approach recommended to aid rigour (Levac, Colquhoun and O'Brien, 2010), where there was any uncertainty around whether to include or exclude after the full text studies were obtained, decisions were discussed with two other researchers. Further inter-rater reliability measures were not undertaken for practical reasons and due to time constraints.

2.2.5 Data extraction

Data extraction forms were used based on examples provided by Booth et al. (2016) for qualitative and quantitative articles (see Appendix D for examples). The following items were extracted: citation; location; research objectives; participant details; recruitment and sampling methods; data collection and analysis methods; relevant findings and results; authors' conclusions; and possible new relevant articles from references. To identify findings and results relevant to the research question, I reviewed each article's abstract and results sections. Discussion sections were also scrutinised in case any extra findings had been presented here rather than in the results section.

Figure 2: *Possibly relevant articles identified from electronic searches*



2.2.6 Quality appraisal

I wanted to understand both the range and quality of the existing evidence. However, there is debate about quality appraisal in scoping reviews. Critical appraisal is not usually performed as part of a scoping review, as the aim is simply evidence mapping (Peters *et al.*, 2020). This is a potential weakness, as there is "a danger that the existence of studies rather than their intrinsic quality is used as the basis for conclusions" (Grant and Booth, 2009, p. 101). It is suggested that including quality appraisal in scoping reviews using validated tools is useful for policy makers and other researchers (Daudt, Van Mossel and Scott, 2013) and can enhance identification of gaps in the evidence base (Pham *et al.*, 2014). I therefore decided to follow a quality appraisal process.[4] The aim was to inform the review by giving an overview of the quality of the existing literature as a whole, including the quality of reporting, but without excluding any of the identified articles. Excluding articles could lead to loss of nuance, and an inadequately reported study may have been conducted well; it is better practice to inform readers about inclusion of lower quality papers (Verhage and Boels, 2017). After data extraction the articles were critically appraised using CASP checklists (Critical Appraisal Skills Programme, 2021), validated tools appropriate for use in health-related research (Hannes and Bennett, 2017).

2.2.7 Data analysis

As is recommended to aid rigour (Arksey and O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010), my *Results* section included a descriptive numerical summary and qualitative thematic analysis of key relevant findings. A choice therefore needed to be made regarding the review's data analysis method. I aimed for alliance with the qualitative paradigm and for quality. Braun and Clarke's (2020b) reflexive thematic analysis (RTA) provided an appropriate analytic approach, as it is positioned as suitable for 'Big Q' qualitative research[5], and is suited to critical realist framings of data and meaning (Braun and Clarke, 2020b). RTA is distinct from other types of thematic analysis as it puts the researcher's role in the production of knowledge at centre-stage (Braun and Clarke, 2019). Braun and Clarke prefer to use the terms 'develop' or 'generate' to describe the production of themes (Braun and Clarke, 2019) to reflect the fact that themes are actively created rather than retrieved. They state (2020b, p. 3) that RTA "emphasises the importance of the researcher's subjectivity as an analytic resource, and their reflexive engagement with theory, data and interpretation."

---

[4] Ball, Moore and Leary (2016) also carried out critical appraisal.

[5] 'Big Q' means using qualitative techniques inside a qualitative paradigm (Kidder and Fine, 1987).

The steps for completing RTA are as follows (Braun *et al.*, 2019):

1. familiarization with the data: reading and re-reading, noticing interesting features, making notes and asking reflexive questions
2. generating codes: inductively identifying clear labels for important features throughout the dataset and collating relevant extracts
3. generating candidate themes: identifying meaning-based patterns in the codes and data
4. reviewing themes: checking the candidate themes against the dataset, ensuring each relates to a central concept, and sensing how each theme relates to the others
5. defining themes: naming and developing a detailed analysis of each.

As the scoping review was essentially descriptive, I chose to use a more inductive analytic process and generate semantic (rather than latent) codes, which stay at the surface of the data (Braun and Clarke, 2020b). Examples of themes developed include ‘loyalty’, ‘stigma’, and ‘future’. Developing the themes was a consciously creative process, requiring reflection and thoughtfulness (Braun and Clarke, 2019). Asking questions of myself about how I was responding to the data was important throughout the analysis process. For example, in the ‘familiarisation’ phase, I tried to notice whenever I was surprised, as this indicated I had an existing assumption. During the development of themes, I needed to monitor whether my attention was being given disproportionately to vivid data I found personally interesting, in order to ensure the process was “thorough, inclusive and comprehensive” (Braun and Clarke, 2021, p. 19). Asking reflexive questions helped me to check my judgements and decisions as theme development proceeded.

Quirkos Qualitative Data Analysis (QDA) software was used to aid analysis and contribute to an audit trail (Booth, Sutton and Papaioannou, 2016). The summarised findings from each paper were uploaded into *Quirkos.* This enabled codes to be clustered and combined, helping identify meaning-based patterns. For example, clusters named ‘difficult feelings’, ‘positivity’ and ‘coping strategies’ combined, becoming the theme *Dealing with Difficult Feelings.* A screenshot of *Quirkos* in use during Step 3 of the analysis process is given in Appendix E.

2.3 Results

2.3.1 Processing of retrieved articles

The articles retrieved from the database searches were processed as follows (see Figure 3):

- After duplicate removal, 449 articles were retrieved.
- Of these, 414 were excluded after review of title or abstract.
- The remaining 35 articles' full text was obtained, and their citation lists reviewed for possibly relevant articles. Along with Google Scholar searches, this process resulted in 10 further potentially relevant articles being obtained in full text.
- Eligibility criteria were applied, leading to exclusion of 29: seven focussed primarily on QOL measurement, four focussed on physical symptoms/treatments, five used mixed samples, three were not research articles, four did not mention mesothelioma in title or abstract, and six focussed on intervention development.
- This left 16 articles eligible for review.
- I subsequently learned from a nurse specialist (CNS) about an article Walker et al. (2019) published in December, which met the search criteria. I included this.

The review's findings are presented in two ways: a basic analysis of the characteristics of the included studies, and a report of the themes developed from the data (Arksey and O'Malley, 2005; Peters *et al.*, 2020).

2.3.2 Characteristics of the included studies

An overview of the charted characteristics and critical appraisal data for each included article is presented in Table 2 (p. 38 ff).

Figure 3: *Possibly relevant articles identified from electronic searches*

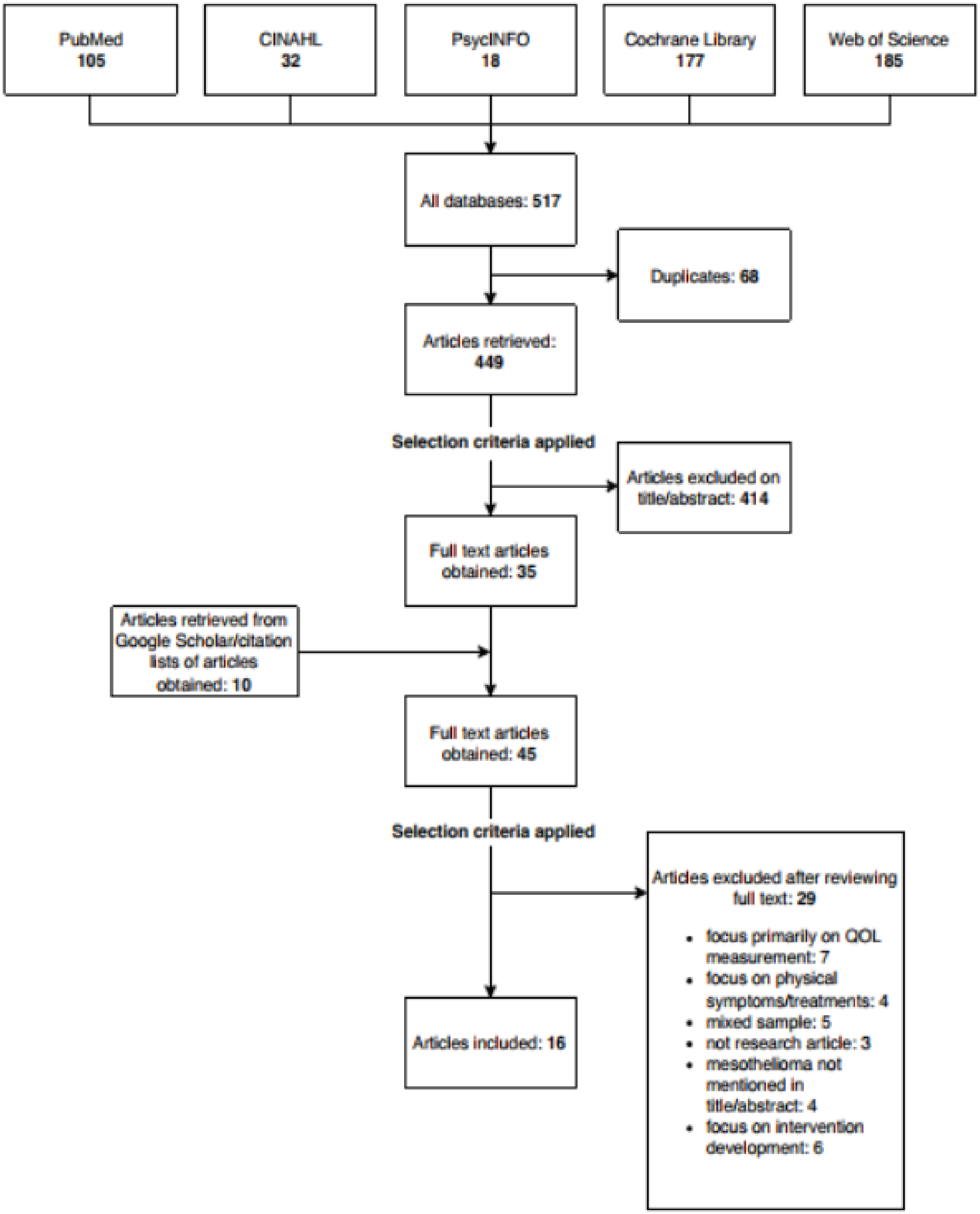


Table 2: *Summary of 17 identified studies*

Author(s)	Country	Aim	Study design/method	Key relevant findings
ARBER, A. & SPENCER, L. 2013. It's all bad news': the first 3 months following a diagnosis of malignant pleural mesothelioma. Psycho-Oncology, 22, 1528.	UK	Explore patients' experience during the first 3 months after diagnosis of MPM	Qualitative; semi-structured, face-to-face interviews (10 patients); grounded theory. South England acute hospital trust setting.	• Key concept: uncertainty and lack of control leading to emotional, physical and psychosocial distress. • Three themes informed the key concept: 'it's all bad news'; 'good and bad days'; 'strategies of amelioration'. • Patients worked with short-term perspective on their illness, but worried about long-term outcome and speed of deterioration.
BALL, H., MOORE, S. & LEARY, A. 2016. A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer. Eur J Oncol Nurs, 25, 62-67.	UK	Evaluate if psychological care needs differ between pleural mesothelioma and advanced lung cancer patients	Systematic literature review; 17 qualitative and mixed methods studies; quality appraised using CASP checklist; narrative synthesis and meta-ethnography.	10 key concepts identified across meso studies: • Uncertainty – impacted on wellbeing; related to prognosis and worries about progression; led to feeling out of control. • Normality – relates to living normally; a need to live a purposeful life and fulfil social & family roles for as long as possible in most studies. • Hope/hopelessness - hopelessness due to incurability, limited prognosis and lack of effective treatments. • Blame/stigma – anger and betrayal at employer; also conflicted loyalty; one study identified stigma as source of distress. • Family/carer concern – concerns & fears in relation to family members/carers; fear of being a burden; fear of causing upset/pain to others. One study reports concern around exposing family member to asbestos. • Physical symptoms – source of psychological distress (impact on social roles & independence, intensity and speed of onset, marker of disease progression and impending death).

				- Experience of diagnosis - delays caused distress, impacting on coming to terms with illness experience; timing of info about compensation & benefits claims caused distress; negative messages of hopelessness from HC profs; anticipatory anxiety from knowledge of friends/colleagues' disease. - Iatrogenic distress – poor communication regarding responsibility for care and treatment decisions; fragmented and uncoordinated care; lack of referral to supportive care. - Financial/legal – source of distress in all studies; paperwork and meetings an extra burden; one study identified comfort from sense of financial security. - Death and dying – concerns and fears about time and manner of death; need to ensure affairs in order to ease burden on family.
BONAFEDE, M., GHELLI, M., CORFIATI, M., ROSA, V., GUGLIELMUCCI, F., GRANIERI, A., BRANCHI, C., IAVICOLI, S. & MARINACCIO, A. 2018. The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: A systematic review of published studies. Am J Ind Med, 61, 400-412.	Italy	Review published research focusing on psychological aspects of MM patients/asbestos-exposed people	Systematic review; qualitative and quantitative studies (12 on MM patients, 9 on asbestos-exposed people); no quality assessment	Themes relating to MM were: - Psychological state of individuals with MM diagnosis: many studies detected shock/dismay reactions at diagnosis, leading to anxiety, depression, apathy, discomfort, difficulty concentrating, & social dysfunction. Intensity of event depends on HCPs' communication skills. Anguish and sometimes Damocles complex caused by initial prognosis, rapid progression, symptom expression & incurable nature. Fear of degeneration and ultimate outcome. Chemo & surgical treatments seem to have negative QOL impact especially in terms of role and social function.

				• Emotional aspects related to occupational context: some studies focused on relationship between distress, occupational context and employer's responsibility to provide risk info. Mostly risk info seems to come from non-employer sources. Most commonly reported responses were disbelief & being unlucky. Long latency period and sense of loyalty/solidarity with employer suggest feelings of anger often redirected towards family members/physicians. Fears of indirect household exposure often arise after diagnosis, leading to patient feeling responsible for familial contamination. • Coping strategies: main coping mechanisms for patients to address psychological distress are avoidance and denial. Some show optimistic behaviour and restored sense of empowerment, leading to active role in disease management/greater control over lives. One study investigated 'sickness behaviour' in response to MPM: constellation of non-specific symptoms of fatigue, anorexia, fever, depression, cognitive impairment & exaggerated responses. • Patient experiences with treatment: subjective experience varies according to individual's physical & psychological conditions. Most frequently reported conditions are pain & discomfort. Unpredictable & rapid onset of MM linked to acute distress, compromising efforts to cope, inducing feelings of uncertainty & distrust regarding healthcare protocols. • Factors affecting QOL: patients gain sense of control over MM by complementary & alternative medicine; being in ASAG; palliative care; physiotherapy. Same effect from access to clear & accurate legal info on compensation. Some studies emphasised role of support groups in managing MM.

CLAYSON, H., SEYMOUR, J. & NOBLE, B. 2005. Mesothelioma from the patient's perspective. Hematol Oncol Clin North Am, 19, 1175-90, viii.	UK	Explore mesothelioma from patient’s perspective	Qualitative; face-to-face semi-structured interviews (15 patients); grounded theory. Northern England, recruited by CNS.	Four main themes; • coping with symptoms; • burden of medical interventions; • finding out about meso; • psychosocial issues.
DOOLEY, J. J., WILSON, J. P. & ANDERSON, V. A. 2010. Stress and depression of facing death: Investigation of psychological symptoms in patients with mesothelioma. Australian Journal of Psychology, 62, 160-168.	Australia	Investigate stress and depression symptoms in men diagnosed with mesothelioma	Quantitative; N=49 male patients; measures used were TSI, IES-R, CES-D, GHQ, SCL-90-R, completed during assessment session including clinical interview; statistical analysis carried out. Australian men assessed as part of civil lawsuit against employer.	• All participants reported significant levels of traumatic stress symptoms (particularly re-experiencing in form of intrusive thoughts about impending death). • These symptoms associated with increased symptoms of depression, anxiety, somatic complaints and social dysfunction.
GIRGIS, S., SMITH, A., LAMBERT, S., WALLER, A. & GIRGIS, A. 2019. "It sort of hit me like a baseball bat between the eyes": a qualitative study of the psychosocial experiences of mesothelioma patients and carers. Support Care Cancer, 27, 631-638.	Australia	Explore psychosocial experiences of mesothelioma patients/carers	Qualitative; thematic analysis; semi-structured individual phone interviews (5 patients, 3 carers), or focus groups (3 patients, 3 carers). Recruited from clinic records at 3 tertiary hospitals in Sydney.	• Time of diagnosis particularly difficult period. Shock, anger, stress common. • Timeliness, accuracy and balance of meso information is problematic. Varying levels of receptiveness. Mainly negative content of info could cause hopelessness. Avoidance or discounting of internet statistics. • Coping strategies ranged from antagonism (battle analogy showing resilience) to acceptance. Sense that their situation was unique. • Emotional and physical load of caring for the patient is significant. Difficult decisions for carers about sharing info. Some c’s hid own emotions to protect family members, to own detriment. Full-time nature of demands. • Carers need one-to-one support. C’s valued support from caseworkers (bridging medical gap

				plus chance for intimate emotional support) and from other meso carers who understood.
GUGLIELMUCCI, F., BONAFEDE, M., FRANZOI, I. G. & GRANIERI, A. 2018A. Research and malignant mesothelioma: lines of action for clinical psychology. Annali Dell Istituto Superiore Di Sanita, 54, 149-159.	Italy	Present two studies: (1) literature review aimed at identifying psychological needs of MM patients, and (2) study to assess [psychological impact of MM on patients and families	Study (1): systematic literature review; 12 studies; PRISMA guidelines. [Same data as Bonafede et al. (2018).] Study (2): qualitative; semi-structured interviews (33 MM patients, 28 caregivers); thematic analysis. At Interdepartmental Functional Unit for MM at Turin, as part of recruitment for brief psychodynamic group interventions.	Study (1) Themes • Psychological impact of MM diagnosis on individuals: several studies detected shock/dismay at diagnosis, leading to anxiety, depression, apathy, discomfort, difficulty concentrating, & social dysfunction. Uncertainty about MM, rapid progression & incurable nature generate intense anxiety. • Emotional aspects related to occupational context: main emotions related to occupational context were disbelief/being unlucky. Long latency period, sense of belonging/loyalty to the company, & legal matters seem to convey anger towards family/ physicians. Fear of indirect household exposure/causing familial contamination. • Coping strategies: see Bonafede 2018. • Treatment experiences: most frequently reported conditions are pain & discomfort. Medical treatments experienced with acute emotional distress. Healthcare protocols linked with feelings of uncertainty and distrust. • Factors affecting QOL: patients may get increased sense of control via complementary & alternative medicine, palliative care, physiotherapy, special diet. Access to correct compensation info increases patients' feelings of agency. Support groups could play pivotal role in helping patients manage negative emotions.

				Study (2) Four different themes detected: • Physical symptoms, affects and defences – facing new limitations/needs; painful emotions; death/aerial contagion phantasies; strategies of denial/avoidance/withdrawal. • Living in or near National Priority Contaminated Site – awareness of increased risk; need for support/sharing; damage and compensation. • “Nothing is like it was” – trapped in the present vs forward-looking; aggressiveness/withdrawal circuit. • “What will become of us?” worries for loved ones; difficulties in talking openly about MM and future; summing up one’s life.
GUGLIELMUCCI, F., FRANZOI, I., BONAFEDE, M., BORGOGNO, F., GROSSO, F. & GRANIERI, A. 2018B. "The Less I Think About It, the Better I Feel": A Thematic Analysis of the Subjective Experience of Malignant Mesothelioma Patients and Their Caregivers. Front. Psychol., 9.	Italy	Explore subjective experience of MM patients/carers in order to understand psychological sequelae	Qualitative; open-ended interviews (10 patients, 9 caregivers); thematic analysis. At Interdepartmental Functional Unit for MM at Turin, as part of recruitment for brief psychodynamic group interventions.	Four themes detected: • Bodily symptoms and embodied emotions – managing new emerging needs, talking about physical side; denying negative emotions, unable to put them into words; avoiding reality of deadly illness. • Living in or near National Priority Contaminated Site – awareness of increased health risk, including to loved ones; fear of ‘aerial contagion’, identity as ‘plague spreaders’; need for support outside family; damage and compensation, legal battle. • “Nothing is like it was” - impact of diagnosis on everyday life; changes [in family relationships; things that are still possible to do; mourning process, different approaches. • “What will become of us?”- worries about impact of diagnosis on loved ones; carers’ negativity about changes in patient; death and legacy- few patients talk about this.

HENSON, K. E., BROCK, R., CHARNOCK, J., WICKRAMASINGHE, B., WILL, O. & PITMAN, A. 2019. Risk of suicide after cancer diagnosis in England. JAMA Psychiatry, 76, 51-60.	England	Quantify suicide risk in patients with cancers in England and identify risk factors that may assist in needs-based psychological assessment	Quantitative; population based study using data from National Cancer Registration and Analysis Service in England and Office for National Statistics; standardized mortality ratios and absolute excess risks calculated.	• Of patients with cancer, 50.3% were men and 49.7% women. • 74.3% aged 60 or older at diagnosis. • Patients with cancer who died by suicide made up 0.08% of all deaths in follow-up period. • Overall SMR for suicide was 1.20 and AER per 10000 person-years 0.19. • Risk was highest among meso patients, with a 4.51-fold risk corresponding to 4.20 extra deaths per 10000 person-years. • This risk was followed by pancreatic, oesophageal, lung and stomach cancer. • Suicide risk highest in the first 6 months following cancer diagnosis. • Patients with mesothelioma had highest risk of suicide in first 6 months after diagnosis, with an 8.61-fold risk compared to general population.
HUGHES, N. & ARBER, A. 2008. The lived experience of patients with pleural mesothelioma. International Journal of Palliative Nursing, 14, 66-71.	UK	Explore the lived experience of patients with pleural mesothelioma	Qualitative; in-depth face-to-face open-ended interviews (5 patients), with spouse/partner present; descriptive phenomenological method. Recruited from patients referred to local Macmillan nursing service, Guildford.	• Patients have many unmet psychosocial and emotional needs. • Patients and carers experienced frustration, distress and anger due to physical experiences; mourning loss of previous life. Relationship changes and difficulties, including loss of intimacy. • Lack of information provided to patients about specialist supportive and palliative care services, leading to dissatisfaction. Some patients unable to take in info about available care due to shock at diagnosis. Some not going to have active treatment e.g. chemo felt abandoned. • Additional burden (sometimes involving anger/distress/conflict) for patients and spouses/carers was involvement in complex medico-legal matters sometimes continuing after death.

				- Feeling of social isolation reported (including avoidance of talking about illness) and some patients would welcome opportunity to meet others in same situation. - Urgency of patients wanting to tell their story and be heard, despite experiencing intense distress whilst doing so.
KASAI, Y. & HINO, O. 2018. Psychological Transition Characteristics of Patients Diagnosed with Asbestos-Related Mesothelioma. Juntendo Medical Journal, 64**,** 114-121.	Japan	Explore MPM patients' experiences of post-diagnostic psychological transition	Longitudinal qualitative; semi-structured face-to-face interviews (5 patients), 6.4 times over 26 months; phenomenological hermeneutical analysis. Interviewed after medical examination in university hospital, Tokyo.	Four main themes of transition attitudes identified, with individual attitudes classed as disruption or reconstruction processes. 5 transition points in disease journey tracked: diagnosis; a few weeks after diagnosis; 1st treatment; 2nd treatment; progression/exacerbation. 4 themes were: - attempting to continue independent living and manage symptoms; - accepting incurability of disease despite being overwhelmed; - deciding on treatment and life through uncertainty; - maintaining positive relationships with family. These themes influenced six main themes of transition action: - creating new self-care regime; - gathering information about asbestos exposure and MPM; - preparing for dying through self-experience or experience of other patients; - receiving emotional support from family, co-workers, care providers; - developing positive rapport with hospital staff toward effective treatment; awarding of compensation.

LEBOVITS, A. H., CHAHINIAN, A. P., GORZYNSKI, J. G. & HOLLAND, J. C. 1981. Psychological aspects of asbestos-related mesothelioma and knowledge of high risk for cancer. Cancer Detection and Prevention, 4**,** 181-184.	USA	Explore psychological aspects of asbestos-related mesothelioma and knowledge of high risk for cancer	Qualitative; face-to face semi-structured interviews (10 patients). Chemo patients at Mount Sinai Hospital, New York.	• Only 2 of 7 patients with direct occupational asbestos exposure acquired risk information from professional source; 4 from media; none from employer/physician (pre-diagnosis). Median time span between diagnosis and risk info acquisition 2.5 years. • Lack of concern (3 patients) and denial/minimising of personal exposure (2) were reactions most frequently reported to risk information. 1 was concerned. 1 never knew risk. • Behaviour confirmed lack of concern: none of 8 smokers stopped smoking after receiving increased risk information; no patients increased visits to physician. • Patients commonly expressed feelings of being unlucky and/or disbelief in reactions to disease. 7 of 10 patients denied any feelings of anger towards asbestos industry, many expressing gratitude for good jobs. Anger displaced by some patients onto families/doctors.
LEBOVITS, A. H., CHAHINIAN, A. P. & HOLLAND, J. C. 1983. Exposure to asbestos: Psychological responses of mesothelioma patients. American Journal of Industrial Medicine, 4**,** 459-466.	USA	Explore issues regarding MM patients' awareness of increased risk, acquisition of risk information and subsequent response, especially in relation to alteration of smoking behaviour	Qualitative; face-to-face semi-structured interviews (38 patients); 2 interviewers evaluated answers, having trained to ensure good rater reliability. Chemo patients at Mount Sinai Hospital, New York.	• Only 10% of directly asbestos exposed patients acquired risk information from professional sources pre-diagnosis; others knew from media/friends, 4 were unaware. • Most frequently reported reaction to learning of increased risk of cancer was denial of risk by minimising account of personal exposure. • Few reported being concerned about information of increased risk. • Smoking behaviour unchange**d** as result of risk information. No increase in regular visits to physicians. • Feelings of depression and anxiety evident.

				• Disbelief that exposure could have caused their illness was a frequent response (long latency/brief exposure). Others who assumed the link expressed guilt, remorse and anger towards self. Rarity of meso contributed to feelings of being unlucky. • 65% of patients with direct/indirect exposure denied feelings of anger towards the industry. Several expressed gratitude for their good job.
MOORE, S., DARLISON, L. & TOD, A. M. 2010. Living with mesothelioma. A literature review. Oxford, UK.	UK	Identify what is known about experience of people living with mesothelioma	Selective literature review; 5 qualitative and 7 quantitative studies, plus 1 survey; no quality assessment.	Impact of mesothelioma is multidimensional on: • Physical symptoms (especially pain, breathlessness, fatigue, cough, sleep disturbance, appetite loss and sweating); • Emotional functioning (anxiety, depression, fear and isolation); • Social consequences (changes in roles and relationships); • Interventions (necessity of frequent anti-cancer treatments and admissions for symptom control).
NAGAMATSU, Y., OZE, I., AOE, K., HOTTA, K., KATO, K., NAKAGAWA, J., HARA, K., KISHIMOTO, T. & FUJIMOTO, N. 2019. Physician requests by patients with malignant pleural mesothelioma in Japan. Bmc Cancer, 19.	Japan	Determine needs of patients within health services, particularly regarding interactions with their physician	Qualitative; MPM patients; cross-sectional descriptive study using mailed survey (73 patients); qualitative content analysis plus quantitative analysis of prevalence of response categories between groups. Patients from 64 Japanese hospitals and 15 support groups.	• The majority of requests were related to patient-physician communication. • Patients wanted clear and understandable explanations about MPM, spending enough time and allowing questions. • Patients wanted physician to deliver treatment based on patient's perspective. Also providing emotional support, including being kind and cheerful, and empathizing with anxiety and pain. • Customising the "breaking bad news" was important. • Patients expected physicians to be dedicated to their care and establish improved medical support system for MPM patients.

TAYLOR, B. H., WARNOCK, C. & TOD, A. 2019. Communication of a mesothelioma diagnosis: developing recommendations to improve the patient experience. 6, e000413.	UK	Develop recommendations to improve the patient/carer experience of communication of MPM diagnosis	Qualitative ; framework analysis; 31 individual phone interviews (6 patients, 9 carers, 14 lung cancer nurse specialists, 1 doctor, 1 support worker), 2 group interviews (N=42), electronic consultation exercise (N=39). Nationwide recruitment via patient support group and professional networks.	• Shocking impact of diagnosis means some participants could not take in extra information initially, impacting subsequent info and support needs. • Importance of regarding diagnosis as process (with BBN possible at many points), and provision of continuity and consistency (MM journey to diagnosis often long & uncertain; fractured communication distressed patients and families). • Clinical nurse specialists and effective MDT working provided vital contributions to successful meso diagnostic communication. LCNS should be informed immediately meso is suspected. MDTs helpful in preparation and planning, so carers and patients know what to expect. • Huge variation in how much info people want to know and can take in at diagnosis consultation. Facilitators to diagnostic communication included honesty (whilst balancing upsetting news with hope) and timeliness, partnership working and maintaining patient-centred approach (including gauging what to say, when and how). Effective MDT working helped maintain hope. • Challenges to enhancing meso diagnosis communication included accessing ongoing training, ensuring suitable clinical environment (quiet and private) and being able to allocate appropriate time. Importance of communication style being warm, inclusive, respectful and participatory. Responsibility for communication of diagnosis should be shared across range of specialist practitioners and services.

WALKER, L., CRIST, J., SHEA, K., HOLLAND, S. & CACCHIONE, P. 2019. The lived experience of persons with malignant pleural mesothelioma in the United States. Cancer Nursing, 2019 Dec 27. doi: 10.1097/NCC.0000000000000770.	USA	Explore the lived experience of MPM in the US and identify unmet patient needs.	Qualitative; semi-structured, face-to-face interviews (7 patients); descriptive phenomenology. Recruited at Philadelphia university medical centre.	Three themes: *Uncertainty/worry about the future* • Coping with uncertainty • Passage of time • Maintaining hope and optimism • Concerns about future suffering *Adapting to a new norm* • Processing diagnosis and prognosis • Symptom burden • Adapting to loss of physical functioning • Maintaining sense of control • Change in outlook on life *Value in relationships* • Alterations in relationships with loved ones • Forging trusting relationships with healthcare team • Communicating with others with MPM Identification of unmet needs: peer support, better communication with HCPs, more research.

The 17 articles comprised 11 qualitative, two quantitative and three literature reviews (Moore, Darlison and Tod (2010), Bonafede et al. (2018), Ball, Moore and Leary (2016)) and one article (Guglielmucci, Bonafede, *et al.*, 2018) combining the reporting of a qualitative study with a literature review (see Table 3 for details). The precise definition of mesothelioma varied across the articles (see Table 3).

Table 3: *Comparison of included papers*

a) Comparison of inclusion by Bonafede et al. (2018), Ball, Moore and Leary (2016) and Moore, Darlison and Tod (2010)

	Meso or mixed sample	**Bonafede**	**Ball**	**Moore**	**Qual.**	**Quant.**	**Other**	**Country**	**My reason for exclusion**	**Treatment of missing data**
Lebovits 1981	Meso (MPM and peri.)	yes	yes	yes	yes			USA	n/a	n/a
Lebovits 1983	Meso (MPM and peri.)	yes	yes	yes	yes			USA	n/a	n/a
Nowak 2004	Meso (MPM)	yes		yes		yes		Australia	Questionnaire validity	In Discussion section
Clayson 2005	Meso (MPM)	yes	yes	yes	yes			UK	n/a	n/a
Moore 2008	Meso (not specified)	yes			yes			UK	Clinician’s perspective	n/a
Ribi 2008	Meso (MPM)	yes				yes		Switzerland	Questionnaire validity	Submission rates shown in Results section
Dooley 2010	Meso (MPM)	yes				yes$		Australia	n/a	None missing
Ugalde 2012	lung/pleural cancer (MPM)	yes				yes		Australia	Mixed sample	In Results section
Arber & Spencer 2013	meso (MPM)	yes			yes			UK	n/a	n/a
Granieri 2013	meso (MPM)	yes				yes		Italy	QOL measurement	In Methods section
Kao 2013	meso (MPM)	yes				yes		Australia	HR-QOL measurement	In Discussion section
Wood 2013	Lung cancer/ MPM	yes			yes			UK	Mixed sample	n/a
Chapple 2004	MPM mixed with LC		yes		yes			UK	Mixed sample	n/a
Hawley 2004	Meso (MPM and peri.)		yes	yes			Lit review	International literature	Physical symptoms/ treatment	n/a
Krishnasamy 2007	MPM mixed with LC		yes		yes			Scotland	Mixed sample	n/a
Hughes & Arber 2008	Meso (not specified)		yes	yes	yes			UK	n/a	n/a

Lee 2009*	MPM mixed with LC		yes				case study, incl. 13 interviews	Australia	Mixed sample	n/a
Ellis 2013	MPM mixed with LC		yes		yes			UK	Mixed sample	n/a
Muers 2008	MPM			yes		yes		UK, Australia	Medical treatment	Discussed in Results
O’Brien 2006	Meso (MPM and peri.)			yes		yes		UK	Medical treatment	In Results section
Bottomley 2006	MPM			yes		yes		Europe	HR-QOL/medical focus	Details given in Methods
Hollen 2004	MPM			yes		yes		Five continents	Question-naire development	In Methods section
Chahinian 1982	Meso (MPM and peri.)			yes		yes		USA	Medical treatment	Not mentioned
Ruffie 1989	MPM			yes		yes		Canada	Medical treatment	Analysed complete data
BLF 2009	MPM			yes		yes		UK	Not peer-reviewed	*Article not accessible*

b) The psychological effects of mesothelioma on patients and carers: summary of identified studies not already covered by the three reviews

Study	**Meso or mixed sample**	**Qual.**	**Quant.**	**Other**	**Country**	**Treatment of missing data**
Girgis 2019	?MPM**	yes			Australia	
Guglielmucci 2018A	Meso (MPM and peri.)	yes		Lit review (and qual study)	Italy	
Guglielmucci 2018B	Meso (MPM and peri.)	yes			Italy	
Henson 2019	Meso (not specified)		yes		England	Discussed in limitations
Hughes 2008	MPM	yes			UK	
Kasai 2018	MPM	yes			Japan	
Moore 2010	Meso (not specified)			Lit review	International literature	
Nagamatsu 2019	MPM	yes			Japan	
Taylor 2019	MPM	yes			UK	

Key to Table 3:

$ Assessment session included ‘clinical interview’ which informed their discussion section.

* Identified by Ball, Moore and Leary as a meso only study but it covers M/ARLC – only has 2 patients, both meso?

** Type of meso not specified but participants were identified by LC care coordinator.

Notes to Table 3:

- Ball, Moore and Leary only included qualitative papers or MM if qualitative aspects present; only pleural meso.
- Bonafede et al. included quantitative and qualitative; preferred more than 5 participants; included all MM types; 1980-2016.
- Guglielmucci et al. 2018A review covers the same papers as Bonafede et al. 2018.

Considering the qualitative studies first, four were conducted in the UK, one in Australia, two in Italy, two in Japan, and three in the USA. Nine articles aimed to explore the subjective experience of mesothelioma and identify care and support needs. Two studies explored psychological issues around risk awareness (Lebovits *et al.*, 1981; Lebovits, Chahinian and Holland, 1983). One developed recommendations to improve the diagnosis experience (Taylor, Warnock and Tod, 2019). The majority investigated malignant pleural mesothelioma (MPM), while four looked at MPM plus peritoneal. The range of participants was 5 to 112. Eight studies were situated in large teaching hospitals. Two recruited via local specialist nurse referrals, and two via nationwide hospitals, groups and networks. The qualitative studies commonly excluded anyone judged ‘not well enough’ to participate, or who had a psychiatric diagnosis, or who might experience aggravated emotional distress. Only three included carers and relatives in their design (Guglielmucci, Bonafede, *et al.*, 2018; Girgis *et al.*, 2019; Taylor, Warnock and Tod, 2019). In four articles attention was paid to teasing out patient and carer experiences at different time-points in the disease's course: at diagnosis (Arber and Spencer, 2013; Taylor, Warnock and Tod, 2019) , and in the first 6 months (Guglielmucci, Bonafede, *et al.*, 2018). Kasai and Hino (2018) conducted the first longitudinal qualitative study in this field, examining five transition points in disease progression with participants diagnosed 5 to 8 years previously. Whilst the majority of cases of mesothelioma in the literature were men who had been exposed occupationally, the Italian articles (Bonafede *et al.*, 2018; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018) included a higher proportion of females, as they studied people exposed by living in or near National Priority Contamination Sites (rather than occupationally exposed males as is typical).

Of the quantitative studies, one was conducted in the UK (Henson *et al.*, 2019), with no specified mesothelioma type, and one in Australia (Dooley, Wilson and Anderson, 2010), about MPM. Dooley, Wilson and Anderson (2010) assessed 49 patients who were suing their employer, aiming to investigate stress and depression symptoms in men with mesothelioma. Henson et al. (2019) aimed to quantify suicide risk in patients with cancer and identify risk factors to help with psychological assessment. They covered the whole population of people who died by suicide after cancer diagnosis in England. Their statistical study allowed comparison of the first 6 months after diagnosis to the rest of the patient's life. For the handling of missing data in the quantitative articles, see Table 3.

In the three literature reviews, studies conducted in the UK, Europe, the USA and Australia predominated (see Table 3). Moore, Darlison and Tod (2010) aimed to identify what was known about the experience of living with mesothelioma. Bonafede et al. (2018) reviewed the research on psychological aspects of MM patients and asbestos-exposed people. Ball, Moore and Leary (2016) evaluated whether MPM and advanced lung cancer patients' psychological care needs differed. The number of participants ranged from 6 to 63 (Bonafede *et al.*, 2018), 2 to 15 (Ball, Moore and Leary, 2016) and 5 to 409 (Moore, Darlison and Tod, 2010). Ball et al.'s (2016) review only covered MPM, whereas the others looked at all mesothelioma types. Only Moore, Darlison and Tod (2010) included the experience of carers or families.

2.3.3 Quality appraisal

The critical appraisal carried out informs the following overview of the field's quality. Of the qualitative articles, three were rated as low risk of bias (Clayson, Seymour and Noble, 2005; Taylor, Warnock and Tod, 2019; Walker *et al.*, 2019) the rest were rated unclear (see Table 4).

Table 4: *CASP Qualitative Checklist*

Walker et al. (2019)	**Taylor et al. (2019)**	**Nagamatsu et al. (2019)**
Yes	Yes	Yes
Yes	yes	Yes
Yes	yes	Cannot tell
Cannot tell	yes	Cannot tell
Yes	Yes	Cannot tell
Yes	Cannot tell	No
Yes	Yes	Yes
Yes	Yes	Yes
Yes	Yes	Yes
Relates to current practice and relevant research.	Developed 10 Top Tips for health care professionals.	Identifies new research areas. Makes practice recommendations.
Low	Low	Unclear

Girgis et al. (2019)	**Guglielmucci et al. (2018A)**	**Guglielmucci et al. (2018B)**	**Hughes & Arber (2008)**	**Kasai & Hino (2018)**	**Lebovits et al. (1981)**	**Lebovits et al. (1983)**
Yes	Yes	Yes	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes
Cannot tell	Yes	Yes	Yes	Cannot tell	Cannot tell	Cannot tell
Yes	Yes	Yes	Cannot tell	Yes	Cannot tell	Cannot tell
No	No	No	Cannot tell	No	No	Cannot tell
Cannot tell	Cannot tell	Cannot tell	Yes	Yes	No	No
Yes	Cannot tell	Yes	Cannot tell	Cannot tell	Cannot tell	Cannot tell
Yes	Cannot tell	Cannot tell	Cannot tell	Yes	Yes	Yes
Suggests new research areas. Relates to current practice & research.	Highlights lack of interventions & measures. Makes practice recommendations.	Relates to existing knowledge & relevant research. Makes practice suggestions.	Relates to existing knowledge & research literature. Identifies new research areas.	Contributes new framework. Relates to practice/policy.	Relates to practice. Identifies new research areas.	Suggests guidelines for practice.
Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear

	Question	**Arber & Spencer (2013)**	**Clayson et al. (2005)**
1	Clear statement of aims?	Yes	Yes
2	Qualitative methodology appropriate?	Yes	Yes
3	Research design appropriate?	Yes	Yes
4	Recruitment strategy appropriate?	Yes	Yes
5	Data collected in a way that addressed research issue?	Yes	Yes
6	Relationship between researcher and participants considered?	No	Yes
7	Ethical issues taken into account?	Cannot tell	Yes
8	Data analysis sufficiently rigorous?	Yes	Yes
9	Clear statement of findings?	Yes	Yes
10	How valuable is the research?	Relates to research literature. Makes practice recommendations.	Informs service development. Highlights unmet needs.
Risk of bias	Risk of bias	Unclear	Low

Of the quantitative studies, Henson et al. (2019) was rated low, and Dooley, Wilson and Anderson (2010) was rated unclear (see Table 5).

Table 5: *CASP Quantitative Checklist*

	Question	**Dooley et al. (2010)**	**Henson et al. (2019)**
1.	Addresses clearly focused issue?	Yes	Yes
2.	Cohort recruited in acceptable way?	No	Yes
3.	Exposure accurately measured to minimize bias?	Yes	Yes
4.	Outcome accurately measured to minimize bias?	Can’t tell	Yes
5a.	Identified all important confounding factors?	Yes	Yes
5b.	Taken account of confounding factors in design/analysis?	No	Yes
6a.	Follow-up of subjects complete enough?	N/A	Yes

6b.	Follow-up of subjects long enough?	N/A	Yes
7.	What are the results?	See Supporting Information S1	See Supporting Information S1
8.	How precise are results?	Good.	See Supporting Information S1
9.	Do you believe the results?	Can’t tell	Yes
10.	Can results be applied to local population?	No	Yes
11.	Do results fit with other evidence?	Yes	First study to address this issue.
12.	What are implications for practice?	Highlights for HCPs the possibility of posttraumatic stress in this population.	Identifies specific cancers with significantly elevated suicide risk, and first 6 months post-diagnosis requiring greater vigilance for psychological distress.
Risk of bias		Unclear	Low

All three reviews (Moore, Darlison and Tod, 2010; Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018) were rated unclear (see Table 6).

Table 6: *CASP Systematic Review Checklist*

	Question	**Bonafede et al.**	**Guglielmucci et al. 2018A**	**Ball et al.**	**Moore et al.**
1.	Addressed a clearly focused question?	Yes	Yes	Yes	Yes
2.	Looked for the right type of papers?	Yes	Yes	Yes	Yes
3.	All important, relevant studies included?	Yes	Yes	Yes	Yes
4.	Enough done to assess quality of included studies?	No	No	Yes	No
5.	If results were combined, was that reasonable?	Yes	Yes	Yes	Yes
6.	What are the overall results?	See Supporting Information S1	See Supporting Information S1	See Supporting Information S1	See Supporting Information S1
7.	How precise are results?	Few confidence intervals stated	Few confidence intervals stated	Qualitative studies only	No confidence intervals stated
8.	Can results be applied to local population?	Yes	Yes	Yes	Yes
9.	All important outcomes considered?	Yes	Yes	Yes	Yes
10.	Benefits worth harms and costs?	N/A	N/A	N/A	N/A
Risk of bias		Unclear	Unclear	Low	Unclear

A limitation commonly reported was generalisability: numbers of participants were small, due to mesothelioma's rarity and recruitment difficulties caused by its debilitating nature. The only large-scale study was Henson et al. (2019), which added a new dimension to the field by uncovering suicide risk. Kasai and Hino (2018), in the only longitudinal study, marked out the illness into five time-periods and provided a useful new framework, but could only follow five participants. All three literature reviews (Moore, Darlison and Tod, 2010; Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018) highlighted the paucity of studies on psychological aspects and lived experiences of mesothelioma patients and carers. They also usefully drew out differences between the experience of mesothelioma patients and those with lung cancer or asbestos-exposed people. The reviews together gave a wider reach across the field, each having a different emphasis and scope of their search (see Table 3).

The Italian group added a new psychoanalytical perspective (Bonafede *et al.*, 2018; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018). Along with Dooley, Wilson and Anderson (2010), their articles were the only ones to refer specifically to trauma theory. Overall, the studies presented clear rationales, used appropriate methods, and gained appropriate ethical approval. They related their findings to practice and relevant research-based literature, suggesting areas for future research (e.g., developing needs-assessment tools) and practice improvements. However, there was sometimes a lack of clarity around the purpose and extent of involvement of carers and family members in the interviews.

In terms of the standard of reporting, as assessed by the critical appraisal checklists (Critical Appraisal Skills Programme, 2021), only four articles could be considered excellent (Clayson, Seymour and Noble, 2005; Henson *et al.*, 2019; Taylor, Warnock and Tod, 2019; Walker *et al.*, 2019). Amongst the others, there was some lack of transparency regarding reporting of methods. It is possible the journals' limited word counts had an effect. The most noticeable area of omission was detailing the relationship between researcher and participants. There was little critical examination of the researcher's own role, with potential for bias and influence, both in the formulation of questions and in data collection, and there was sometimes lack of clarity around the role of the patient's own medical team. However, more consideration was given to potential bias in the analysis process. In terms of representation, the voices of participants were heard more easily, and showed more range, in some studies than others.

This section has presented the findings relating to the characteristics of the 17 identified articles. Next, this review summarises the findings relating to three key themes developed, which captured the range of data in the articles. These key themes were ‘The Passing of Time’, ‘Dealing with Difficult Feelings’ and ‘Craving Good Communication’.

2.3.4 Theme 1: The passing of time

This theme appeared in all 17 articles, in different guises: the importance of timing for various interventions; delays in the medical journey; awareness of different time-phases in mesothelioma; and the uncertainty/certainty axis (Table 7).

Table 7**:** *Participant quotations: The passing of time*

Theme	Quotation	Source
The passing of time	Many friends of mine died because of mesothelioma. This makes you wonder who will be the next one.	Patient, Guglielmucci et al. (2018)
	When the ultimate diagnosis arrived, it killed me in a moment […] I've been killed that day.	Patient, Guglielmucci et al. (2018)
	I do not know what tomorrow will bring or next month. I do not even know if I can look to Christmas…really, I do not know the speed of these things.	Patient, Ball, Moore and Leary (2016)
	You need a little bit of time just to discuss or talk about it. You go away, you know nothing. You do not even know what mesothelioma is.	Patient, Taylor, Warnock and Tod (2019)
	We filled all the forms in…and we have not received anything yet. […] I'm still waiting for some crazy doctor to come to disprove what the hospital proved. And that's my worry, that's my biggest worry.	Patient, Clayson, Seymour and Noble (2005)

The mesothelioma journey tended to cover a long span of time, falling into four distinct periods: pre-diagnosis and the diagnostic pathway; diagnosis; the time spent living with the disease; and the post-mortem period. Four studies (Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018) mentioned the first time-period. For mesothelioma, there is an extra dimension around causality, compared to many other cancers. Exposure to asbestos has usually occurred decades prior to symptoms emerging (Health and Safety Executive, 2020). For some people, a retrospective awareness of personal risk from known asbestos exposure, termed ‘Damocles syndrome’, can occur. This awareness prior to diagnosis was identified as a cause of anxiety and distress (Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018). These feelings could also be generated by awareness that the patient's own contact with asbestos may have led to the second-hand exposure of family members, for example, by washing work clothes (Bonafede *et al.*, 2018). Two studies (Guglielmucci, Franzoi, *et al.*, 2018; Taylor, Warnock and Tod, 2019) highlighted another difficult aspect of this initial period: the long, frustrating journey to a definitive diagnosis.

Diagnosis was a significant time-point in 14 articles, bringing shock, anger, anguish, numbness, anxiety and depression. The fact that the patient's time was now limited brought a terrible certainty. However, alongside the certainty came distressing *uncertainty* about disease progression and the future (Ball, Moore and Leary, 2016; Kasai and Hino, 2018). Issues of timing caused distress at diagnosis (Girgis *et al.*, 2019; Nagamatsu *et al.*, 2019; Taylor, Warnock and Tod, 2019). For example, the appointment might not be long enough, with patients needing time to process what they are being told (Nagamatsu *et al.*, 2019; Taylor, Warnock and Tod, 2019). Sometimes too much information about the illness and compensation was given at this early stage, leaving patients and carers feeling overloaded (Arber and Spencer, 2013; Girgis *et al.*, 2019; Taylor, Warnock and Tod, 2019).

The initial phase of the illness is critical in terms of suicidality. Henson et al. (2019) showed that, when considering variation in suicide risk by years since diagnosis, out of all cancer types mesothelioma patients had the highest risk of suicide in the first 6 months, with an 8.61-fold risk compared with the general population. Hopelessness was identified as a result of negative messages from healthcare professionals by Ball, Moore and Leary (2016) and Girgis et al. (2019).

After the initial period, the speed and unpredictability of disease progression caused intense anxiety, as three studies showed (Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018; Guglielmucci, Bonafede, *et al.*, 2018). Sometimes, lack of continuity with medical staff left patients unsure about the next treatment steps, with an inability to plan ahead accompanied by distrust of medical interventions and healthcare professionals (Bonafede *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018). In a study examining the communication of a mesothelioma diagnosis Taylor, Warnock and Tod (2019) aimed to understand how a diagnosis can be communicated well and distress can be minimised. They highlighted that breaking bad news (BBN) could occur at many different time-points. Across the mesothelioma patient journey there were multiple episodes of bad news: although diagnosis was the main one, there were others, such as not being eligible for a trial.

‘The future’ as a stimulus for worry about loved ones was a time-related feature reported by several articles (Dooley, Wilson and Anderson, 2010; Ball, Moore and Leary, 2016; Guglielmucci, Franzoi, *et al.*, 2018). Clinically significant posttraumatic stress symptoms were linked by Dooley, Wilson and Anderson (2010) to physical symptoms, reminding patients they were going to die and making them think about their families' future. Legal and financial issues took up frustrating amounts of precious time, and the patient's death was not the end-point of the journey, as legal/financial matters dragged on further (Hughes and

Arber, 2008; Ball, Moore and Leary, 2016; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018).

2.3.5 Theme 2: Dealing with difficult feelings

All 17 articles presented difficult feelings and allied coping strategies. ‘Difficult feelings’ includes negative emotions, and also feelings around identity and states of being (Table 8).

Table 8: *Participant quotations: Dealing with difficult feelings*

Theme	Quotation	Source
Dealing with difficult feelings	It was a terrible ordeal. No pain, no. Not painful at all, but it's the weirdest experience [pleural drainage].	Patient, Moore, Darlison and Tod (2010)
	It's like living as rats in the hole.	Carer, Guglielmucci et al. (2018)
	He gets very frustrated and irritable [and] then he cries because he wants to be doing things. […] it's very hard, I feel like a punch bag. There is a lot of anger, and it's not my fault.	Carer, Hughes and Arber (2008)
	It does not pay to think too far down the road because that's bad news. As you say, head in the sand.	Patient, Arber and Spencer (2013)
	He [husband] does not want to talk about my disease […] He does not talk with anybody. […] he is annoyed, because he says this is our business.	Patient, Guglielmucci et al. (2018)
	I ain't going away without a fight!	Patient, Girgis et al. (2019)
	Samurai had the good grace to die, because they guarded the Shogun against enemies. I thought they were brave men with great mental vigour.	Patient, Kasai and Hino (2018)
	I'm not just going to carry on. I'm going to crack on. Well, what we are going to do is to enjoy each day.	Patient, Moore, Darlison and Tod (2010)
	I hope I've walked well in my life, to have spent it well and that's it. If [the treatments] will go well, I am really happy, because I still have some ambitions to realize. If it will go bad, it does not matter.	Patient, Guglielmucci et al (2018)

These feelings had a range of causes, some described above. Physical symptoms, for example, pain and sweating, were inherently upsetting or frightening, and also frustrating in their impact on independence and social roles (Hughes and Arber, 2008; Arber and Spencer, 2013; Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018). Feeling socially isolated was mentioned in several articles, resulting from depression, apathy and stigma (Hughes and Arber, 2008; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018).

The physical burden took its toll on carers, and patients worried about being a burden (Ball, Moore and Leary, 2016) or agreed to treatment to keep relatives happy (Kasai and Hino, 2018), who in turn could feel guilty (Moore, Darlison and Tod, 2010; Girgis *et al.*, 2019).

Distress sometimes resulted from the effect of professionals' activities. It was caused by medical treatments (Moore, Darlison and Tod, 2010; Guglielmucci, Bonafede, *et al.*, 2018); lack of continuity (Ball, Moore and Leary, 2016; Taylor, Warnock and Tod, 2019); feeling abandoned if chemotherapy was not an option (Hughes and Arber, 2008); and feeling like guinea pigs during trials (Guglielmucci, Franzoi, *et al.*, 2018). The anger that was identified was linked to two causes. The first was patients' frustration at not being able to do ordinary activities, with carers also feeling helpless or angry about changes in the patients, such as their sense of identity, willingness to live a normal life, or their irritability (Hughes and Arber, 2008; Guglielmucci, Franzoi, *et al.*, 2018). Second, complex medico-legal matters led, for some, to feelings of anger and betrayal towards employers. For others, conflicted loyalty towards former employers meant anger was redirected towards families or doctors (Hughes and Arber, 2008; Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018).

These many difficult feelings led patients and carers to experience a lack of control. This could include feeling powerless over the disease; having to relinquish family responsibilities; fearing total loss of agency at end-of-life; and insecurity about how to live and who could help (Arber and Spencer, 2013; Walker *et al.*, 2019). To cope, they engaged in a wide range of strategies. Avoidance/denial was identified as the main mechanism (Bonafede *et al.*, 2018). Strategies included deciding that statistics do not apply; limiting information (Girgis *et al.*, 2019); trying to live normally (Ball, Moore and Leary, 2016); and denying negative emotions (Guglielmucci, Franzoi, *et al.*, 2018). Refusing to talk or think about things was frequently used both by patients and carers (Hughes and Arber, 2008; Guglielmucci, Bonafede, *et al.*, 2018; Guglielmucci, Franzoi, *et al.*, 2018). However, this tended to increase social isolation, brought relationship difficulties, and came at a cost to the individual.

A fighting spirit was identified as helping to protect a sense of control (Kasai and Hino, 2018; Girgis *et al.*, 2019). Other factors giving a sense of control were accessing complementary/alternative medicine, support groups, palliative care, physiotherapy and maintaining fulfilling social and family roles (Ball, Moore and Leary, 2016; Bonafede *et al.*, 2018).

Some participants had an accepting attitude, reviewed their lives, mourned their losses and looked for the positive (Moore, Darlison and Tod, 2010; Guglielmucci, Franzoi, *et al.*, 2018; Kasai and Hino, 2018; Girgis *et al.*, 2019). Patients were more likely to report acceptance than carers (Moore, Darlison and Tod, 2010).

Only the quantitative studies (Dooley, Wilson and Anderson, 2010; Henson *et al.*, 2019) highlighted suicide as a coping strategy. Henson et al. (2019) showed patients with mesothelioma had the highest suicide risk of all English cancer patients. All participants in Dooley, Wilson and Anderson's study (2010) reported significant traumatic stress symptoms co-morbid with increased depression and anxiety, which could put them at risk of suicide. Hopelessness appeared as an important aspect of the mesothelioma experience compared with that of lung cancer (Ball, Moore and Leary, 2016), with the difference explained by mesothelioma's incurability, poor prognosis and lack of treatment options.

2.3.6 Theme 3: Craving good communication

Issues around the sharing of information and positive/negative aspects of communication were reported by 16 articles (Table 9).

Table 9: *Participant quotations: Craving good communication*

Theme	Quotation	Source
Craving good communication	She was able to explain a lot of it and she used drawings and pictures and things to show me because I had not even got a clue.	Carer, Taylor, Warnock and Tod (2019)
	Being well-informed and knowing my results eases my anxiety and gives me a sense of control.	Patient, Nagamatsu et al. (2019)
	I want my doctor to tell me everything, including bad news.	Patient, Nagamatsu et al. (2019)
	Do not tell me the bad news. Just let me know something good.	Patient, Nagamatsu et al. (2019)
	I knew that she [CNS] would be there, she told me, she'd be on the phone, and I could ring her any time.	Carer, Taylor, Warnock and Tod (2019)
	I hope my doctor not only treats my tumour but also takes care of me. I am not a box with cancer; but a living person.	Patient, Nagamatsu et al. (2019)
	I do not have a companion. At night, I find myself alone. You cannot say: 'I have someone to whom I can talk about that'.	Patient, Guglielmucci et al. (2018)
	I wanted to talk to people, but they were [not] going through the same thing. And there was no one there for me.	Carer, Girgis et al. (2019)

In Nagamatsu et al.'s (2019) study of patients' requests to doctors, most focused on communication. Inept or thoughtless information delivery caused huge distress and hopelessness. This happened at diagnosis (Ball, Moore and Leary, 2016; Girgis *et al.*, 2019; Taylor, Warnock and Tod, 2019), when shock affected capacity to absorb information, or later, regarding specialist supportive care services and responsibility for treatment decisions (Hughes and Arber, 2008; Ball, Moore and Leary, 2016). The timing of compensation/benefits information needed special care (Ball, Moore and Leary, 2016). Participants wanted clear, understandable explanations, with opportunity to ask questions (Nagamatsu *et al.*, 2019; Taylor, Warnock and Tod, 2019). Getting accurate information at the right time could be very helpful, for example, by lessening worries about progression, or giving comfort and a feeling of agency about finances (Ball, Moore and Leary, 2016; Guglielmucci, Bonafede, *et al.*, 2018; Nagamatsu *et al.*, 2019).

The importance of getting the balance right for each individual was stressed, using a customised, patient-centred approach to reflect the huge variation in what people want and can take in (Girgis *et al.*, 2019; Nagamatsu *et al.*, 2019; Taylor, Warnock and Tod, 2019). Whilst the majority of Nagamatsu et al.'s (2019) participants wanted honesty, a significant minority preferred only good news.

As well as difficulties with doctor-patient information transfer, there were issues within families. Carers struggled to decide who to share with (Girgis *et al.*, 2019), and worried about upsetting others (Ball, Moore and Leary, 2016). Some patients were overwhelmed with shame and guilt which they could not verbalise (Guglielmucci, Franzoi, *et al.*, 2018). Bonafede et al. (2018) also highlighted that initial information about the risk of asbestos exposure seemed to be gleaned not from employers but haphazardly, from the media or healthcare professionals (HCPs).

Participants clearly valued good communication skills and practices in health care professionals. Effective multi-disciplinary team-working meant informing specialist nurses immediately mesothelioma was suspected; breaking bad news was shared across the team; participants knew what to expect; and hope could be maintained (Bonafede *et al.*, 2018; Taylor, Warnock and Tod, 2019). A kind, warm, inclusive way of talking was appreciated (Nagamatsu *et al.*, 2019; Taylor, Warnock and Tod, 2019). Caseworkers were useful for communicating across the gap between physicians and patients/carers, and providing much needed individual emotional support (Guglielmucci, Franzoi, *et al.*, 2018; Girgis *et al.*, 2019).

Several studies presented the need of carers and patients for communication with others who had the same experience and understood the nuances of this rare disease (Hughes and Arber, 2008; Kasai and Hino, 2018; Girgis *et al.*, 2019). They valued the emotional support, and some patients found it helped them prepare for dying (Kasai and Hino, 2018). For some families, talking to each other about mesothelioma and its effects was extremely difficult, and they wanted to be helped by psychologists to find new ways to communicate (Guglielmucci, Franzoi, *et al.*, 2018). Skilled listeners, for example, psychologists were identified as able to provide valuable emotional support (Guglielmucci, Franzoi, *et al.*, 2018).

Hughes and Arber (2008) found their participants were grateful for being heard, telling their stories urgently despite becoming very distressed. They also reported their participants had issues with sex and intimacy, as did Dooley, Wilson and Anderson (2010), though this was only alluded to in other studies.

2.4 Discussion

2.4.1 Overview

This review has provided insight into the literature of the psychological effects of mesothelioma on patients and carers. The characteristics of the studies were presented, along with quality appraisal. The majority of the 17 included articles were qualitative. Only two were quantitative. Studies conducted in Europe, North America and Australia predominated. Most of the literature related to the overall experience of mesothelioma over the course of the disease from the patient's perspective. The majority of included studies were assessed as having unclear risk of bias, with only four having low risk. Three themes relating to the research question were developed from the data. The first showed aspects regarding time passing, which are specific to the mesothelioma journey. The second indicated the difficult feelings and allied coping strategies experienced by patients and carers. The third provided a picture of communication issues.

2.4.2 Suggested areas for further research

Until relatively recently, researchers did not place emphasis on psychological effects at different stages of the disease, or consider the variety of prognoses, treating the mesothelioma journey as uniform (Moore, Darlison and Tod, 2010). The general need for more nuance has been recognised and is starting to be addressed, for example, by Ball, Moore and Leary's (2016) differentiation of mesothelioma from lung cancer. With attention now being paid to the early stages of the disease, there is a need for focus on the impact of progression, taking into account the difference between indolent and aggressive types of mesothelioma (Moore, Darlison and Tod, 2010). This is important as new treatments come on line, and survival times vary even more.

The sparse nature of the field of evidence means there are many research gaps. Few studies included patients with peritoneal mesothelioma. Where included, their experience was not differentiated from malignant pleural mesothelioma, so more research is needed. The majority of the qualitative studies had exclusion criteria such as existing psychiatric diagnosis, risk of aggravating distress, or being considered ‘well enough’. In addition, mainly hospital patients were studied, omitting those receiving only supportive care (Ball, Moore and Leary, 2016). Therefore, it is likely people who have more psychological difficulties (such as PTSD and dementia) or distress are missing from the picture, except in the quantitative data. There is potential for qualitative research to be opened up to such people, for example, those affected by military experiences, with sufficient ethical safeguards in place. Studies show that vulnerable participants can find benefit from participating, even if it is a distressing experience (Wolgemuth *et al.*, 2015; Alexander, Pillay and Smith, 2018). There is an important question about psychological trauma being caused by catastrophic diagnosis, frightening medical treatments, and symptoms such as breathlessness (Faretta and Civilotti, 2016; Gieseler *et al.*, 2018; Taylor, Warnock and Tod, 2019) which requires investigation in regard to mesothelioma.

Despite the review's search terms allowing for positive effects to be reported, the emphasis in the studies was mostly on the negative. The most recent article, by Walker et al. (2019), was an exception, with its finding that participants frequently expressed hope and optimism. The wider cancer literature includes studies on posttraumatic growth, benefit-finding and hope (Li and Loke, 2013; Broderick, Deignan and Combes, 2017; Casellas-Grau, Ochoa and Ruini, 2017; Ozen, Ceyhan and Büyükcelik, 2019). There is therefore scope to explore positive aspects of the mesothelioma experience, which might help counter the hopelessness often transmitted by HCPs.

None of the studies explored the unique experience of carers. If included at all, they were mixed in with patients, so their particular concerns and needs were muted and overlooked. This lack of inclusion may in part be due to lack of recognition by carers themselves, since many relatives, friends or partners of patients might reject the term ‘carer’ as not applying to them (Eifert *et al.*, 2015). It may also reflect a lack of recognition by researchers and healthcare systems (Angood *et al.*, 2010; Laidsaar-Powell, Butow and Juraskova, 2019; Mbozi, Ratcliff and Roberts, 2020). A nuanced exploration of the psychological effects on this group is needed. The studies hint that there are issues related to intimacy and sex for people with mesothelioma and their partners, which could be explored in future research.

The studies included in the review came from a limited number of developed countries. The findings from Italy, which particularly showed stigma and social isolation where a whole community was contaminated, suggest that local variations in circumstance can bring different effects. It is important therefore to research the experience of mesothelioma in other countries, such as South Africa, where incidence is under-reported and healthcare is limited (Abdel-Rahman, 2018).

So far, no studies have reported the effects on populations who differ by type of workplace (e.g., education, healthcare), causation (e.g., secondary exposure, unidentified), gender, social class or age.

2.4.3 Study limitations

A single researcher carried out the review, using a reflexive process. However, the process and the themes identified were extensively discussed with my supervisors. Existing studies with psychological effects as secondary outcomes could include valuable relevant information: the decision not to include these was therefore a limitation. The scope of my search could have been wider (there was no inclusion of grey literature or attempt to find on-going research). In mitigation, the aim was to be reproducible through transparency in conduct and reporting, with provision of good documentation (Booth, Sutton and Papaioannou, 2016).

2.4.4 Clinical implications

This review has highlighted the importance of clinical practitioners being aware of the complex psychological impact and sequelae of mesothelioma. The findings indicate currently there is little evidence to inform clinical practice related to the psychological impact of mesothelioma, especially with regard to carers. However, my findings could inform the development of an assessment tool to identify psychological issues and address risk. They could also impress upon HCPs the importance of communication skills training.

2.5 Review conclusions

Though limited, the evidence indicates that mesothelioma, with its high symptom-burden, incurability, rarity and asbestos-related causation, leads to complex and inter-relating psychological effects on patients and carers. These effects are both negative and positive. The sparse literature gives a limited picture and demonstrates an urgent need for more nuanced research. Studies exploring the experiences of specific groups are recommended, such as people exposed in different workplaces. No study has addressed the unique experience of carers. When one considers the high symptom burden and complexity of this disease, research that seeks to understand the psychological effects on carers is needed.

This review has identified gaps in the existing literature and made suggestions for future research, thus informing my research aims, objectives and questions. The gaps identified which relate to my PhD project are:

1) The sparseness of overall evidence on the psychological effects of mesothelioma on patients and carers.

2) The need for more nuanced research, with an awareness of possible positive as well as negative psychological effects.

3) The lack of any studies specifically from the carers' perspective.

4) The lack of any studies looking at the experience of those from a specific workforce, such as the Armed Forces.

My research aims, objectives and questions are detailed in the following section.

2.6 Research aims and objectives

2.6.1 Aims

The aims of this doctoral study are:

1) to contribute to international knowledge about the psychological effects of mesothelioma on patients and their carers
2) to contribute to understanding of the psychological impact of mesothelioma on UK military veterans, from the carers' perspective.

2.6.2 Objectives

After the conducting of a scoping review of the literature about the psychological effects of mesothelioma on patients and carers, which has been presented above, the research following on from the review has two objectives. The first objective is to conduct a secondary data analysis (SDA) of eight transcripts of semi-structured interviews with carers of UK military veterans with mesothelioma. These interviews were carried out as part of the Military Mesothelioma Experience Study (MiMES) conducted at the University of Sheffield in 2019. The purpose of the SDA is to generate initial insight, identify sensitising issues for the main empirical study and allow fine-tuning of the research questions and interview schedule. Interpretative Phenomenological Analysis (IPA) methodology will be used to analyse the data.

The second objective is to conduct a new empirical qualitative study collecting and analysing data from semi-structured interviews with up to ten carers of UK military veterans with mesothelioma. IPA methodology will again be used.

2.6.3 Research questions

The primary research question is: "What are the psychological effects of mesothelioma from the perspective of family carers of UK military veterans?"

The secondary research questions are:

a) "How do family carers of UK military veterans experience the psychological effects of mesothelioma on themselves?"

b) "How do family carers of UK military veterans make sense of the psychological effects of mesothelioma on themselves?"

c) "How do family carers of UK military veterans experience the psychological effects of mesothelioma on the patient?"

d) "How do family carers of UK military veterans make sense of the psychological effects of mesothelioma on the patient?"

2.7 Conclusion

In this chapter I have justified my choice of a scoping review and presented my methods, results and discussion. I have also shown how my review informed my research aims, objectives and questions. In the next chapter, I consider my choice of methodology.

Chapter 3: Methodology

3.1 Introduction

In the previous chapter, I justified my choice of a scoping review and presented the review's methods, results and discussion. I also showed how my review informed my research aims, objectives and questions. This chapter considers the conceptual framework within which I addressed those aims, objectives and questions. The aims of the thesis were to contribute to international knowledge about the psychological effects of mesothelioma on patients and their carers; and to contribute to understanding of the psychological impact of mesothelioma on UK military veterans, from the carers' perspective. The primary research question was: "What are the psychological effects of mesothelioma from the perspective of family carers of UK military veterans?" To meet the aims and answer the primary and secondary research questions (see section 2.6.3), I adopted a critical realist epistemology informed by a feminist perspective. A qualitative methodology was used, specifically IPA. I outline here my justification for adopting this approach and provide reasons for rejecting alternatives.

3.2 Research paradigms and philosophical assumptions

It is important for researchers when they are trying to develop knowledge on a phenomenon to be explicit about their paradigm positioning, i.e., their own particular world view (Haigh *et al.*, 2019), as their own beliefs and assumptions will influence the research (Bogdan and Biklin, 1998; Mackenzie and Knipe, 2006; Chilisa and Kawulich, 2012). I state here my philosophical assumptions to orient my research study and to enhance its credibility and utility (Carter and Little, 2007; Levitt *et al.*, 2017).The literature on research paradigms is complex (Mackenzie and Knipe, 2006; Denzin and Lincoln, 2018; Lincoln, Lynham and Guba, 2018). Therefore, in considering my own paradigm position, for clarity I use the categories set out by Mackenzie and Knipe (2006) as being the most common (postpositivist/positivist, interpretivist/constructivist, transformative, and pragmatic), plus an additional newer postcolonial/indigenous paradigm (Chilisa and Kawulich, 2012). (For a more detailed account of these paradigms, see Appendix F.) None of these categories matched my own epistemological and ontological stance for this study. My reasons for rejecting them are shown in Table 10.

Table 10: *Common research paradigm categories with reasons for rejection*

Paradigm	**Description**	**Reason for rejecting**
positivist/postpositivist	• uses quantitative methods for collecting	I believe people interpret the world

	and analysing data, using precise observation and replicable measurement • believes there is an independent reality which science can study • begins with a theory which is tested	differently, i.e., there is not a single reality which I could test.
interpretivist/constructivist	• sees reality as socially constructed and dependent on the mind of the individual person	My understanding is whilst people interpret the world differently, there is still something that has independent ontological status.
Transformative/ emancipatory	• places social justice at the heart of research, as both its origin and its goal • assumes there are multiple realities shaped by social, political, cultural, economic, race, ethnic, gender and disability values, where some values are right and some wrong	This was a step too far for me, in aiming to empower participants who might not agree with my analysis of their situation, and possibly causing ethical problems by imposing an external, dominant theory.
postcolonial indigenous	• aims to challenge deficit thinking and pathological descriptions of the former colonized and reconstruct a body of knowledge that promotes transformation	This was not appropriate to the population of my project, the UK military community, as they do not constitute a formerly colonised social group (apart from those Commonwealth troops such as Gurkhas).
pragmatist	• has a practical emphasis • research problem is positioned as central, and methods are picked which seem most likely to furnish insights	This would not provide a set of internally consistent elements, and would not give me an accepted and well-developed approach to build on.

3.3 Justification for a critical realist epistemology

Critical realism is not a research paradigm, but a meta-theory informed by philosophy (Archer *et al.*, 2016), particularly the work of Roy Bhaskar, which “sits between positivism and interpretivism” (Social Sciences Centre for Education Studies, 2019). In *A Realist Theory of Science* (2008), originally published in 1975, Bhaskar aimed to develop a systematic realist account of science as an alternative to the positivism he saw as having taken it over; he termed this account *transcendental realism*. He argued that "knowledge must be viewed as a produced means of production and science as an ongoing social activity in a continuing process of transformation" (Bhaskar, 2008, p. 17). Bhaskar addressed the *epistemic fallacy*, the idea that "reducing what we say is 'real' or exists (ontological statements) to what we can know or understand about the 'real' (epistemological statements)" (Social Sciences Centre for Education Studies, 2019). His account made a distinction between ontology and epistemology (Bhaskar and Lawson, 1998). Bhaskar described scientists as acting "in an endeavour to express to themselves in thought the diverse and deeper structures that account in their complex manifold determinations for all the phenomena of our world" (Bhaskar, 2008, p. 20). Alongside transcendental realism, Bhaskar developed *critical naturalism,* a philosophy focused on the human sciences, "entailing a transformational model of social activity and a causal theory of mind" (2005, p. xii).

The term *critical realism* arose later from other authors, a linking of *transcendental realism* and *critical naturalism,* which Bhaskar accepted (1998, p. ix). In the critical realist research paradigm, reality is conceptualised as having three strata: empirical (structures with the power to activate causal mechanisms), actual (caused events and effects) and real (observed/experienced events-effects) (Haigh *et al.*, 2019). Actual-level "events-effects can only be explained with reference to the real level, where unseen causal powers associated with such entities as class, gender, and capitalism are triggered" (Haigh *et al.*, 2019). Examples of studies taking a critical realist approach are Sword et al.'s (2012) on postpartum mental health, and Perversi et al.'s (2018) on reasoning mechanisms in ward rounds.

My experience as a counsellor since 2008 has given me deep access to many people's individual perspectives on life, their *interpretations* of the world. My understanding is that whilst people interpret the world differently, there is still something that has independent ontological status. As well as material things in the physical world, "people's interpretations and social practices can be seen to constitute a 'reality' that exists independently of what the researcher may have to say" (Willig, 2016, p. 2). I therefore chose a realist ontology, which combined explanation with interpretation (Archer *et al.*, 2016).

From a critical realist position, my research questions sought to explore participants' experiences and interpretations and provide some insights into their lived realities (Willig, 2016). The fact that "critical realists seek to avoid being trapped within the silos of single disciplinary views" (Haigh *et al.*, 2019) made sense to me as I manoeuvred within perspectives from different disciplines (e.g. nursing, psychotherapy, psycho-oncology, sociology). Maxwell (2013, p. 40) in fact suggests that

> "the most productive conceptual frameworks are often those that bring ideas from *outside* the traditionally defined field of your study, or that integrate different approaches, lines of investigation, or theories that no one had previously connected."

I hoped that the counsellor's perspective I was bringing to the field of nursing/patient experience would prove fruitful.

Bhaskar (2016, p. 79) characterises the interests of critical realist researchers as "typically exploratory" and "primarily interested in *explanation"* rather than prediction. I therefore needed to choose a methodology (such as IPA) and methods which would be appropriate for this outlook.

3.4 Justification for a feminist perspective

I have understood myself to be 'a feminist' since being a teenager in the 1970s and 1980s. Through a process of reflection during the initial stage of my PhD, I realised that my feminist position was part of my identity and needed to be made transparent. Feminism in the context of qualitative research in the 21st century is a challenging and contentious space (Olesen, 2018). Despite the complexity of approaches, key concerns remain reflexivity, analysis of power, voice, advocacy, representation, intersectionality, gender and ethics (McHugh, 2014; Olesen, 2018; Lafrance and Wigginton, 2019). A defining aspect of feminist research is a commitment to social change "through the adoption of methods intentionally designed to do just that" (Lafrance and Wigginton, 2019, p. 13). This intention positions a feminist approach within the transformative/emancipatory paradigm, but I had rejected the transformative/ emancipatory paradigm for my own study paradigm (see Section 3.2 page 69). The reason I gave was that I could not feel comfortable aiming to empower participants who might not agree with my analysis of their situation and possibly causing ethical problems by imposing an external, dominant theory. A whole-heartedly feminist methodology was not suitable for my study.

However, I also considered whether feminism might be helpful in approaching the military context, which has been described as a "hyper-masculine culture" (Sparrow *et al.*, 2020).

Feminist research is no longer confined to advocating for and prioritising the perspective of women, but is concerned with all gender-based inequalities (Leavy and Harris, 2018, p. 7). Taking a feminist *perspective* - a “less well-developed system” than a paradigm (Denzin and Lincoln, 2018, p. 12) - would mean paying attention to how gender could be affecting the experiences of veterans (male and female) and their families in my study. Feminist theory is increasingly being applied to the study of veterans, highlighting the reality that their identities and experiences are not homogeneous, but encompass masculinities, femininities and intersectionality, e.g., Eichler (2017), Bulmer & Eichler (2017) and Baker et al. (2016). The longstanding feminist concerns around affect (Liljestrom, 2016) and care (Bergeron, 2016) were relevant to a topic which involved the interplay between patient and carer in a context where emotion could be problematic (McAllister, Callaghan and Fellin, 2019). Also, the feminist focus on power relations matched my understanding of psychological distress and problematic behaviour as being helpfully conceptualised via the Power Threat Meaning Framework (Johnstone and Boyle, 2018)[6], providing a potentially fruitful way to consider the psychological effects of mesothelioma. To sum up, using a feminist perspective provided a way for me to transparently embrace feminist values and concerns in the broadest sense, enhancing my ethical approach and adding to my understanding of the data.

3.5 Justification for a qualitative approach

In a critical realist approach, qualitative methods may be chosen because they “help to clarify complex relationships and processes that are unlikely to be captured by predetermined response categories or standardised quantitative measures” (Parr, 2020, pp. 259–260). Qualitative research has been defined by Aspers and Corte (2019, p. 139) as “an iterative process in which improved understanding to the scientific community is achieved by making new significant distinctions resulting from getting closer to the phenomenon studied.” As the aim of my study was to explore the perspective of carers, a qualitative approach was appropriate to gain a deeper understanding of their personal experiences and perspectives, rather than the wider, more general or probability-based data which could be sought using quantitative techniques (Leavy and Harris, 2018). Qualitative researchers are interested in ‘outliers’ in a way that quantitative researchers are not (De Chesnay and Banner, 2015). Van

---

[6] The framework (Johnstone and Boyle, 2018, pp. 7–8) replaces the traditional psychiatric question “What’s wrong with you?” with these questions:
“What has happened to you?” (How is power operating in your life?)
“How did it affect you?” (What kind of threats did this pose?)
“What sense did you make of it?” (What is the meaning of these situations and experiences to you?”
“What did you have to do to survive?” (What kinds of threat response are you using?”

Wijngaarden et al. (2017, p. 1739) suggest that qualitative approaches in health care research have advantages over quantitative techniques in three ways: they are person-oriented and ‘real-life’, rather than population-oriented; they focus on people’s individual needs and preferences, rather than just their disease; and they aim to include social and existential contexts, thus avoiding “undeserved depoliticization of certain diseases”, and addressing issues that would otherwise not be researchable.

My personal skill set and qualities, developed over many years as a secondary school teacher and then as a counsellor, made me a good fit for the role of qualitative researcher (Rowling, 1999; Collins and Cooper, 2014; Heinonen and Nissen-Lie, 2020). Saldana (2018, pp. 5–6) suggests ten characteristics for a qualitative researcher (see Box 1). By embracing these characteristics, I would be more likely to conduct a rigorous study and answer the research questions.

Box 1: *Saldana’s characteristics for a qualitative researcher*

- meticulous vigilance of details
- unyielding resiliency
- visionary reinvention
- social savvy
- humble vulnerability
- representational responsibility
- finding your methodological tribes
- emotional immersion
- gifting your ideas
- knowing and understanding yourself.

3.6 Consideration of alternative qualitative approaches

Researchers influenced by critical realism tend to have an approach to methods which is “highly flexible and adaptive”; for them, “the role of a research method is essentially to connect the inner world of ideas to the outer world of observable events as seamlessly as possible” (Ackroyd and Karlsson, 2014, p. 21). In aiming to achieve this seamless connection, within the qualitative paradigm, there were various different ‘approaches to’ (Creswell and Poth, 2018) or ‘strategies of’ (Denzin and Lincoln, 2018) inquiry that I could choose from. Creswell and Poth (2017) consider the five main qualitative approaches to be narrative, phenomenology, grounded theory, ethnography, and case study, from which researchers need to choose the best option to fit their own research questions and interests, in keeping with methodological integrity (Levitt *et al.*, 2017). These five approaches are those which are most often seen in the social, behavioural and health sciences literature (Creswell and Poth, 2017). There are other possible strategies aligned to the qualitative paradigm, such as discourse analysis, but for practical reasons I confined my consideration of alternative approaches to these five. In Table 11 I set out my reasons for rejecting four of these qualitative approaches: narrative, grounded theory, ethnography and case study. (For full details of each approach and my reasons for rejection, see Appendix G).

Table 11: *Consideration of alternative qualitative approaches*

Name of approach	**Definition**	**Aims of research**	**Reason for rejecting**
Narrative	"A distinct form of communication; it is meaning making through the shaping of experience; a way of understanding one's own or others' actions; of organizing events, objects, feelings, or thoughts in relation to each other; of connecting and seeing the consequences of actions, events, feelings, or thoughts over time." (Chase, 2018, p. 549)	Narrative researchers are interested in the content of stories, or their structure, or how cultural stories relate to those stories people tell themselves about their own experiences.	Entails multiple meetings for data collection. My approach must minimise the burden on carers in terms of time. Including carers from around the UK would make multiple visits potentially difficult (travel time and expense).
Grounded theory	"A set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area", with data collection and analysis processes which are "simultaneous, sequential, subsequent, scheduled and serendipitous"	Aims at explaining and giving convincing portrayals of social processes.	My research aim was not to theorise about the social world, but to explore the individual experiences of a particular participant group.

	(Glaser and Holton, 2004, p. 3).		
Ethnography	Typical features: relatively long-term data collection process; in naturally occurring settings; relying on participant observation, or personal engagement; employing a range of data types; aimed at documenting what actually goes on; emphasises the significance of the meanings people give to objects, in the course of their activities; holistic in focus (Hammersley, 2018, p. 5).	Participant-observer aims to understand local rules, practices and shared knowledge.	My study sought to explore the lived experience of people who did not live in the same location and was not looking at meanings of cultural phenomena.
Case study	“In-depth, multi-faceted explorations of complex issues in their real-life settings” (Crowe *et al.*, 2011).	Aims to get information about people’s perceptions and decision-making in a particular time-frame and interaction.	My focus was on the experience of the carer, rather than the holistic picture of interactions from many angles. I was not intending to test an existing hypothesis. My participant population was geographically spread and it would be impractical for me to attempt to observe them in a real-life setting.

3.7 Phenomenological Research

3.7.1 Introduction

Having rejected other qualitative approaches, I identified phenomenology as a suitable approach to address my study’s aims and answer my research questions. In this section, I justify my decision to choose phenomenology, after considering the philosophical tradition. I then consider various phenomenological research approaches and show why I rejected them. I then present an account of IPA methodology and reasons for its selection.

3.7.2 Phenomenology – the philosophical tradition

A critical realist approach sees humans as “equally and irreducibly materially embodied and part of nature, and emergent conceptualising, reflexive and self-conscious beings”, whose interior social life is “at least partially conceptualised and reflexively accessible”, thus allowing qualitative research to produce rich, thick descriptions of their experience (Bhaskar, 2016, p. 82). The philosophical tradition which focusses on the study of human experience is phenomenology. Here, I give an overview of its development and the ideas of four philosophers that went on to inform IPA methodology: Husserl, Heidegger, Merleau-Ponty and Sartre. A more detailed account of this philosophical tradition is given in Appendix H.

Phenomenology was originally developed by Husserl (see Appendix F on the *interpretivist/constructivist* paradigm, p. 325). He showed that the positivist paradigm’s idea of objectivity as detached and value-free was impossible; humans were always in a lifeworld which provided the foundation of all understanding (Husserl, 1970). He asserted it was necessary to move from taking for granted our everyday experience to take on a ‘phenomenological attitude’, focussing in a reflective way on our inner perception of what we encounter (Smith, Flowers and Larkin, 2009; Van Wijngaarden, Van Der Meide and Dahlberg, 2017). Consciousness was always from a particular perspective (Zahavi, 2019), so it was necessary to go back to the *things themselves* (Husserl, 2001) in a process of ‘bracketing’, i.e., turning away from any interpretations, theories and prejudices, in order to have an open mind (Zahavi, 2019). Husserl’s approach was essentially descriptive and eidetic (interested in the universal essence or ‘eidos’).

Husserl’s student, Heidegger, moved towards a hermeneutic and existential emphasis (Smith, Flowers and Larkin, 2009). His conceptualisation (1962) of a human being as ‘Dasein’, meaning ‘there-being’ or ‘Being-in-the-world’, paid attention to existence as related to and involved with the world (Eatough and Smith, 2017). The concept of ‘intersubjectivity’ was key (Zahavi, 2019). Heidegger engaged a hermeneutic lens because he understood appearance as having two aspects, visible meanings and latent or disguised meanings (Heidegger, 1962). To interpret a phenomenon which appeared, it was essential to be aware that fore-conceptions would always be there (Heidegger, 1962).

Merleau-Ponty developed Husserl's account of human experience as rooted in perception, describing perception as an *embodied* process (Merleau-Ponty, 2012). A human had an individually situated, subjective perspective on the world, so their knowledge of it was interpretative (Smith, Flowers and Larkin, 2009). Humans were essentially 'body-subjects', with their relationship to others stemming from their own embodied perspective, i.e., from a position of difference (Smith, Flowers and Larkin, 2009). The body had a dual role: firstly, a physical object that could be viewed from a third-person perspective, and secondly, the site of consciousness and subjectivity, experienced in the first-person (Carel, 2016).

Sartre's work also involved existential phenomenology. He saw human beings as in a process of becoming and developing, rather than having a fixed, unified self (Sartre, 1948). Experiences took place in an interpersonal context (Smith, Flowers and Larkin, 2009). Sartre highlighted the difference between self and other, with an awareness of 'radical otherness' (Zahavi, 2019). He analysed the body as having three orders: the objective (the physical), the subjective (first-person experienced), and the intersubjective (Carel, 2016). He stressed that, because humans were in an evolving and unfixed state, they had freedom to choose and were responsible for their own actions, within the constraints of the context in which they found themselves (Sartre, 1948).

3.7.3 Justification for phenomenology

Since the late 20th century, others have built on the work of these four philosophers to bring phenomenological approaches to bear on medicine and health, e.g., Leder (1990), Svenaeus (2018) and Toombs (1992). Considering this more recent work helped me understand how phenomenology could be useful for my study. For example, an advantage of taking a phenomenological approach is that it narrows the gap between objective, medical assessments of illness and its effects, and individual, subjective experiences, thus enabling better patient-HCP communication and better understanding of impacts on well-being (Freeman, 2018). Feminist phenomenology has also made a contribution to the study of medicine and health, e.g., Shildrick (1999); Slatman (2012); Zeiler (Zeiler, 2014), showing "how themes of difference, vulnerability, and volatility are central to, rather than deviations from, human experiences, and moreover, that they have important implications within the sphere of medicine" (Freeman, 2018, p. 2).

In addition, having been through my own experience of serious illness, I found that the work of philosopher Havi Carel resonated for me. Carel (2016) draws on the existing phenomenological literature about illness, e.g., Toombs' (1992, p. 229). She considers the important differences between disease and illness, between the objective body and the body as lived, and between health and illness. Using her own experience as a respiratory patient, she develops a 'phenomenology of breathlessness,' and also includes considerations of posttraumatic growth and the personal/cultural interface with death. Her stance helped me to envisage how phenomenology could be useful for taking an open-minded approach towards an illness commonly described as devastating, and for trying to add to the literature on illness as experienced by the 'body as lived'. Phenomenology is thus an appropriate qualitative approach to meet the aims of my study and to answer my research questions, focussing as they do on the lived experience and sense-making of carers for people with an incurable and life-limiting illness.

3.7.4 Consideration of alternative phenomenological research approaches

Having given an overview of the development of phenomenology and justified this as my chosen qualitative approach, I now consider various phenomenological approaches used for research, and show why I rejected them in favour of IPA. These approaches are *descriptive*, *hermeneutic, enactivist,* and *phenomenologically grounded.* In Table 12 I present each approach with my reasons for rejection. Appendix I provides a more detailed account of the approaches and of my reasoning.

Table 12: *Alternative phenomenological approaches with reasons for rejection*

Originator(s)	**Type of approach**	**Description**	**Reason(s) for rejection**
Giorgi (2012)	descriptive	• draws on Husserl's concepts of reduction, description and the search for essences	I do not believe it is possible to carry out the reduction stage completely, achieving some kind of non-influence/neutrality. I see a continuum between description and interpretation.
Colaizzi (1978)	descriptive	• thematic • involves bracketing pre-suppositions • aims to stick closely to the phenomenon as experienced	I do not believe it is possible to carry out the reduction stage completely, achieving some kind of non-influence/neutrality. I see a continuum between description and interpretation.
Van Manen (1990)	hermeneutic	• stays true to Heidegger • rejects bracketing	It has a restricted range of interest and a

		- only considers *pre-reflective* experience - explains existing beliefs and bias - strongly normative	potentially unethical moralising aspect.
Stilwell & Harman (2021)	enactivist	- uses a broader '5E model' of sense-making: embodied, embedded, enactive, emotive, and extended - involves semi-structured interviews, real-time observations, & exploration of participants' engagement with relevant objects	This was not practical for my PhD project and is still in the early stages of development.
Køster & Fernandez (2021)	phenomenol-ogically grounded	- uses concept of 'existentials' to create initial framework - requires intense and prolonged focusing for participants	This would give such a narrow focus as to likely be less than helpful for informing practice and would not be appropriate for carers already under pressure from this incurable disease.

3.8 Interpretative Phenomenological Analysis (IPA)

3.8.1 Overview of Interpretative Phenomenological Analysis

In this section I present an account of IPA methodology and the reasons for its suitability as my phenomenological research approach. Having a critical realist stance meant I needed not just to "collect and repeat" participants' own explanations and interpretations but to aim for a wider understanding; "it is researchers' access to information (theoretical and experiential or data) that respondents are unlikely to have, which allows them to adjudicate between accounts and provide fuller and more adequate explanations" (Parr, 2020, p. 264). In the following discussion of Interpretative Phenomenological Analysis (IPA), my chosen methodology, I show how it aligns with my critical realist outlook.

IPA is a qualitative approach which has a dual phenomenological and hermeneutic stance, with experience, idiography and interpretation as key characteristics (Eatough and Smith, 2017). IPA treats the participant as the "experiential expert", and wants to understand their lifeworld, acknowledging the contribution of subjective knowledge as well as 'objective' scientific knowledge (Eatough and Smith, 2017, pp. 9–10). IPA looks at two aspects of a participant's account, their key objects of concern, and their experiential claims, moving from a focus on one individual by developing themes to explore patterns of meaning across the sample around a shared experience (Smith, Flowers and Larkin, 2009). Six steps are used for the analysis process (Smith, Flowers and Larkin, 2009). A double hermeneutic is invoked: "the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith, Flowers and Larkin, 2009, p. 3). The researcher both takes an empathic stance and also is critical, probing for meanings in ways the participants do not (Eatough and Smith, 2017).

3.8.2 The development of Interpretative Phenomenological Analysis

IPA was introduced by J A Smith (1996) in the context of debates that were happening, particularly in social psychology, between discourse and social cognition. He showed the theoretical roots of IPA in phenomenology and symbolic interactionism[7] and argued that IPA could make a contribution to health psychology, giving as an example his study on the patient's perception of renal dialysis. Smith (2009, p. 194) stressed the importance of having an account of "how the *situated* and *related* qualities of human understanding come about", and saw IPA as partly "an inquiry into the cultural position of the person" (Smith, Flowers and Larkin, 2009, p. 195).

IPA quickly became an established qualitative methodology in the field of psychology; by 2008, 293 papers on IPA studies had been published (Smith, 2011b). Of these papers, 24% were concerned with illness experience, which was unsurprising due to illness tending to be of existential importance and thus naturally suited to IPA's focus on lived experience (Smith, 2011b). Smith (2011b) developed a guide for evaluating the quality of IPA studies (see Chapter 4 *Methods* for how I used this guide). An IPA approach to focus group data was developed (Palmer *et al.*, 2010). Later, IPA began to be used in dyadic research designs (e.g. McGregor *et al.*, 2014; Wawrziczny *et al.*, 2014); it was possible "to maintain a particularly strong idiographic focus alongside their relational analyses, because couples and partnerships of one kind or another present us with a very coherent and recognisable unit of analysis" (Larkin, Shaw and Flowers, 2019, pp. 188–9). More recently, strategies for larger multi-perspectival designs have been suggested (Larkin, Shaw and Flowers, 2019), where a

---

[7] Symbolic interactionism is a theory based on the teachings of G. H. Mead (1934), and it is concerned about "how meanings are constructed by individuals within both their social and personal world" (Shinebourne, 2011, p. 17). Mead (1934) understood the self as both relational and symbiotic, and described communication as the comprehension of another's gestures, i.e., a social act.

commitment to depth is maintained and augmented with systemic, multi-perspective dimensions.

3.8.3 Interpretative Phenomenological Analysis and phenomenology

IPA is influenced by the work of Husserl, in particular "his attempts to get at the *content* of conscious experience – by focussing upon experience itself and describing it in terms of its particular and essential features" (Smith, Flowers and Larkin, 2009, p. 14). Husserl's (Palmer, 1971) concept of adopting a phenomenological rather than a natural attitude was developed by Smith, Flowers and Larkin (2009, p. 189) into a movement between four *layers of reflection*:

1. 'pre-reflective reflexivity' – a minimal level of awareness
2. 'the reflective "glancing at" a pre-reflective experience' – intuitive, undirected reflection, e.g., daydreams, imagination, memory
3. attentive reflection on the pre-reflective – experience becomes 'an experience' of importance and requiring attention
4. 'deliberate controlled reflection' – conducting a formal analysis, i.e., a phenomenological reflection on earlier spontaneous reflection.

In an IPA study, the reflection moves on from the individual (as in the list above) because the researcher enters the loop: the participant engages in reflection at levels 2 and 3, and maybe at level 4, and the researcher carries out a full level 4 analysis after the interview (Smith, Flowers and Larkin, 2009, p. 190). Husserl's (Palmer, 1971) concept of 'bracketing' the taken-for-granted world is also a constituent part of IPA (Smith, Flowers and Larkin, 2009) (see section 3.8.4 below on hermeneutics). From Heidegger's work, IPA takes two main ideas (Smith, Flowers and Larkin, 2009, p. 18):

1. that human beings can be conceived of as 'thrown into' a world of objects, relationships and language
2. that our being-in-the-world is always perspectival, always temporal, and always 'in-relation-to' something – and consequently, that the interpretation of people's meaning-making activities is central to phenomenological inquiry.

Merleau-Ponty's development of phenomenology in the direction of embodiment and the centrality of the individually situated perspective on the world also influenced IPA (Smith, Flowers and Larkin, 2009). His idea that humans' way of knowing about the world is fundamentally shaped via the body is "critical" for IPA; "the lived experience of being a body-in-the-world can never be entirely captured or absorbed, but equally, must not be ignored or overlooked" (Smith, Flowers and Larkin, 2009, p. 19). IPA also drew on the thought of Sartre, who emphasised the *worldliness* of human experience, and its dependence on the presence and absence of relationships, offering "perhaps the clearest glimpse of what a phenomenological analysis of the human condition can look like" (Smith, Flowers and Larkin, 2009, p. 20). Overall, IPA conceptualises a human as "intrinsically a self-reflexive, sense-making agent who is interpreting his or her engagement with the world", and IPA "comes into its own when examining people's perceptions of major experiences happening to them and which engage hot cognition" (Smith, 2019, p. 167).[8]

3.8.4 Interpretative Phenomenological Analysis and hermeneutics

Unlike research approaches which use a *descriptive* phenomenology based on Husserl, such as Giorgi's (2012), IPA is *interpretative,* and is particularly influenced by the ideas of three hermeneutic theorists: Schleiermacher, Heidegger and Gadamer. Schleiermacher (1768-1834), a theologian and philosopher, was concerned with two aspects of a text: the language the author uses, with its expectations and standard forms, plus the unique psychological aspect of the author (Schleiermacher, 1998). His work suggested interpretation was not mechanical but "a craft or art, involving the combination of a range of skills, including intuition" (Smith, Flowers and Larkin, 2009, p. 22). The analyst, because of their "receptivity for all other people" (Schleiermacher, 1998, p. 92) could add an extra perspective on the text, with meaningful insights. In IPA this added extra comes from detailed textual analysis, plus seeing connections from the rest of the dataset, plus engaging with relevant theory (Smith, Flowers and Larkin, 2009).

Heidegger was concerned with hermeneutics in *Being and Time* (1962): he derived the term 'phenomenology' from the Greek *phenomenon* – a thing appearing after being hidden; and *logos* – word/account/reason. A phenomenological interpretative analyst facilitates and makes sense of the thing appearing: "the thing is there ready to shine forth, but detective work is needed to enable that to happen" (Smith, 2019, p. 171). Heidegger's (1962) discussion of *fore-structures* suggests that humans always naturally bring these when considering a phenomenon, and we should try to make sense of them in terms of the thing itself. Smith, Flowers and Larkin (2009, p. 25) state that, because it is not possible to know in

---

[8] Hot cognition is a mental process whereby emotion influences reasoning (VandenBos and American Psychological Association, 2020).

advance which fore-structures are relevant to a particular situation, bracketing needs to be cyclical, and it cannot be completely achieved.

The philosopher Gadamer (1900-2002) was particularly concerned with interpreting texts from the past. For Gadamer (1990, p. 269), a sensitive interpretation

> "involves neither neutrality with respect to content nor the extinction of one's self but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings."

This again highlights that awareness of fore-structures is a cyclical process. Smith, Flowers and Larkin (2009, pp. 27–28) use the model of the *hermeneutic circle* as a way to think about the iterative processes which are part of IPA: "to understand any given part, you look to the whole; to understand the whole, you look to the parts." This occurs at many different levels (e.g., paragraph – whole text; interview – research study), with shifting, dynamic inter-relations. Fore-structures can fit into this conceptualisation thus: "the 'whole' is the researcher's ongoing biography, and the 'part' is the encounter with a new participant" (Smith, Flowers and Larkin, 2009, p. 35). A key feature of IPA is the *double hermeneutic*: "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith and Osborn, 2003, p. 51). The double hermeneutic appears in the way the researcher tries to interpret the experiential meaning of the phenomenon in a second-order way, without direct personal access to the participant's experience (Smith, 2019). It also appears in another way, as IPA combines Ricouer's (1970) two positions, a hermeneutics of empathy and a hermeneutics of suspicion, into a centre-ground position where the analyst tries to see things from the participant's point of view and also is 'questioning' from a theoretical stance (Smith, Flowers and Larkin, 2009). Increasingly deep levels of analysis must be grounded firmly in the text itself (Smith, Flowers and Larkin, 2009). The participant can be conceptualised as an *experiential expert* while the researcher is an *enabler* (Eatough and Smith, 2017, p. 30), which requires the researcher to be "open and receptive to novel and/or unexpected topics and issues introduced by participants" and to act "in a sensitive, empathic manner, recognizing that the interview constitutes a human-to-human encounter." (This is akin to the stance of the person-centred therapist (Rogers, 1978), which makes sense to me from my professional training.) Because of the researcher's active role in the hermeneutic phenomenological approach, and the need for on-going awareness of fore-structures, *reflexivity* is essential throughout an IPA study. The researcher's role is actively explored:

> “The interviewer’s thoughts and feelings are admitted as explicit and thus legitimate components of the enquiry, and their congruence or divergence from those of the participant are matters of proper enquiry.” (Biggerstaff and Thompson, 2008, p. 122)

I discuss the issue of reflexivity in more detail in Chapter 4 *Methods*.

3.8.5 Interpretative Phenomenological Analysis and idiography

The terms *idiographic* and *nomothetic* were introduced by Wilhelm Windelband (1893): nomothetic refers to the study of classes or cohorts, and idiographic refers to focussing on the unique, the individual, and the contingent. IPA is idiographic as it has a commitment to detail, which necessitates deep analysis, and to the perspective of particular people in a particular context (Smith, Flowers and Larkin, 2009). An idiographic approach is seen as useful because, unlike the nomothetic which produces aggregated, statistical descriptions where real individuals are turned into averages, it allows a view of an individual’s unique personal perspective on and relationship to a phenomenon (Smith, Flowers and Larkin, 2009). IPA sees that generalised structures in social science can start from the individual and be built upwards (Eatough and Smith, 2017). An IPA study can add to existing nomothetic research by discussing the findings in relation to the published literature (Smith, Flowers and Larkin, 2009). Thus, analysis in IPA studies moves from detailed consideration of each individual case to looking at differences and similarities across cases, so as to show patterns of meaning-making in a shared experience (Shinebourne, 2011). “In a good IPA study, it should be possible to parse the account both for shared themes, and for the distinctive voices and variations on those themes” (Smith, Flowers and Larkin, 2009, p. 38).

3.8.6 Criticisms of Interpretative Phenomenological Analysis

In recent years, controversy has arisen around the use of the term ‘phenomenological’ with regard to qualitative research: should phenomenological qualitative research be purely descriptive of essentials, or should it look at individuals’ experience and be interpretative, and how closely does it need to adhere to philosophical principles? (Zahavi, 2019). For example, Paley (2017) criticises Giorgi, van Manen and Smith for not being clear enough about their definitions and misinterpreting philosophical authors, thus rendering their methods “arbitrary” (Paley, 2017, p. 147). Zahavi (2019) judges that Giorgi tries to stay faithful to phenomenological philosophy, but that this orthodoxy does not result in impressive outcomes. He also claims (2019, p. 127) that, although IPA “clearly wants to stress the link between its own endeavour and the phenomenological research tradition, it is not obvious, however, that that link amounts to much.” Van Manen, in turn, (2017, p. 778) asserts that Smith’s themes, being too focused on the person rather than the phenomenon, “do not get at the primal meanings” and that the “‘emotional psychological themes’ of an IPA study tend to be assessed as superficial and shallow from a phenomenological perspective.”

In response to these criticisms, the following points have been made. Steen Halling (2020) refers to Merleau-Ponty’s belief that there were many different ways to practise phenomenology, and calls for studies to be evaluated by their products. She quotes Karp (1996, p. 202): “the ultimate value of a study’s worth is that the findings ring true to people and let them see things in a new way.” Smith (2018) defends IPA as phenomenological on grounds which include that studies can be both phenomenological *and* psychological, and that it is legitimate to be concerned with both the pre-reflective and the reflective, as an important part of lived experience. Larkin (2021b) explains that IPA is different from other methods that are closer to Husserl’s account in that it is not a directly philosophical endeavour, but is using phenomenological ideas “as a lens for understanding the psychosocial world.”

3.8.7 Justification for Interpretative Phenomenological Analysis

Maxwell (2013) suggests that a key aspect of qualitative research is taking into account the theories of the participants, as well as those of ourselves and other academics, and he identifies an interpretive, hermeneutic approach such as IPA as facilitating this. Willig describes IPA as having “realist aspirations” (Willig, 2016, p. 4) because its typical research questions address a phenomenon (an experience) that has ontological existence. Reid et al. (2005, p. 21) point out IPA’s “broadly realist ontology”, meaning it can facilitate the integration of research with practice. In IPA methodology, “language is assumed to reflect and communicate what people think and feel” (Braun and Clarke, 2020a, p. 5).Therefore, my choice of IPA aligned with my critical realist position outlined above, and could generate findings with potential to have an impact on health care practice.

My feminist perspective required me to pay attention, where possible, to “dimensions of social, cultural, political, economic, scientific, national and transnational life that go undetected in mainstream discourses” (Hawkesworth and Disch, 2016, p. 10). The rich, idiographic accounts provided by IPA methodology could help me fulfil this ethical requirement. As Halling (2020, p. 10) says:

> “It is an approach that is animated by the desire to address phenomena and personal existence in a three-

> dimensional way, to do justice to life as lived. In other words, it has within it an ethical dimension, even though this may not always be explicitly stated."

IPA has been used for research into illness experience since its inception, with particular interest in experience that has existential importance (Smith, 2011b). Examples of studies include explorations of living with anorexia (Fox and Diab, 2013); having head and neck cancer (Threader and McCormack, 2016); and caregivers' coping experiences (Williams, Morrison and Robinson, 2014). This previous history of use made IPA potentially suitable for my topic. IPA suits studies with a focus "on personal meaning and sense-making in a particular context, for people who share a particular experience" (Smith, Flowers and Larkin, 2009, p. 45). My participants shared the experience of caring for a veteran with a mesothelioma diagnosis, which had an existential, meaningful dimension for the patients and themselves. The dual empathetic and probing process in IPA felt familiar from my experience as a counsellor. I hoped this familiarity would enhance my conduct of the interviews and my analysis process, as I would feel comfortable with finding the balance between these two attitudes. IPA's idiographic approach aims to connect the individual's unique life with the shared experience amongst the participants. Paying attention to individual nuance in the illness experience seemed to me to sit well with the results of my scoping review, which showed that nuance was missing from the existing literature (Sherborne *et al.*, 2020).

Regarding the recent criticisms made of IPA, I considered that my purpose in conducting my research project was not to contribute to the field of academic philosophy but was to do with illuminating a particular illness experience in a new way, which I hoped would bring benefits in practice. This meant I did not find IPA lacking as a methodology for exploring this experience. Therefore, my overall judgement was that Interpretative Phenomenological Analysis was an appropriate choice for my project in methodological, practical and personal terms.

3.9 Conclusion

In this chapter I considered the conceptual framework within which I addressed my research aims, objectives and questions. I justified my use of the qualitative paradigm, critical realist epistemology, and a feminist perspective. Various qualitative research approaches were considered, with reasons given as to why they were not appropriate for my project. I outlined different phenomenological approaches and showed that Interpretative Phenomenological Analysis methodology was a good fit for my project in methodological, practical and personal terms. In the next chapter, I set out the methods I used, in alignment with this methodological framework, to address my research questions (see section 2.6.3).

Chapter 4: Methods

4.1 Introduction

In this chapter I describe the study design developed to address my research questions. The study was designed in two stages: Stage One, a secondary data analysis (SDA) of existing interview data from the Military Mesothelioma Experience Study (MiMES), and Stage Two, my main empirical interview study. The methods used sit within the conceptual framework described in the preceding chapter, that is, the qualitative paradigm, with a critical realist epistemology and a feminist perspective, using IPA methodology. I will demonstrate how the chosen methods are appropriate for answering my research questions (see section 2.6.3). After presenting my chosen methods, I will consider the ethical aspects and then move to provide a discussion of quality assessment. In designing the study I used three established quality assessment frameworks: a set of principles for assessing the quality of qualitative health research (Yardley, 2000); a guide for assessing the quality of IPA work (Smith, 2011a, 2011b); and a rubric for evaluating pre-existing qualitative data for use in secondary analysis (Sherif, 2018). These frameworks are summarised in Table 13. I will come back to discuss how these influenced the quality of my study at the end of the chapter.

Table 13: *Quality assessment frameworks*

Reference	**Purpose of framework**	**Summarised Criteria**
Yardley (2000)	To assess the quality of qualitative health research	sensitivity to context
		commitment and rigour
		transparency and coherence
		impact and importance
Smith (2011b, 2011a)	To assess the quality of IPA work	clearly subscribes to theoretical principles of IPA
		sufficiently transparent
		coherent, plausible & interesting analysis
		sufficient sampling from corpus
		well focused
		strong data & interpretation
		engaging and enlightening
Sherif (2018)	To evaluate data for secondary analysis	fit and relevance
		general quality (completeness, sufficiency, accuracy)
		trustworthiness
		timeliness

The methods used for each of the two stages of my study will now be considered in turn.

4.2 Stage One: Secondary data analysis

4.2.1 Aim

The aim of this stage of the study was to generate initial understanding of the psychological impact of mesothelioma from the perspective of family carers by conducting secondary data analysis of existing interview data. Secondary data analysis (SDA) has been defined as "any further analysis of an existing dataset which presents interpretations, conclusions, or knowledge additional to, or different from, those presented in the first report on the inquiry as a whole and its main results" (Hakim, 1982, p. 2). In my research study, the SDA served to support and inform my main empirical study (Stage Two). The SDA was able to generate initial insight, identify sensitising issues and allow for fine-tuning of the empirical study's research questions and interview schedule. The data I intended to re-use came from the qualitative arm of the Military Mesothelioma Experience Study (MiMES), conducted at the University of Sheffield. The purpose of MiMES was "to generate insights into the experience and health/support needs of British Armed Forces veterans with mesothelioma and identify how best health professionals and support agencies can support them" (Ejegi-Memeh, Taylor, *et al.*, 2020, p. 4).

There are practical and ethical advantages and disadvantages to SDA which needed to be considered (Sherif, 2018; Ruggiano and Perry, 2019). In recent years, there have been growing calls for research data to be made available for access and use by other researchers and stakeholders beyond the original research team. This means existing data and knowledge can be built upon (Chauvette, Schick-Makaroff and Molzahn, 2019). This has positive ethical implications, for example in terms of efficient and economical use of data from research which has been funded publicly or by charities. In addition, it minimises the burden on participants, as existing data can be utilised (Sherif, 2018; Chauvette, Schick-Makaroff and Molzahn, 2019). These implications applied to the MiMES data, as they came from a study funded by Mesothelioma UK which recruited from a population that is inherently small, British veterans with mesothelioma and their informal carers. MiMES had proven slow to recruit from this very small pool of potential participants. Including this SDA in my study was a way to increase the rigour overall in case my final sample size was smaller than planned. Understanding the military context properly by immersing myself in the MiMES data helped me to do justice to Yardley's (2000) first quality criterion, sensitivity to context, and to be respectful to my main study participants. Carrying out the SDA also gave me an opportunity to enhance my understanding of IPA methodology by applying it to this dataset ahead of my main study. As well as encountering the practical side of using this methodology, I was able contemporaneously to glean useful insights from attending training sessions and joining in online discussions with the community of researchers who use IPA. Using IPA to analyse the transcripts in the SDA also meant there was continuity between the two halves of my research study.

4.2.2 Design

The MiMES study had aimed to explore the experience of living with mesothelioma for both patients and carers. To collect suitable data to achieve this, the team used semi-structured interviews, and to write up the findings they used thematic analysis (Ejegi-Memeh, Darlison, *et al.*, 2020). The sample comprised 13 veterans living with mesothelioma, one patient who had been contracted by the Ministry of Defence (MOD), ten family members of veterans with mesothelioma and eight staff members (Ejegi-Memeh, Taylor, *et al.*, 2020). Three researchers had carried out the interviews in 2018 and 2019. The interviews were conducted either in the participant's home, or by telephone. The digitally recorded interviews lasted 24-99 minutes. They were then transcribed verbatim by a transcription service. My SDA used IPA methodology to re-analyse a selection of these transcripts.

The MiMES interview schedule was flexible enough to give participants the chance to talk about what was important *to them*. The transcripts provided many examples of participants describing the psychological effects of the illness, such as how they had been impacted by receiving the diagnosis, how health care professionals' attitudes affected them, how their relationships with others were changed, and coping strategies they had used. They also included examples of participants making sense of these experiences. The data therefore seemed rich enough to be appropriate for analysis using IPA.

In choosing to use IPA for the SDA of this existing dataset I was informed by the method of Spiers and Riley (2019), in which they carried out a dual analysis of interviews with general practitioners (GPs) to uncover barriers to help-seeking. They considered that because their interviews were semi-structured and the interviewers had followed up on topics which interested the participants, the transcripts were suitable for both TA and IPA. Their two analyses "contrasted in terms of breadth versus depth, semantic versus hermeneutic interpretations, and pragmatic versus existential concerns" (2019, p. 281). They recommended that using both TA and IPA on a large qualitative dataset could bring out a "complex, multi-layered understanding" (Spiers and Riley, 2019, p. 286). A further suggestion was that having different researchers do each of the analyses would lead to more differentiated findings. I was in a position of being able to conduct my own SDA analysis of the MiMES data. This added to the evidence generated by that study. I had direct access to the original researchers with whom I could share my developing ideas, checking my interpretations against their experiences of the data.

Whilst conducting a ‘live’ interview allows the researcher to have a dialogue with the participant and follow up interesting comments as they happen (Smith, Flowers and Larkin, 2009), IPA has also been used successfully on non-contemporaneous datasets including diaries, postal questionnaires and email dialogues (Smith, Flowers and Larkin, 2009, p. 57). Although I had not written the MiMES interview questions to specifically answer my research questions, because the transcripts enabled me to extract rich relevant data (i.e., data from participants making sense of an experience of existential import), IPA would be appropriate to use (Larkin, 2021a; Spiers, 2021). Therefore the use of IPA for my SDA seemed a good fit.

4.2.3 Sample

The MiMES inclusion criteria (see Table 14) were that patient-participants had to have been diagnosed with mesothelioma and have served in the British Armed Forces; family members had to have a family member with mesothelioma who was serving/had served in the British Armed Forces; participants should not consider themselves to be experiencing physical or emotional distress which could be aggravated by participating; they could give informed consent; and could speak English (Ejegi-Memeh, Darlison, *et al.*, 2020). These inclusion criteria were suitable for participants who could inform my research questions.

Table 14: *MiMES inclusion criteria*

Criteria	*Patient*	*Family member*
Is diagnosed with mesothelioma	yes	n/a
Has served in British AF	yes	n/a
Has a family member with mesothelioma who is serving/had served in British AF	n/a	yes
Doesn’t consider themselves to be experiencing physical/emotional distress potentially aggravated by participating	yes	yes
Can give informed consent	yes	yes

Can speak English	yes	yes

My research questions intended to explore the psychological effects of mesothelioma from the particular perspective of family carers of UK military veterans. In the MIMES dataset there were only seven transcripts of interviews conducted either with a veteran's carer on their own or of joint interviews with the patient. Initially, I intended to analyse all of the seven available transcripts. As this SDA's purpose was to identify sensitising issues and inform the main research questions and interview schedule, a small sample size was appropriate. Also, a small sample size such as this is appropriate for IPA methodology (Smith, Flowers and Larkin, 2009). (See section 4.3.4 below for a more detailed discussion of sample size and IPA methodology.) A decision needed to be made about the four interviews conducted jointly with the carer and the patient. As IPA has an idiographic aspect, focusing on the individual's unique experience and world view (Smith, Flowers and Larkin, 2009), it would have been complicated to try and unravel the subjective experience of each party in the interview, though IPA with dyads is possible in some cases (Larkin, Shaw and Flowers, 2019). Also, the intention of the original interviewers was not to delineate the differing experiences of carers and patients, so this would have made the process more difficult in terms of how their questions were phrased. Therefore, I decided to use a full IPA process on the four transcripts where carers were interviewed on their own. In addition, I carried out a careful read-through of the joint transcripts. One carer, F9FC, was interviewed on her own while her spouse went to the toilet part way through the joint interview. I therefore treated this section of their joint transcript as a solo interview for analysis, as well as carefully reading the rest of the transcript.

Table 15 shows the range of participants included in the seven available transcripts. The first four shown are those whose transcripts were analysed using IPA for the SDA.

Table 15: characteristics of SDA participants

Characteristics	**F7MM**	**F9FC/P12MN**	**F6FC**	**F2MM**
Carer:				
Veteran	RAF	No	No (but dad was)	RAF
Age	61-65	mid 50s	66-70	71-75
Bereaved	Yes	No	Yes	Yes
Sex	M	F	F	M
Patient:				

Service branch	Army	Royal Marines	Navy (subs) – senior officer	RAF + contractor
Meso type	MPM	MPM	MPM	MPM
Age	Early 60s	Mid 60s	Early 70s	66

Characteristics	**F10FC/P13MN**	**F3FC/P8MA**	**F4FC/P11MA**
Carer:			
Veteran	No	No	No (but Dad was)
Age	66	58	44
Bereaved	No	No	No
Sex	F	F	F
Patient:			
Service branch	Navy – engineer, rose from artificer to lieut. commander	Royal Engineers Army carpenter	The Paras
Meso type	MPM	MPM	MPM
Age	68	61	65

4.2.4 Data analysis

I now describe the process I followed to analyse the four transcripts using IPA. The interview transcripts and related audio recordings were stored on the university department's shared drive. I downloaded each transcript and prepared the text by creating wide margins to give room for annotations during the analysis process.

Smith, Flowers and Larkin's (2009) six steps were followed to analyse the transcripts; these steps are not intended to be prescriptive, but they provide a clear heuristic framework which uses processes and strategies appropriate for IPA, thus allowing commitment and rigour to be demonstrated (Shinebourne, 2011). Although I completed each of the six steps, in practice the process was not "uni-directional" (Smith, Flowers and Larkin, 2009, p. 81), as I sometimes revisited earlier steps, following the hermeneutic circle. The steps were:

1) Reading and re-reading
2) Initial noting - descriptive, linguistic, and conceptual comments

3) Developing emergent[9] themes
4) Searching for connections across emergent themes
5) Moving to the next case
6) Looking for patterns across cases.

In Table 16 I summarise each of the six steps. I will then go on to describe how I operationalised each of the steps in the secondary data analysis. The same steps for analysis were used for both the SDA and the analysis of the stage two interview data. Any differences between the analysis of the two stages are detailed below in Section 4.3.7. (Due to the same process being used in both stages of the study, examples used to illustrate my operationalising of the steps in this section are taken from both the SDA and the main study analysis.)

Table 16: *Smith, Flowers and Larkin's (2009) six steps to analysis*

Step	**Process**	**Description**
One	*Reading and re-reading*	Aiming at immersing oneself in the data, becoming actively engaged, getting a sense of the overall flow and shape of the interview, whilst also noticing one's own reactions.
Two	*Initial noting*	Is detailed and takes time, involving descriptive, linguistic and conceptual comments, which often include personal reflection, i.e., reflexivity, but making sure that this is "inspired by, and arose from, attending to the participant's words, rather than being imported from outside" (Smith, Flowers and Larkin, 2009, p. 90).
Three	*Developing emergent themes*	Using the initial comments (rather than the data) to map patterns, creating phrases which have "captured and reflect an understanding", not all of which may be incorporated into the next step, depending on the research questions (Smith, Flowers and Larkin, 2009, p. 96).
Four	*Searching for connections across emergent themes*	Using ways of looking for connections including: • *abstraction* (grouping together under a title, making a 'super-ordinate theme'), • *subsumption* (using an emergent theme as a 'super-ordinate theme'), • *polarization* (looking at oppositional relationships as an organising device),

---

[9] As Smith, Flowers and Larkin used the term 'emergent' in their well-known (2009) explanation of the six steps, I have also used it here. However, as IPA is a fundamentally interpretative process, themes cannot be conceptualised as 'emerging' from some hidden state to be 'discovered' by the analyst. The outcome of the initial commenting process is the *development* of themes: "the themes reflect not only the participant's original words and thoughts but also the analyst's interpretation. They reflect a synergistic process of description and interpretation" (Smith, Flowers and Larkin, 2009, p. 92). I have used the term 'emergent' in my thesis to align with Smith, Flowers and Larkin's terminology. (In the newly launched iteration of IPA (Smith and Nizza, 2021), too late for my thesis, 'emergent themes' are renamed 'experiential statements'.)

		- *contextualisation* (attending to narrative, temporal and cultural links), - *numeration* (noticing the frequency of a theme's appearance).
Five	*Moving to the next case*	Repeating the previous steps with the next participant's data, keeping one's focus on the new case to align with IPA's idiographic nature.
Six	*Looking for patterns across cases*	Aiming to show where "participants represent unique idiosyncratic instances but also shared higher order qualities"; often presented in a table showing nesting of themes with illustrations for each participant (Smith, Flowers and Larkin, 2009, p. 101).

Step one - reading and re-reading

In Step one, I immersed myself in the data. After downloading each transcript, I read through it fairly quickly, to start my familiarisation with the data[10]. I then listened to the original audiotape while re-reading the transcript. I also read any field notes. I did this because different levels of engagement with data, ranging from doing the interviewing, to listening to the audio or merely reading the transcript, mean there are potential gains and losses in terms of a secondary researcher's likelihood of biasing their interpretation (Rodham, Fox and Doran, 2015). For example, a participant's tone of voice can illuminate usage of an expression which may be ambiguous on the page. Unfortunately, the audio file for one carer was not available (F2MM). However, as confidentiality was shared amongst the MiMES research team, I was able to find out that this participant was someone well known in the mesothelioma patient and carer community, whom I had met. I was therefore able to 'hear' his voice as I read the transcript, which helped balance the unavailability of the audio. Whilst reading the transcript and listening to the audio, I took notice of my own reactions and kept reflexive notes (see Appendix J for an example). These notes were filed systematically to provide an audit trail and to allow me to re-read them during later stages of the analysis.

Step two – initial noting

On each transcript, initial comments were recorded systematically alongside the text (see Appendix K for an example of a transcript page). The annotated transcripts would ideally have been scanned and saved electronically to provide a long-term audit trail, but this option was not available due to home working necessitated by Covid restrictions. Descriptive

---

[10] I chose not to amend the existing SDA transcripts by adding any repetitions, ums and ahs, etc. in order to keep consistency between the original MiMES dataset and the one I used for the SDA. Also, the time I dedicated to the SDA analysis needed to be proportionate.

comments were coloured blue, linguistic were green and conceptual were purple. There was also a red column for reflexivity comments. It is considered good practice throughout the research process to keep memos, as this encourages and records reflexivity (Smith and Osborn, 2015). I kept reflexivity notes throughout my PhD journey. During the SDA, any reflexive thoughts that seemed to relate directly to the transcript I was analysing were added into a separate column on the transcript. I wanted to make sure that any reflexive comments added to the transcript were rooted in the participant's data. When I added any further reflexive comments to the column as part of the interative process, recording extra thoughts and reactions when reading back over previous comments, I dated these to show they came later. Other reflexive thoughts which were more general, for example, about the analysis process itself, were kept in my handwritten research journal, which was always available as I carried it with me. (See Box 2 for an example of a reflexive note from my journal.)

Box 2: *transcribed extract from my reflexivity journal*

> 8/7/20
> Still feeling *very* reluctant to do F6FC's emergent themes. Is it the way the printout looks – it's a version with lots of horizontal lines – makes my eyes uncomfortable? Or is it to do wth the interview – my view feels illicit/ incompetent/ fictional? Have tried to imagine her as one of my clients to see if that helps my engagement – but that feels "wrong". Does she 'want' my engagement?? It's like there is a STAY AWAY force-field around this interview!!

These journals were each scanned and saved when they were full (though this was not possible during lockdown due to lack of access to the departmental scanner). Whilst there is increasing use of electronic media to make reflexivity notes, creating an audit trail to enhance quality and validity (Vicary, Young and Hicks, 2016), I found handwriting could aid my intuition and help avoid thoughts and feelings becoming too mechanistic during the process of recording. My systematic filing of notes meant that a hard copy audit trail remained accessible.

During step two of the analysis, I sometimes used the 'deconstruction' technique (Smith, Flowers and Larkin, 2009, p. 90) as a de-contextualisation strategy, fracturing the narrative flow, to get an awareness of the participant's particular words and meanings. This meant reading and annotating sections of the transcript out of order. This helped if I felt I was taking the data for granted at any point; it forced me to pay closer attention to each sentence. As I got nearer to the end of the initial noting process, I noticed more links and contradictions between sections, and potential themes started popping into my head. These were noted down on a hand-written sheet.

Step three – developing emergent themes

Once the initial notes had been made on the transcript, emergent themes were added in black ink in a separate column. (See Appendix K for a photograph of an annotated transcript page.) I developed these themes by using the red, green, purple and red comments on the transcript, rather than the participant's actual words, to produce phrases which conveyed an understanding. An example is presented in Table 17: this shows the handwritten comments from the photograph in Appendix K.

Table 17: *Table showing emergent themes developed on one transcript page*

Line no.	*Interview data, with linguistic comments in green*	*Descriptive comments*	*Conceptual comments*	*Reflexive comments*	*Emergent themes*
389	In the chain of command [mil. concept], if someone who was in a responsible [important adjective]	It [talking about asbestos – previous page] was taboo in the chain of command.	This taboo was in the chain of command, who had responsibility.		Talking about asbestos was taboo in the chain of command
390	position was asked a question about asbestos in a home or in a				
391	billet or in an aircraft or in an office [listing, covers different types of location] then the stock [cf. line 290] reaction would be				Passing responsibility upwards
392	to pass it up the line. In the armed forces you have what they call a	Any questions about asbestos were passed up the line.	Stock reaction of passing questions upwards seems like medics' stock reaction – avoids responsibility?		NHS & MOD seek to avoid responsibility
393	chain of command, but you don't step outside [physical metaphor] of your role. So, you				
394	are responsible [repetition] for whatever is in the square, but you don't actually	You are only responsible for what is in the square.			The square limits your responsibility

395	go out of [physical metaphor] the square, or you don't make the square [repetition of mil. jargon] any bigger. You		The square: it is fixed size. Stay in yours & don't make it bigger.		
396	pass it on to somebody else who's in command of their square [repetition] and				
397	so on, and up the ladder [metaphor] it goes. And very [emphasis] rarely was anything ever	Once it went up the ladder, action was rarely taken.		Sense of things disappearing up that ladder into the mists, the clouds. Ladder & squares makes me think of 'Snakes & Ladders'!	
398	done about anything of this nature, because once it got further up	It was a question of affordability, not of right or wrong.	Lower down the chain there is idea of right and wrong, but higher up it's about affordability.		Right and wrong is operating lower down the chain
399	that chain, then it became not a question of whether it was right or				
400	wrong, it became a question of whether [repetition points up contrast] any remedy could be				
401	afforded, if you're with me on that [checks interviewer understands his criticism of the military]. In other words, can we afford to				Higher up the chain, affordability is the priority
402	eradicate [stresses totality] all that asbestos from that block or that…				

At this point in the analysis process, there were a very large number of emergent themes. To facilitate the stage of mapping patterns between these themes, *Quirkos*, a computer-assisted qualitative data analysis software (QDAS) package, was used. In using IPA methodology, researchers are encourage to "explore and innovate in terms of organising the analysis" (Smith, Flowers and Larkin, 2009, p. 96). There did not appear to be any published articles on the topic of using *Quirkos* software to aid IPA by which I could be guided. I therefore experimented with using it not just to cluster and map in step three, but also in step four, where I was searching for connections across emergent themes.

Following Paulus et al.'s (2017) recommendations for reporting the use of qualitative data analysis software (QDAS), I here give some detail on how I used this to improve quality. All the initial themes for each participant were uploaded to *Quirkos* and assigned to Quirks. A Quirk (or node) is a coloured bubble representing a particular topic of interest in a project (Quirkos Limited, 2020). The Quirks could then be moved around on the screen and clustered together in an iterative process, thus mapping patterns. This process felt creative yet rigorous, providing an audit trail and lending itself well to the iterative nature of IPA. It also provided an efficient way to link themes and quotations at the writing up stage. (See Appendix L for an example *Quirkos* map of emergent themes.)

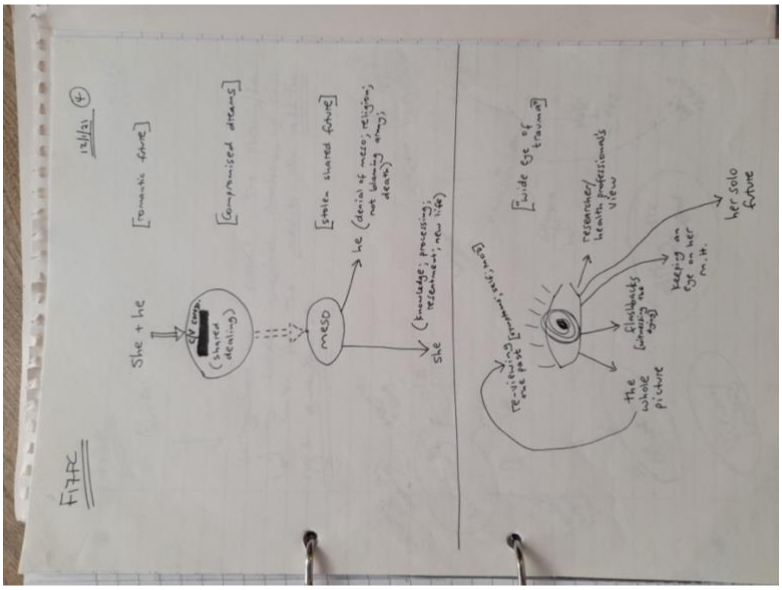
Also in step three, for each participant I created an 'important quotes' list, i.e., of things they said which stood out for me. This was a process which helped me to start developing themes. It was also a useful resource to send to my supervisors, as it gave them a flavour of the raw data before they heard my interpretations. I added dates to my reflexive comments as I amended these, adding some extra thoughts and reactions when reading back over previous comments during the iterative process.

During step three, I felt a great sense of responsibility, and needed to remind myself that the interpretative nature of IPA meant my 'take' was legitimate and important. However, I found that the huge initial psychological impact of Covid-19 and lockdown in Spring 2020 caused me to mistrust my judgement, as if I did not have my usual parameters to measure my responses against. As a counsellor, I was used to having good reflexive awareness, which helped me to know what was 'my stuff' and what was my client's. Covid had plunged everyone into an uncertain world and my accustomed solid sense of self had disappeared[11]. It took a while for my confidence to return. Drawing maps and diagrams became a useful technique for me to explore the initial themes and work towards super-ordinate themes (see Image 1 for an example). My supervisors were able to connect these diagrams with the data, finding them useful tools to make the process of my thinking tangible. This reassured me particularly at the time when my own sense of self in the world was wavering. Allowing myself time for my unconscious to mull over the data seemed to help me see patterns and connections. These often came into my mind when I was out running.

---

[11] The novelist Robert Harris (Preston, 2021) reported a parallel experience of lockdown's unsettling effect: "It made it hard to write the book. I've realised over the years that a lot of writing is done in the subconscious. And to stimulate the subconscious you need to relax. You need to see friends, go out, go to the theatre. When you can't do that, the mind becomes a very strange place. I couldn't work for more than three or four hours a day. I had to stop at noon. And what Stephen King calls 'the boys in the basement' – the subconscious – they weren't there to call on in lockdown."

Image 1: *Example of an exploratory diagram*



Step four – searching for connections across emergent themes

In this step, I developed super-ordinate themes, with up to three sub-themes within each of these (see Table 18). (The third SDA super-ordinate theme did not suit being broken down into sub-themes.)

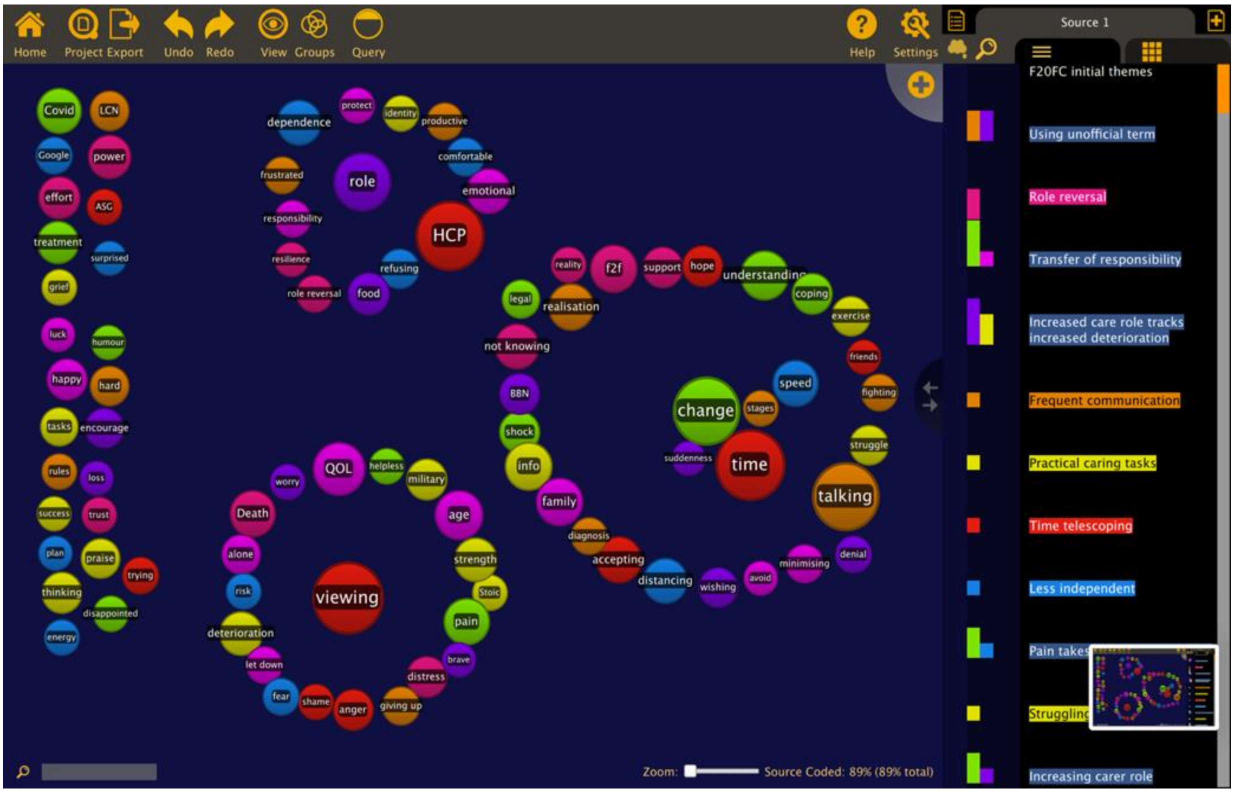
Table 18: *Overview of SDA super-ordinate themes and sub-themes*

Super-ordinate themes	**Sub-themes**
1. Control and responsibility	The chain of command
	Controlling language and thinking
	The out-of-control body
	The proactive carer
2. Openness: is it safe?	Secrecy and intimacy
	Official secrets
	Becoming vulnerable
3. Human connections: getting support	*No sub-themes were developed for this super-ordinate theme*

Image 2 presents an example of a *Quirkos* screen for F20FC, showing work-in-progress of grouping as I moved towards sub-themes and super-ordinate themes.

I used various strategies for making connections within the emergent themes. *Abstraction* meant looking for themes (in the right-hand column) which could be grouped together in a Quirk. For example, ‘less independent’ went into the ‘dependent’ Quirk; ‘using unofficial term’ (i.e., not a HCP’s technical term) went into the Quirks named ‘role’ and ‘talking.’

Image 2: *Quirkos screen showing work-in progress in step four (F20FC)*



Subsumption meant using an emergent theme as a super-ordinate theme. In practice, this strategy resulted in my using some emergent themes as sub-themes, rather than super-ordinate themes, e.g. 'the chain of command' sub-theme in Table 18 (above) was originally an emergent theme. I found *polarization* to be a helpful strategy: many themes could be grouped with others with which they had an oppositional relationship, and this could be reflected in the naming of some sub- and superordinate themes. For example, F17FC (in stage two) had a super-ordinate theme '*(Dis)connection and withdrawal',* with sub-themes '*To have and to hold',' Choosing to withdraw'* and '*Connecting to support'.* This super-ordinate theme included a strong element of disconnection as well as connection, which I chose to show with the name *(Dis)connection*. When I used the strategy of *contextualisation,* I was paying attention to narrative, temporal and cultural links. This was important as participants were narrating the illness experience, which tended to have several key moments and where the passage of time was an important aspect. Image 3 presents one cluster, '*the long, tough meso journey'*, from F7MM's *Quirkos* screen, illustrating how contextualisation could play out in step four of the analysis.

Image 3: *A cluster from F7MM's Quirkos screen*

Using *numeration,* noticing the frequency of a theme's appearance, was made easier by the *Quirkos* software, as the more themes that were coded to a particular Quirk, the larger it grew (see Image 3 above). I was able to use this as a possible indicator of how important this aspect of their experience might be to a participant (Smith, Flowers and Larkin, 2009). I also bore in mind that a participant might also have a rarely occurring theme which nevertheless conveyed a very meaningful part of their experience. For example, Gary (F15MM) had the theme 'a grown man' only twice, yet it seemed to reflect a fundamental aspect of how he had experienced the mesothelioma journey.

For finalising the sub- and super-ordinate themes, I used a combination of the *Quirkos* screen and hand-drawn diagrams (see Images 4 and 5 for examples of these diagrams).

Once the sub- and super-ordinate themes had been finalised, they were transferred to a table for that participant, along with illustrative quotations (taken from the 'important quotes' document). The layout of the table is shown in Appendix M.

Image 4: *F16FC's sub-themes development diagram*

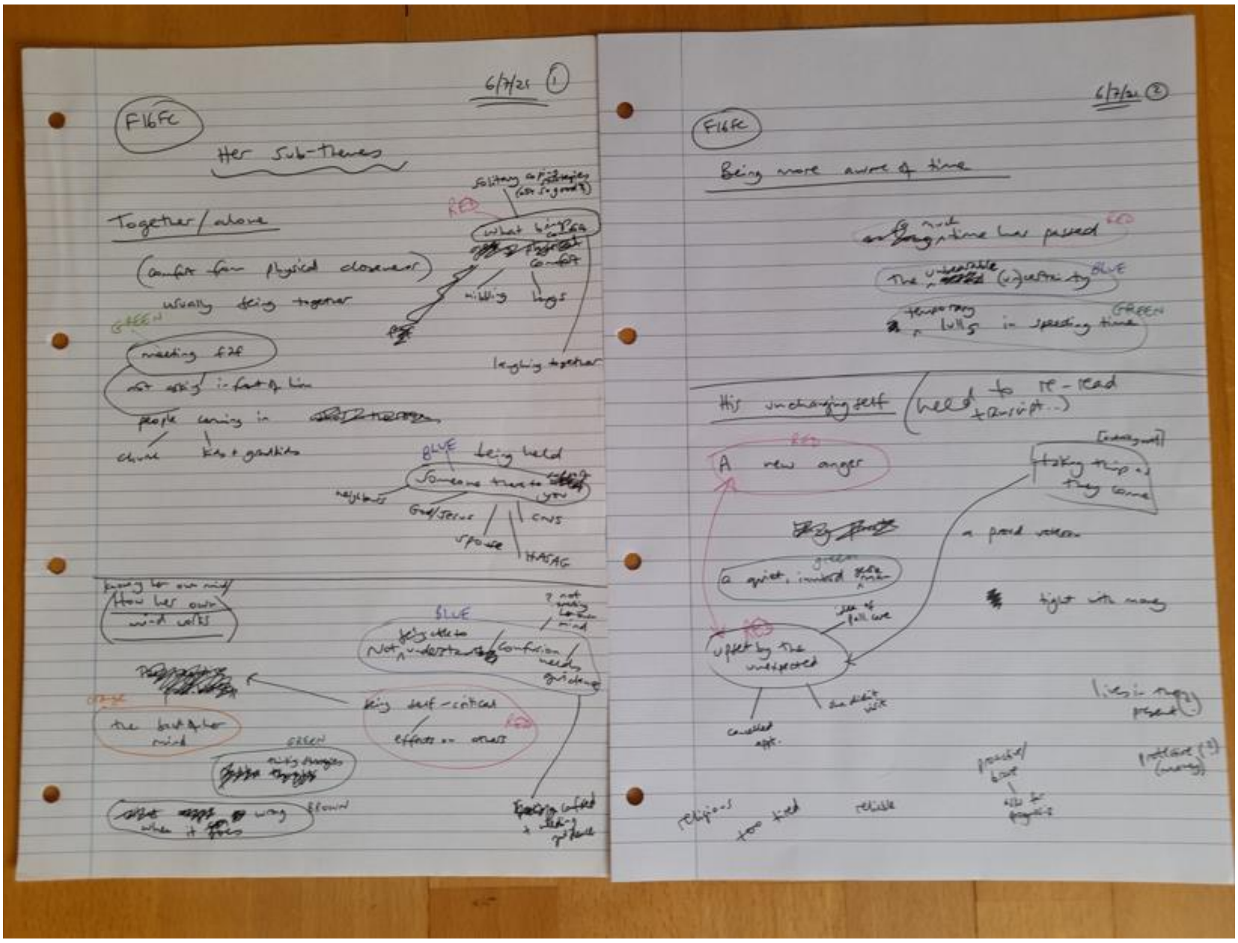
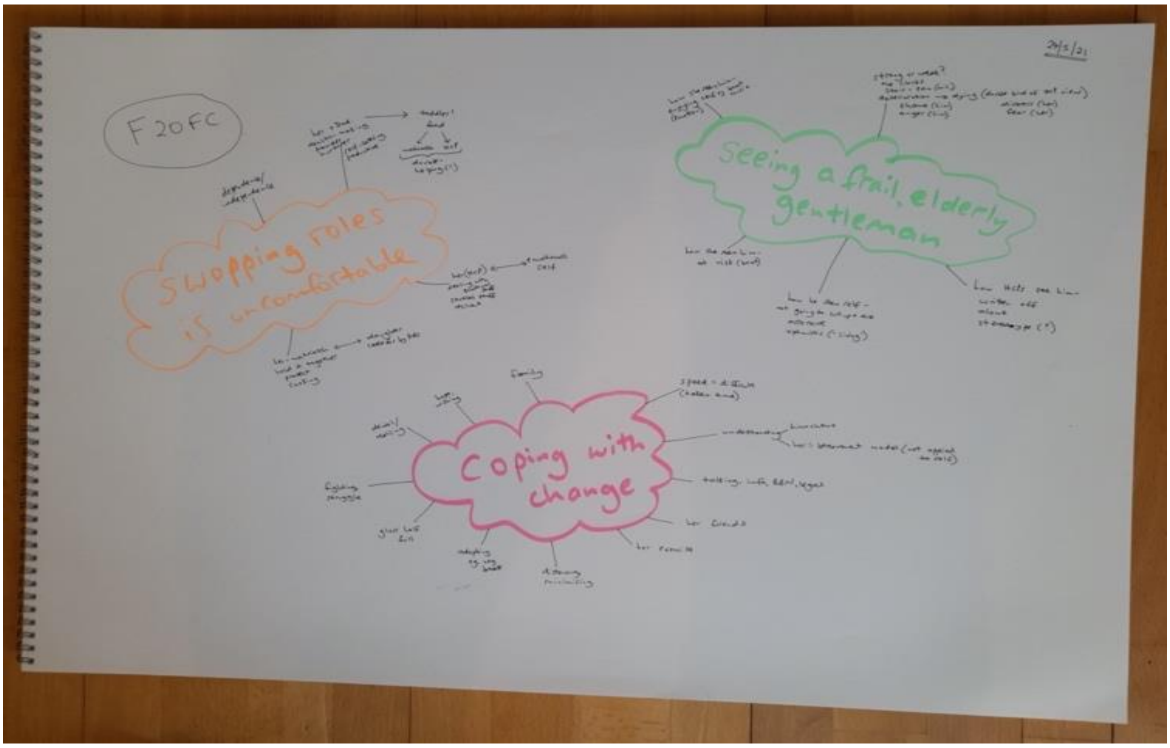


Image 5: *F20FC's super-ordinate themes diagram*



Step five – moving to the next case

In this step, I repeated steps one to four with the next participant's transcript. It was important to put to one side the previous participant's case as far as possible, so as to keep my focus on this new individual's experience, as is required to match the idiographic stance of IPA (Smith, Flowers and Larkin, 2009). My experience as a counsellor was helpful at this point, as I had been trained to focus on the client in front of me during sessions, and to try not to draw comparisons with the experience of previous clients or myself. Although links between participants' data would come to mind every so often, I mentally put them to one side and refocused. Keeping reflexive notes helped this process. Also, rigorously going through each of the steps allowed room for new themes to be developed (Smith, Flowers and Larkin, 2009). Each participant's data were processed using these steps before moving on to the next.

Step six – looking for patterns across cases

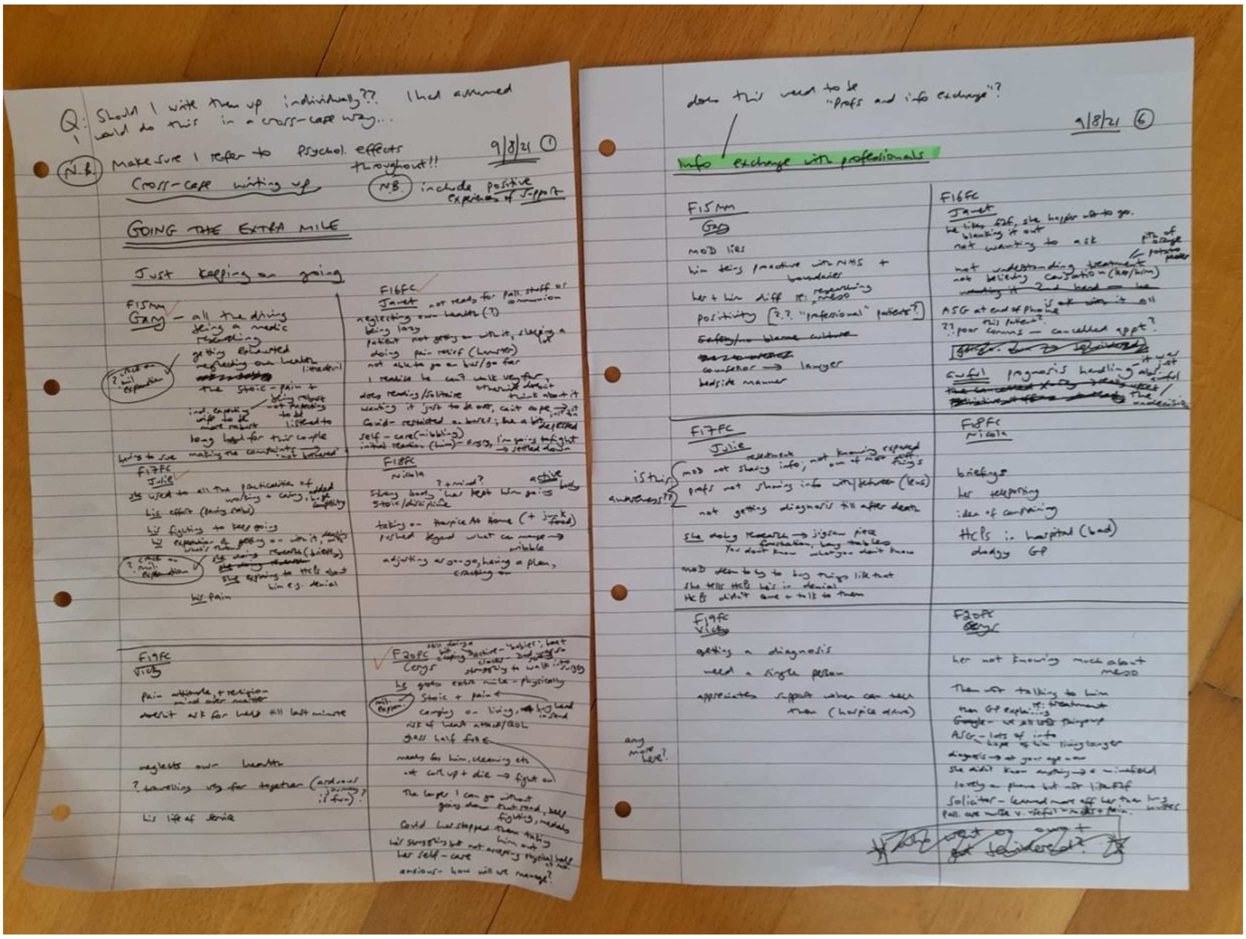
With this step, the aim was to show where "participants represent unique idiosyncratic instances but also shared higher order qualities" (Smith, Flowers and Larkin, 2009, p. 101). Again, I was able to use a combination of the *Quirkos* software and my hand-drawn diagrams to begin exploring connections and finding new understandings in the interface between the themes. I made a master table by combining each participant's table of sub- and super-ordinate themes, which gave me access to all of these in one place for cross-referencing. The final step prior to writing up the findings was to make a hand-written plan of all the cross-case themes and their appearance in each participant's data (see Image 6).

My ambition in this step was to reach a sophisticated level of interpretation by moving from a cautious, descriptive approach to "dig deeper" (Smith, Flowers and Larkin, 2009, p. 105). This meant treading a middle way between a hermeneutics of empathy and a hermeneutics of suspicion, a process which required staying close to the data itself (Smith, Flowers and Larkin, 2009).

4.2.5 Discussion

I chose not to write a discussion of the SDA findings at this stage, but to write a combined discussion when I had the findings from the main interview stage. This strategy was chosen to avoid repetition, as there was likely to be overlap between the two sets of findings. See section 4.3.8 for detail on how the two sets were combined.

Image 6: *Chart of Stage Two cross-case themes and their appearance in each participant's data*



Q: Should I write them up individually?? I had assumed I would do this in a cross-case way...

N.B. Make sure I refer to psychol. effects throughout!!

9/8/21 ①

Cross-case writing up

N.B. include positive experiences of support

GOING THE EXTRA MILE

Just keeping on going

F15MM
Gary – all the driving
being a medic
researching
getting exhausted
neglecting own health
the stoic – pain + being robust
not expecting to be listened to
long haul for this couple
making the complaints "not believed"

F16FC
Janet
not ready for pall. stuff or communion
neglecting own health (?)
being lazy
patient not getting on with it, sleeping a lot
doing pain relief
not able to go on bus/go far
I realise he can't walk very far, otherwise doesn't think about it
does reading/solitaire
wanting it just to be over, can't cope
Covid – restricted on buses; he a bit depressed
self-care (nibbling)
initial reaction (him) – [illegible], I'm going to fight → settled down

F17FC
Julie
she used to all the practicalities of added working + caring, high complexity
his effort
his fighting to keep going
his expectation of getting on with it
she doing research (briefly)
she explaining to HCPs about him e.g. denial
his pain

F18FC
Nicola
strong body has kept him going
stoic/discipline
taking on Hospice At Home (+ junk food)
pushed beyond what can manage → nibble
adjusting as go-go, having a plan, cracking on

F19FC
Vicky
pain attitude, + religion
mind over matter
doesn't ask for help till last minute
neglects own health
? travelling very far together
his life of service

F20FC
Carys
he gets extra [illegible] – physically
stoic + pain
carrying on living
glass half full
meals for him, cleaning etc
not curl up + die → fight on
The longer I can go without going down that road, keep fighting
his struggling but not accepting physical help
her self-care
anxious – how will we manage?

does this need to be "Profs and info exchange"?

9/8/21 ⑥

Info exchange with professionals

F15MM
Gary
MOD lies
him being proactive with NHS + boundaries
her + him diff re: researching meso
positivity [?.? "professional" patient?]
~~Safety/no blame culture~~
counsellor → lawyer
bedside manner

F16FC
Janet
he blanking it out
not wanting to ask
not understanding treatment
not believing causation
ASG at end of phone
?? poor comms – cancelled appt?
awful prognosis handling – it was just awful

F17FC
Julie
is this awareness??
MOD not sharing info; resentment, not knowing
profs not sharing info with/between (HCPs)
not getting diagnosis till after death
she doing research → jigsaw piece
You don't know what you don't know
she tells HCPs he's in denial

F18FC
Nicola
briefings
idea of complaining
HCPs in hospital (bad)
dodgy GP

F19FC
Vicky
getting a diagnosis
need a single person
appreciates support when can tell them (hospice [illegible])
any more here?

F20FC
Carys
her not knowing much about meso
ASG – lots of info
she didn't know anything → a minefield
Solicitor – learned more off her than [illegible]

4.2.6 Sensitising issues identified from the Secondary Data Analysis

The sensitising issues were factors generated from the secondary data analysis which informed the practicalities of conducting interviews in Stage Two. It was important for me to identify these issues to help create a respectful, trusting relationship between myself and the participants. As a civilian 'outsider' researcher, I wished to avoid making the participants feel uncomfortable, and to make sure I was not disconcerted by responses from them which might be unexpected. Examples of how my conduct of the interviews was enhanced by my new understanding will now be presented as I go on to summarise these sensitising issues. (For a more detailed account of these issues, with illustrative quotations from the transcripts, see Appendix N. A full presentation of the SDA findings will be made in Chapter 5.) The sensitising issues in the following six paragraphs are highlighted by italics.

The SDA suggested that *military culture and values* stay with veterans after they transition into civilian life. At a practical level, the carers valued efficiency and the fact that professionals they met were well-equipped. I therefore understood that I needed to be well-prepared for my interviews, with all the technology in place and working, with a clearly explained plan, and with attention paid to the time.

Hierarchies of power came up often in the interviews. The chain of command in the military was very present as an organising principle, leading participants to have strong expectations about responsibility: people high up in the chain of command should care about those lower down; they should be trustworthy; they should face up to things when mistakes happen. Carers and patients described instances of being let down by those perceived to be powerful. I knew I would need to pay particular attention to the issue of power in the participant-researcher relationship.

I also became aware of the potential overlap between *the participants' experiences of medical research* and my own research. Because the illness is currently incurable, there is a great deal of focus within the mesothelioma community on medical trials. The participants often referred to their experience of the *idea* of research and their participation in it. There was a sense that the researchers were high status and rather detached from the patients, not bothering to communicate with them about the work. At times, it seemed as if the participants' understanding of the research process was rather hazy. This included a lack of awareness of how exactly their experience might be of interest and use to researchers. Participants often expressed their willingness to help with research. However, there were hints that they found, or expected, the interview to be difficult. I saw that I might be positioned as powerful, as an 'expert researcher', with the accompanying expectations of care and potential for letting down my participants. I hoped to listen to my participants in a way that they experienced as being respectful and curious, rather than coming from a directive, arrogant, powerful position. I needed to be clear about the purpose of my study, and to be respectful and explicit about the valuable contribution the participants would be making.

An important aspect of my research setting was *the sense of there being 'insiders', the military community, and 'outsiders', civilians.* There was a general feeling that civilians can't understand people from the Armed Forces community. I was pleasantly surprised at how willing the participants were to be patient with the civilian interviewers and not use much military jargon. However, one carer spelled out the adverse effect on the patient of being questioned by a civilian taking an occupational history during the compensation process. I learned that as a civilian I would need to tread carefully, and perhaps rein in my usual counsellor-style empathy, whilst trying to show warmth and understanding less obviously.

Throughout the SDA process, I was aware of *a discomfort amongst the participants regarding difficult emotions*, though some seemed to be ‘allowed’, i.e. fear, anxiety and anger. There seemed to be a taboo particularly around loss, grief, sadness and feeling ‘low’. The phrase ‘poor me’ cropped up on several occasions, and was associated with feeling sorry for yourself and being rather pathetic. In fact, there seemed to be a feeling among some participants that allowing emotional upset into awareness could be catastrophic. In terms of my interviews, this made me wonder what might happen if my questions led to participants feeling ‘upset’, as feeling vulnerable seemed to be avoided. I hoped not to make participants feel shamed. It would be essential for them to have support easily available after the interview, and it was probably important that *I* did not appear to be upset by anything that I heard.

The SDA process led me to question how emotionally aware this group of participants were. There seemed to be some difficulty in naming feelings or putting them into words. Participants did, though, sometimes vocalise the emotional impact of events using expressive sounds or metaphors (often physical/military). I was struck how some participants were talking about potentially highly emotive things, but just didn’t ‘go there’, i.e. they didn’t mention having any feelings about these issues. This left me with some anxiety that my study participants might not be able to articulate or be aware of the psychological effects I wanted them to discuss.

A final sensitising issue was *the use of humour*. A sense of humour is highly valued in the British Armed Forces as a way of allowing individuals to face danger and of enhancing group bonding (King, 2004). There were many examples of participants using humour as a coping mechanism, often at moments of pathos, when sad or fearful feelings might have been around, or where there was a sense of powerlessness or betrayal. I would need to be ready for this strategy to be used by my participants, and to be sensitive about probing at that point. Also, it could be helpful if I was not too solemn from the start of my contacts with participants, whilst at the same time being respectful towards them. Having identified the sensitising issues from the STA in Stage One of the study, in the next section I will present the methods chosen for Stage Two of my study.

4.3 Stage Two: Main interview study

4.3.1 Aim

The aim of Stage Two, the main interview study, was to explore the psychological effects of mesothelioma from the perspective of carers of UK military veterans.

4.3.2 Design

Individual semi-structured audio-recorded interviews were carried out between 28/9/20 and 30/3/21 virtually[12] using an online platform (Google Meet) with six carers of UK military veterans who had a diagnosis of mesothelioma. Within IPA methodology, data has tended to be collected via semi-structured interviews with individual participants who share a perspective on a single phenomenon (Smith, Flowers and Larkin, 2009). However, in recent years there have been calls for the use of multi-perspectival designs, with the aim of "capturing more complex and systemic experiential phenomena", for example to understand an inherently relational topic like a caring relationship (Larkin, Shaw and Flowers, 2019). It was possible that constructing a dyadic design, with both the person with mesothelioma and the carer present, would have been illuminating for my study in terms of including the additional relational/ "in between" dimension. However, it seemed more appropriate to honour the absence of carer-only research studies revealed in my scoping review. I wanted carers to have an opportunity to speak freely without the presence of the patient. A longitudinal design was also considered. This could have been useful to capture changes in the experience of living with mesothelioma at different stages of the disease. However, potential difficulties relating to such studies have been identified, including needing to ensure that "gathering and analysis of collected data are achievable within the allocated study time" (Farr and Nizza, 2019, p. 204). Carrying out a longitudinal study within the time constraints of my PhD was unrealistic.

Data for IPA methodology need to be rich, meaning that participants have expressed their ideas, concerns and stories at length and in detail (Smith, Flowers and Larkin, 2009). This is so that the researcher has enough suitable data available to "map out" experiences in terms of how the participants understood them, and also to set these in their cultural and physical contexts (Larkin, Watts and Clifton, 2006, p. 117). Individual interviews alone are only one way to facilitate this; for example, focus groups (Palmer *et al.*, 2010), photography (Quincey, Williamson and Wildbur, 2021) and painting (Kirkham, Smith and Havsteen-Franklin, 2015)

---

[12] Face-to-face interviews, which had been originally planned, were impossible due to the COVID-19 pandemic (see section 4.3.3).

have been used. I chose semi-structured single interviews to minimise the burden on my participants in terms of time, and to make sure that a suitable agenda was framed and structured sensitively.

4.3.3 Setting

Originally the interviews were intended to be conducted face-to-face at the participant's home or a place of their choosing, or by telephone if necessary. I preferred to meet face-to-face to enhance rapport, gain a holistic picture of the participant (e.g. body language), and ensure confidentiality (McCoyd and Schwaber Kerson, 2006). However, the Covid-19 pandemic intervened, and all the interviews were carried out using the University of Sheffield's approved online platform, Google Meet, which was deemed to be appropriately secure. An amendment to the ethics application was made to change the interview medium. Archibald et al.'s (2019) paper on using videoconferencing for qualitative data collection proved useful, as did Turner's (2020) tips for conducting qualitative interviews online. At the same time, I had to move my counselling practice online, which meant I rapidly became familiar with establishing rapport remotely. The only technological problem with interviewing remotely occurred in the final interview, with a participant in rural Wales. Her internet connection was unreliable and deteriorated during the call to the extent that around 15 minutes before the end I chose to switch to a telephone call. The recording device failed to pick up our final ten minutes of conversation, but as a fail safe because her replies seem very faint on the phone line, I had decided to make contemporaneous hand-written verbatim notes, without adding or paraphrasing. I typed up these notes and felt justified in adding them to the end of the transcript as I knew that all the phrases were exactly as she had worded them.

4.3.4 Sample

In IPA studies, researchers purposively sample to create a "reasonably homogeneous" group (Smith, Flowers and Larkin, 2009, p. 3) which can give particular insight into a phenomenon. The research question must be meaningful for the sample, "who 'represent' a perspective, rather than a population" (Smith, Flowers and Larkin, 2009, p. 49). As mesothelioma is a rare illness, the topic itself defined my sample's boundaries (Smith and Osborn, 2015). My purposive sample focused on participants who shared two life experiences: caring for someone with mesothelioma and being part of the military community (i.e., serving personnel, both regular and reservists, veterans and military families). Within my sample there was variation in terms of gender, age, military/civilian status, service branch, type of mesothelioma, geographical location, and relationship of carer to patient.

I also needed to consider sample size. Sample sizes are often not justified in published qualitative studies, affecting credibility, and suggestions have been made regarding best practice (Marshall *et al.*, 2013; Boddy, 2016), including demonstrating saturation statistically. A sample size of 12 has been suggested as enabling saturation in a homogeneous population (Marshall *et al.*, 2013; Boddy, 2016). However, this approach is positivistic, assuming at some point researchers can *know everything* about a topic. IPA takes a more flexible approach to sample size: it depends on the richness of the data, the commitment to in-depth engagement with it, and practical constraints (Smith and Osborn, 2015), recognising that the next interview could always bring unique data (Cronin and Lowes, 2016). I therefore aimed for 8-10 participants, using examples in the literature as a guide, e.g. Smith judged 14 a “relatively large” sample for IPA (Smith, 2011a, p. 24).

4.3.5 Identification and recruitment

The following recruitment criteria were chosen (see Box 3). Participants had to be aged 18+; the main informal carer (whoever was the main source of informal support, including partner, relative or friend) for a UK military veteran with a diagnosis of mesothelioma, either living or up to 12 months deceased; and capable of consenting to participate.

Box 3: *Main study recruitment criteria*

- aged 18 or over
- the main informal carer (whoever was the main source of informal support, including partner, relative or friend) for a UK military veteran with a diagnosis of mesothelioma
- the veteran is either living or up to 12 months deceased
- capable of consenting to participate

The inclusion of newly bereaved as well as current carers was justifiable in terms of getting a fairly up-to-date view of the mesothelioma experience, as well as covering the end-of-life period. This could be missing otherwise due to the demands on carers at that stage of the illness. Issues have been identified regarding the appropriate time to interview bereaved people after a death, including how saliently they recall what has happened; ensuring informed consent; and allowing for the many practicalities relatives have to deal with (Addington-Hall and McPherson, 2001; Williams *et al.*, 2008; Sque, Walker and Long-

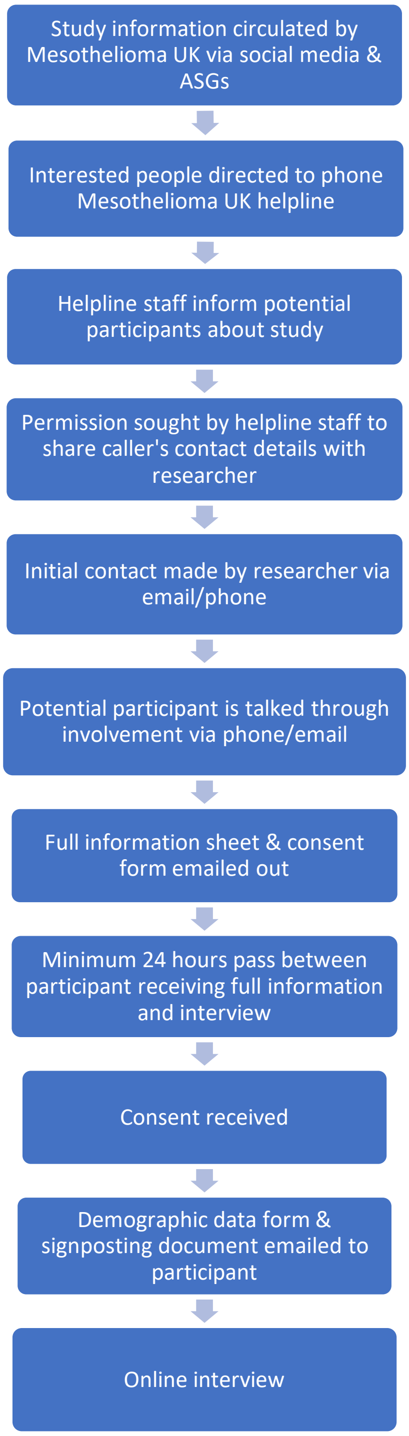
Sutehall, 2014). Sque, Walker and Long-Sutehall (2014, p. 949) drew up a framework for ethical decision-making in research with bereaved families, suggesting that the ideal time-frame for inclusion was 3-12 months after bereavement, thus balancing “respect for a period of mourning and a salient account of personal insights”. Studies on bereaved participants’ experience of being interviewed have found that they accepted their fluctuating emotional state would affect the interview data (Hynson *et al.*, 2006) and would feel comfortable being interviewed within 5 months of the death, though some would prefer to wait to allow time to reflect (Bentley and O’Connor, 2015).

There was not an inclusion criterion based on speaking English, as an interview could be conducted using an interpreter if necessary. From a feminist perspective, it was important to try to include members of marginalised or vulnerable groups of people (Clarke and Braun, 2018). Within the British Armed Forces family there are people from communities such as the Gurkhas and other Commonwealth countries (Ministry of Defence, 2021). Carers for veterans in these communities might not speak English but should not be excluded from my study. I hoped to recruit diverse participants within my homogenous sample. Differences could be in terms of ethnicity, age, type of mesothelioma, geographical location, sexuality, gender and type of relationship.

The recruitment process was conducted as follows (see Figure 4 for a flow diagram). All participants were recruited through mesothelioma stakeholder groups and organisations: Mesothelioma UK, military support organisations and local Asbestos Support Groups. This meant that NHS ethical and governance approvals were not required. Recruitment was conducted in partnership with the Mesothelioma UK helpline. Information about the study was circulated by Mesothelioma UK by email, website, Facebook and Twitter. Information was also circulated via the support organisations and groups. If interested, people were asked to phone the Mesothelioma UK helpline. The helpline staff informed potential participants about the study, who then had a free choice whether to participate.

Permission was sought by the Mesothelioma UK helpline staff to share interested people’s contact details with me using an 'Expression of Interest Form' I had provided. With that permission, I made initial contact through the person’s preferred route (email or phone). I then talked the potential participant through involvement, either by phone or through exchange of emails. I then emailed a full information sheet and consent form (see Appendix O). It was important to ensure that at least 24 hours had passed between the participant receiving the full information and the interview taking place, to allow the participant time for reflection and discussion with others. The interview only took place once the consent form had been signed. After consent was given, a 'Participant Characteristics Form' was emailed to the participant to collect demographic data (see Appendix P). I chose to seek a wider range of demographic data than the original MiMES study had done to get a more nuanced view of my participant group.

Figure 4: *Flow diagram of the recruitment process*



Recruitment had been due to begin in the Spring of 2020. However, the arrival of the COVID-19 pandemic meant that adjustments had to be made to my data collection methods, which entailed a revision of my university ethics application (see Appendix Q), causing some delay. Recruitment finally opened at the start of September 2020. Recruitment was very difficult, probably partly due to the very small pool of eligible participants, but also because the pandemic was claiming the attention of both the mesothelioma stakeholder organisations' staff and the carers. It felt inappropriate to keep reminding them about my study at this difficult time. By November, only three participants had been recruited. I therefore applied for an ethics amendment to widen my inclusion criteria to carers who had been bereaved up to *two* years previously, to widen the pool of potential participants. This amendment was granted. On 31/3/21 I closed recruitment to leave enough time to complete the analysis and to write up the findings. A total of seven participants had come forward. One of these dropped out after receiving the Participant Information Sheet, without giving a reason. Although this number was disappointing, it was still an acceptable number as IPA can be carried out with a sample size as small as one (Smith, 2011b). Monitoring the realities of collecting in-depth data and responding to difficulties is an important research skill, and this may involve reducing the sample size (Robinson, 2014). The British veteran population had proven hard to reach for MiMES, and I experienced the same issue with recruitment for my study. Reducing the sample size to six still allowed me to meet IPA's idiographic aim (Robinson, 2014). Using sample sizes in the published literature as a guide (Smith, 2011b), I noted that six is a typical number of participants for an IPA study (Pietkiewicz and Smith, 2014). An identification code was allocated to each participant, using the same system as the original MiMES study. Pseudonyms were given to each participant and their veteran patient, e.g., Gary and Marie.

4.3.6 Data collection

My interviews needed to enable discussion of topics relevant to the research questions and to let them be answered afterwards by means of analysis (Smith, Flowers and Larkin, 2009). My topic guide therefore drew on my literature review for consideration of which topics would be relevant, such as coping strategies and experiences of changing relationships, but it also needed to be broad enough to incorporate unexpected elements. I followed Smith, Flowers and Larkin's (2009) suggestions for constructing a topic guide for semi-structured interviews. I used open rather than closed questions, and ones which did not make assumptions about the participant's experiences. Between six and ten prompts would be suitable for an interview of about an hour (Smith, Flowers and Larkin, 2009). A flexible approach to the order of questions helped funnel towards more sensitive issues as the interview progressed.

I used probes (e.g., ‘What do you mean by “unfair”?’) and prompts (e.g., ‘Can you tell me a bit more about that?’). The topic guide is presented in Appendix R.

As well as paying attention to the sensitising issues identified from the SDA, I used other strategies to further finesse the interview schedule. For example, I included a request at the start to be allowed to continue audio recording right until we ended the video call, explaining that sometimes participants said really interesting and important things after the formal questions had ended (Newing, 2010). I also asked as my second question what terms the participants used to describe themselves, e.g., ‘carer’. This was a relatively easy question which also aimed to give them a sense of ownership of the discussion (Leavy and Harris, 2018). I aimed to use their individual term during the rest of the interview, an example of paying attention to power dynamics. (See Appendix R for the full interview schedule.)

My experience as a counsellor gave me confidence in approaching the interviews, in terms of being used to talking to people about very sensitive topics; in knowing how to use open questions; how to avoid leading questions; how to make split-second decisions on what thread to follow when there was an option; and how to move back organically to a topic from earlier in the interview. The individual characteristics of a researcher will influence data collection, and Pezalla, Pettigrew and Miller-Day (2012) propose three individual styles of interviewing: neutral, affirming and interpretive. My style of interviewing matches most closely to the neutral style. This was defined as *“*not engaged on one side of the argument or another; neither affirming nor disapproving of respondent’s stories” (Pezalla, Pettigrew and Miller-Day, 2012, p. 172), with interviewer comments being minimal and unopinionated, rather than showing affirmation, interpretation and self-disclosure. Pezalla, Pettigrew and Miller-Day (2012, p. 181) suggest the neutral style “could be characterised as traditionally masculine”, which may help participants talking about “high risk topics” feel more comfortable and able to disclose information as they wanted to. My style may have helped some of my participants feel more at ease talking about emotive issues in this masculinised military context.

Interviews were digitally recorded and transcribed by an approved transcription service. Each interview started with the obtaining of informed consent. Field notes were made after each interview. Before the first official interview, I piloted the topic guide with my husband as the participant. I used Google Meet to make sure I was familiar with the technology and also with explaining how to access it. I used the topic guide to familiarise myself further with the questions and with using prompts. An added benefit of piloting the topic guide was to practise discussing sensitive and potentially upsetting topics in the less familiar role of researcher, rather than counsellor. As I was interviewing my husband about his experience of being a carer for me when I had lung cancer, there was potential for me to hear personally upsetting material which I would need to handle in a professional manner. The trial run proved very helpful in practical terms and also provided an opportunity for me to reflect further on my own 'insider' experience before I began the real interviews. The first official interview was considered a pilot and informed the conduct of subsequent interviews. The transcript of this pilot interview was of good quality and therefore formed part of the research data.

The interviews lasted between 58 and 115 minutes. Participants responded freely with a lot of detail. Occasionally they became emotional, with voices choking up and/or tears. When this happened, I gave them the option to pause the interview, but none wanted to do this. If it seemed appropriate, I reminded them about the 'sources of support' list I had emailed in advance. One participant who was upset checked out with me whether it was hard for me to hear such upsetting things, and I explained that it sometimes was and yet how important it was for these stories to be heard. In contrast, one participant laughed frequently throughout the interview. In Appendix S, I present the participants' unprompted comments on how they had experienced being interviewed.

With each of the participants I was able to cover all the issues in the topic guide, with many being covered by the participants in their extended response to question two ("Please could you tell me about your experience of being a carer for your *partner* [insert correct relationship] with mesothelioma?") Working with online technology was seamless except for the final interview, with F20FC who lived in a rural location. She told me her internet was not always reliable, and we did have to resort to a phone call for the final fifteen minutes or so of her interview. I made verbatim notes of this part of the interview as I was worried the audio recorder would not pick up our speech, which is what in fact happened.

4.3.7 Data analysis

The process of data analysis was described in detail for the Stage One secondary data analysis in Section 4.2.4 above. The same method was applied for the Stage Two interview data as for the SDA. Any differences in the method used are now presented.

After each interview, the audio recording was uploaded to the transcription service's platform. After I received each transcript, I went through it, listening to the audio and typing in all the repetitions, wordless sounds, pauses and so on. This allowed me to begin immersing myself in the data and produced a more nuanced transcript. This process also allowed me to correct any transcription errors. This was worthwhile; for example, the phrase ‘pig tank’ turned out actually to be ‘food chain’ when I listened to the audio! Each transcript was then analysed using IPA’s six steps (see section 4.2.4 above). *Quirkos* software was used as an aid for mapping the themes (see section 4.2.4 above).

4.3.8 Discussion

In preparation for writing the discussion, I juxtaposed the findings from the SDA and the main interview stage in a document. This allowed me to notice any similarities and differences. Bringing together the results from both stages represented a further turn of the hermeneutic circle. I was able to revisit the SDA findings in the light of the main interviews, allowing me to notice them from a new perspective and view the parts in relation to the whole dataset. I also chose to re-read the four SDA transcripts to refresh my memory before beginning to write the discussion. My experience of the main interview data informed my re-reading, just as the SDA findings had informed my conduct of the interviews (e.g., by priming me to probe more deeply when the issue of pain was mentioned).

4.3.9 Dissemination

It is important for my study’s findings to have impact; I therefore need to identify potential audiences and find appropriate ways to reach them (Leavy and Harris, 2018). My research relates to two under-researched populations: people with mesothelioma, and UK military veterans. My PhD has generated unique findings that will add to the body of knowledge in both these areas. I am therefore motivated to disseminate these findings into the academic arena. The main output from my thesis would be a peer-reviewed academic article for a high-quality journal such as *Psycho-oncology*. Presenting at conferences such as the British Thoracic Oncology Group conference and King’s Military Mental Health conference would be appropriate.

As the study was funded by a charity, Mesothelioma UK, I want to make sure their investment bears fruit in terms of raising awareness and bringing benefit to UK military veterans with mesothelioma and their carers. In addition, I have recommendations for practice which will need to be disseminated to achieve impact. I aim to write a clinically facing paper to develop the practice-focused implications for nursing staff. This would be aimed at a reputable peer-reviewed professional journal with wide circulation for maximum impact (e.g., *Nursing Standard*). I also intend to present at events for mesothelioma patients, carers and allied professionals, such as asbestos support group staff.

4.4 Ethical considerations

4.4.1 Introduction

The study received ethical approval from the University of Sheffield's Ethics Committee (see Appendix Q for the ethics full application). A range of ethical concerns has been identified particularly pertaining to in-depth interviews, including privacy and confidentiality; informed consent; harm; dual role and over-involvement; and power (Allmark *et al.*, 2009). The following sections discuss in turn issues relevant in developing my study in an ethically robust way: recruitment, consent, and payment of participants; potential harm to participants; personal safety; data processing, storage and confidentiality.

4.4.2 Recruitment, consent, and payment of participants

In the literature, there are ethical issues specifically relating to secondary data analysis (Long-Sutehall, Sque and Addington-Hall, 2011; Chauvette, Schick-Makaroff and Molzahn, 2019; Ruggiano and Perry, 2019). It is important for the researcher to respect the principle of non-maleficence by going through the proper approval processes (Beauchamp and Childress, 2001). I therefore submitted the secondary data analysis proposal to the university ethics system.

One ethical issue for conducting secondary data analysis is consent. I considered whether the participants in MiMES had given consent for their data to be re-used for secondary data analysis. The original participant consent form for MiMES included permission for data to be used for future research. This was important as re-use of data should pay attention to the original participants' agreement to take part (Long-Sutehall, Sque and Addington-Hall, 2011; Chauvette, Schick-Makaroff and Molzahn, 2019). I also paid attention to ethics regarding the original researchers' confidentiality (Ruggiano and Perry, 2019).

For the Stage Two interviews, recruitment of participants took place through stakeholder groups and organisations. Healthcare professionals were not involved with recruitment, thus removing the possibility of participants feeling pressurised to take part. Interested participants had to give consent via Mesothelioma UK's information line for their contact details to be shared with the researcher. It was important for participants to be fully informed about the study before they consented to take part. I gave information to them initially in a phone conversation or email exchange, where they were invited to ask any questions. I followed this up by emailing a detailed information sheet and consent form (see Appendix O). It was important for the participant to have time to digest this information and potentially discuss it with others, so a period of at least 24 hours was left before the interview took place. Written consent had to be received from the participant before the interview, and the first part of the interview was a confirmation of their consent, as I read out each of the consent form's clauses and the participant answered.

The issue of financial payments was discussed in a meeting with members of the MiMES research team and Liz Darlison (Head of Services, Mesothelioma UK). Discussion included general ethical issues around exploiting participants. For the previous MiMES interviews, participants had been recruited through the charity Mesothelioma UK and had not been paid, and it was decided to follow this precedent. However, any out-of-pocket expenses incurred by participants for this study would be reimbursed. This was not required as all participants were interviewed in their own homes at a time convenient to them.

4.4.3 Potential harm to participants

There was no risk of physical harm to the participants in this interview-based study. However, the study covered highly sensitive topics (i.e., physical/mental health conditions; religious/spiritual/other beliefs; sex life; personal finances) which might be upsetting for participants to discuss (University of Sheffield, 2019a). It also involved potentially vulnerable people; the participants did not constitute a vulnerable group per se, but because of their caring responsibilities or bereaved status, they might find certain parts of the interviews challenging or distressing. Ethical issues specifically relating to recruiting and interviewing the bereaved, such as being able to give informed consent while in state of emotional upheaval, have been debated in the research literature, e.g. Bentley and O'Connor (2015); Williams et al. (2008); Hynson et al. (2006). My scoping review showed that participants were commonly excluded from studies on the grounds of being 'not well enough' to participate, or having a psychiatric diagnosis, or potentially experiencing aggravated emotional distress. Ethical conduct of research "is not a matter of avoiding potentially high-risk research. It is, rather, about preparing for and managing risks; it is a matter of being risk aware, not risk averse" (University of Sheffield, 2019a). I therefore aimed to balance avoiding harm to participants, and to anyone else beyond them (Leavy and Harris, 2018), with the potential benefits of inclusion, e.g. altruism, social interaction, developing new perspectives, self-advocacy (Carter *et al.*, 2008; Wolgemuth *et al.*, 2015; Opsal *et al.*, 2016; Whitehead and Clark, 2016; Alexander, Pillay and Smith, 2018). Signposting to relevant support was therefore built into the interview process. Prior to each interview, along with the

Google Meet invitation I emailed to participants a document entitled ‘Signposting list for post-interview sources of support’. (See Appendix T for a copy of the signposting document.) I introduced this with the following sentence: “Sometimes after a research interview where difficult experiences have been discussed, people like to talk things through with a supportive listener.” This flagged up that the interview could be upsetting and normalised the idea of getting support afterwards. It also helped me to stay out of my counsellor role, as I knew participants had access to support.

4.4.4 Personal safety

My original plan for the study involved face-to-face interviews. This could have exposed me to danger when visiting unfamiliar places and entering participants’ homes. However, the switch to online interviews meant this was no longer a consideration.

4.4.5 Data processing, storage and confidentiality

A data management plan was put in place to ensure that all issues concerning data processing, storage and confidentiality were covered, with the aim of respecting privacy and confidentiality throughout the study. Interviews were conducted in a room where others could not overhear. Because the transcription service had access to identifiable data, to ensure trustworthiness I used the service approved for use for transcribing previous MiMES interviews. After transcription, all identifying information (e.g., names, regions, organisations) was removed and pseudonyms allocated to participants. Following transcription, only the anonymised data was used. Identifying codes matching the format of the existing MiMES dataset were placed on each recorded file and in the headers of transcripts. A key matching each code to each participant and their identifiable information such as name, age and contact details was stored securely on the departmental database. It is important for participants not to be identifiable in any future publications resulting from my study. Due to the tight-knit nature of the UK mesothelioma community, any data or description which could identify an individual will only be included with the express permission of the participant, or minor omissions will be made in publications. It is possible that other researchers may find the data I collected useful in answering future research questions. Participants were therefore asked to provide their explicit consent for their data to be shared in this way. Only anonymised data will be shared with other researchers.

It was important to plan how to keep all data secure to preserve confidentiality. Password-protected data files were stored on the university server and only accessible to the MiMES research team. Transcripts and digitally recorded interviews were saved to the project file. Transcripts were pseudonymised. Only pseudonymised transcripts were printed, which were stored securely. All recordings were quickly transferred from my devices and deleted from the recorder. All consent forms were stored on the project file. Recordings will be deleted at the study's end but transcripts and pseudonymisation logs will be saved for 10 years following UKRI (2015) recommendations.

4.5 Feminist considerations

4.5.1 Introduction

In conducting my study, I was influenced by a feminist perspective, as discussed in the Methodology chapter. This perspective was especially relevant to my consideration of ethical issues. In this section I specifically consider how a feminist perspective related to various aspects of my study's ethics, and how I incorporated this awareness throughout my planning and study design. The following ethical issues are discussed here: bringing out neglected voices; the potential for role conflict; emotional labour and researcher vulnerability. It was important to me to bring a critical, feminist perspective, as "the history of theorizing morality and how, in fact, we determine right from wrong has itself been shaped by androcentric (male-centred) bias" (Leavy and Harris, 2018, p. 96). I have been influenced by Gilligan's (1982) work on ethical decision-making and her view of women's prioritising of relationships over principles. Her work challenged dualistic thinking, leading the way for situational and relational views of morality, e.g. Walker's *practices of responsibility* (Walker, 2007); Noddings' *ethics of care* (2003).

4.5.2 Bringing out neglected voices

Feminists have favoured semi-structured, open-ended interviewing methods as a way of bringing out neglected voices (DeVault and Gross, 2012), and my study gave attention to carers, who had been overlooked in the mesothelioma literature, and also to the partners and family members who take 'second place' in the military system. I also intended to include where possible (given the time and resource constraints of PhD research) diverse participants, who may tend to be excluded from research for practical reasons, e.g., being non-English speaking; being homeless; having mental health difficulties. In so doing, I was aware of an "ethical quagmire" as it was essential to acknowledge that by trying to speak for others or represent their experiences I could "colonise" their accounts (Leavy and Harris, 2018, p. 104). A feminist perspective also pays attention to intersectionality, meaning I needed to be aware of the co-existing, shifting systems of power affecting my participants

(Lafrance and Wigginton, 2019). Reflexivity was a tool that could help manage these challenges.

4.5.3 Potential for role conflict

In one-to-one interviews, feminist researchers value active listening, an engaged practice involving taking in information and also processing it, with the potential to be affected (DeVault and Gross, 2012). It also entails listening carefully to be aware when accounts are being silenced or told from two perspectives, as a result of a patriarchal culture (Leavy and Harris, 2018). It was important to consider the question of how close to get to participants, as sharing information and ongoing interaction could increase rapport but could also create difficulties (Philip and Bell, 2017). This consideration was relevant to my decision about whether to share my counsellor status with my participants. This was something I could potentially have put into my information sheet and flagged up at the start of the interview, whilst emphasising that I was not in that role today, but in my researcher role. I wondered if it might help participants to know that I was used to sitting with people who got upset and talked about distressing or embarrassing things. Or perhaps it would make them feel negatively towards me. In practical terms, there was a fair amount of information about me as a counsellor online. I raised this question during an IPA training, and it was suggested participants could have differing expectations: some might feel safer; some might have had a bad previous experience of counselling; others might be ‘counselled out’, and could welcome a research interview as less hard work. It was also possible to share the information at the *end* of the interview, providing an explanation as to why I was doing this particular research. In the end, I decided not to disclose, but hoped to provide an environment that felt very safe by using my skills. I needed to prepare myself to stay in the researcher role and to differentiate this from my counsellor role. There was similarity between my relationship with the participants and my clients: for both, I needed to try to understand their life-world, and to have my own interpretation. However, my clients were always in a position of wanting help/wanting to change, and that was their reason for talking with me. Research participants were different, so I needed to be very careful not to position them in that same space. I found it helpful to take a very person-centred approach (Rogers, 1978), which meant not wanting at all to fix the participant, but just to understand deeply.

4.5.4 Emotional labour and researcher vulnerability

Reflexivity is a key aspect of a feminist approach, helping researchers pay attention to issues of difference, hierarchy and power throughout the process (Clarke and Braun, 2018; Leavy and Harris, 2018). It also draws attention to the emotional labour for the researcher involved in studying sensitive topics (Carroll, 2013; Clarke and Braun, 2018; Leavy and Harris, 2018), requiring consideration of whether a topic will involve vulnerability in the researcher as well as the participants (Kumar and Cavallaro, 2018; Nikischer, 2019). Because of this emotional labour, it is important for a researcher to consider whether researching a specific topic may open them to being emotionally challenged and vulnerable, whether during data collection or other parts of the research journey. In my study, this issue was especially relevant to me, as I was diagnosed with lung cancer in Autumn 2018, and my husband had also been investigated surgically for a lung nodule six weeks earlier. He was subsequently diagnosed with prostate cancer at the end of 2019, an experience which included a false diagnosis of metastasis in February 2020. He underwent major surgery in the hospital opposite my PhD office. I switched from carer to patient to carer within 18 months. My personal experience therefore partially overlapped with my participants' experiences, and this happened during my PhD journey. This entailed an unforeseeable transition from 'outsider' to 'insider' researcher. The University of Sheffield's (2019b) Research Guidance Paper 'Emotionally Demanding Research: Risks to the Researcher' was a relevant resource for me, as was Mallon and Elliott's (2019) paper providing action points for researchers. I became aware that my own illness experiences had given me additional insight, and that there were implications for my reflexivity and relationships in the research process. My training and substantial experience as a counsellor helped me to manage these, enabling me to safeguard my participants and myself. I had a variety of sources of support in place, including regular counselling supervision, research supervision, and the University of Sheffield's 'Ill and Disabled Researcher' and 'Emotionally Demanding Research' networks. Further discussion of reflexivity is included in the following section on quality considerations.

4.6 Quality considerations

4.6.1 Use of quality criteria

Whilst there is considerable disagreement regarding criteria for evaluating qualitative research (Hammersley, 2007; Torrance, 2018; Lester and O'Reilly, 2021), it can be helpful to have frameworks from which researchers can demonstrate research quality (Seale, 1999). The three established quality assessment frameworks I used are presented in turn in this section. I used Yardley's (2000) criteria for assessing the quality of qualitative health research to guide my conduct of both the secondary data analysis and main empirical study. Also useful for considering how to aim for quality in terms of IPA methodology was Smith's (2011a, 2011b) evaluation guide designed specifically for assessing IPA work. For the SDA, Sherif's (2018) diagnostic guide for evaluating data for secondary analysis was helpful. See Table 19 for a summary of the quality assessment frameworks I used. How far my study met the various quality criteria will be considered in the Discussion chapter (section 7.7.1).

Table 19: *Quality assessment frameworks*

Reference	**Purpose of framework**	**Summarised Criteria**
Yardley (2000)	To assess the quality of qualitative health research	sensitivity to context
		commitment and rigour
		transparency and coherence
		impact and importance
Smith (2011b, 2011a)	To assess the quality of IPA work	clearly subscribes to theoretical principles of IPA
		sufficiently transparent
		coherent, plausible & interesting analysis
		sufficient sampling from corpus
		well focused
		strong data & interpretation
		engaging and enlightening
Sherif (2018)	To evaluate data for secondary analysis	fit and relevance
		general quality (completeness, sufficiency, accuracy)
		trustworthiness
		timeliness

4.6.2 Yardley's criteria

Yardley (2000) developed her criteria with the intention they should be flexibly applicable guidelines rather than rigid rules, allowing for the inherent complexity and ambiguity of qualitative approaches. Yardley's criteria have been suggested as suitable for assessing validity and quality in IPA studies (Shaw, 2011; Shinebourne, 2011). The first criterion concerns *sensitivity to context.* This relates firstly to the theoretical context of the study, meaning that the researcher needs to have a good grounding in the philosophy of the adopted qualitative approach. Secondly, this criterion considers the study's socio-cultural context, including the social context of the participant-researcher relationship and the balance of power.

The second criterion looks at *commitment and rigour.* Commitment refers to on-going engagement with the study's topic, whether as researcher and/or as someone who has experienced the phenomenon personally; immersion in the data; and development of skill in using the research methods. Rigour concerns the completeness of the dataset and its analysis.

Transparency and coherence comprise the third criterion, which concerns the presentation of the study, in terms of clarity of description of findings and persuasiveness of the discussion. For IPA, this entails providing detail of all the research processes; matching IPA's underlying theory; and resonating with the ultimate reader (Shaw, 2011; Shinebourne, 2011).

Yardley's final criterion is *impact and importance.* The value of any piece of research will depend on the meeting of its objectives and the relevance it has to a particular community. Impact and importance can be judged for an IPA study by considering if it "tells the reader something interesting, important or useful" (Smith, Flowers and Larkin, 2009, p. 183). In the Discussion chapter (section 7.7.1) I consider how my study met Yardley's criteria for quality.

4.6.3 Smith's guide for IPA papers

A quality evaluation guide specifically developed for IPA papers was available to inform my study (Smith, 2011b, 2011a). This guide aimed to set out criteria for judging whether IPA papers were acceptable for publishing, and also to provide guidelines for researchers "when conducting their studies in order to help achieve an acceptable standard for postgraduate theses" (Smith, 2011b, p. 18); Smith also hoped to mark out what made an IPA paper good, rather than just acceptable. The criteria for *acceptability* are (Smith, 2011b, p. 17, 2011a) (bullet points in original):

- clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic
- sufficiently transparent so the reader can see what was done
- coherent, plausible and interesting analysis, including summaries and interpretation of extracts
- sufficient sampling from corpus to show density of evidence for each theme.

The extra criteria for *good* quality are (Smith, 2011b, p. 17) (bullet points in original):

- well focused; offering in-depth analysis of a specific topic
- data and interpretation are strong
- reader is engaged and finds it particularly enlightening.

Smith (2011b, p. 24) points out good analysis pays attention to how participants "manifest the same theme in particular and different ways. This nuanced capturing of similarity and difference, convergence and divergence is the hallmark of good IPA work." Also, during my analysis process, Nizza, Farr and Smith (2021, p. 1) published a paper on the hallmarks of high-quality IPA: “constructing a compelling, unfolding narrative; developing a vigorous experiential and/or existential account; close analytic reading of participants’ words; attending to convergence and divergence.” This gave me added confidence in step 6 of the analysis (looking for patterns across cases) and writing up my findings. Consideration of how I met the IPA quality criteria is presented in the Discussion (section 7.7.1).

4.6.4 Sherif’s diagnostic guide for evaluating data for secondary analysis

Rigour in SDA is a concern, for example if earlier data are re-analysed without attention being paid to potential changes in social and political context (Sherif, 2018). As I was planning my SDA whilst the original data collection was still occurring, this concern did not seem relevant. Another possible issue is that lack of personal involvement in data production may hinder the researcher’s interpretation, but Long-Sutehall, Sque and Addington-Hall (2011) suggest this is less of a problem if the secondary analyst has access not just to transcripts, but also field notes, audio recordings, and the original researcher(s). The MiMES dataset was produced by colleagues working in the same research centre as myself, which therefore gave me potential access to all the notes, recordings and personnel.

Sherif’s (2018) diagnostic guide for evaluating data for secondary analysis was applied to the SDA dataset. This guide aimed to answer the question: “Are pre-existing data suitable, sufficient, and of high enough quality to obtain new theoretical, empirical, and/or methodological understandings?” (Sherif, 2018, p. 1). The rubric assesses the fit and relevance, general quality (completeness, sufficiency, accuracy), trustworthiness, and timeliness of the dataset. Criteria are grouped into columns showing ‘fully met’, ‘partially met’ and ‘not met’. Sherif makes clear that the rubric should be used in conjunction with critical evaluation of the data’s general story plus consideration of my own research questions and objectives. (See Appendix X for the rubric annotated with my assessment for each criterion.)

By reviewing the MiMES dataset against the whole rubric, I concluded that the criteria were generally scoring in the ‘fully met’ column. ‘Partially met’ criteria related to the pre-existing data being centred around the topic of interest (psychological effects) along with other topics (other aspects of the mesothelioma lived experience). The only ‘not met’ criterion was ‘dataset consists of one type of data’ i.e., interviews. Sherif’s framework needs to be tailored to the particular methodology being used. Because IPA methodology does not rely on the concept of triangulation and the individual interview is seen as well suited to collecting appropriate data (Smith, Flowers and Larkin, 2009; Palmer *et al.*, 2010), I did not consider this unmet criterion to be a problem. The rubric suggested that the MiMES dataset was suitable for use for a secondary data analysis. I considered that the general story of the MiMES interviews matched closely enough, even though not perfectly, to my own research questions and objectives that new empirical understandings could be possible. Sherif's framework proved a useful tool to help me assess the fit of the dataset for re-analysis using IPA.

4.6.5 Patient and Public Involvement (PPI)

Involving patients and other members of the public (PPI) can enhance the quality and relevance of research, with positive impacts being reported at all stages of a research project (Brett *et al.*, 2014). To obtain informed views, I used channels typically used in research, e.g., accessing asbestos support groups and the 'Supporting Our Armed Forces' steering group for PPI input. Examples included providing comments on the value and contribution of my proposed study during development, helping develop my interview schedule, and informing plans for dissemination.

Also, I used opportunistic moments for integrating stakeholders' opinions. For example, I attended a number of Mesothelioma UK events, where I actively sought out conversations with patients, carers, bereaved relatives, compensation lawyers and specialist nurses. Because of my own lung cancer journey, I was able to have opportunistic conversations with other patients. My insider status gave me access to a possibly more diverse group beyond "the usual suspects" involved in PPI (Reynolds, Ogden and Beresford, 2021, p. 7).[13] After these conversations, I made notes and fed highlighted issues into my study design and conduct.

4.6.6 Reflexivity

Reflexivity is fundamental to all qualitative research (Lazard and McAvoy, 2020). The researcher must be able to notice and articulate all the contextual, intersecting relationships existing between them and their participants to enhance the study's credibility and help readers get deeper understanding (Dodgson, 2019). For IPA, maintaining awareness of one's own feelings, thoughts and experiences is important whilst analysing data as it can provide a "touchstone" (Smith, Flowers and Larkin, 2009, p. 90). However, the question arises of how to 'do' reflexivity; published literature on the practicalities of the reflexive

---

[13] For example, while recovering from my surgery on the hospital ward I was able to chat with the patient in the opposite bed, who had mesothelioma in both lungs. From her, I picked up sensitising issues about her patient pathway, such as how HCPs spoke to her and the physical impact of her treatment. As I left the ward to go home, she was too unwell to be discharged. Her parting words to me were, "Put me in your book!" I am pleased to fulfil her wish here.

process is lacking (Trainor and Bundon, 2020). For my own reflexivity practice, I initially used free-flowing hand-writing for each participant after listening to the audio. I noted my somatic and emotional responses, just as I notice these responses when counselling a client. I also aimed to be aware of any assumptions and responses when doing the interpretative work on themes, and to note these down. In practice, this process felt rather haphazard, and I wondered if there was a more structured way to handle it. I next describe a method I discovered, which I went on to use.

Before moving on to the main study, I encountered the idea of *bridling* in the context of phenomenological research. Van Wijngaarden et al. (2017, p. 1740) explained "all researchers have some relationship and a certain understanding of the phenomenon in focus, known from experience or through established knowledge. Researchers thus attempt to understand the world or a phenomenon as something they are already part of." Because pre-understanding is always present, it is necessary for a phenomenological researcher to *bridle* the constant, rapid process of understanding to lessen its impact and have an "open, wondering phenomenological attitude", with a focus on "discovering that he or she was wrong" (Van Wijngaarden, Van Der Meide and Dahlberg, 2017, p. 1741). Dahlberg and Dahlberg (2020, p. 460) call bridling "an art of being present and asking questions to one's own understanding of a phenomenon rather than taking it for granted. Its goal is to open for many possibilities of understanding." To maintain this ongoing openness, Vagle (2010) recommended using a reflexive bridling journal at particular points in the research process. Stutey et al. (2020) set out Vagle's four components for bridling as shown in Table 20.

Table 20: *Components of the bridling process*

Stage of study	*Component*
Planning	Create initial bridling statement
Data collection	Record experiences in bridling journal
Analysis	Use journal in structured way Re-read initial bridling statement
Analysis	Seek external perspectives

Bridling gave me a structure which helped me be more consistent in my reflexivity process for my main study. See Table 21 for an illustration of bridling during my analysis process.

Table 21: *An example of bridling during the analysis process*

Participant	**Quotation**	**Initial comments** (blue=descriptive; green=linguistic; purple=conceptual)	**Excerpt from Bridling Statement**	**Consideration**
Cerys (F20FC) quoting Hywel (patient)	"“We’re not the type, Cerys,” he said, “to just sit in a chair and curl up and die.”	He told Cerys they were not the type to just die. Dictionary: curl up & die = feel very ashamed and sorry; wish one could escape/instant relief from being mortified/extremely embarrassed. He experiences ‘no treatment’ as meaning he should give up. He would be ashamed to do that (?). He identifies this as a shared trait/attitude.	*The seeds of my pre-understanding about illness were planted in my childhood, particularly by my mother. Her behaviour taught me and my sisters that to be ill or incapacitated was a personal failure, with shame attached.*	Was I reading shame into this quotation because of my own pre-understandings? I used the dictionary to check out the meaning of the expression. I also asked a third party (keeping confidentiality) if they felt my interpretation of shame in this context was appropriate.

4.7 Conclusion

In this chapter I set out the methods used to answer my research questions, describing how I conducted individual semi-structured audio-recorded interviews between 28/9/20 and 30/3/21 via videoconferencing with six carers of military veterans with a mesothelioma diagnosis. I justified my choice of methods, showing how they were appropriate for answering my research questions and aligned with my chosen methodology, IPA. I considered my methods in terms of ethics and the study’s quality. In the following chapter, I present the findings of my secondary data analysis.

Chapter 5: Findings of Stage One – Secondary Data Analysis

5.1 Introduction

In the previous chapter I presented and critiqued the methods I employed to conduct a secondary data analysis (SDA) and an empirical study, using interpretative phenomenological analysis (IPA) methodology to answer my research questions (see section 2.6.3). In this chapter, I present the findings of the SDA conducted on the four transcripts from the MiMES study where carers were interviewed alone. The SDA's purpose was to identify sensitising issues and allow fine-tuning of my research questions and interview schedule. Three super-ordinate themes, developed by looking for patterns across all four participants' data, are presented with supporting quotations. These themes are: '*Control and responsibility*'; '*Openness: is it safe?*'; and '*Human connections: getting support'* (see Table 22). The first two super-ordinate themes are presented with nested sub-themes, while the third is presented as a single whole. For ease of reading, all illustrative quotations have been edited to remove repetitions, pauses and so on, unless these seemed essential to a statement.

Table 22: *Overview of super-ordinate themes and sub-themes*

Super-ordinate themes	**Sub-themes**
Control and responsibility	The chain of command
	Controlling language and thinking
	The out-of-control body
	The proactive carer
Openness: is it safe?	Secrecy and intimacy
	Official secrets
	Becoming vulnerable
Human connections: getting support	n/a

The presentation of the themes is developed as a full narrative[14]. These findings are then summarised as seven key findings. Pseudonyms are used for carers and patients throughout. The participants' and patients' characteristics are presented in Table 23.

---

[14] Providing a 'full narrative' entails presenting detailed commentary on extracts from the data (Smith, Flowers and Larkin, 2009), emphasising "both convergence and divergence, commonality and nuance" (Smith, Flowers and Larkin, 2009, p. 79). The aim is to construct "a compelling, unfolding narrative" which "tells a persuasive and coherent story", operating within and across themes (Nizza, Farr and Smith, 2021, p. 3). Such a full narrative "helps realise the requirement for IPA findings to offer coherence, focus and depth" (Nizza, Farr and Smith, 2021, p. 16).

Table 23: *SDA Participants' and patients' characteristics*

	F7MM	**F9FC/P12MN**	**F6FC**	**F2MM**
Carer:				
Pseudonym	Graham	Janice	Andrea	Malcolm
Veteran/civilian status	Veteran - RAF	Civilian	Civilian (her father was in Armed Forces)	Veteran - RAF
Age	Mid 60s	Mid 50s	Late 60s	Mid 70s
Bereaved	Yes	No	Yes	Yes
Gender	M	F	F	M
Region	Midlands, England	South of England	South-West of England	East of England
Patient:				
Pseudonym	Dorothy	Keith	Eric	Patricia
Service branch	Army	Royal Marines	Navy – senior officer	RAF and later contractor
Meso type	MPM	MPM	MPM	MPM
Age	Early 60s	Mid 60s	Early 70s	Mid 60s
Gender	F	M	M	F

5.2 Super-ordinate theme One – *Control and responsibility*

5.2.1 Overview of Super-ordinate theme One – *Control and responsibility*

This super-ordinate theme includes issues relating to forward planning, following rules and protocols, protecting others, powerlessness, and awareness of hierarchical command structures. The four sub-themes are: '*the chain of command'; 'controlling language and thinking'; 'the out-of-control body';* and '*the proactive carer'* (see Table 24*).*

Table 24: Super-ordinate theme One with sub-themes

Super-ordinate theme	**Sub-themes**
Control and responsibility	The chain of command
	Controlling language and thinking
	The out-of-control body
	The proactive carer

All four participants provided data relevant to this super-ordinate theme. See tables in each of the following sub-sections for selected illustrative participant quotations. Further quotations are included in the full narrative account.

5.2.2 *The chain of command* sub-theme

The name of this sub-theme refers to a key feature of the Armed Forces: the chain of command. This hierarchical power-structure defines the relationships of all personnel to each other and "determines authority, responsibility, decision-making, and communication flow" (Atuel and Castro, 2018, p. 76). The sub-theme explores how participants had high expectations of large organisations and institutions with respect to efficiency, communication and accountability, and how these expectations affected their experience of caring for a veteran with mesothelioma. See Table 25 for selected illustrative participant quotations.

Table 25: '*The chain of command' sub-theme*

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**
Control and responsibility	The chain of command	"There's so many facets to that saying how wrong it is, but principally why did they stamp it [AF medical records]? [.] It certainly wouldn't have been a local initiative because people don't do that kind of thing; it must have been a directive from higher up." *Graham* "I fully expect him [MP] to just fob me off and tell me it's not…it's outside his remit or something." *Graham* "It's just so dreadful that the government knew, it's all written down saying, oh, well, not we'll keep quiet, but, oh, it will be all right". *Andrea* "If the coroner couldn't get the information, how was a little person like me going to get the information?" *Malcolm*

The two male veteran carers paid a lot of attention to hierarchical command structures they encountered during the mesothelioma journey, both before and after the patient's death. These structures showed up in the MOD, the NHS, the government and the legal system. The question of who bears responsibility for decisions and actions was a focus for discussion, and these carers often made judgements about the conduct of those within the hierarchy. Malcolm was keen to spell out for the interviewer his understanding of the chain of command from his military experience:

"Where everything is defined for you, and it's defined by what's in the rules."

"You don't step out of your role. You are responsible for whatever is in the square but you don't actually go out of the square [.] You pass it on to somebody else who's in command of their square and so on, up the ladder it goes."

“When you’re in a responsible position [.] you either face up to it and you accept your responsibilities and you know that that may affect other people if you make a wrong decision, but you get on and do it anyway, and you take the plaudits if you’ve done something right, but you also take the brick bats if you’ve done something wrong.”

Malcolm applied this understanding of the military chain of command explicitly across to the NHS, and was very judgemental of what he saw as people with authority within the organisation *“playing fast and loose with the situation”.* He used the word *“post-trauma”* to describe the profound effect of NHS incompetence on him after his wife’s death. Malcolm was also judgemental about the way civilian employers try to dodge any responsibility for mesothelioma compensation claims:

“If you’ve got a dozen different employers that they’re having to deal with, and one say oh, it wasn’t us, it was them, oh no, it wasn’t them, it was them, and then it’s like ping pong.”

He stressed the damaging effect of such behaviour on claimants by using a military metaphor *(“like a minefield”).* He said that if his wife had had to go down the route of suing civilian employers, the stress of this process *“would have killed her off a lot earlier.”*

Graham was also shocked at how crucial decisions were taken without accountability:

“There’s so many facets to that saying how wrong it is, but principally why did they stamp it [AF medical records]. [.] It certainly wouldn’t have been a local initiative because people don’t do that kind of thing; it must have been a directive from higher up.”

He has expectations about those whose role gives them responsibility, and makes clear his judgements about them:

“This difficult person, who I think was in charge, came back with, well, if you can go for your hospital appointments you don’t need us [district nurses].”

“They [surgeons] had completely misjudged the problem. They seemed to…they ought to realise that it was mesothelioma that was the cause of the problem.”

“I fully expect him [MP] to just fob me off and tell me it’s not…it’s outside his remit or something.”

Both the male carers spelled out their own powerless position vis a vis more powerful entities:

“I can’t do anything about it personally really, I’m too low down the food chain for that, but somebody needs to raise a question.” Graham

“If the coroner couldn’t get the information, how was a little person like me going to get the information?” Malcolm

The theme of the chain of command and responsibility was much less prominent in the female carers’ data. When she talked about the idea of not coping, Andrea put this in the context of *“being a senior officer’s wife”.* She did mention the government’s duty of care *“because they knew that the asbestos was there and how dangerous it is*”. She also condemned the Navy as *“very crafty”* for using a cut-off year for compensation claims, and said:

“It’s just so dreadful that the government knew, it’s all written down saying, ‘Oh, well, not we’ll keep quiet, but, oh, it will be all right’”.

Janice’s transcript, however, contained nothing that even nodded towards this theme. This might reflect the lack of this issue in her personal experience, or it could be that the full range of her experience was not expressed due to the limited time available for her interview (while the patient took a toilet break during a joint interview).

5.2.3 ‘*Controlling language and thinking’* sub-theme

This sub-theme looks at how carers and patients employed control over language and thinking as a coping strategy. This included frequent use of humour and irony. See Table 26 for selected illustrative participant quotations.

Table 26: *‘Controlling language and thinking’* sub-theme

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**
Control and responsibility	Controlling language and thinking	“She [patient] made a joke of everything.” *Malcolm* “We just lurched from one crisis to the next, really. We were laughing in the end; it was like a black comedy.” *Andrea*

		"He kept saying, oh, I'm sure I'm going to get…I said, for crying out loud, you're wishing yourself into having it. *Andrea* "We never discussed that this might lead to her death. We tried to keep positive." *Malcolm* "We don't want to keep talking about it. The thing is when you just constantly talk about the same thing all the time it's just bringing you down. I would advise anyone to do the same thing." *Janice*

A feature that showed up particularly in the female carers' data was the idea of gaining a sense of control by how you use language. For both genders, expressing yourself in a humorous way to cope with difficulty was seen as a helpful strategy. Humorous usage included irony and dark humour. Controlling language in this way could be used to deal with the painful physical side of mesothelioma, or to cope with feeling powerless or let down.

"She [patient] made a joke of everything." Malcolm

"She [patient] said to him, 'What would you do if it was one of your family? And he said, 'I'd have surgery, I'd recommend surgery.' But he was a surgeon [laughs]." Graham

"We just lurched from one crisis to the next, really. We were laughing in the end; it was like a black comedy." Andrea

"They didn't tell us at the time but afterwards they thought he had sepsis, and it was all good fun." Andrea

Whilst Malcolm mentioned several times his wife's use of humour as a coping strategy, his own tone in the interview was serious throughout, often with a rhetorical and highly structured turn of phrase. This again exhibits control over language use when dealing with emotive material, e.g. *"I didn't have a problem with the MOD. I did have a problem with the NHS."*

Andrea's interview had many instances of her using irony to express herself. Janice, in contrast, used very little humour, her only example being, *"When you're told you have a terminal illness, how long is terminal? How long is a piece of string?"* However, her tone of voice was relentlessly cheerful, and she spelled out for the interviewer her strategy of avoiding speaking about the illness:

"We don't want to keep talking about it. The thing is when you just constantly talk about the same thing all the time it's just bringing you down. I would advise anyone to do the same thing."

She also policed her own language to keep things from sounding negative:

"Everybody deals with, I don't want to say a catastrophe, but a situation everyone deals with individually, don't they?"

Malcolm also explained that he and his wife controlled what they spoke about:

"We never discussed that this might lead to her death. We tried to keep positive."

Noticeably, neither female carer used the word 'mesothelioma' anywhere in their interview. This seems like deliberate avoidance, though it is impossible to know their precise motivation for this strategy. For the two women, it seemed that proactive control of language could help control thinking, which could somehow fend off the reality of the illness's future and any resulting sense of powerlessness. Even before Andrea's husband was diagnosed, she was attempting to exert this control:

"He kept saying, oh, I'm sure I'm going to get…I said, for crying out loud, you're wishing yourself into having it.

Janice stated that *"you just have to suck it up because whatever time there is, I don't want it to be miserable".*

5.2.4 *'The out-of-control body'* sub-theme

In this section, I present a sub-theme which deals with the embodied aspect of the mesothelioma experience. Here control was possible to achieve to some extent but was limited by the physical deterioration of the patient's body and by the reality of symptoms. See Table 27 for selected illustrative participant quotations.

Table 27: '*The out-of-control body' sub-theme*

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**

Control and responsibility	The out-of-control body	“You could see the weight was falling off, because he was over six foot, he was a big man, and you could see the weight was just falling off him.” *Andrea* “Patricia never flinched when this procedure [draining] was taking place, and it was virtually taking place every day.” *Malcolm* “It was principally pain management all through that, which was difficult [.] because they didn’t seem to give her anything that effectively dealt with it.” *Graham* I wouldn’t have wanted him, you know, being…suffering like that for another six months, knowing that he was in pain.” *Andrea*

There were limits to how much control over thinking could be exerted in the face of the patient’s bodily decline. The visibility of physical change over time was mentioned by three of the participants. Janice spoke about the suddenness of her husband’s physical decline:

“One minute, if you were to see Keith, he looks really well, he’s a healthy colour, he’s a big fella. It just came as a complete blow. [.] He was at one time taking them [dogs] out twice a day for a walk, but then he just couldn’t do it.”

Malcolm, using the present tense to express vividness, and with his characteristic precision, said:

“As it gets into January, she’s getting very gaunt, she’s lost a lot of weight. She went from 13 stone down to six stone over that period.”

Andrea’s awareness of her husband’s previous physical presence and strength appeared several times in her transcript. Initially she talked about his former daily fitness routine. Later she said:

“You could see the weight was falling off, because he was over six foot, he was a big man, and you could see the weight was just falling off him.”

As she described his final moments, she explained:

“He was a big man, even though he’d lost so much weight.”

It’s almost as if her two images of him, as big and strong and then so weak, were co-existing: she had not fully caught up with the dreadful reality.

The issue of controlling physical pain was brought up by three participants. Malcolm praised his wife’s ability to tolerate pain and discomfort:

“Patricia never flinched when this procedure [draining] was taking place, and it was virtually taking place every day.”

Graham mentioned how unrelieved post-operative pain had been a dominant symptom for a year:

“It was principally pain management all through that, which was difficult [.] because they didn’t seem to give her anything that effectively dealt with it.”

Andrea’s husband only lived for six months after his diagnosis. She expressed it thus:

“Probably for him [this] was good, because I wouldn’t have wanted him, you know, being…suffering like that for another six months, knowing that he was in pain.”

Whilst three of the participants brought up physical pain as an issue, the limited amount of data for the fourth, Janice, means we cannot know whether this was an issue for her and her husband or not.

5.2.5 *‘The proactive carer’* sub-theme

In this sub-theme, we observe the carers and patients taking control and taking responsibility by being proactive. This occurred via different roles and to different degrees, and there were implications in terms of whether needs were met. See Table 28 for selected illustrative participant quotations.

Table 28: ‘*The proactive carer’ sub-theme*

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**
Control and responsibility	The proactive carer	“She was taking 28 different forms of medication every day. So, I was managing her medication regime. [.] I set up my own little control sheet.” *Malcolm* “We just seemed to bumble along, you know, from day to day. [.] You just do it; you go into autopilot.” *Andrea*

		"There was nothing to suggest that, you know, it needed support. If I'd've known, then obviously I'd've gone with her. After that I started going with her to appointments, but not all of them. Towards the latter part of her journey, I went to every one." Graham "I said to Keith, if somebody asks you how you are, just say fine." *Janice* "You get into this 'get up, do whatever' and you just…you just carry on doing it". *Andrea*

Within the carer-patient dyad, there is potential for roles to be taken up and for assumptions to be made about how each should behave when one person becomes ill. Malcolm seemed to be clear that each partner had discrete responsibilities. During their earlier life together, his wife *"was responsible for bringing up our child".* He now took on the role of carer as his job. His description of how he helped with one aspect of her illness experience was very task-based:

"She was taking 28 different forms of medication every day. So, I was managing her medication regime. [.] I set up my own little control sheet."

He also mentioned changing oxygen bottles at night, buying her a transit chair, and organising the decoration of their new flat. His experience of being a carer is described as very practical, as a job which is his own responsibility: *"I did it all myself".* He didn't expect or look for any support with caring for his wife.

Also as part of his carer role, Malcolm saw it as his responsibility to protect his wife. When he was told by the hospital staff that his wife had only a month left, his reaction was:

"I had to put that to her. I had to find a way."

He understood that if she was given the news in the consultant's hospital room, her reaction would be like this:

"The first thing she would think about would be how that would affect me [.] and that would be pressure she didn't need. So, I said to them, you tell me, and I'll tell her."

Like Malcolm, Andrea also did not look for any practical support as a carer to Eric. As the wife of a senior naval officer and subsequently of a high-status manager in the civilian world, she expected him to be in charge and for her to be in a supporting role:

“He was very much ‘do it and get on’ and used to being in charge.”

Even when he had just been diagnosed with a terminal illness, he carried on with organising a huge military banquet. From Andrea’s perspective, Malcolm was not the sort of person to *“give in to anything”,* including being ill when he had a task to fulfil. Throughout their marriage, he had seen his role as protecting his family:

“He was a great one for protecting us. [.] He would say, well, I don’t want to worry you, or, well, you know, it’s not going to make any difference.”

He carried on with this role of protector even when he was told he had weeks to live, and he did not disclose this to Andrea. This meant she and the family were not able to plan ahead at all, so when he suddenly died, she had not thought about practicalities such as the name of an undertaker or how to sort out his gun licence. It also meant that as a couple, as he became increasingly weak and ill, no one was ‘in charge’. Andrea described this rudderless period thus:

“We just seemed to bumble along, you know, from day to day. [.] You just do it; you go into autopilot.”

Despite the physical burden and lack of sleep she experienced, it did not occur to her to ask for help. She said:

“You get into this ‘get up, do whatever’ and you just…you just carry on doing it”.

It was only on the day before his death that she thought:

“I can’t go on doing this, I’m going to have to ask somebody for help”.

She seemed unable to take up a proactive role as carer, and in her account, she seems curiously passive. For example, when Eric was suddenly critically ill, it was their neighbour who *“screamed”* down the phone for the ambulance to be sent urgently. The only example of her being proactive is when she initially made him go to the GP. Once they were in a life-threatening situation, he took control and she defaulted to her familiar secondary position in the face of mortal danger:

“You live with this [awareness of risk] all the time, I think, when you’re in the services”.

Graham’s experience of the carer role seems rather different. Near the start of his interview, he described how he became *“more of a carer than a worker”* as his retirement coincided with his wife being diagnosed. Perhaps his words suggest he did not see the carer role as ‘work’, unlike Malcolm. He gives the impression that an important part of his role was to accompany his wife to appointments. She was alone for her diagnosis at what they thought would be a routine appointment:

“There was nothing to suggest that, you know, it needed support. If I’d’ve known, then obviously I’d’ve gone with her. After that I started going with her to appointments, but not all of them. Towards the latter part of her journey, I went to every one.”

Graham’s wife, unlike Malcolm’s, made her own practical arrangements for how to manage as she became more disabled:

“She had a conservatory built, she had a downstairs toilet and washroom built so that she didn’t have to go upstairs at the end.”

There is a sense of a partnership between them, as can be seen in the use of the pronoun ‘we’ in this quote:

“When we were having trouble coping towards the end, they got a nurse to come and sit with her at night, which was a tremendous help because I just couldn’t be up 24 hours a day.”

There does not appear to be any sense of shame for Graham about asking for help, and the couple seem to have been able to make appropriate adjustments as their circumstances changed.

For Janice and her husband Keith, the sense of ‘we’ is even stronger, to the extent that the dyad merge together. For example, Janice said:

“When we were told it had come back, we just told everyone again and we said, but we don’t want to keep talking about it.”

This means that potentially Janice’s own needs as carer could be overlooked. We get a hint of this when she mentions how her husband avoids answering the phone:

"When the phone goes in this house it doesn't matter where I am, I usually answer it."

Janice paints a picture of herself as making decisions and shaping the dyad's response to his illness:

"I said to Keith, if somebody asks you how you are, just say fine."

She has a lot of 'rules' for living, such as:

"You have to deal with every situation as it comes, don't you, really."

"You can't be resentful of other people's good fortune, can you?"

We have already seen how Janice uses language to try and control thinking. Perhaps her 'rules for living' and upbeat attitude are providing her with a buffer against the reality of devastating change, but they may make it difficult to adjust and adapt in a gradual way.

In this section, we have seen how Super-ordinate theme One '*Control and responsibility'* illuminated issues relating to forward planning, following rules and protocols, protecting others, powerlessness, and awareness of hierarchical command structures. Patients' and carers' strategies for taking control were described, as were the consequences for meeting needs when control was difficult. In the next section, I go on to present Super-ordinate theme Two, '*Openness: is it safe?'*

5.3 Super-ordinate theme Two - *Openness: is it safe?*

5.3.1 Overview of Super-ordinate theme Two – *Openness: is it safe?*

This super-ordinate theme covers ideas about openness in terms of sharing information and the consequent risks and benefits. This information can be of different kinds, ranging from military secrets to someone's innermost feelings. The three sub-themes are: '*secrecy and intimacy'*; '*official secrets';* and '*becoming vulnerable'* (see Table 29).

All four participants' transcripts contained data relating to this super-ordinate theme. See tables in each of the following sub-sections for selected illustrative participant quotations. Further quotations are included in the full narrative account.

Table 29: Super-ordinate theme Two with sub-themes

Super-ordinate theme	**Sub-themes**
Openness: is it safe?	Secrecy and intimacy
	Official secrets
	Becoming vulnerable

5.3.2 ‘*Secrecy and intimacy’* sub-theme

This sub-theme presents the way that participants experienced openness with regard to the sharing of important information and feelings, which had the potential to affect levels of intimacy. A habit of secrecy, ascribed explicitly to the military context, could have an impact, and being open about feelings was not necessarily seen as safe. See Table 30 for selected illustrative participant quotations.

Table 30: ‘*Secrecy and intimacy’ sub-theme*

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**
Openness: is it safe?	Secrecy and intimacy	“Some of the jobs that I did were…well, I couldn’t talk about them because they were classified, and so you’d come home and it’s like, ‘how’s your day?’ ‘Yeah, it was okay.’ And you can’t go into any details and so you don’t really talk about it. [.] She knew I wouldn’t answer her, so she probably didn’t talk, and that perhaps was the thin end of the wedge.” *Graham* “I’m happy…emotionally I’m perhaps quite a strong person anyway, and so having said she was independent, I’m quite independent too. And no, I don’t think that I had many emotional needs that I needed help with.” *Graham* “I suppose because we’re both fairly independent, I think I’ve had to be, being married to somebody in the Navy, and Eric was very, very independent.” *Andrea* “I just think if you tell somebody then they know. I don’t believe in keeping secrets anyway; I’m a bit like ‘what you see is what you get’”. *Janice*

Two of the participants spoke about military culture and how it had affected the relationship between them and their loved ones. Graham and his wife Dorothy were both military veterans, and he recognised that having to be careful about revealing information had over time changed their level of intimacy.

“Some of the jobs that I did were…well, I couldn’t talk about them because they were classified, and so you’d come home and it’s like, ‘how’s your day?’ ‘Yeah, it was okay.’ And

you can't go into any details and so you don't really talk about it. [.] She knew I wouldn't answer her, so she probably didn't talk, and that perhaps was the thin end of the wedge."

This meant that this couple were not in the habit of exchanging information about their feelings, and so this seems to have left Graham guessing about his wife's experience rather than hearing her express it openly. Graham explained how things were when she received her mesothelioma diagnosis on her own and returned home to tell him:

"She wasn't a great one for communicating her feelings, but she would've been absolutely devastated."

He is rather tentative when he is describing to the interviewer some aspects of his wife's emotional journey:

"I think at first she was afraid of dying and the counselling sort of helped her to get it straight in her head."

He is also not sure how much she talked intimately with her close friends:

"She maybe confided in one or two of those."

However, Graham was clear about certain emotions his wife did display:

"She got a placebo, which irritated her intensely."

In terms of his own feelings during the mesothelioma journey, it is difficult to tell from the transcript, as he rarely mentions them. He tends to describe situations using a third-person perspective, e.g., *"it's a shocker"* or *"it just seemed so unfair"* or *"it's excellent, it's a really happy group and very friendly",* rather than saying 'I'. He comes across as an observer, somehow slightly detached and unemotional. The only time he names a personal feeling is in the following description of his own character, where he equates strength with emotional independence in a way that is characteristic of British military culture:

"I'm happy…emotionally I'm perhaps quite a strong person anyway, and so having said she was independent, I'm quite independent too. And no, I don't think that I had many emotional needs that I needed help with."

In Andrea’s transcript, the issue of openness about feelings threaded throughout. We have already seen how her husband had kept the secret of his end-of-life stage in order not to ‘upset’ her and their daughters. Keeping military secrets, including about very emotive incidents, had been part of his life as a [senior naval officer] from the early days of their marriage onwards:

“I remember thinking there you are on a [vessel] that had a dreadful accident, and it’s only just now come to light, people are talking about it.”

Andrea identified the same idea of independence as Graham:

“I suppose because we’re both fairly independent, I think I’ve had to be, being married to somebody in the Navy, and Eric was very, very independent.”

The resulting withdrawal and lack of intimacy between the two is poignantly shown in Andrea’s description of Eric’s end of life:

“Towards the end, he hardly spoke. I’d be rabbiting on about anything but he would hardly…You’d get maybe a yes or a no, he wouldn’t…I suppose he definitely went into himself.”

In contrast to these three carers, Janice described her philosophy like this:

“I just think if you tell somebody then they know. I don’t believe in keeping secrets anyway; I’m a bit like ‘what you see is what you get’”.

This statement occurred when she was giving a vignette about how her sister-in-law reacted to hearing the news of her husband’s diagnosis:

“His sister in [abroad] was absolutely hysterical when he told her. She was just beside herself.”

This shows Janice’s awareness that a consequence of being open with upsetting information is people’s distress can be huge and difficult to manage.

5.3.3 ‘*Official secrets’* sub-theme

The question of keeping information secret did not only show up in the data in terms of intimate couple relationships: it was a feature of the carers’ relationships with big organisations as well. This sub-theme shows how participants’ experiences with such organisations in terms of openness of information sharing impacted on them and their loved ones. See Table 31 for selected illustrative participant quotations.

Table 31: ‘*Official secrets’ sub-theme*

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**
Openness: is it safe?	Official secrets	“They didn’t say to us you know, you may’ve been exposed, or you need to take these cautions or…It was…it’s a scandal really.” *Graham* “The situation after Patricia had died with regard to the NHS and the loss of the documents that were holding something up for me was probably the worst time of my life. [.] When I think about these things, as I do daily, I would never be able to accept that we believed one thing based on information that we were given, and yet that was not the full story.” *Malcolm* “I couldn’t believe that one hospital hadn’t told the other, I thought that was pretty poor.” *Andrea*

Three of the participants told about distressing instances where either the NHS or the MOD had mishandled or hidden information, sometimes with potentially very serious consequences for safety.

Graham was very concerned about a stamp placed in his military records noting his exposure to asbestos. This information had been recorded but without any accountability and without his attention being drawn to it.

“They didn’t say to us you know, you may’ve been exposed, or you need to take these cautions or…It was…it’s a scandal really.”

He seemed to feel let down by the MOD, along with others who had also *“slipped through that net”.* He was very aware that this vital information, which he had only found out by accident, ought to be in his NHS records, for his protection:

“If I was taken by ambulance and I’m not conscious then I can’t tell them my experiences and if it’s not in my notes then nobody knows.”

When he did receive his service records as requested, he was left alone to find his way through them, without any guidance:

“It turns up and there’s no covering letter or anything; it’s just up to you to delve into it.”

Malcolm’s transcript also mentioned the MOD’s military records, highlighting their extensive, all-encompassing nature. In his wife’s case, there was no problem with these records, but he mentioned how other people who were entering into asbestos-related litigation were treated by the MOD:

“They [MOD] say, ‘Oh, we’ll leave it to them to come up with the proof.’ They [MOD]’ve got the proof. [.] It’s a case of whether they want to spend the money to actually find it.”

For Malcolm, the big difficulty regarding records was within the NHS. His wife had been misdiagnosed, and precious months had been lost while she had the wrong treatment. After her death, when he felt able to investigate the misdiagnosis, her medical records for this period mysteriously went missing. This held up the coroner’s verdict. Malcolm described the devastating impact this mishandling of information had on him:

“The situation after Patricia had died with regard to the NHS and the loss of the documents that were holding something up for me was probably the worst time of my life. [.] When I think about these things, as I do daily, I would never be able to accept that we believed one thing based on information that we were given, and yet that was not the full story.”

From Malcolm’s viewpoint, the diagnosis was incompetent and the disappearance of the relevant records unscrupulous. This was too much for him to bear, as someone who had such high standards in terms of efficiency and accountability. His assumptions about the world were shattered, leading to signs of possible traumatisation.

The transcript of Andrea’s interview contained two vignettes about NHS incompetent handling of confidential information. In the first, she described her husband being sent home from hospital with someone else’s medical records and medication instructions. This caused high emotions:

“Then it was panic, because [daughter’s name] said ‘Oh my God! Is he taking the wrong tablets?’”

They rang the hospital, and a nurse was off-hand and seemingly unconcerned:

“[Daughter] was so angry she rang somebody else who was in charge of it all.”

In the second incident, Andrea was phoned up by a hospital after her husband’s death to offer him a place on a trial.

“I couldn’t believe that one hospital hadn’t told the other, I thought that was pretty poor.”

These two examples showed Andrea and her family being upset and angry due to miscommunication. They expected this large organisation to be much more careful with sensitive information and to pay attention to risk.

5.3.4 ‘*Becoming vulnerable’* sub-theme

In this sub-theme, the issue of openness in sharing personal feelings is highlighted. This includes individuals’ tendencies in expressing personal feelings of various kinds. The sub-theme also presents how for some, being open about distress feels uncomfortable and/or risky and could lead to a sense of vulnerability. See Table 32 for selected illustrative participant quotations.

Table 32: ‘*Becoming vulnerable’ sub-theme*

Super-ordinate theme	**Sub-theme**	**Participant quotations (selected)**
Openness: is it safe?	Becoming vulnerable	“Well, you have good days and bad days. I don’t want to be…I can’t deal with sympathy very well. I find that if somebody gets upset around me, I’d rather be the person dishing it out than getting it, if you see what I mean.” *Janice* “You’d never want to admit you can’t cope, because they [the military] would say, well, what’s wrong with you?” *Andrea* “I think there’s a fair possibility that it was me bringing it home on my clothes that gave it to my wife, but whether that’s the case or not I don’t know.” *Graham* “It [support group] was all this, all sharing your feelings and half of them were crying, and I thought, ‘Oh my God, it’s not for me’”. *Andrea*

When the interviewer asked Janice about how she herself had been doing, her answer showed a reluctance to ‘own’ any difficult feelings:

“Well, you have good days and bad days. I don’t want to be…I can’t deal with sympathy very well. I find that if somebody gets upset around me, I’d rather be the person dishing it out than getting it, if you see what I mean.”

We can notice her use of the generic ‘you’ within a cliché, indicating her discomfort. The phrase ‘dishing it out’ has a hint of negativity. It seems that needing sympathy is potentially shameful as it means weakness and vulnerability. Rather than admitting to any negative feelings, Janice is determined to express herself positively. For example, when another mesothelioma patient’s wife was afraid to ring her with news of a clear scan, Janice was comfortable showing positive emotion:

“I said, ‘Well that’s just good news, and I wouldn’t rain on you parade, I’m glad it has been good for him.’”

She also used the word ‘hope’ twice when describing her husband’s upcoming drug trial:

“Let’s hope that when we go tomorrow, he’s accepted. [.] Let’s hope he gets it and he is that two out of the three that gets the real thing and let’s go from there. That’s all you can do really, isn’t it?”

The idea that openly showing distress means you are weak and ‘wet’ was often in evidence in Andrea’s transcript. Andrea was proud that she and her daughters were *“capable”* because of their upbringing in the military community. There seemed to be a link for her between showing emotional pain and being a baby or child, along with the sense that one should grow out of this. There was therefore shame attached to being an adult who communicated distress. Some examples from Andrea are:

“You’d never want to admit you can’t cope, because they [the military] would say, well, what’s wrong with you?”

“It [support group] was all this, all sharing your feelings and half of them were crying, and I thought, ‘Oh my God, it’s not for me’”.

“[Toddler grandson] keeps saying ‘Where’s Grandpa, where is he? I miss him!’ You’re like ‘Oh God!’”

This quote about her grandson is the only place in the interview where any grief is openly expressed, and it is through the mouth of a child who has not yet learned the military way. For Andrea, her discomfort with distress seems to extend to the issue of physical pain: she described her husband as *"popping pills like Smarties",* again linking the experience to childhood via this metaphor about sweets.

We have already seen how Graham's account seemed rather lacking in content about his own emotions as expressed from a first-person perspective. Even when he was talking with the interviewer about topics that might evoke difficult feelings, he framed these in a factual way. For example, his wife suffered a great deal from post-operative pain in the first year. He talked about this rather factually, without giving much sense of what this experience *felt* like for him or his wife, apart from that it was *"difficult".* At another point, he explained his possible role in his wife's exposure to asbestos:

"I think there's a fair possibility that it was me bringing it home on my clothes that gave it to my wife, but whether that's the case or not I don't know."

There is no hint of guilt in his expression here. Nor is there any sharing of anxiety when he talks about the possibility of needing a hospital to know about his exposure in any future emergency. He experiences the *facts* of possibly exposing a loved-one and having Damocles syndrome without expressing (or even having?) the emotions we might expect from the academic literature. Interestingly, Andrea also exhibits the same factual approach to Damocles syndrome, talking about another veteran's wife without any sense that she could be talking about her own situation:

"There was one lady who was fighting for compensation because she used to wash her husband's overalls and he was in the services, and she got it, because you only have to have one little, tiny fibre."

(This is despite the fact that her husband clearly did have Damocles syndrome: he matter-of-factly explained his diagnosis to her as *"oh, well, it's got me".)*

Malcolm's transcript also tends towards factual expression, rather than communicating explicitly his or his wife's emotions. One of the few examples where he does is "it was devastating", about his wife's misdiagnosis. Whilst Malcolm was clearly devoted to his wife, he, like Andrea, does not directly express any grief about losing her. Instead, he narrates how he received an email after her death from a young woman who had known his wife in childhood:

“She said, ‘My family and I are very sad, and my dolls are sad too’”.

It was as if it was acceptable for a young person/child to vocalise grief in a way that would not be appropriate for an adult like Malcolm. Malcolm also used impersonal phrasing to convey emotional aspects of his bereavement, e.g., *“A great loss”* and *“It’s a labour of love now, and it’s her legacy.”*

In this section, I presented Super-ordinate theme Two, *‘Openness: is it safe?’* This super-ordinate theme covered ideas about openness in terms of sharing information, e.g., medical data, and personal feelings. Also shown were the possible consequent benefits and risks, such as feeling uncomfortably vulnerable. In the next section, I go on to present the third super-ordinate theme, ‘*Human connections – getting support’.*

5.4 Super-ordinate theme Three - *Human connections: getting support*

5.4.1 Overview of Super-ordinate theme Three – *Human connections: getting support*

This super-ordinate theme looks at how the participants experienced connections with other people during the mesothelioma journey. It includes consideration of the importance the carers placed on connections to others, what categories of people were present in their accounts, and to what extent these connections were supportive or not. There are no sub-categories within this super-ordinate theme, so it will be presented as a whole. See Table 33 for selected illustrative participant quotations. Further quotations are included in the full narrative account.

Table 33: Super-ordinate theme Three – Human connections: getting support

Super-ordinate theme	**Sub-themes**	**Participant quotations (selected)**
Human connections: getting support	n/a	“She had a very tight circle of work friends and they kept in touch right to the end. [.] They were really, really good and they helped.” *Graham* “Just people caring. Just people phoning up for a chat.” *Janice* “The only people that probably really let us down, I think, were the surgeons.” *Graham*

		"I've got a limited amount of support from my family because most of them are my age and most of them have health issues of their own." *Malcolm* "They [cancer charity] probably don't know this, but they've been so good for my therapy. This has not been a one-way ticket." *Malcolm* "Because they [daughters]'ve had that sort of [military] lifestyle [.] obviously if somebody had come and offered some help, but we wouldn't have gone out looking for it because it's not been the way we've been used to doing things." *Andrea* "One of them said, 'Oh, we'll call in and see how Andrea is', well, nobody has called, not that I'm saying 'oh, poor me.'" *Andrea*

5.4.2 Super-ordinate theme Three - Human connections: getting support

In Janice's transcript, the value she placed on social interactions and the support they provided was clear. Her answer to a question about what sort of support was useful to her was:

"Just people caring. Just people phoning up for a chat."

She talked about how she and Keith went dog-walking every night with a group of people who met up in the park. A plan to go on holiday with friends and their grandchildren was described in detail, with gratitude for the thoughtfulness of the friends. The holiday's multi-generational aspect seemed to be a positive for her. Janice carefully categorised their *"really good support network"* into friends they had had for more than 40 years and then local acquaintances made over the last three years, who she said had been *"fabulous absolutely"* and *"extremely supportive".* The pronoun she used when talking about these connections was *"we",* i.e., these were connections for the patient and carer as a dyad. In terms of professional support, Janice listed various types of specialist nurse, including named individuals, and also the local ASG. All of these had been *"fabulous", "really great"* or *"really fantastic".* Janice expressed the fact she felt they were *"very, very lucky"* to have this support network.

A supportive net of people also appeared in Graham's data. This consisted of friends and professionals. However, this time the friends seem from his descriptions to belong to his wife, rather than to the two of them, and to be interacting with *her*. For example:

“She had a very tight circle of work friends and they kept in touch right to the end. [.] They were really, really good and they helped.”

“The counsellor she talked to, they formed a really good bond, a friendship outside of work and it was…it went far beyond just…in fact the counsellor came to her funeral.”

Graham mentioned various supportive professionals, including a *“brilliant”* ASG representative, *“excellent”* and *“superb”* named mesothelioma doctors, the *“unbelievable”* local hospice, and the new GP who went out of his way to introduce himself and catch up with Dorothy’s situation (*“excellent”* behaviour). Not everything was rosy, though: we have already heard about the difficult district nurse, and Graham also said:

“The only people that probably really let us down, I think, were the surgeons.”

Overall, he paints a positive picture of supportive people around his wife, with his wife interacting with them closely and appreciating the support. He also talked about how she was a volunteer for [cancer charity], as *“she was all for paying back”.* The impression is of his wife fully participating in supportive relationships. For Graham himself, the support he valued (mentioned in much less detail) was the ASG rep helping them sort out paperwork at the start, and the happy, friendly support group he was still attending after Dorothy’s death.

For Andrea and Malcolm, the picture looks more complex. Malcolm’s transcript contains a few brief glimpses of family members. He mentioned they had a child, but there is no other reference to them. He also succinctly states (after a question about family from the interviewer):

“Yes, family visited, which was good.”

The only other mention comes when he describes the very difficult period after his wife died:

“I’ve got a limited amount of support from my family because most of them are my age and most of them have health issues of their own.”

In his whole interview, Malcolm didn’t use the word ‘friend(s)’ once. Instead, he referred to colleagues and *“people I knew”* or *“people we hadn’t seen for yonks”.* He did all the practical end-of-life caring himself, without anyone else coming in. The only practical help at that time was from *“people we knew”* who owned a hotel and let them live in a ground floor suite:

“They were very good to us.”

Malcolm therefore seems to have experienced the time before his bereavement as a period when he did not need or expect much emotional or practical support. However, after Patricia died, it appears that he was struggling. One the one hand, he was used to being alone:

“I’d been on my own many times before, and so had she been on her own, so being on our own didn’t cause a problem for either of us.”

This chimes with comments about independence we saw from Andrea and Graham in the second section, and in fact Malcolm described the point at which his wife returned to work as *“after [child] was old enough to deal with things <u>on her own</u>”* [my emphasis].

On the other hand, he was overwhelmed by the issues of the misdiagnosis, the NHS lost records and delay to the inquest. When asked by the interviewer what support he had at this time, he said:

“I think I could best answer that in two words: [cancer charity]. They were my support”.

Noticeable here is the naming of an organisation, rather than any individuals, unlike Graham and Janice’s accounts. Malcolm is clearly very grateful for this support, and in turn has volunteered extensively for them. He finds it hard to imagine that the cancer charity could understand this relationship as mutual and two-way:

“They probably don’t know this, but they’ve been so good for my therapy. This has not been a one-way ticket.”

The fact that one important aspect of [mesothelioma charity]’s official role is emotional support seems to be somehow outside of his awareness. Malcolm feels comfortable bonding with organisations (e.g., the wounded servicemen’s club he attends) rather than with particular individuals, such as friends or named nurses. Recognition for his wife from the wider armed forces community meant a great deal to him and clearly made him feel proud. He described in detail military honours she was given, such as a fly past and guard of honour. This kind of support from an official body of people makes sense and feels right to Malcolm.

Finally, we turn to Andrea's connections and her experience of getting support. Andrea's transcript was the most difficult for me to analyse: the process felt almost painful and took longer than the others. Eventually I came to realise that there was a deep ambivalence in Andrea's response to her mesothelioma experience, which felt painful for her and involved feelings of shame. We have already seen how she had been indoctrinated into the military culture where it is vital not to seem 'wet' or vulnerable. Her husband *"wouldn't really accept any [emotional] support",* and prioritised the avoidance of people getting upset to the extent of forbidding a church funeral, making this decision without any discussion:

"He said 'I don't want the coffin to go into the church', which is very strange because he had a very strong faith, we are regular churchgoers, and he said 'No, it will be too upsetting.'"

He was avoiding his family showing any distress, which overrode any need they might have to *share* this important experience with others in a traditionally supportive setting. Andrea and their daughters went along with this decision, despite its being out-of-kilter with what they would have expected. Perhaps it made sense to them in terms of the military culture of women and children needing to be protected.

For Andrea, her children and grandchildren are around during Eric's illness. She mentions that her daughters visited, but there is no detail about how this might feel supportive. In fact, the presence of younger people at times seems risky for her. As we have seen, for her, young children have not yet learned how to suppress emotions, may become upset and therefore be a source of pain and vulnerability for the adults around them. When Andrea narrates Eric's actual death, which was a huge shock for her, she only slips into the present tense when she gives this particular detail:

"Meanwhile, our daughter comes over with her husband and her [small child] and a [age removed] baby, my other daughter and her husband are driving down."

Her use of the present tense suggests there is still something 'live' for her about the arrival of these younger relatives. Andrea believes that being alone during difficult situations is better. Talking about her own experience of being a cancer patient in hospital, she said this:

"You're much stronger on your own, because you go in and there are two or three people there and they're all putting their arms around them and saying, 'Oh, well, how are you?' I'm much better if I'm focusing, you know? I don't want to be sat there, crying, and making everyone else upset."

The presence of others giving physical comfort and emotional support is seen as risky and negative. Andrea ascribes this attitude to military culture, and links this to not seeking help:

"Because they [daughters]'ve had that sort of lifestyle [.] obviously if somebody had come and offered some help, but we wouldn't have gone out looking for it because it's not been the way we've been used to doing things."

Friends are presented as part of the picture for Andrea. A friend would take Eric for his chemo appointments:

"They'd usually just stop and have a meal somewhere, have a chat, so [friend] was very good, yes, I see a lot of [friend] and [friend's wife]. I've got some very, very good friends, I'm very lucky."

Andrea also compared talking with friends to being in a cancer support group:

"I've got very good friends who if I want to talk they're there, but I find it a bit odd everybody sitting around in a circle, you know? [.] Perhaps I'm the odd one, but…"

The impression is that for her and Eric, friends are around but perhaps in a more practical way, which provides some valued sense of normality during his illness.

However, in that quotation, we can also notice the ambivalence in Andrea's sense of herself. In the following quotation, she describes how she feels abandoned by the HCP's who had said they would call or visit after Eric's death, and in the same breath she disowns her own vulnerable state:

"One of them said, 'Oh, we'll call in and see how Andrea is. Well, nobody has called, not that I'm saying, 'Oh, poor me.'"

This wish to be thought of, cared for, asked if she needed help, is a strong thread in Andrea's transcript. For example, towards the end of the interview, describing trying to cope at the end of Eric's life, she said:

“I did think, well, this is mad, but I did think that like the district nurses came in, but not once did they say ‘Can we do anything? [.] How can we help you?’ I suppose because they came in and we were coping.”

Part of her imagines and craves warm, thoughtful support, and it seems that she did in fact receive this from her neighbour:

“He’d not been very well, poor old [cat’s name] [.] So I took him to the vet and he had to be put to sleep. And poor old [neighbour] who was there when Eric died, she took me, so she’s been sharing it all.”

Her ambivalence arises from simultaneously feeling the benefit of emotional support but not being able to understand that the giving of this support could be a *positive* for the giver, that there could be a sense of mutuality and safety within a supportive relationship. Andrea somehow feels uneasy with her habitual independence (it’s *“mad”* and *“odd”*) but also uncomfortable with being looked after in her distress. Perhaps she is in a transition stage, with potential change catalysed by her experience of mesothelioma.

5.4.3 Conclusion

In this section, I presented Super-ordinate theme Three, ‘*Human connections: getting support’*, looking at how the participants experienced connections with other people during the mesothelioma journey. It included consideration of the importance the carers placed on connections to others, what categories of people were present in their accounts, and to what extent these connections were supportive or not. In the next section, I go on to present my key findings from the cross-case analysis.

5.5 Key findings

5.5.1 Introduction

In this section, I present key findings which aim to support and inform my empirical study. The seven key findings were drawn, in a summarising process, from each of the super-ordinate themes. Key finding one relates to two super-ordinate themes as it links between the sub-themes *‘The chain of command’* and *‘Official secrets’*. See Table 34 for the SDA themes presented with their key findings.

Table 34: SDA themes and key findings

Super-ordinate themes	**Sub-themes**	**Key findings**
1. Control and responsibility	The chain of command	***Key finding one*** Carers’ high expectations of big organisations/institutions (with respect to efficiency, communication and accountability) are: a) reassuring when things go well (high praise is expressed); b) causing distress and even traumatisation when carers feel let down. Carers’ high expectations of organisations meant they were particularly distressed by the mishandling or hiding of information.
	Controlling language and thinking	***Key finding two*** Carers and patients use control over language and thinking as a coping strategy, including humour and irony.
	The out-of-control body	***Key finding three*** Control of physical pain was an important issue for carers. Also, carers’ awareness of visible change and decline in the patient’s body was hard to ignore. This could interfere with attempts to control thinking and feeling about the situation’s severity.
	The proactive carer	***Key finding four*** Participants’ proactivity as carers, acceptance of role, and comfort with help-seeking in the *practical* sphere showed different patterns: a) proactively attending to practicalities, planning ahead, doing it all yourself, and coping; b) following the lead of veteran patient who proactively attends to practicalities and plans ahead, and accepts lots of external practical (and emotional) help; c) attending to practicalities *without* planning ahead, not asking for practical help, just getting on with it, doing it all yourself, struggling/burning out.
2. Openness: is it safe?	Secrecy and intimacy	***Key finding five*** A habit of secrecy, ascribed explicitly to the military context, leads to hiding of important information within the couple/family, including the sharing of feelings. ‘Protecting’ the partner/family is highly valued. This affects levels of intimacy. No carer said they felt closer to their partner over the course of the illness.
	Official secrets	*See Key finding one* Carers were particularly distressed by the mishandling or hiding of information.
	Becoming vulnerable	***Key finding six*** Carers and patients seem to have limited awareness of their own feelings. Some talk in a *factual* way about topics which we might expect to be accompanied by expression of strong feelings (e.g., Damocles syndrome; guilt at contaminating family). There is also for some a sense of

		shame and risk around certain types of emotional expression.
3. Human connections: getting support	n/a	***Key finding seven*** Some patients and carers showed discomfort or even lack of awareness about the possibility of emotional support, with no sense of mutuality within a supportive relationship. None of the carers emphasised family as a source of emotional support, and for some, interaction with family brought a sense of unease as it could lead to 'risky' emotions. Three carers did express strong appreciation of support from friends (both veteran and non-veteran), while one did not use the word 'friends', but talked glowingly of support from organisations (both military and civilian).

5.5.2 Key finding one

Carers had high expectations of big organisations and institutions, such as the NHS and the MOD, in particular with respect to efficiency, communication and accountability. These expectations provided reassurance when things went well, with the carers often expressing high praise. These same high expectations of organisations caused distress and even traumatisation when the carers in my SDA felt let down. Carers were particularly distressed by the mishandling or hiding of information.

5.5.3 Key finding two

Carers and patients used control over language and thinking as a coping strategy, including humour and irony.

5.5.4 Key finding three

Control of physical pain was an important issue for carers. Also, carers' awareness of visible change and decline in the patient's body was hard to ignore. This could interfere with attempts to control thinking and feeling about the situation's severity.

5.5.5 Key finding four

All the participants appeared to accept their carer role without difficulty. Different patterns were identified across the participants in terms of how proactive they were as carers and comfortable they were with help seeking in the practical sphere:

a) proactively attending to practicalities, planning ahead, doing it all yourself, and coping (Malcolm);

b) following the lead of the veteran patient who proactively attends to practicalities and plans ahead, and accepts lots of external practical (and emotional) help (Graham);

c) attending to practicalities *without* planning ahead, not asking for practical help, just getting on with it, doing it all yourself, and struggling or burning out (Andrea).

[The limited data from Janice meant a pattern could not be determined, though she said it was important to deal with each situation as it arose.]

5.5.6 Key finding five

A habit of secrecy, ascribed explicitly to the military context, led to hiding of important information within the couple/family, including the sharing of feelings. ‘Protecting’ the partner/family was highly valued. This affected levels of intimacy. No carer said they felt closer to their partner over the course of the illness.

5.5.7 Key finding six

Carers and patients seemed to have limited awareness of their own feelings. Some talked in a *factual* way about topics which we might expect to be accompanied by expression of strong feelings (e.g. Damocles syndrome; guilt at contaminating family). There was also for some a sense of shame and risk around certain types of emotional expression.

5.5.8 Key finding seven

Some patients and carers showed discomfort or even lack of awareness about the possibility of emotional support, with little sense of mutuality within a supportive relationship. None of the carers emphasised family as a source of emotional support, and for some, interaction with family brought a sense of unease as it could lead to ‘risky’ emotions. Three carers did express strong appreciation of support from friends (both veteran and non-veteran), while one did not use the word ‘friends’, but talked glowingly of support from organisations (both military and civilian).

5.6 Conclusion

In this chapter I presented the findings of the secondary data analysis (SDA) conducted on the four transcripts from the MiMES study where carers were interviewed on their own. The three super-ordinate themes, which were developed by looking for patterns across the four cases, were presented with supporting quotations from participants. These themes were: ‘Control and responsibility’; ‘Openness: is it safe?’; and ‘Human connections: getting support.’ The presentation of the themes was developed as a full narrative, with detailed commentary on extracts from the data. These findings were then summarised in the form of seven key findings, which supported and informed my main study. The SDA’s findings showed similarities and differences between the carers’ experiences of the mesothelioma journey and its psychological effects. There were many instances of the impact of military culture, both on the patients and the carers themselves. In the next chapter I go on to present the findings of my main empirical study.

Chapter 6: Findings of Stage Two – Interview Study

6.1 Introduction

In the previous chapter I provided the findings of the Stage One secondary data analysis. I now move on to present the findings of the Stage Two main empirical study. First, the characteristics of the main study participants and the veteran patients they cared for are presented in two ways: a table of demographic data (section 6.2.1) and a set of pen pictures (section 6.2.2). The purpose of presenting these characteristics is to be transparent about the dataset's scope, and also to align with IPA's commitment to the idiographic (Smith, 2011b, 2011a). Sketching the participants and their relatives in pen pictures allows the reader to develop a sense of each individual participant before the findings related to their experiences are presented in detail. I then present the findings of step six in the IPA process (*looking for patterns across cases).* Three super-ordinate themes were developed: '*Going the extra mile', 'Staying the same person',* and '*Needing to know'.* Each super-ordinate theme with its associated sub-themes is presented in turn (see Table 35 for an overview).

Table 35: *Overview of Stage Two interview study themes*

Super-ordinate themes	*Sub-themes*
Going the extra mile	Just keeping on going
	Expecting and receiving committed back-up
Staying the same person	The recognisable patient
	The recognisable carer
Needing to know	Choosing what to share
	Information exchange and professionals
	Raising awareness

6.2 Patients' and carers' characteristics

6.2.1 Demographic data

The characteristics of the main study participants and the patients they cared for are presented in Table 36. This gives their available relevant demographic data.

Table 36: *Main interview study patients' and carers' demographic data*

[Note: patients' data are *italicised*]

I.D. code	**F15MM**	**F16FC**	**F17FC**	**F18FC**	**F19FC**	**F20FC**
Interview date	28/9/20	5/10/20	14/10/20	3/12/20	26/2/21	30/3/21
Pseudonym	Gary *Marie*	Janet *Arthur*	Julie *Dave*	Nicola *Len*	Vicky *Mike*	Cerys *Hywel*
Relationship of carer to patient	spouse	spouse	spouse	daughter	spouse	daughter
Age (within range)	45-49 *45-49*	75-80 *85-89*	50-54 *50-54*	40-44 *85-89*	65-69 *65-69*	55-59 *85-89*
Gender	Male *Female*	Female *Male*	Female *Male*	Female *Male*	Female *Male*	Female *Male*
Ethnicity	White British *White British*	White British *White British*	White British *White British*	White British *White British*	White British *White British*	White British *White British*
Education	Degree *A level*	Not supplied *Not supplied*	Masters *O level*	BSc (Hons) *School certificate; apprenticeship*	University diploma *Master's*	University diploma *School certificate; apprenticeship*
Armed Forces branch	Army & RAF *RAF*	n/a *RAF*	n/a *Army*	n/a *Army*	n/a *Army*	n/a *Army*
Service dates	1988-2014 *1994-2000*	n/a *1953-1955 (National Service)*	n/a *1987-1990*	n/a *1949-60*	n/a *1971-1976*	n/a *1954-56 (National Service)*
Date of mesothelioma diagnosis	2016	Jan 2020	Post-mortem April 2020	May 2019	Aug 2020	Nov 2020
Mesothelioma type	peritoneal	MPM*	MPM	MPM	MPM	MPM
Date of death	June 2020	n/a	Mar 2020	Oct 2019	Nov 2020	n/a
UK region	N. W. England	Southern England	S. W. England	Southern England	E. Midlands, England	Wales

*Malignant Pleural Mesothelioma

6.2.2 Pen pictures

The characteristics of the participants and the patients they cared for are now presented in the form of brief pen pictures. A pen picture is a “written description that gives background narrative to the participants involved” (Rogers, 2020, p. 944)[15]. I chose to compose a pen picture of each participant at the point immediately prior to carrying out the cross-case analysis. This re-introduced me to each individual, as part of IPA’s iterative process. I also re-read my bridling notes about each participant with the aim of “keeping an ever-present eye to reflexivity” and “staying true” to the individuals (Golsteijn and Wright, 2013, p. 301). Pen pictures provide a concise description which helps attention to stay focussed on the diversity within the sample (Golsteijn and Wright, 2013), thus matching IPA’s ideographic aspect. They also provide contextual features, which “help readers understand the meaning of quotations and findings” and allow the reporting of how these features are “linked to variations and processes within the findings”, thus enhancing utility (Levitt *et al.*, 2017, p. 364). The information in the pen portraits presented here was compiled from two sources: the Participant Characteristics Form, and the interview data. A process diagram of each patient’s mesothelioma journey is included.

F15MM Gary

Gary is a male veteran in his late forties, living in the North-West of England. His wife, Marie, died in her late forties in the summer of 2020 from peritoneal mesothelioma. Their children were young adults when Marie died. They met many years ago whilst both were serving in the RAF, where Gary attained the rank of Warrant Officer and Marie was a Senior Aircrafts Woman. Prior to the RAF, Gary had also served in the Army, joining at the age of 17. In total, he served 26 years in the Armed Forces and Marie served 6 years. After transitioning to civilian life, they both continued to do work for the military, which Gary still does.

Getting a correct diagnosis for Marie’s illness was very challenging and took several years. Gary described the journey as involving more than one period of being “in limbo”. Figure 5 gives an overview of Marie’s complex mesothelioma journey.

Gary and Marie’s experience of living with mesothelioma included making a complaint against their local NHS trust, a process which took 18 months. Also, the MOD refused to

---

[15] I am not using this term, as it is sometimes used, to mean composite fictional personas or portraits made up of multiple people’s characteristics (Golsteijn and Wright, 2013).

accept that Marie's peritoneal mesothelioma had been caused by asbestos contamination during her service, and the couple had to sue for compensation. Both these issues were very stressful for the couple alongside Marie's physical illness. Gary worked full-time until a year before her death, when he went down to four days per week. He found being with his military colleagues provided "a release". Marie's parents were able to live with them for extended periods as a support. The couple had some counselling together and Gary had some individual counselling through his work, but he didn't find it very helpful. Gary took on medical tasks for Marie, such as draining fluid, and he also made great efforts to get referrals to expert medical professionals and trials.

The interview with Gary took place on 28th September 2020, four years after Marie received her diagnosis and four months after her death.

Figure 5: *Overview of Marie's mesothelioma journey*[16]

---

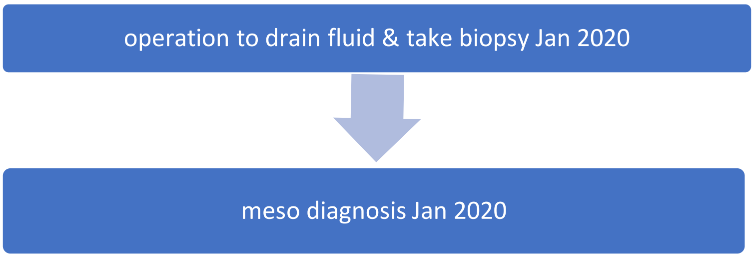
[16] In this diagram and those which follow for the other patients' journeys, precise timings of events and medical terms are not always given, as verbatim information was used from the interview transcripts.

F16FC Janet

Janet is a female civilian living in the South of England with her veteran husband, Arthur. Janet is in her mid-seventies and Arthur is in his mid-eighties. They are both retired: she worked in the service sector, and he was an administrator after serving as a junior rank in the Royal Air Force for his National Service in the 1950s. Arthur and Janet didn't meet until after he had left the service, and they have been married for over 50 years. Two of their children live close by and are supportive. Their relationship with all their children and grandchildren is close. Janet has a sister whom she feels close to, and a brother in Australia who has dementia. They lost their mother to cancer when Janet was a young girl. The Christian church has played a big part in their family life over the years. Janet and Arthur have felt very well supported by their neighbours, by the local asbestos support group, by their specialist nurse, and by Veterans UK, but Covid restrictions have limited their ability to meet face-to-face, which they miss.

Arthur was diagnosed with malignant pleural mesothelioma at the start of 2020. The doctor who gave them the news said he had "about a year" to live, which was very difficult for Janet to hear. At the time of the interview, Arthur was still living. In terms of treatment, surgery had been ruled out, but chemotherapy was a possibility. Janet is diabetic and has been taking low-dose antidepressants since the menopause. Arthur has reduced vision due to glaucoma. See Figure 6 for an overview of Arthur's mesothelioma journey.

Figure 6: *Overview of Arthur's mesothelioma journey*



The interview with Janet took place on 5th October 2020, seven months after Arthur's diagnosis.

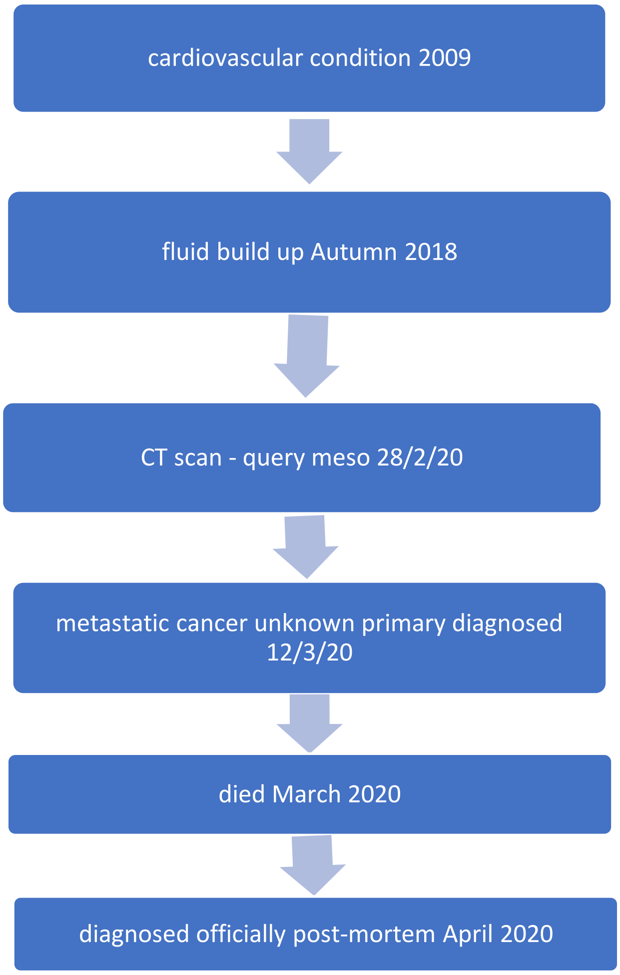
F17FC Julie

Julie is a female civilian in her mid-fifties, the widow of Dave, a male veteran who died from malignant pleural mesothelioma in his early fifties. Their home is in the South-West of

England. Julie has a career in a health-related profession. Dave and Julie were married for more than ten years. Julie was also a military wife in a previous marriage, and she has an adult child from that relationship. The couple shared a Christian faith, though at the time of his death Dave's was much stronger than Julie's. Dave served in the Army for three years, after joining up in his late teens. During his service, he was the victim of a bombing, which left him with PTSD.

A few years after they married, Dave was seriously affected by a cardiovascular condition, which left him disabled. Julie describes him as having "complex multiple physical and emotional health needs." Julie balanced caring for him with her own work, supported by outside carers coming in. Dave's metastasised pleural mesothelioma was not diagnosed officially until after his death, and he died on a respiratory ward in March 2020 as the Covid pandemic was escalating. Julie described his last two weeks as "so traumatic." See Figure 7 for an overview of Dave's mesothelioma journey.

Figure 7: *Overview of Dave's mesothelioma journey*



Julie was only able to access support from a mesothelioma charity after his death. Julie is unhappy that some of Dave's symptoms were ascribed to other health conditions, rather than mesothelioma, as she now suspects they were connected. Dave, whose brain injury left him confused, did not accept that he had mesothelioma. Since her bereavement, Julie has felt herself withdrawing from people, though she has been in touch with her adult child frequently, and she has not coped well with being alone during Covid lockdown. She has accessed bereavement counselling. Julie went back to work soon after Dave died, and she looks after herself by taking exercise and eating healthily.

The interview with Julie took place on 14th October 2020, seven months after Dave's death/diagnosis.

F18FC Nicola

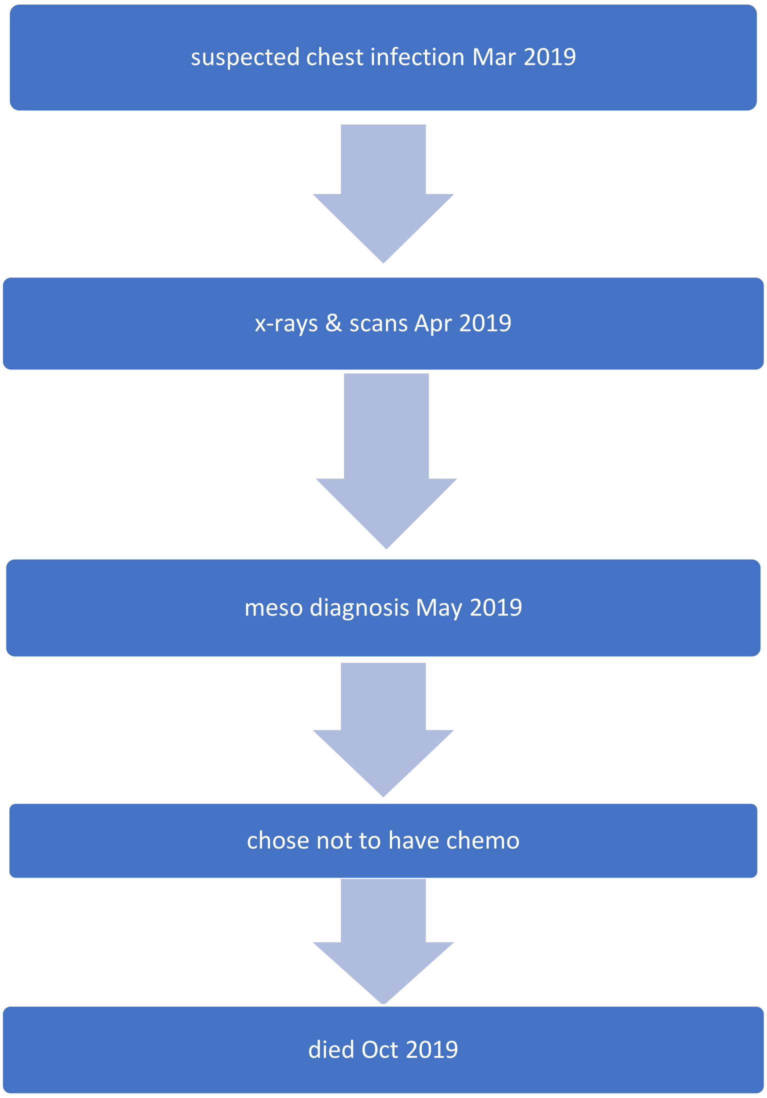
Nicola is a female civilian in her early forties, and her father, Len, was a male veteran in his late eighties, living in the South of England. He died from pleural mesothelioma in October 2019, five months after being diagnosed. He initially presented with a chest infection which did not respond to antibiotics, and further tests indicated mesothelioma. See Figure 8 for an overview of Len's mesothelioma journey.

Len lived in the family home he and his wife had shared for fifty years. Len was caring for his wife, who has dementia, until he became too unwell himself, at which point she went into a care home. Nicola is their only child and she does not have any children. She is working in a health-related profession as a civilian in the Armed Forces. Her husband is currently serving in the Armed Forces. Len was in the Army for eleven years (before Nicola was born). He went on to work in a craftsman trade. Nicola proudly says: "I see myself as more military than civilian."

When her father was given his diagnosis, Nicola made it her goal for him to have great quality of life in his remaining months and to die a "good death." They went on many trips out and even a holiday whilst he was well enough. Although they were not able to access the Hospice at Home service as she had hoped and planned, due to lack of capacity, Nicola and her husband took on this responsibility and cared for Len at the end of his life. In managing this they were very well supported by district nurses and the care agency who had been engaged to care for his wife. Nicola felt generally well supported by their friends and the military community.

The interview with Nicola took place on 3rd December 2020, 18 months after Len's diagnosis and 13 months after his death.

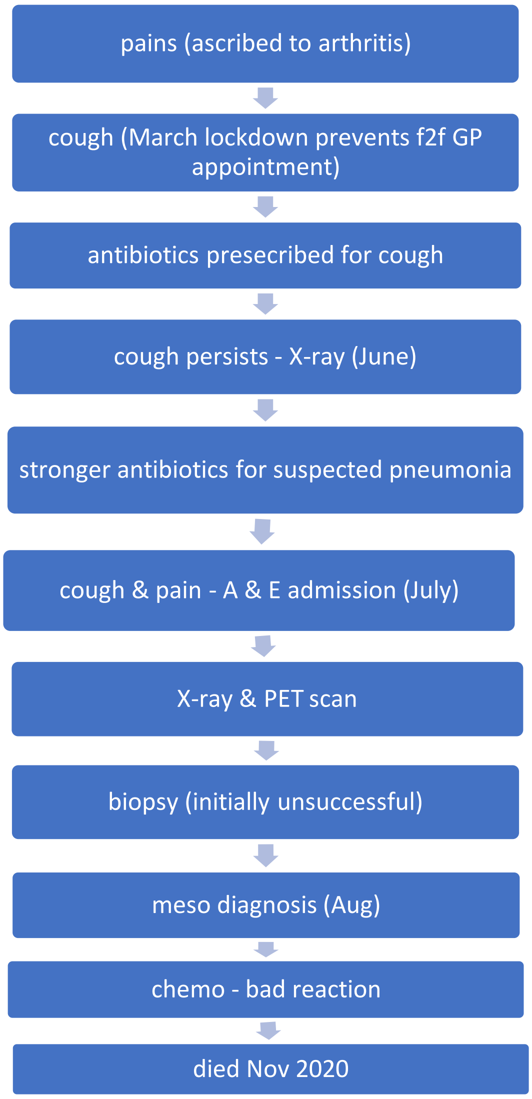
Figure 8: *Overview of Len's mesothelioma journey*



F19FC Vicky

Vicky is a female civilian living in the East Midlands of England, the wife of Mike, a male veteran. Vicky is in her mid-sixties and Mike was in his late sixties when he died from pleural mesothelioma in November 2020. His death occurred three months after his diagnosis. He had a persistent cough at the start of the Covid-19 pandemic. As access to their GP was restricted because of Covid, this was initially treated as pneumonia until he ended up visiting A & E with chest pains. See Figure 9 for a diagram of Mike's mesothelioma journey.

Figure 9: *Mike's mesothelioma journey*



Mike served in the Army in the 1970s in a role which required great secrecy. After leaving the service, he worked with children and young people. The couple met after Mike left the Army. Vicky also worked with children and young people, and she currently works part-time in a local community role. Vicky is a member of an evangelical Christian church, and Mike was a practising Roman Catholic. Vicky was married previously, and she has an adult child who lives several hours' away and visits regularly. Mike and Vicky were keen cyclists and overseas travellers until his illness. Vicky has a supportive sibling living nearby, plus lots of support from other people locally. She had some mental health difficulties about five years previously and found counselling helpful then; she has had some pre-bereavement

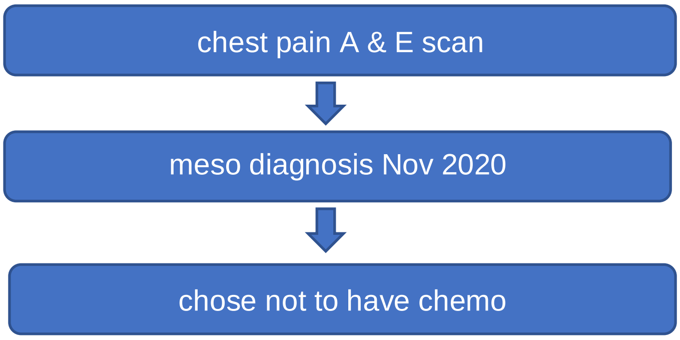
counselling at a hospice. She is pre-diabetic and also has some intermittent joint problems. Mike had suffered with arthritis for years. The local ASG and Veterans UK helped sort out his financial claim very quickly and efficiently. Vicky has found the mesothelioma online support groups very helpful.
The interview with Vicky took place on 26th February 2021, six months after Mike's diagnosis and three months after his death.

F20FC Cerys

Cerys, a female civilian, and her father Hywel, a male veteran, are Welsh. They live in rural Wales. She is in her late fifties, and he is in his late eighties. Hywel lives on his own near enough to Cerys for her to visit him most days. His wife died a few years ago, and Hywel coped well with looking after himself until recently, but he is now requiring increasing levels of practical support. Cerys is a retired healthcare professional. Hywel left school aged 15 to take up an apprenticeship and then spent two years in the Army for National Service. After that, he was mostly self-employed in a construction trade. Cerys lives with her husband, and they have several grown-up children. Both Hywel and Cerys enjoy being active outdoors: she plays golf and swims, and he has been an avid gardener and sailor in his small boat. They both enjoy meeting up with friends.

Hywel's malignant pleural mesothelioma was diagnosed in November 2020. Initially he was not told about or offered any treatment. After a few months of feeling "numb", he became increasingly interested in finding out more about treatment options. He was able to discuss chemotherapy with his GP, who explained about the potential for QOL to be impacted, and the decision was made not to go ahead. See Figure 10 for a diagram of Hywel's mesothelioma journey.

Figure 10: *Overview of Hywel's mesothelioma journey*



Because of the Covid-19 pandemic, many of Hywel's interactions with HCPs have not been face-to-face. Cerys has found their specialist solicitor to be particularly informative and helpful about many aspects of mesothelioma. They have also been supported by a palliative care nurse and specialist lung cancer nurses. Cerys joined an asbestos support group, which she found helpful. She is starting to feel anxious about how they will manage the final stages of Hywel's illness.

The interview with Cerys took place on 30th March 2021, four months after Hywel's diagnosis.

6.2.3 Summary of patients' and carers' characteristics

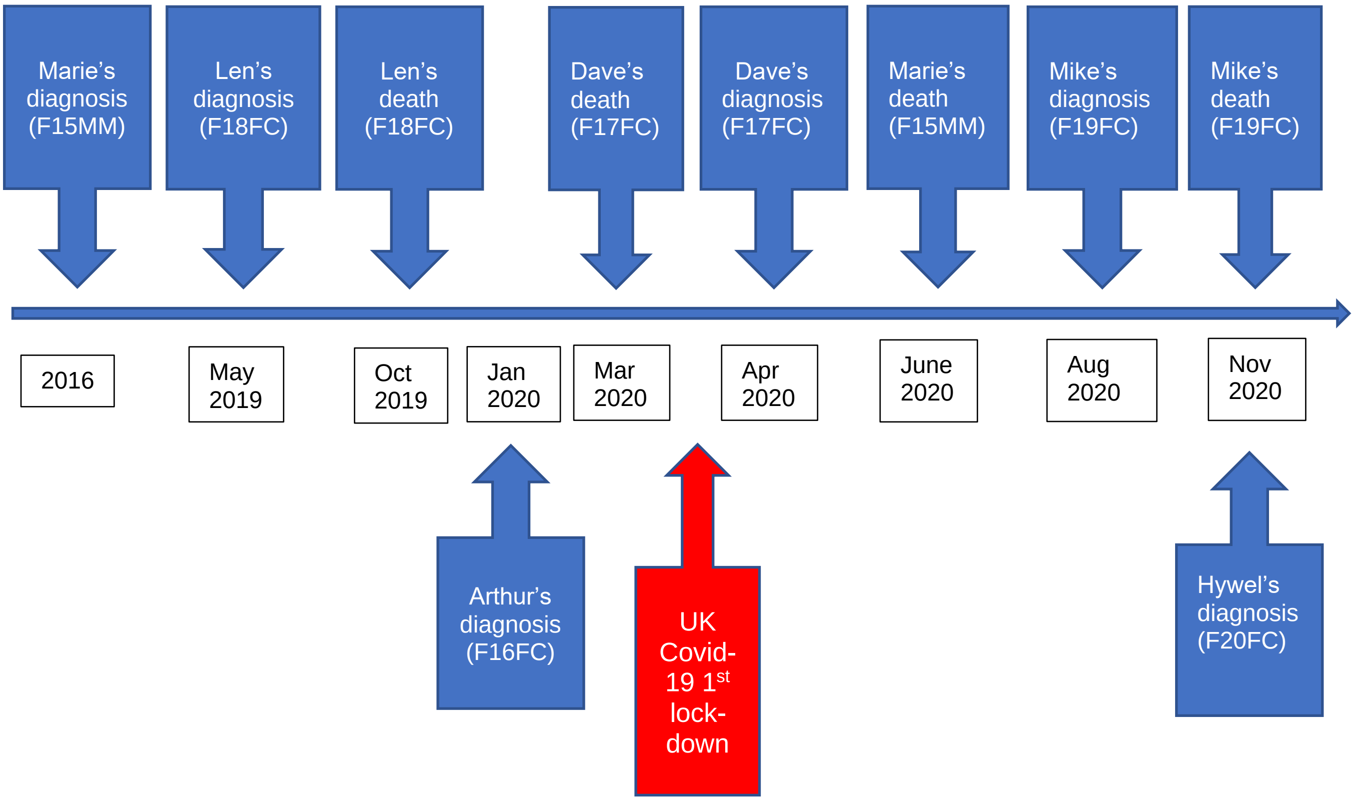
In this section, I summarise the similarities and differences between the participants. Two of the carers (F16FC Janet and F20FC Cerys) had not yet experienced the death of their loved one, whereas the others had been bereaved up to two years before the interview. The majority of participants were the patients' spouses, with two being their daughters (F18FC Nicola and F20FC Cerys). Three of the carers would consider themselves to be members of the military community, either having served in the Armed Forces for many years (F15MM Gary), having been a service wife (F17FC Julie), or having grown up in a family with a military tradition, being a service wife and working as a civilian for the MOD (F18FC Nicola). The others, although caring for a veteran, had not experienced life alongside the patient's military service: F20FC (Cerys)'s father and F16FC (Janet)'s husband had served only two years for National Service in the 1950s; F19FC (Vicky)'s husband had left the Army before they met. F15MM (Gary)'s wife was the only veteran to have been diagnosed with peritoneal mesothelioma rather than the malignant pleural form. The young age at death of F15MM (Gary)'s and F17FC (Julie)'s spouses marked them out from the rest of the group, and F17FC (Julie)'s husband was the only veteran with complex pre-existing medical conditions. Cerys (F20FC) and Hywel were the only two to live outside England. Three of the carers had a health-related career (F17FC Julie, F18FC Nicola and F20FC Cerys). The Covid-19 pandemic did not impact the experience of F18FC (Nicola), as her father was diagnosed and died before the outbreak; however, all the other participants' loved ones were either diagnosed, or died, or were living with the illness during the pandemic. A timeline of the patients' diagnoses and deaths in relation to the pandemic is presented in Figure 11.[17]

---

[17] See the Institute for Government's (2021) timeline for further detail on UK lockdowns.

Having presented the characteristics of the individual participants and the veterans they cared for, I now move on in the next section to present the findings of IPA's step six, *looking for patterns across the cases*.

Figure 11: *Timeline of patients' diagnoses and deaths*



6.3 Findings of the cross-case analysis

6.3.1 Overview of the cross-case analysis findings

Three super-ordinate themes were developed for the dataset as a whole: '*Going the extra mile*', '*Staying the same person'*, and '*Needing to know.'* [18] See Figure 12 for a diagram representing the super-ordinate themes with their associated sub-themes.

The prevalence of these super-ordinate themes and their associated sub-themes across the participant group is presented in Table 37. Most of the themes were relevant to all the

---

[18] The set of super-ordinate and sub-themes was developed for the dataset as a whole, after themes had been developed for each participant individually. For a table presenting the individual participants' themes with a selection of illustrative quotations see Appendix M.

participants. The only exception was the sub-theme ‘*Raising awareness*’, which did not appear in the data of the two participants who were not yet bereaved.

Figure 12: *The three super-ordinate themes with their sub-themes*

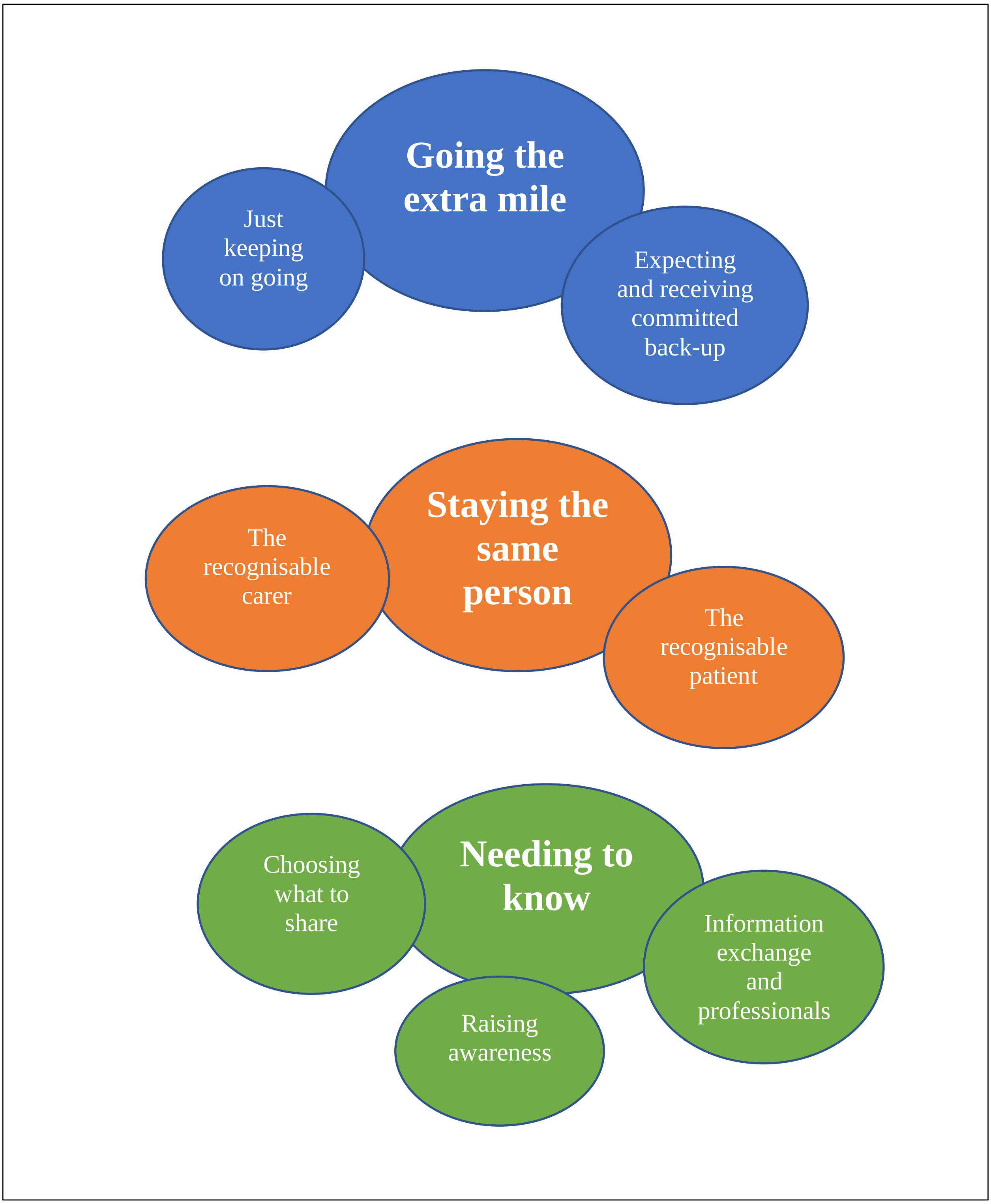


Table 37: *Prevalence of themes across the group*

Super-ordinate theme	*Sub-theme*	*F15MM*	*F16FC*	*F17FC*	*F18FC*	*F19FC*	*F20FC*
‘Going the extra mile’	‘Just keeping on going’	✓	✓	✓	✓	✓	✓
	‘Expecting and receiving committed back-up’	✓	✓	✓	✓	✓	✓
‘Staying the same person’	‘The recognisable patient’	✓	✓	✓	✓	✓	✓
	‘The recognisable carer’	✓	✓	✓	✓	✓	✓
‘Needing to know’	‘Choosing what to share’	✓	✓	✓	✓	✓	✓
	‘Information exchange and professionals’	✓	✓	✓	✓	✓	✓
	‘Raising awareness’	✓	X	✓	✓	✓	X

The findings of the cross-case analysis are summarised in Box 4, with one illustrative quotation for each sub-theme. This allows the reader to gain an overview of the themes prior to the full presentation below. See Appendix Y for a master table showing super-ordinate themes for the whole dataset with nested sub-themes and illustrative quotations for each participant, as is typically provided for IPA studies (Smith, Flowers and Larkin, 2009).

In the following sections I present in full narrative form each cross-case super-ordinate theme in turn with its associated sub-themes. For ease of reading, all illustrative quotations have been edited to remove repetitions, ums, pauses and so on, unless these seemed essential to a particular statement. Ellipses are indicated by [.].

My research questions addressed both how the carers experienced the psychological effects of mesothelioma and their sense-making in this military context. At times in the interviews, they explicitly talked about how military experience and values had affected either them or their relatives. When they did this, I have made it clear in my narrative. At other times, they did not allude to the military context, yet it seemed that this was having an influence on their experience, outside of their awareness. I therefore included this in my interpretation. Many aspects of the carers’ experiences would be typical for the civilian context as well. Although these aspects were not unique to the military context, they were important to present, as this study was the first to focus on the perspective of *carers* for people with mesothelioma, whether civilians or veterans.

Box 4: *Summary of themes from the cross-case analysis*

1. **Going the extra mile**

Just keeping on going

F18FC Nicola: He never really left the military. [.] He was always sort of, “Stand by your beds!” I wouldn’t say strict, but just very, very disciplined. [.] Quite stoic, and I guess probably some of that did have an impact on how he dealt with processing the prognosis. [.] “Bloody nuisance, this,” and “Crack on.”

Expecting and receiving committed back up

F16FC Janet: I said [to 13-year-old granddaughter], “What on earth am I going to do without Granddad?” She says, “Don’t you worry, Grandma, you’ve got us.”

2. **Staying the same person**

The recognisable patient

F20FC Cerys: To look at him then [at diagnosis] I would’ve thought we’d have a good, few years left with him, but it’s actually quite rapid how things have been changing. Because he’s been quite young for an 87-year-old, you know, he hasn’t been a frail gentleman.

The recognisable carer

F15MM Gary: That’s not me at all, but I don’t care anymore. [.] I’ve changed as a person.

3. **Needing to know**

Choosing what to share

F17FC Julie: From the minute that the consultant came into our cubicle and drew the curtain around and told us, I felt him withdraw from me. And I think that was because he was afraid but also, he didn’t want to scare me.

Information exchange and professionals

F19FC Vicky: It was just there were so many people involved. If we’d have just had one central person, which [laughs] it’s impossible, isn’t it, but that would have been lovely. If we’d have just had one person that we phoned to say now, you know, this is happening this week, next week.

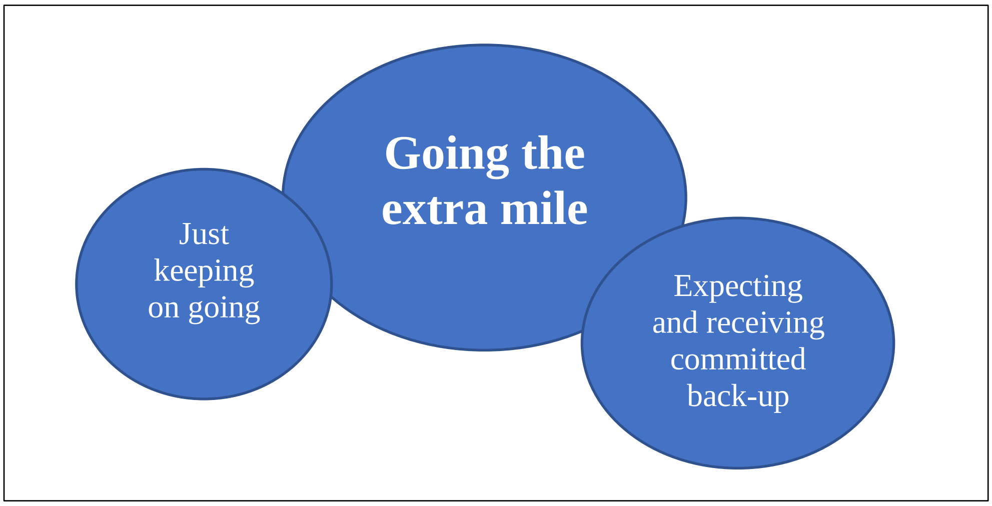
Raising awareness

F15MM Gary: The disappointment with the [local NHS] Trust is just awful, and I’m in the [safety critical] industry, we always get told if you make a mistake, put your hands up, it’s a no blame environment.

6.3.3 Cross-case super-ordinate theme 1: 'Going the extra mile'

The first super-ordinate theme, '*Going the extra mile'*, was present in all the participants' data[19]. It related to the psychological impact on both the carer and the veteran patient. Two sub-themes were developed: *'Just keeping on going'* and *'Expecting and receiving committed back-up'* (see Figure 13).

Figure 13: *Super-ordinate theme one 'Going the extra mile' plus sub-themes*



This super-ordinate theme encompassed how patients and carers reacted to the diagnosis and prognosis; how they coped with the day-to-day practicalities of managing living with a terminal illness; and how they experienced the efforts and commitment of others, such as health care professionals. The influence of military culture was highlighted by the carers particularly in the sub-theme *'Just keeping on going'*, where most of them talked about stoicism and self-reliance. Regarding the sub-theme *'Expecting and receiving committed back-up'*, military values concerning teamwork, efficiency, respect for others, loyalty and selfless commitment were influential, but the carers tended not to refer to these explicitly.

'Just keeping on going' sub-theme

The sub-theme *'Just keeping on going'* related particularly to the veteran patients' and carers' reactions to the diagnosis of this incurable, rare disease, with its typically poor prognosis. It also concerned their ways of dealing with the symptoms, which can be difficult to palliate, including breathlessness, pleural effusion, pain, cough, weight loss, lack of appetite, and

---

[19] The cross-case super-ordinate theme '*Going the extra mile'* was also initially developed as one of Gary (F15MM)'s super-ordinate themes.

fatigue. The impact of the disease's unpredictable progression, often with sudden deterioration, was relevant here, as was the effect of carers needing to take on more and more practical tasks to support the patient, both with symptom management and practical daily living. Firstly, I consider the veteran's determination to just keep on going. Next, I cover the carer's experience of just keeping on going. Then, I present how the carers made sense of the military context as it related to this determination to keep going. Finally, the carers' experiences of self-care are considered.

The veteran's determination to 'just keep on going'

Four participants reported the patient's response to the diagnosis and prognosis as a determination to fight on with life and not give up. Vicky and her father Len had a shared response, which was immediately to focus on practical planning and getting on with things:

"He wasn't going to give in, absolutely not. I mean, straight after the clinic appointment, I think, he described it to me as 'a bloody nuisance' [laughs], and we then both of us went promptly off to go and collect the caravan."

Initial shock and numbness generally turned quite quickly into the determination to keep on going and not let the illness get in the way:

"To begin with, he [Arthur] was very upset and angry and then he'd more or less say, 'Well, I'm going to fight this.'" (Janet)

Hywel also was unwilling to give up: he told Cerys he wasn't the type "*to just sit in a chair and curl up and die. [.] We fight on.*" For Dave, who was already disabled and who experienced additional symptoms from his undiagnosed mesothelioma, it was a question of constantly fighting just to keep on going:

"Every day was a battle for him. And I remember vividly him saying that every day was a series of paving slabs to be moved to get to the one thing he needed to do that day."

Julie's battle imagery shows her own sense of the efforts Dave had to make, and how difficult it was. Dave's own 'paving slabs' metaphor conveys his experience of the sheer relentless physical effort of his daily living. Once mesothelioma was added into the equation, it meant "*emotionally that added a huge amount of complexity to [.] what we'd been dealing with for 11 years*" (Julie).

The carer's experience of 'just keeping on going'

Along with the patients being characterised as taking up a 'fighting' attitude, one of the carers, Gary, also described himself in this way. Not only did he have all the practical tasks of caring to cope with, he had extra, complex difficulties to handle, i.e., a complaint against the NHS, plus a law suit against the MOD. He forced himself to just keep on going to the point of exhaustion:

"I was fighting all these [NHS issues]. I use the word fighting, I was fighting really, making myself ill because [.] I was still having to work all the time with this, and I was crying in the car on the way to work, just not sleeping."

The only instance where Julie used military language about herself was where she said she should have *"carried on fighting"* on behalf of Dave when the HCPs judged it was time for him to be allowed to die. Vicky also only used such language once about herself, saying there would be *"a battle ahead"* when she applied for a more responsible job in the future, as Mike had encouraged her to do.

Janet and Cerys, on the other hand, did not talk about themselves in terms of battling or fighting. In fact, for Janet, the abrupt way the news of Arthur's prognosis was broken led to her initially feeling it was just too much for her, and that she could not bear to 'keep on going':

"I said to my son, 'I just want it all to be over. I can't cope with this.' Then, after time, it all changed and I realised, well, he wasn't really disappearing just yet. And then that was it. And you just got on with it."

Even though Janet expressed her experience of a shift towards just getting on with life, at times this despairing feeling would recur:

"I sometimes feel as if I want the next couple of years or however long just to be over.
I'm wishing my life away because I feel sometimes, I don't want to cope with this."

It therefore appeared that four carers were comfortable using military language and imagery to make sense of their relatives' responses to the mesothelioma diagnosis and prognosis. Gary, a veteran himself, talked about his own experience in the same terms, but did not use this language about his wife. Vicky's husband showed a *"deep acceptance*" of his approaching death, so this may be why she did not use any language to do with fighting about him. So, both Vicky and Julie only used military language when they were talking about doing things on behalf of or urged by their veteran relative. The carers' use of military language and imagery helped them articulate their own sense of how they and the patient were (or weren't) 'just keeping on going'.

The carer making sense of the military context

The idea of the patients and/or carers defaulting to getting on with things and of 'just keeping on going' was explained by four participants in terms of the military background. I present Julie's extended explanation as it touches on various aspects of this perception:

"He [Dave] was much more stoic about the pain he experienced, about the difficulties it caused him, because he wasn't very mobile. I think he just accepted that and just got on with it, accepted that as his lot, because that's what's drilled into them [military personnel] – you deal with whatever's thrown at you, and I think he was just dealing with it. I don't think he opened up about it very much and I don't think he asked for help enough. So, I think it affected the way he coped with his illness in a positive way, in that he just got on with it, he just dealt with it and treated it as something he had to deal with. But then, I think, in a negative way because he was not very good at flagging up that he needed help, and he was even worse at accepting help – he thought he was just supposed to deal with it. [.] He was very self-reliant, I guess, and didn't really want to have to admit that anything was difficult."

We see here the idea of the stoic veteran who just wants to "*crack on*" (Nicola) without asking for support. Also touched on is the way that military training teaches recruits not to query orders from the chain of command or second guess situations, but to accept and *"deal with"* difficult circumstances. Julie also highlights how military culture involves keeping emotions closed down, being self-reliant and appearing strong, rather than asking for help.

Stoicism led to both positive and negative effects. For example, a stoic attitude to pain caused difficulties for some of the carers. Dave did not really notice pain when he was hospitalised at the end of his life, which caused him to deny the doctors' opinion, insisting to Julie that he expected to just keep on going, and reassuring her:

"He was still very careful to try and make sure that I knew that he thought it was a load of rubbish and that he thought we would fight it and he'd come home, and we'd prove them wrong."

Julie was left in the difficult position of having to explain his denial to the HCPs, and also not being able to come to terms with things together as a couple. Denial of pain was also a tricky issue for Cerys. She was aware that her father was quite often trying to conceal his pain, as he didn't want to "*give in to pain relief*." This made Cerys feel anxious, and she had to work hard to get him to start taking medication.

For Gary and Marie, his attitude to medical matters had complex implications. Gary was very clear that his military background had affected how he approached physical pain and injury, medication, and the medical profession. During military service, he had learned to embody this mindset:

"You think, well, there's no point in even saying anything because no one is going to listen to you, you just crack on with it."

From his time in the military, he had a negative attitude towards doctors themselves:

"I never go to a doctor, I just never do, not that I don't like doctors, I just don't think they help me."

Despite Marie being a veteran herself, Gary did not attribute to her this militarised attitude to pain and HCPs. During her illness, his attitude caused some tension between them. Gary thought she should be *"a little bit more robust,"* and he admitted that at times he influenced her not to go to the doctor. Gary didn't like taking medication, including painkillers, preferring to just keep on going. He thought of pain as "*part of being a human*," and described his current anti-depressants as *"stupid happy pills*" which his children had to remind him to take. However, he also saw his attitude as leading to "*my failures*." He used the phrase in the context of describing Marie's awareness of his disapproval of pain relief:

"*I think subconsciously she used to, at first, think, 'Oh, I'll just try and manage the pain when it happens,' but, actually, towards the last year and a bit, she should have been more proactive at taking pain relief before the pain occurred because the pain was so severe."*

Gary's use of the word *"failures"* suggests he experienced regret that Marie's pain relief had not been optimally managed.

The veteran patient's attitude to pain also came up in Vicky's data, though she did not link this explicitly to military culture. Her husband Mike had his own theory about dealing with pain:

"He wouldn't take painkillers for his arthritis, or when he did take them, he said they didn't work, so he'd just use his mind. Because he was a big believer in the power of the mind."

In fact, Mike's attitude to pain intersected with his religious beliefs in a crucial way as he approached the end of his life. As a devout Catholic, he believed that taking one's own life was against God's will. He was therefore prepared to refuse a morphine syringe-driver to help him deal with distressing end-stage symptoms and to just keep on going. It shocked Vicky when he required his priest's approval of the driver.

Mike had strong willpower when it came to pain. He also had a life-long focus on maintaining a healthy body. As Vicky said, *"All his life, he'd tried not to abuse his body with chemicals or anything. He detested anybody who smokes."* When he became ill with mesothelioma, this was a cause of guilty feelings for Vicky. Whilst he had always 'gone the extra mile' in terms of practising healthy habits, she had previously smoked. She used to say to him it should have been *her* who got cancer, not him, because *"it just seemed so unfair".*[20]

The idea of sheer mental power and determination as relevant to a veteran's mesothelioma experience also appeared in Nicola's data. She explained that the fact her father Len had not become ill until recently was a question of "*mind over matter and physical fitness, and just maybe also a bit of luck, of how long his body managed to fend it off."* For her, his mental and physical strength were protective factors.

In Julie's extended quotation earlier (see page 180), we saw that the veteran expected to stay self-reliant, and valued this. Five participants talked about this aspect of their mesothelioma experience, and how the veteran's strong wish for independence had a psychological impact. Mike and Dave were reluctant to allow anyone except their wives to carry out intimate care tasks, adding to their carers' physical workload, though both Vicky and Julie seemed to accept

---

[20] This sense of unfairness was generally not emphasised by the other carers; instead, they had a sense that *"these things happen"* (Julie). This seemed to be due to the military context, where the chance of getting injured or dying was accepted as part of signing up. Gary however did not experience asbestos exposure as acceptable, but saw it as potentially avoidable by the mid-1990s:
"We met in basic training in the RAF, we had to scrub the walls, the pipes, everything. The pipes were laden with asbestos. She breathed it in, they [MOD] killed her, that's it. They negligently allowed her or told her to do something without doing due process."

this as part of being in a loving partnership. As a result, Vicky experienced guilt due to the fact she wasn’t able to ‘just keep on going’ without help:

“I felt like I’d failed him, because he was a very personal man and having to have other people wash him and care for him...But right to the end, he didn’t let anybody else pass him his urine bottle except for one carer on the third night before he died. Yeah. So that was hard.”

For this couple, there seemed to be a joint assumption they would not need anyone else to help them. Then suddenly, it was too late: a crisis point was reached:

“It was that moment when he’d had a shower and he couldn’t get out [.] I realised, ‘I can’t do this on my own.’ And he literally had to drape himself over my shoulders so I could help him back to bed. That was the crux for me, when I thought I’m not physically able. Mentally I was able, just about, but it was like I hit a brick wall.”

Her account showed how she was being pushed to the limit, but without realising. Her metaphor of the brick wall conveyed a suddenness, a physical shock, and the impossibility of getting any further. She characterised this issue as about her *physical* limits, but also accepted that she was only just coping mentally, too.

In the case of Gary, it was his *own* military mindset that caused him to just keep on going without help until he was exhausted. When the district nurses were not trained to use a particular type of drain, he had to “*learn to be a medic in a way.”* Due to regular difficulties with getting hold of medical equipment, he would drive extra miles to source them:

“My wife felt uncomfortable, so I wasn’t going to hang around, so I just drove anywhere to get these things. But again, that was the logistics of it, it was just a bit of a nightmare.”

Gary was shocked that it was down to him, rather than HCPs, to find the right treatment for Marie, which resulted in him constantly researching and approaching different specialists:

“I was surprised, I was like, ‘Well, why are you not giving me options or looking into options? Why is it left to <u>me</u> to look for options for my wife?’”

<u>The carers and self-care</u>

Building on points made in the previous section, the findings describe how participants balanced caring for their relative with looking after their own physical and mental health. Some were pushed to the limit in terms of what they could manage by trying to 'just keep on going' without enough support. Military culture, with its emphasis on 'service before self', was particularly relevant to the experiences of Gary and Nicola.

Gary neglected his own health because of his determination to look after his wife. He explained:

"I'm totally unhealthy now, I've got about five stone that I don't need just because I never wanted to leave her side. I wouldn't go to the gym. I wouldn't do anything because it meant that I was away from her."

Even though Marie herself urged him to go swimming for the sake of his health, he wouldn't:

"There'd be a little devil in me or something to say, 'No, don't go now, don't go now, just wait, Marie might need you,' and it's totally illogical because I had her parents living with us for a long time, as a back-up."

His description of the contrary *"little devil"* hints that he experienced something taking hold of him, something that drove him to go that extra mile in terms of protecting Marie even at the cost to himself of a healthy activity he loved. When his counsellor suggested that Gary should look after himself more, he *"couldn't deal with"* this and gave a dismissive response: *"Pff, OK, whatever, I'm a grown man."* The idea of caring for himself as well as Marie was not compatible with his image of himself as an adult man; a grown man should be able to 'just keep on going' in the service of others.

Gary was not the only carer who chose to neglect their own health, prioritising caring for their loved one and/or using unhealthy coping strategies to keep on going. Besides reading books or playing Solitaire to distract herself when Arthur's fatigue triggered her to remember his life was limited, one of Janet's coping strategies was "*nibbling*" on snacks:

"I suppose I do it to keep him company as much as anything. We just sit and I think, 'Well, why not? 'Cos I might not have him for ever.' I don't know what my [diabetes] nurse will say when I see her."

When Dave was admitted to hospital, Julie, despite having more stress to deal with, was not able to use some of her coping strategies, such as exercising. She just had to ‘keep on going’, because she “*was working and then going to visit and then coming home and then going back to visit, so there weren’t enough hours in the day.”* After Dave died, though, she was able to practise more self-care, literally going the extra mile:

“I went out running around 5K every day for 26 days immediately after he died as a challenge, and it just really helps, it really frees me up.”

In contrast, Cerys was able to balance her caring responsibilities with looking after her own health. She combined getting emotional support from her friends with exercising, either playing golf or swimming:

“I did that yesterday morning. It was raining down here, but I still went out and just played five holes of golf and it’s just great to be out in the fresh air, and it’s exercise.”

For Nicola, the way to keep on going was to plan very efficiently and to be able to adapt to changing circumstances. Her goal was for her father to have a “*good death*.” There was a strong sense from her data of father and daughter as a team, ‘just keeping on going’ together. Practical planning allowed her father to keep going for longer in the activities that mattered to him, such as completing projects in his workshop, and to feel that he could still achieve:

“Towards the end, it got to the point where, say, dad wasn’t physically strong enough perhaps to use some of the machines. But my husband would help him with it and bring him in, so he was still doing a part of it, so he wasn’t seeing that he couldn’t do certain stuff.”

Nicola’s willingness to ‘just keep on going’ to the end was clear when they found out that the *Hospice at Home* service which they had planned to use had no availability. Nicola and her husband took this on themselves, moving into Len’s house. For Len’s final two weeks they “*would kind of run shifts*” and stocked up with *“such unhealthy stuff to eat and drink. There was full-fat Coke, there were sweets, crisps, it was just anything to keep us going.”*

Nicola explained:

“I guess I ploughed a lot of my efforts into that [achieving a good death] as well as the physical care. And I guess also the emotional and spiritual care.”

Her use of the verb *"ploughed"* conveys the sense of practicality, productivity and purpose which characterised her sense of herself in the carer role. She felt making these efforts was the *right* thing to do, and stressed the reciprocal nature of this care:

"It's the least that I could have done for my dad because he cared for me so much."

Despite all Nicola's expert planning and support from the district nurse and palliative care services, having to plug the gap in the end-of-life care took its toll:

"It was just that extra drain on us, whilst trying to process that you're in those last final days, I did have a slight breakdown wibble one evening. I think it must have been within the last week, because it was kind of that thing of [.] wanting things to kind of hurry up because I didn't want him to be in that sort of situation for much longer."

Nicola understood that she was pushed to the limit by trying to both manage the practicalities of end-of-life care and to process the emotional meaning of her father's imminent death. Her phrase "*slight breakdown wibble*" demonstrated the way she minimised and even gently mocked her own distress.

Summary of the sub-theme 'Just keeping on going'

In this section I explored how carers and patients who were military veterans had expectations about 'just keeping on going'. Veterans' stoic attitudes were often attributed to military culture. The effect could be to give the veterans a feeling of control and self-reliance. However, carers could be pushed beyond the limit in terms of what they could manage by trying to keep going without enough support. The military code of 'service before self' was influential for two of the carers. Also, as physical fitness is emphasised in military training, having to choose to neglect one's own bodily health had the potential to leave carers experiencing shame.

'Expecting and receiving committed back-up' sub-theme

This sub-theme covers how the carers and veteran patients experienced needing and receiving support. The carers talked about how the level of effort made to support them impacted them psychologically. The sources of support mentioned included health care professionals, care agencies, Ministry of Defence representatives, lawyers, coroners, counsellors, Asbestos Support Groups (ASGs), specialist charities, the Christian church, work colleagues, neighbours, relatives and friends. The carers' interactions with these sources of support impacted them both positively and negatively. Military culture values teamwork, respect for others, loyalty and selfless commitment, and expectations of the level of supporters' effort tended to be high. Therefore, when carers and/or patients felt let down, this could be particularly difficult to cope with. However, the carers rarely expressed an awareness of this link to the military context. I begin this section by presenting how the carers experienced receiving good support in line with expectations. This is followed by findings illustrating how they experienced the impact of expectations for support not being met.

Receiving good support in line with expectations

All the carers gave examples of how they had been well supported by others, and several saw the research interview as an opportunity to express their gratitude. The ASGs and Veterans UK received very positive feedback. Vicky's comments about her ASG were typical:

"From day one, this young woman called [name], she said, 'You don't worry about anything financially, we'll take over, we'll do that. All we want you to think about is you and Michael.' And they were amazing. She sent out these forms and literally I just had to put his name, his date of birth, his National Insurance number and the address. Oof, and that was it."

The sense of sheer relief that Vicky felt at having the complicated paperwork taken off her shoulders is clearly expressed in the *"oof"* sound she made. We also see how important it was to her to have time to focus on the reality of Mike's illness and their relationship, rather than being distracted by administration. Gary also experienced this sense of relief when he was finally told by his counsellor to hire a lawyer rather than trying to do everything himself:

"She [counsellor] put us in touch with a lawyer and we just handed everything over to them and left it. And that was important because that made a huge impact on our quality of life at the time. We weren't dealing with phone calls; we weren't dealing with letters all the time. And for me, I could just concentrate fully on looking after my wife and I didn't have to fight anybody anymore. Someone else was doing it for me, and they were doing it really well."

Gary's sense of relief here can be understood in terms of the military 'square', which demarcates each person's sphere of responsibility[21]. Unlike in the clear military chain of command, no lines had been drawn to show Gary the limits of his responsibility as a carer,

---

[21] See page 132 for F2MM's account of this concept.

so he ‘just kept on going’, trying to do everything, until someone else (the counsellor) showed him the edges.

As well as administrative support, the ASGs also provided opportunities for patients and carers to meet other people who were living with mesothelioma. Janet and Arthur attended ASG coffee mornings both in person and online:

“It was meeting other people that had the same thing. That was so wonderful. On the Zoom there’s a couple there that have had mesothelioma and they’ve been about three or four years.”

As Janet was struggling dreadfully with Arthur’s one-year prognosis, meeting other patients who had lived far longer gave her hope. Cerys mentioned the same experience, saying she had “*caught onto that bit of hope*” from meeting long-term survivors.

Hospices were mentioned as providing emotional support as well as practical back-up. Their premises seemed to be ‘safe spaces’ where patients could feel comfortable and unembarrassed, and where staff took the time to talk with people in distress:

“The people in there [hospice café] have got symptoms of all sorts of conditions. So, when he [Len] used to get some of his symptoms, like a really bad cough, or sometimes, towards the end, he’d get lots of burping, which he just couldn’t help. [.] But there, it didn’t matter. I mean, he’d be like, ‘Sorry about that,’ but nobody batted an eyelid.” (Nicola)

“I don’t know how I got there to be honest, I was in a bit of a state, I shouldn’t really have driven, thinking back. And she [hospice consultant] made me sit down and talk for a while. And I’m so glad she did.” (Vicky)

Clinical nurse specialists, for mesothelioma and for palliative care, were often mentioned as being great sources of information and support. For example, Janet’s CNS *“really made a difference,”* and Nicola said, *“I can’t thank her ever enough for the link and the support that she gave us.”* Cerys had a slightly different experience interacting with the specialist nurses; there seemed to be something of a disconnect, which was disappointing for her. Cerys explained that because of Covid-19 restrictions, the nurses had been *“lovely on the phone, they’ve been very caring, but it’s nothing like a face to face.”*

The support that the carers in this study valued could be in the form of practical help and also in the form of someone being there to talk to. Nicola particularly valued practical help. One example was her husband (currently serving in the military) stepping in to do personal care for her father, who was more comfortable when this was “*bloke to bloke*.” Another example was military friends offering to instantly courier over a coffin drape. These instances of the military family pulling together to support one of their own meant a lot to Nicola. When Len died, she made sure to say thank you for the extra efforts that the care team made to support them in the final two weeks, which allowed her to feel very positive at the end:

“I had that sort of, I suppose, elation that we did achieve a good death, that everybody’s efforts, and I was really eager that almost anybody that was coming in from our care team, coming through the door, like thanking each and every one of them for the part, big or small, that they played.”

Talking was specified as a coping strategy by several carers and having someone there to listen really mattered. For example, Janet had many neighbours, church members, and family members to talk to, who visited often. She was open with them about her worries, and this allowed her to be comforted:

“I said [to 13-year-old granddaughter], “What on earth am I going to do without Granddad?” She says, ‘Don’t you worry, Grandma, you’ve got us.’

She also drew on her religious faith to find reliable, comforting back-up:

“I’ve got someone [God/Jesus] to talk to before I go to sleep at night and when I wake up in the morning, and you feel better if you’ve had a little prayer and a little hope.”

The impact of expectations not being met

For Vicky and Mike, support from family and friends at the end of his life was very welcome. She described how many of the people he had supported in his work over the years came to visit, as well as relatives. However, the British government’s Covid-19 restrictions had a big impact here, as all this supportive presence was suddenly withdrawn from her when she really needed it:

“It’s been particularly hard because of COVID. Because when Michael was classed as terminal, people could come and visit. [.] But the day that he died, that all had to stop. And it was like going from this wonderful bubble of love, lots and lots of love, to, oh…”

The quote expresses a general sense from Vicky's data of her being let down at a governmental level. She conveyed this when she talked about the psychological impact on her of Mike's delayed diagnosis:

"I've always got in the back of my mind, and it won't go away, if the government hadn't laid down such strict rules for the doctors at the beginning, if he'd have been seen sooner, would the chemo have been able to have worked on him?"

Experiencing a lack of committed back-up could have minor or major psychological effects for the patients and carers. When friends or relatives did not step up to provide expected levels of support, for some participants this was merely irritating, and could be explained by the idea that this sort of thing happens because certain individuals cannot handle death and dying. Nicola, for example, said:

"There are maybe two or three people in our network that kind of basically distanced themselves. One in particular, I was probably quite glad in a way, because I didn't have the capacity to be dealing with her demands or hand-holding her."

Others experienced this as more hurtful. Vicky's relative did not greet her after the funeral:

"That really hurt that she could…oh [sigh]. But there you are, they always say there are arguments at funerals."

Gary and his wife reacted differently to each other when long-standing friends let them down:

"A couple who were our best friends for 20 years, they just fell away, they couldn't deal with it, and her best friend [.] never came to see her for 18 months and she's only a few miles away and it was crazy. [.] For Marie, she would wave it off, 'I'm not bothered, I'm not bothered,' but for me, I was angry."

Gary seemed to be angry about this on his own behalf and on Marie's. For him, their friends not making an effort to offer support was added to the failure of organisations to back them up, i.e., the MOD and the NHS. Gary explained his expectations of the NHS in terms of his military experience:

"I always thought the NHS was a big company like the military but it's not. It's fractured all over the place."

Because Marie had very rare peritoneal mesothelioma, the NHS system did not manage her case well, to the extent that the couple felt compelled to put in a formal complaint. The terrible distress caused to both by the lack of progress in looking after and treating her is conveyed in Gary's description:

"Marie fell into this hole of limbo, and nobody wanted to touch it, but left her in pain and agony."

When the MOD refused Marie's pension claim, arguing peritoneal was not the same as 'diffuse' mesothelioma, despite information being sent from Marie's consultant, Gary was left incredulous and outraged:

"After a full career in the RAF and the army and we've lived out lives travelling around with the MOD and I was like, 'What is the, what is the problem?'"

For Gary, military culture gave him strong expectations about loyalty, teamwork, professionalism and commitment. When these were lacking from close friends, the NHS and the MOD, the effect was devastating.

Gary was the only participant who experienced not being backed up by the MOD regarding compensation. Others praised the speedy compensation process, and several talked with gratitude about the wider military community providing support for funerals. However, distress caused by unmet expectations of the NHS featured in five participants' data. (Gary was the only carer who explicitly expressed a link between their experience of the military and expectations of the NHS.) For Arthur, Covid-19 restrictions caused two upsetting incidents to do with hospital visits:

"He had to go in on his own and I think he was a bit bewildered. [.] The few days before, he'd been to have a chest X-ray, and somebody had cancelled his appointment. And he was really, really upset and it really got him down."

Cerys had a sense that HCPs were not showing enough commitment in interacting with her father, Hywel, just after his diagnosis. She explained that he had been *"previously [feeling] a little abandoned, no, that's too strong a word, but no faces to names. 'Oh well, he's 87', a feeling of he's not being dealt with as robustly."*

From her perspective, this lack of effort in meeting his needs was to do with the HCPs' attitude to his advanced age. It is also important to note his diagnosis occurred during the second UK lockdown, when HCPs and patients were having to become accustomed to lack of face-to-face contact, which may explain Arthur's disquiet about "*no faces to names*."

Nicola perceived an upsetting lack of committed effort from a locum GP who came to certify her father's death:

"There was an element where this doctor, with how she undertook it, it was as if, 'Oh, I might leave things.'"

Nicola understood this to mean that, to make things simpler for the doctor, Len's body would be left unattended in the house over the weekend. Nicola described her own reaction:

"Half of it was a bit numb, half of it was a bit comedy. I thought, 'Oh gosh, this is like something out of 'The Office' with Ricky Gervais!' And then there was an element where I thought, 'If I start to get angry, I'm going to get very angry.'"

Nicola was also not satisfied with the cause of death this GP put in the report to the coroner, and took upon herself the burden of making sure this was rectified:

"I was very concerned that it was not clear enough to say that mesothelioma expedited his death. So, I had that as well to provide, because, again, I wanted to fight for my dad's name on this, and again, to raise awareness. So, I sort of carried that for about four months, to do all the work on that."

Julie was another carer who felt let down by a GP after the death:

"How my needs have been met by my GP, I'm extremely disappointed in that. I have had no direct contact from them, no follow-up really. I had a card about four days after he died, but they've not rung me once, they've not followed up to see if I'm okay."

Julie's feeling of being let down came in the context of her having cared for her husband's complex health issues for 11 years; this required a historical relationship with the local GP surgery, a relationship which seemed to have suddenly vanished. During Dave's end-of-life hospital admission, Julie also had difficulties feeling supported by the HCPs. This was partly explained by the speed of his deterioration and the fact he did not have a definitive diagnosis:

"It all happened so fast that there wasn't time to access any of that [cancer support], so I felt like I didn't know where to turn, I felt quite unsupported."

Right until very near the end of his life, hospital staff were expecting to discharge him to home. Julie made sense of the situation thus:

"Their hearts were in the right place. [.] The most important thing at that point was to do the best thing for the patient rather than what actually was…The best thing for Dave was perhaps not the best thing for me, but he had to be their priority."

There was a sense from her data that she experienced being side-lined, of her being an observer who was not really attended to by the HCPs. They were the ones making the decisions, yet she was implicated in them. This led to a very distressing end point, with lasting psychological effects for Julie:

"I then had to go and watch him fighting for breath and have him asking me for his BiPAP machine back; that's the last words he said to me, 'BiPAP.' He was so desperate to still be able to breathe; he was so desperate to still be able to fight it. I had to stand and watch while they decided not to give it back to him because it was doing him more harm than good. And because we'd decided that this was the last moments and that actually he needed to stop fighting. And that's had an enormous impact on my mental health. I feel guilty, I feel as though I should've carried on fighting for him. [.] I feel as though I didn't let him carry on fighting, I just allowed them to just let him go."

In this description of Dave's dying moments, we can hear Julie sensed he expected her to back him up, to commit to carrying on fighting. She was in a complex position of being somehow part of the healthcare team ("*we'd decided*") but also not ("*they decided*"). She had power in this scenario ("*allowed them*") but also felt powerless. The resulting guilt was very difficult to deal with and was unresolved at the time of the interview, an example of the enduring psychological impact of the illness experience. Earlier in the interview, Julie had described how, in their marriage, she and Dave had been *"an amazing team".* Military culture values trustworthiness and reliability in moments of extreme danger, and Julie felt she had now betrayed Dave's trust.

Summary of the sub-theme 'Expecting and receiving committed back-up'

This sub-theme showed how carers and patients were impacted by receiving good support in line with expectations or by not having their expectations met. Expectations of the level of supporters' effort tended to be high, influenced by military values regarding teamwork, loyalty and selfless commitment. Positive psychological effects included experiencing relief, hope, elation, gratitude, comfort and being accepted. Negative impacts included experiencing guilt and anger, and feeling side-lined, let down and abandoned.

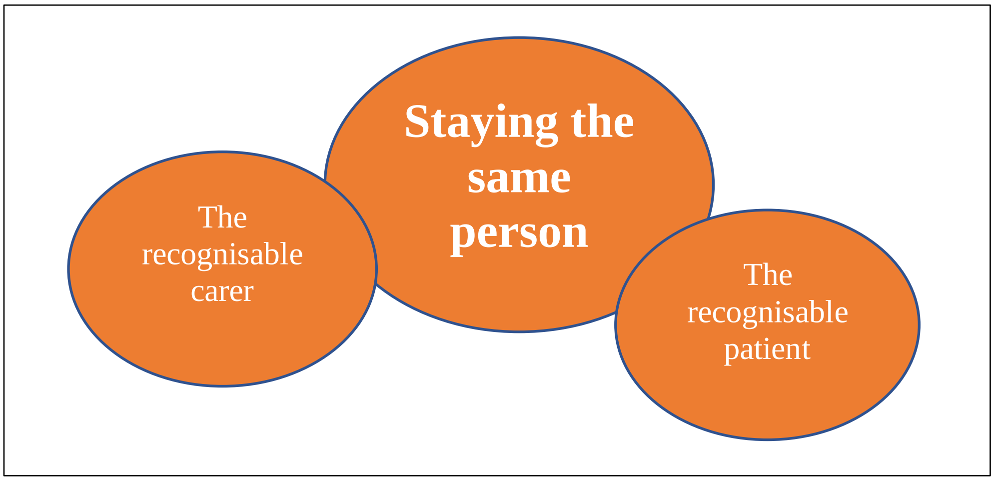
Summary of the super-ordinate theme 'Going the extra mile'

In this section, I presented the super-ordinate theme *'Going the extra mile',* with the two sub-themes '*Just keeping on going'* and *'Expecting and receiving committed back-up'.* I showed how the veteran patients and carers were impacted both positively and negatively, with some experiences leading to feelings of hope, elation, comfort, acceptance and love, whilst other experiences left them feeling disappointed, guilty, angry, let down and abandoned. Most of the carers ascribed to military culture certain aspects of their experience of the psychological impact. Other aspects were influenced by military values, but these were not highlighted as such by participants. In the following section I move on to a full narrative presentation of the second super-ordinate theme *'Staying the same person'.*

6.3.4 Cross-case super-ordinate theme 2: 'Staying the same person'

The super-ordinate theme *'Staying the same person'* related to issues to do with identity. It concerned the way the illness experience had the potential to change how the patients and carers saw themselves and how others saw them. Two sub-themes were developed: *'The recognisable patient'* and '*The recognisable carer'* (see Figure 14).

Figure 14: *Super-ordinate theme two 'Staying the same person' plus sub-themes*



Participants described and made sense of ways in which they and/or the veteran patient appeared to have changed as a person or stayed the same. Military values were rarely mentioned by the participants in relation to this super-ordinate theme, though the underlying influence of military culture was noticeable within the findings relating to some of the patient-carer dyads.

'The recognisable patient' sub-theme

This sub-theme explores how participants experienced their relatives still seeming to be the same as a person, and how they experienced changing views of the patient. These changes could be from the viewpoint of the patient themself, the carer, or others, such as HCPs. An extra dimension was observed for the two younger married couples in terms of spousal identity.

How the patients still seemed the same

None of the participants felt that their veteran relative with mesothelioma had changed profoundly as a person. Nicola, Vicky and Julie were clear that their loved one was still very much the same person. For two of them, the veteran's religious faith was an integral part of them which helped them cope with their illness and approaching death:

"*I didn't notice any changes in Michael at all. He was always caring, kind, deeply religious. So, although he didn't like experiencing pain, he wasn't afraid of what was happening afterwards*." (Vicky)

"I think his single biggest coping strategy was his faith. And looking out for other people. [.] *I think he was just trying to, sort of, reseat himself in his faith and trust that what he believed was what was going to happen, if the worst happened."* (Julie)

Both these carers stressed the patients retained an outward focus, towards helping others. For example, Dave was *"constantly looking out for the other people on his ward"* and *"was still a rock for me even right up till the end*." Mike took the time to meet with a young relative, who was upset about his imminent death, to do drawings together:

"These sheets of paper became a special memory card that they could give each other, which was lovely. And that helped [child] a lot. That was really kind of Michael but that's the sort of person he was."

When people whom Mike had helped in his work came to thank him when he was dying, Vicky saw how much this meant to him at an existential level:

"It was lovely; I'd see this smile come on his face and he knew that his life hadn't been wasted."

Selflessness and putting others first is a key military value. Although the participants did not explicitly make this link about their relative's attitude, this quality was clearly highly valued by both patients and carers. Thoughtfulness towards others was also mentioned by Gary and Nicola as an important and enduring aspect of the patient as a person. We have already seen how Marie did not reject the friends who distanced themselves from her, and Gary described her as motivated to help them:

"I just dumped them. And Marie still kept in touch, but she just did it, she's like a puppy sometimes, she was just doing it to help them."

Gary's 'puppy' metaphor suggested that Marie remained somehow soft and loyal, whereas his reaction was harsher. He also saw her as being inherently protective towards others and being more upset about their struggles than her own:

"You don't want to worry the people that you love, and I think that's what she did. Sometimes, I'd say there was only about five times that she really broke down, but most of the time it was worrying about me, that's the way she was."

Nicola described her father as *"always very much a person of [.] checking other people."* As an example of this, she related how Len had reacted to hearing that he had incurable cancer:

"His first three questions were, 'What will happen to my wife? What will happen to my daughter? How long have I got to live?' In that order."

It seemed to be important for Len to think about how others might feel, and to take action to mitigate any difficulty. His wife had dementia and, although she could not comprehend the situation regarding his diagnosis, she could still potentially pick up on an emotional atmosphere. When it was time for Len to go onto a syringe-driver at the end of his life, he was determined that she should not become distressed. He made a plan to say goodbye to her for the last time in as normal a way as possible, without making any particular show of emotion:

"Even in the last few days, he was still, where possible, wanting to get properly dressed [laugh]. Shirt and tie man! [.] He just wanted that normality right to the end. He didn't even say goodbye to her on the last time, he just said, 'Well, I think it's time that you headed back [to care home] and off you go and find that pussy cat.'"

We can see here again Len's stoic approach, just getting on with what must have been an emotionally very difficult situation. For him, that sense of normality and of being seen to be the same person was key:

"Dad still wanted to be known as that he was a dad, that he was a husband, he was a neighbour, he was a best mate, he was a friend. And yes, you've got this awful diagnosis and prognosis, but he [.] is still Len."

For Nicola, Vicky and Julie, another important unchanging characteristic of the patient was their sense of humour, which was strongly valued. They explained this was how veterans cope and was a way for them to help other people. The value which both Julie and her husband placed on this quality was clear:

"One of the things my lovely husband prided himself on was the ability to make people laugh and it was really important to him, so he would tell them jokes. Constantly, even on the worst days when we'd been shared the worst news. [.] He was still making nurses laugh the day before he died and I'm really proud of that."

Nicola was clear that she had inherited her father's military sense of humour, and valued it very much:

"Humour is so important, so, so important, and it never left my dad either. It never left my dad. So that's another coping strategy."

For Vicky and Mike, sharing jokes and laughter was an important way to tackle adversity and to experience closeness and intimacy:

"His sense of humour never went. He'd got a wicked look in his eyes sometimes and sense of humour. [.] Even on the last day when he couldn't take water and I was dabbing him with a little sponge, so he was getting some comfort, and my finger just went in his mouth. And he bit it and this grin came on his face [she laughs]. Oh dear! But I knew that was him just telling me that he loved me."

This enduring sense of humour was presented by Vicky and Nicola as part of the patient having a positive outlook on life. Terms used included *“always positive, he was never negative”* (Vicky) and *“a very positive, optimistic person”* (Nicola). Although Cerys did not refer to her father’s sense of humour, she did describe him as being “*glass half full.”* However, whilst having a positive outlook was seen as a valued characteristic, it could have a downside when things did not go well. Vicky followed her comment about Mike’s positivity with this:

“We did think that the chemo was going to work, we really did, so that was a huge disappointment when it hadn’t worked. And he had suffered so much that it wasn’t worth…Everybody said to us this: to go for a second round, it’s just going to be torture for him really. Yeah. I think [hospice consultant] summed it up, ‘It’s killing you, Michael.’”

In this extract, there seems to be a sense of Mike being reluctant to let go of that positivity in the face of such disappointment, and to ‘just keep on going’ in the expectation that the chemo would eventually work, no matter what the cost to his quality of life. It required the voices of *“everybody”* to make him accept the negative outcome.

Len, twenty years older than Mike, was a man who, according to Nicola, “*still had things to do*.” She was grateful when this impression was “*backed up*” by the coroner after his death. We have already seen how important it was for Len to appear the same, keeping to a normal routine. With the help of planning and assistance from Nicola and her husband, he was able to make adjustments as his health deteriorated. Nicola’s frequent use of the pronoun ‘we’ showed how she experienced Len’s journey towards death as shared, a team project. They shared a military emphasis on planning ahead and teamwork. Whilst he was still able, they visited organised events and went abroad on holiday. As that became impossible, he was able to share activities they had long enjoyed as a family, such as watching Formula 1 racing on television. Despite being on a lot of medication, he was “*right onto it*” with all the details of the teams, and for Nicola it was “*just a bit like old times, my childhood really*.”

Changing views of the patient

Cerys’s father, Hywel, although also elderly like Len, had been very active up until his illness. He and Cerys had an image of him as being young for his age and physically capable:

“To look at him then [at diagnosis] I would’ve thought we’d have a good, few years left with him, but it’s actually quite rapid how things have been changing. Because he’s been quite young for an 87-year-old, you know, he hasn’t been a frail gentleman.”

With his ‘glass half full’ positive attitude, this meant Hywel was reluctant to see himself any differently. The effect was, frustratingly for Cerys, that he was not interested in planning ahead or getting his affairs in order:

“Dad is a little bit of bury your head in the sand. He’ll say, ‘I’m concentrating on trying to live, not bothered about dying.’ It’s that attitude.”

His view of himself as someone active and busy living was at odds with how HCPs saw him, and this caused an issue after he was told about his suspected disease. Cerys related Hywel’s conversation with the doctor:

“Dad said, ‘I said to him, what do we do about this, then?’ And he said, ‘Well, to be honest, you know, it’s probably best nothing at your age now.’ Dad said, ‘What, just get on with it, is it?’ And he said, ‘Yes.’”

It took Hywel several months to come through being “*in shock*” and to start questioning whether there was really no treatment available for him. The HCPs involved were surprised when he started asking about it. Cerys herself used Kübler-Ross’s (1970) ‘stages of bereavement’ model to make sense of her father’s response to his situation:

“What I could see in him, really, I suppose is, in a way, it’s that stages of bereavement, isn’t it? You’re beginning to realise that, yeah, this is your time, the grim reaper is knocking really. And I could see that dawning on Dad, and areas where he was getting cross, I think, that, ‘Well, why aren’t I having any treatment? And surely there’s something that can be done?’”

As his health deteriorated, Cerys noticed that her father was changing as he moved from denial towards acceptance:

I think he’s now, looking at him, more resigning himself to the fact. I see some of that anger going. It’s that more, ‘I’m too weak to bother.’”

Because Hywel felt frustrated at not being able to keep on doing his usual activities, she experienced him becoming “*a little snappy*” and “*cantankerous*.”

Janet described Arthur, who like Len and Hywel was in his late eighties, as having changed to some extent. Janet described him as having become “*tighter*” with money, something she found amusing and teased him about. She explained:

"He's frightened he's going to go and leave me with…he wants to leave me as much as possible. He's always dealt with the money, which is a bit frightening really. And everything's on the computer which he tries to teach me to do, and I say, [sighing] '[Daughter] can do it.' [Daughter] knows everything. She can do that. I'm not good at…I like to spend it."

From her account, we can see that Arthur saw it as important to look ahead and get his affairs in order, thus protecting his wife. His wish to plan ahead matches the typical military outlook, as does his focus on protecting others. (Arthur's concern to protect his dependents in material terms was shared by Len and Mike.) Though Janet was aware they were both were *frightened* about the future, she made light of this, and also showed that she trusted her daughter to be there to support her when the time came. As well as Arthur being increasingly careful with money, Janet wondered whether he had changed in terms of his expression of anger. When he was hospitalised for a lung operation, Janet and their children were stopped by staff from visiting him during a rest period. Arthur was expecting them, and, thinking they had let him down, he reacted angrily when they did arrive:

"I'd never heard him shout at me like it. [.] My kids were absolutely astounded. They'd never heard their dad talk like that. He was apologetic afterwards, I know he was. But he's not that sort of person. He's what's called a gentleman really. He doesn't sort of shout. He just goes quiet. Sometimes I think, 'Ooh, do I know you as well as I think I do?' and then other times it's just fine."

It seems that Janet was uncertain whether Arthur had changed as a person, or might be changing, because of his illness; she was unsure whether she could trust her long-standing familiarity with his personality. From Arthur's perspective, this incident provides a further example of a veteran becoming upset when he experienced his expected, trusted back-up letting him down.

In comparison to the experience of the three veterans in their eighties, the experience of Marie, a woman in her forties, had an extra dimension. Gary explained:

"*She didn't want her husband to be her carer. [.] I think it upset her because before she was ill, we were both outgoing. She was fit and healthy, we thought. I was fit and healthy and she didn't want to look vulnerable. It affected every aspect of our life as a couple*."

Marie was distressed at the shift in her identity as Gary's wife. There was a sense of the couple having been equals in the way he repeated the matching words *"fit and healthy",* until she became the *"vulnerable"* one. Gary explained that Marie didn't want him, "*her husband, having to wipe her down with wipes around her and deal with her bleeding and all that stuff*." For Marie, it seemed it was especially difficult when she could no longer see herself as recognisably the same person in terms of her relationship, with particular reference to her body. What distressed her was the change in "*the couple element; we didn't have sex hardly at all. She didn't like me seeing her being really skinny and full of lumps*." The couple, who had both been through military training, were used to seeing themselves as physically fit. Gary's non-medicalised language here emphasised the embodied reality of mesothelioma's intrusion into this couple's shared life. There was an echo of this in the experience of the other younger couple, Julie and Dave, but they had been dealing with the impact of illness in their relationship for over a decade. We saw in the sub-theme *'Just keeping on going'* how Dave did not like to receive intimate care from anyone except his wife after he became disabled. Julie related the effect this had had over the years on their relationship as a married couple:

"If I sat now and looked back to the beginning of his illness and the end of his illness it definitely did change the dynamic of our relationship. [.] I think he just wanted to sweep all of those potential issues under the carpet and just, you know, we were fine. And we <u>*were*</u> *fine because we were an extremely strong couple, and we were an amazing team."*

It appeared that Dave defaulted to denial in this situation, as he also did regarding the mesothelioma diagnosis, whereas Julie was more aware of this shift and was able to accept it, valuing the strong emotional bond between them.

Summary of the sub-theme 'The recognisable patient'

In this section I explored how the veteran patients experienced themselves as wanting to stay the same person, and how they were impacted psychologically when this was not possible. I also looked at the idea of the patient being recognisable from the carer's perspective and the impact this had on them. The patient's use of humour as a coping strategy was ascribed by some carers to the military context. Other military influence could be seen in expectations about physical fitness, planning ahead, and selflessness.

'The recognisable carer' sub-theme

I now move on to the sub-theme '*The recognisable carer',* which considers how the carers experienced themselves as staying the same person or not. This could be in their own eyes and/or those of others. The resulting psychological impact is shown. Firstly, I present how two carers experienced themselves changing roles but also retaining a fundamentally familiar sense of self. Secondly, I show how two carers recognised themselves as potentially not mentally and/or emotionally robust enough for the mesothelioma journey. Finally, I consider the two carers who did experience personal change.

Carers experiencing changing roles but a fundamentally familiar self

For two of the carers, Nicola and Cerys, their substantial experience as healthcare professionals gave them a firm foundation from which to approach their fathers' illness. They had training and experience within a clear, boundaried structure, with useful knowledge about how the healthcare system operates and about how people respond to illness. Both often referred to their HCP background in their interviews. For example, when it came to providing personal care, this did not "*faze*" Nicola, as she was comfortable in the HCP role. However, it was harder for the patients to accept this change in who their daughters seemed to be:

"*It took a little bit just for him to get used to his daughter having to undertake some of that care, but I think it brought us even closer*." (Nicola)

Nicola experienced the adjustment in Len's view of how to relate to her as worthwhile and leading to a deeper closeness between father and daughter. Cerys found that her father's loss of appetite and struggles to eat caused tension between them:

"*He loves sweet things [.] but now he's going, 'No, no, don't want it, don't feel like it.' [.] So that's hard because I can feel me, as that [healthcare role] particularly, wanting [laugh]...he said to me yesterday, 'Stop pushing food at me!' [laugh] and I thought, 'No, I know I am,' but you just want to, you're wanting to encourage, because you can see the weight dropping off him and you can see him getting weaker by every day. And that's the struggle, I think, is watching it all."*

Cerys was clear that she saw herself as her HCP self in this situation, and her laughter showed perhaps that she found something incongruous here. There also seemed to be an element of her moving across into a parental role, as her father's words had a hint of the recalcitrant toddler or teenager. Elsewhere in her data there was a sense of Cerys's awareness of this shift as she increasingly had to take on more responsibility for Hywel. She noticed herself moving between her HCP self and her maternal/matriarchal self, and then occasionally slipping into another space outside of these roles, where she felt more vulnerable and unprotected from the reality of what was to come:

"*My [health-related] career, you deal with lots of things that you build that resilience to deal with. But I have my weeping moments in between, you know. [.] You hold it together for everybody else, don't you, as the woman in the family, the mother, the daughter, the sister, everybody comes to me, and so you hold it together for them. But in between I've had my odd little moments where I think, 'Oh! [sharp intake of breath] This is my dad.'"*

Although Cerys used her knowledge of the stages of bereavement to describe Hywel's responses to his illness, she did not apply this to herself, staying in her professional stance. When she did describe her feelings about his approaching death, she started by minimising them, but then as she chose to focus on and express them, the true impact became clear:

"I'm feeling slightly a bit more emotional about it as I can see what the inevitable is going to be. I think it's that realising that, yeah, you haven't got that long really, which is quite frightening. It's that thought of that overwhelming feeling of dread really."

Like Cerys, Nicola had moments of difficult feelings. These came in when, after Len died, she found herself not busy, an unfamiliar state:

"*I'm thinking, 'Oh, what do I do with my time?' Which is a really weird thing for me, because like my mum and dad, I'm not one to sit down and do nothing. [.] It's kind of that, 'Oh, sit down and breathe.' And that's when sometimes thoughts come into my head and then I get quite down."*

The experience of herself in this quiet, sad state was 'weird.' Nicola saw herself as a busy person with a typically military goal-oriented and positive outlook:

"I'm quite a positive person and I always look at the glass half full, of Pimm's, if possible!"

She valued the continuity of this military trait as inherited from her father, along with his sense of humour. During Len's illness, she found herself *"wanting to put on that positive face the majority of the time to my dad, to help him."* Nicola's valuing of humour was part of her proud way of seeing herself as "*more military than civilian*." As we saw above in her reaction to the disappointing locum GP (see page 192), Nicola often chose to use "*dark humour*" as a coping response, seeing this as similar in both military and HCP culture. Her default to the positive meant that even when the planned Hospice at Home service failed to happen, she was able to make sense of it by benefit-finding:

“There’s a reason for everything and those last few days allowed I and my husband to provide that most intimate of care really, which is a times, quite…oh gosh, what’s the word? Quite an honour, really, it’s a very special thing.”

Overall, Nicola presented her experience of herself as being fundamentally unchanged but with temporary effects, where she found herself reacting in unexpected ways. Her coping strategies, rooted in military values of humour, cheerfulness and goal-orientation, helped her feel confident and find benefits in a very difficult situation. Synergy between her military background and her HCP experience gave her extra psychological support.

Carers recognising themselves as potentially not robust enough

In contrast to Nicola and Cerys, Vicky and Janet did not have an HCP background to bolster them in caring for their elderly veteran loved ones. What these two civilian carers shared in terms of recognising themselves as persons was a sense that they might be someone who somehow is not robust enough, who can’t cope. Both mentioned previous episodes of needing mental health support. Janet had been taking an anti-depressant since the menopause, which she said, “*just keeps me on an even keel*.” She seemed to be anxious about how her mind behaved under stress:

“*Someone asked me afterwards, at the beginning, “What’s it like?” I said, “My mind’s like a washing machine. It’s just going round and round and round.”*

However, she also had an awareness of many coping strategies which she was able to use more or less successfully. She saw herself as “*one of these [people] that tries to put it to the back of my mind*.” She distracted herself with reading or playing electronic games such as Solitaire, and also found that being physically close to her husband and joking with him provided comfort:

“*We have a laugh and a hug and then I more or less forget about it*.”

She also found gratitude helpful. This may have been part of her religious outlook; she expressed it as an imperative:

"We're very, very lucky. Very, very lucky. So that's what you've got to do, is thank you, thank for what you've got."

Overall, there seemed to be a sense of lurking anxiety which Janet had to regularly make an effort to keep at bay. This anxiety seemed to be linked to a way in which Janet felt she had changed as a person:

"*I'm more aware…of time."*

She experienced this new awareness as making her "*very irritable*" and "*very impatient*." She gave an example of how this played out:

"I'm ready to do it [Arthur's eyedrops] and he's faffing about, and I keep going, 'Grr', and I've got to really say to myself, 'Come on, Janet, patience, patience!'"

She also saw herself as changed in another way that related to time:

"*I feel as if…I've got lazy, I think. I don't do so much around the house as I did. I keep looking and thinking, 'Ooh, gosh, I need to do some cleaning today,' and I never get it done. It's always tomorrow."*

Like Janet, Vicky experienced anxiety about how she would cope, based on her previous mental health issue:

"*I did, a few years ago, have a bit of a meltdown, when I asked for some help, and I did get help. And I was concerned after Michael died that I might find myself in the same situation again where I didn't want to get out of bed. But no, I've not reached that far yet*."

She did have coping strategies which she used successfully; those which allowed her to help other people were particularly useful, such as knitting and making posts on mesothelioma group webpages. Vicky was highly orientated towards other people, whether this meant wanting to help them, noticing their opinions of her, or having role models. She often compared herself to others, so when she had pre-bereavement counselling, she felt comforted, "*because I know what I'm experiencing, it's normal*." At times, Vicky's other-directedness[22] left her feeling exposed, and she recognised she had changed as a person since Mike's death in this respect:

"*Sometimes I read things into situations that maybe aren't there, find I'm a bit sensitive if people criticise, not criticise in a nasty way but just say something, I think it's personal to me. [.] I think I'm wanting people to value me, yeah. That's odd…I feel like…I know Michael's made his mark…and I don't want my life to be… wasted*."

Vicky was tearful as she made this comment, making sense of the existential dimension of Mike's death for herself, about the meaning of her life, and how she had started to expect negative views of herself from others. However, she proactively planned to take on more responsibility in her local community:

"*Since he died, I've thrown myself into what he wanted me to throw myself into, which he said I was good at*."

She saw this as making her contribution and fulfilling Mike's vision of her personal strengths. As a couple, Vicky and Mike embodied many aspects of military culture. Humour was a key way of increasing bonding between them. They had extremely high standards about selflessness and service towards others. Mike found satisfaction and acceptance from living within a clear Catholic structure where grey areas could be clarified and faith in God brought certainty. Self-control and determination were vital for him. For Mike, this value-set was helpful. For Vicky, whilst it was positive for her in many ways, it also led to her comparing herself unfavourably to others and doubting her ability to achieve and be robust enough.

Carers experiencing personal change

Turning now to the two carers who were widowed in mid-life, Gary and Julie, it is clear they experienced changes in their sense of self. For Gary, these were mostly negative, and he stated that he had definitely changed as a person. Julie, in contrast, found herself in a process of change which was still unresolved. Having previously adjusted to the change in her sense of herself as Dave's wife in relation to being his carer, she now had to get used to

---

[22] 'Other-directedness' has been defined as having a social character which "ensures conformity by instilling a sensitivity to the expectations and preferences of others" (Zinkhan and Hayes, 1989, p. 825), in contrast to 'inner-directed' and 'tradition-directed' social character. These terms were originally suggested by Riesman, Gitlin, Denney and Glazer (1965).

being single. She was considering actively how her future might be: "*I have to…shape a future that's my future now*." (Julie)

Gary, however, had a more negative perspective, with a sense of inertia:

"*I'm a grown man. I know what I need to do, but it's just moving on. I've got to find something to move on to."* (Gary)

We hear again his *"grown man"* phrase, suggesting he expected himself to be goal-oriented and 'cracking on', in the military way. Gary was explicit about having changed. Phrases he used included "*the change over the few years, it's like chalk and cheese"*, and "*I've changed as a person"*. The only positive aspect for him was becoming more "*robust"* in terms of starting to "*challenge doctors*". Negative aspects were no longer "*being interested in work",* having *"lost a bit of a filter*", and being less smart in his appearance: "*That's not me at all, but I don't care anymore*." Military values concerning having high standards, taking pride in one's job and not challenging authority figures now held less meaning for him.

Gary made sense of his lack of interest in life thus:

"*I've got a different outlook now, as in I tell everybody about it [asbestos]...but [aah]….I'm ready to go, I can't put it in any other way. I've had a great life. I probably am depressed, but I'm not going to kill myself or anything, but if I died of something, I'm not that bothered. I've had my life, this is all part of my life that I was supposed to be living with my best friend, my wife, but I'm not. So, I've had a great life, so I look at it as if to say, 'I don't care, get on with it, I don't care.*'"

These comments, made in the context of asbestos risk to military personnel, suggest Gary was aware of the risk to himself of mesothelioma. He appeared to be referring to mesothelioma obliquely with the words *"if I died of something.*" In his phrase *"get on with it",* as he articulates his despair, we again see the familiar military imperative to 'just keep on going'.

In Julie's case, she was aware of needing to change to move forward into her new single life without carer responsibilities. Whilst she accepted, even welcomed this process, some aspects of the change she was experiencing seemed risky and worrying. She did not "*just want to…survive and tread water"* but wanted to "*make the most of*" her life and "*make a difference."* However, she realised "*I've lost the person who was my reference point for* *everything, so I feel as though I'm losing some confidence in myself*." She noticed herself withdrawing from people because they might not respond as she hoped and then *"you feel a bit disregarded, so it's almost easier not to."* She seemed worried about the risk of this change:

"I like laughter, I like fun. I think it's dangerous for me to withdraw. Dangerous? I suppose, dangerous is a bit of a strong term but I have to make a new start in my life now. [.] If I withdraw from people that care about me or I also withdraw from going out and having new experiences and meeting new people, then my life will be a lot less rich than it could be."

She also expressed this urge to withdraw in terms of interpersonal trust:

"*I don't trust people in the same way. Because, I guess, I don't trust people to like me for me."*

Other changes made it harder to shape her new life. The traumatic nature of Dave's last days had impacted her, including leaving her with *"flashbacks"* of distressing scenes at his bedside. She felt overwhelmed at times and was "*not coping well with being alone*", something exacerbated by Covid-19 restrictions. She explained:

"I'm a lot less able to deal with my emotions. And I don't quite know how to deal with them. I don't know how to process some of this. It's all so big."

She worried about a potential change to her sense of self due to the unnatural, asbestos-related causation of Dave's illness. Her anger at the MOD's failure to flag up his exposure years earlier was strong, and she did not want this to taint her identity as a military wife, in retrospect and for the future:

"I don't want that to define me going forward or to define our life, so that's something I'm still having to come to terms with. [.] I loved my life as a service wife and so this almost in a way has cast some of that into doubt in my mind as well. I already felt to an extent ex-service people are quite let down by the services, by the MOD. And actually, now, I think I feel that even stronger, and I don't want that sense of resentment to build up."

Overall, Julie was aware of a complex interplay of factors impacting her mental health and her sense of being recognisable to herself in her bereavement. Her unease at not having a clear way forward and her issues regarding trust and loyalty suggest core military values were influencing the impact of mesothelioma on her psychological state.

Summary of sub-theme 'The recognisable carer'

In this section I have presented the different ways the carers experienced themselves as staying the same recognisable person or not, and how they made sense of any changes and associated psychological effects. Whilst the two HCP carers did not experience themselves as changed, others felt anxious about ways they might be changed by the impact of mesothelioma. For the two younger carers, negative changes in how they saw themselves were linked to some extent to their altered relationship with the MOD.

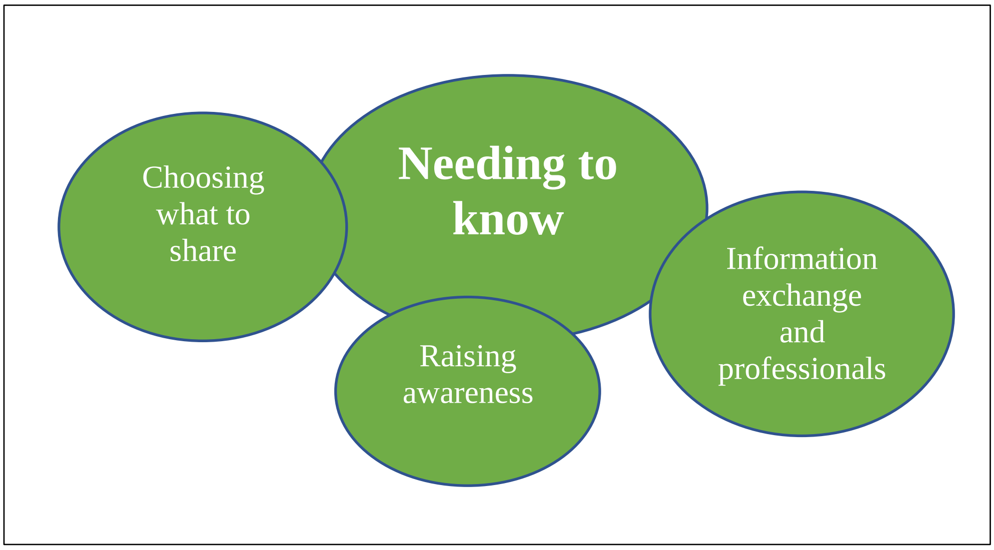
Summary of the super-ordinate theme 'Staying the same person'

The super-ordinate theme *'Staying the same person'* explored issues of identity through the sub-themes *'The recognisable patient'* and '*The recognisable carer'.* The carers saw their veteran relatives as not fundamentally changed as people by their illness, though there was an extra dimension for the younger patients in terms of their shifting identity as a spouse. The carers experienced and made sense of their selves in various ways. Two saw themselves as basically having a familiar self but shifting between roles. Two had anxieties about whether they could be robust enough in their mesothelioma journey. The others did experience negative changes in how they saw themselves. Many aspects of military culture were relevant to this super-ordinate theme, though they were rarely highlighted by participants. Stoicism, selflessness, goal-orientation and humour brought psychological benefits. However, having high military standards, especially around loyalty, could contribute to depression, despair, loss of trust and resentment. In the next section I move on to present the super-ordinate theme *'Needing to know'*.

6.3.5 Cross-case super-ordinate theme 3: 'Needing to know'

The super-ordinate theme '*Needing to know'* had three sub-themes: '*Choosing what to share'; 'Information exchange and professionals';* and '*Raising awareness'* (see Figure 15). Aspects of the experience of living with mesothelioma covered here were how carers and patients shared information with each other and with friends and relatives; how information was exchanged between professionals (e.g., HCPs, the MOD, charities), patients and carers; and the importance of raising awareness widely about asbestos risks among the medical profession, the military community, and the general public. In the military context, clear and efficient communication is key, with information being shared on a need-to-know basis; expectations arising from this contributed to psychological effects on patients and carers.

Figure 15: *Super-ordinate theme three ‘Needing to know’ plus sub-themes*



‘Choosing what to share’ sub-theme

This sub-theme explores how the veteran patients and carers experienced having to make choices about what others needed to know. They talked about choosing what to share between patient and carer, and what to share with others. Factors affecting these choices included whether they wanted to protect others; whether talking was a coping strategy; and whether they desired to keep things private. I first consider how the patients and carers chose to share information between them. I then move on to show how they chose what to share with other people, such as relatives, colleagues and friends.

Sharing information within the veteran-patient pair

For three of the dyads, choosing what information to share with each other did not seem to be difficult. Gary and Marie “*talked about everything, absolutely everything, and we’d never leave anything behind*.” Janet and Arthur “*were closer if anything*.” Len, who on the surface wanted to stay the same, would share his innermost feelings only with Nicola: “*Underneath, and he said it a number of times to me, he was utterly devastated.”* Nicola was keen for her father and her to be able to talk openly about his impending death, so she proactively helped him come up with a metaphor to use:

“*When we were talking about as and when the time comes for him to head off and stuff, he chose from the start that he was going to be going to the caravan site in the sky*.”

They used this metaphor to communicate as his health deteriorated, helping him to understand where he was in the journey, as he wished to do, right up until his death. Having an effective communication strategy was part of Nicola's military-style planning, and Len cooperated with this.

For the other three dyads, there was less openness about sharing information. We have already seen how Hywel tried to conceal his pain. He was also unwilling to talk about the future with Cerys. From her HCP role, she was aware of the benefits of planning ahead, and had discussed with his palliative care nurse the issue of getting him to talk about the end of life. In this situation, she found it difficult:

"I know it's not a subject he's comfortable about talking about. I have chosen my moments and dropped the odd thing in and said, 'We need to start thinking about these things, Dad.' But he gets very, 'Oh, now you're anticipating trouble.'"

Hywel's urge to stay positive and keep on going protected him from the grim reality of his prognosis but frustrated Cerys, as it meant she was prevented from dealing with the situation as well as she wanted to. Hywel was unlike Len in this respect. Both the daughters were experienced HCPs, so perhaps this difference could be explained by the fact that Nicola saw herself as a 'military' person. She expected there to be a clear goal and plans for how to get there, with adaptations for each stage. Her expectations matched Len's, so they were able to march in step and communicate along the way, as a team.

Turning to Vicky and Mike, they did do a lot of talking, which helped them both:

"*Talking to Michael was my biggest coping strategy because we could share how we felt with each other. And that was one of his [coping strategies]*."

From Vicky's data, there was a real sense of intimacy and close bonding between the couple. This was enhanced once Mike received his diagnosis; previously he had refused to declare his love, saying his actions spoke loudly enough. Vicky explained:

"*Once he was diagnosed, I think he told me at least once a day that he loved me, yeah. So, that was the biggest change in our relationship, that he could say that*."

Despite their closeness, the couple had certain things which they kept private. For Vicky, this seems to have been her anger about the injustice of Mike's illness:

"*Sometimes I wanted to just get out, so, I might just go and hang the washing out for five minutes and have a bit of a rant at myself and then come back in."*

Mike, in turn, protected Vicky from knowing about his anxieties, and kept up his image of mental strength. As a veteran who had served in conditions requiring utmost secrecy, he was practised at keeping certain things under wraps. This was much to Vicky's frustration, as she had wanted to know all about his glamorous (as she saw it) military past. After he died, Vicky found notes "*that show that he was worried about some things, about where he would die and that he would have sorted everything out before he died*."

Like Mike, Dave also wanted to protect his wife. His way of doing this was to make a distance between them:

"*From the minute that the consultant came [.] and told us, I felt him withdraw from me. And I think that was because he was afraid, but also he didn't want to scare me*."

Julie made sense of Dave's behaviour as him protecting her but also hiding his fear. He was afraid of two things: cancer ("*one of the biggest fears*") and dying alone:

"*I'm sure he was frightened. His biggest fear was dying on his own; that had always been his fear. [.] I'm sure his mental health must've been in turmoil. Every time when I left to come home for a break, or when I left to go and get something to eat, I think he was probably always worried that might be the end."*

Dave was a veteran who had been diagnosed with PTSD from a bombing. His high anxiety about dying alone is likely to be one of his PTSD symptoms. In turn, Julie was also protecting Dave:

"Emotionally, for me it was really hard because I was having to hold it all, in order to not panic him any further."

A further difficult issue concerning sharing the truth arose for Julie, to do with their Christian faith. Dave's "*single biggest coping strategy was his faith*". He therefore had several factors influenced by his military background bolstering his resilience: humour; serving others; and rock-solid faith in a command-structure (his faith). For Julie things were not so simple; she didn't have a strong faith. She understood that "*one of his distresses*" was that she did not have the comfort of faith:

"*That's a slight guilt factor for me as well because I don't think I ever really gave him that reassurance, although when he was in his last moments [.] I told him that he could go to God and that he didn't need to worry about me. So, hopefully, in his head I was able to reassure him*. *But I'm struggling with it in the aftermath*."

What Julie found hard was reconciling all the difficulties they had suffered with the question, "*If there was a God, why would God do that?"* For her, after Dave's death it was "*a challenge*" for the future to find her way back to faith.

Sharing information with relatives, colleagues and friends

When it came to choosing what to share with other people, such as relatives, colleagues and friends, for some participants this was fairly straightforward. Nicola, on behalf of her father, was "*promoting that normality*", but also, as she explained,

"I wasn't afraid to talk to people about dad's illness, if they asked. I was quite matter of fact about it. Sometimes that went down well, sometimes that didn't go down so well with people, but I was just saying it as it was."

Cerys found talking with her husband a lot was one of her coping strategies, as was talking with her older children, though *"there's a part of me trying to protect them as well."* Again, we see the tension for Cerys between her maternal role and her vulnerable side. Janet and Arthur had different needs when it came to talking with others:

"He's not so outgoing. He can't talk about things quite the same as what I do. I find that it's my way of releasing things."

An example of what Janet found helpful was talking to a neighbour who was already widowed. This was "*uplifting*." When Arthur was first diagnosed, Janet was so distressed she felt compelled to talk to people, though she was aware she could have been asking too much:

"*And I did talk about it, to anyone I saw practically. They were probably fed up with me*."

Vicky had the same response as Janet: she really needed to talk about Mike's diagnosis. However, his military instinct for secrecy kicked in:

"Michael initially didn't want people outside of really just me and Katy [daughter] knowing that he'd got cancer because he didn't want them to look at him as 'Michael with cancer'. And that was tough, because I wanted to go out and say to everybody, 'He's got cancer!' So, I found that really hard."

Even Vicky's sibling who lived very close by was not allowed to know for a while. Michael's military training and service in a role requiring extreme secrecy influenced him to shut down communication at this stressful time. Only the immediate 'team' could know, and that did not include other family members. This meant one of Vicky's main coping strategies was closed off at the start.

Of all the participants, Gary experienced the most profound change when it came to communicating with other people. Before Marie's illness, the couple used to say, "*Let's not tell people bad news, let's just make sure they're okay."* Things changed later; when colleagues asked after Marie, Gary held nothing back:

"I would just broadcast everything. I didn't even listen to what I was saying, I just told them exactly the way it was, and I felt that might have been a bit overwhelming for some people, but it was just the way I dealt with it. [.] I didn't care what people thought anymore."

After Marie was given the wrong diagnosis, the couple decided they would not *"candy-coat the truth."* This affected the relationship with their young adult children:

"*At times they'd say, 'Don't tell me', and I'd say, 'I've got to tell you. [.] I wouldn't be able to live with myself*.'"

Marie would try to end phone calls with their children *"on an upbeat"* to stop them worrying too much. Gary found that their strategy helped him and Marie because the kids always "*knew what the score was."* Gary, who had joined the army aged 17, was careful to explain to me that *"they weren't kids, they were 18 and 16"* when Marie had her initial cancer diagnosis. Gary described having to be a *"grown man"* from the age of 17 due to his military experience. This may have influenced how he expected his teenage children to handle this devastating situation, without needing him to protect them. Although Gary made sense of this change by saying he and Marie were *"still empathetic",* he in particular seems, in the face of such traumatic experiences, to have built a protective strategy which left him unable to attend to others' feelings.

Summary of sub-theme 'Choosing what to share'

In this section, I presented the sub-theme *'Choosing what to share.'* The carers and the veteran patients employed various strategies to get their needs met. For some of the carer-patient dyads, there was a mismatch between the individuals' needs. For some, their choices were straightforward and led to people feeling connected, supported and safe. For others, these choices brought isolation, frustration, guilt and distress. From the participants' experience, military culture had an influence in terms of expectations about information exchange. This resulted either in secrecy or in clear communicating as part of teamwork and planning.

'Information exchange and professionals' sub-theme

This sub-theme related to participants' experiences concerning what they and the patients needed to know from professionals, such as HCPs, Veterans UK, and charities. Sometimes this included information they felt they did not need to know and wished to avoid receiving. Also covered are issues of carers and patients sharing information with professionals, and issues of professionals sharing information with each other. All the participants gave several examples relevant to this sub-theme, and they tended to also explain how they would like things to have gone differently when the psychological effects of an interaction were experienced as negative. I begin by presenting aspects relating to the breaking of the bad news and then those regarding information exchange later in the mesothelioma journey. Finally, I present issues concerning the idea of 'positivity' within information exchange.

The breaking of the bad news

The breaking of the bad news of the mesothelioma diagnosis was mentioned by all participants. Two of the participants, Nicola and Cerys, found a disconnect between their own HCP experience and the reality of being faced with this dreadful diagnosis. Cerys, resorting to *Google* after the appointment, said,

"I didn't know anything about all this, so that was all a minefield really. [.] You hit on all this legal stuff first [.] so it was a bit of a shock."

Nicola explained:

“However many years on the clinician’s side, it’s not until you’re at that other side, and I guess I was a bit numb as well, kind of, ‘Is this really happening to us? [.] Have I just teleported to another situation?’ I think what got me, well, and I’d not heard of mesothelioma until then. It took me a while to even be able to pronounce it, if I’m honest.”

There was a sense that the two women felt they should have known more about mesothelioma already and felt deskilled at this point. For Gary, we have already seen the terrible difficulty there was in obtaining Marie’s definitive diagnosis, which left him feeling *“helpless”* and *“angry.”* He became very proactive in researching specialist clinicians and started *“pushing the boundaries”* in terms of contacting them directly and out-of-hours. In military terms, Gary could be seen as by-passing the chain of command, a new experience for him. It was part of him seeing this research as within his ‘square’ of responsibility. When a particular specialist responded immediately, this meant a great deal (*“fantastic!”),* as generally Gary was *“annoyed”* at what he saw as antiquated communication systems in the NHS. Mike also had some difficulty getting a correct diagnosis, partly because of Covid-19; Vicky explained the disorientating effect on them:

“Until that point, we didn’t know what we were dealing with, and we didn’t know where we were going. We felt really lost.”

In attempting to find out more at this time, Vicky and Mike went against HCPs’ advice:

“Everybody told us not to Google it, but you do, don’t you?”

Covid-19 restrictions may also have affected Cerys and Hywel’s experience of obtaining information after the diagnosis, in that the process seems to have been somewhat extended and haphazard. Cerys eventually found out more from the solicitor, who had *“great knowledge”*, than from HCPs.

One issue that varied across the cases was how much information carers and patients each wanted. For some dyads, there was a clear difference which had implications for psychological effects. Gary and Marie seemed to accept this difference, where he chose to do the relentless research work, protecting her:

“Very rarely would she look it up on the internet. [.] The [charity] bulletin, she would hardly ever read that. But I’d read everything, I’d try and discover everything.”

When Len asked his direct prognosis question at the diagnosis appointment, Nicola was not fazed by this, but in fact noticed *“how difficult it was for the consultant”* to break the news. In contrast, the mismatch in ‘needing to know’ at diagnosis for Janet and Arthur had a catastrophic effect on her. She returned to this issue several times in the interview. The bad news was broken by a doctor they had never seen before and hadn’t seen since. Janet said,

“It just stuck me. It was just absolutely awful. [.] The way the doctor more or less said, ‘Well, that’s it. You’ve got a year.’ [.] I think I’d have been upset anyway, but it was just those words that stayed in my mind.”

The visceral, wounding effect of this news is shown in the verb ‘stuck.’ The doctor’s statement was in reply to Arthur asking directly, *“’How long?’”* In this situation, Arthur’s military training may have contributed to his instinctive wish to understand the threat so he could begin to plan. Clearly, Janet did not want the question to be asked at this point in front of her and now she could not ‘unhear’ the answer. Elsewhere in her interview she described her strategy of avoiding Arthur’s subsequent phone appointments:

“They’ll ring him up for the x-ray he had last week. And I’ll probably go out the room and just let him talk and let him tell me about it afterwards. I suppose it could be a way of…blanking it out.”

However, besides wanting to filter his news by avoiding direct contact with HCPs, she also described wanting to know more information, because of *“the undecision”* [sic], but feeling unable to ask for it, despite Arthur’s view:

“Sometimes you feel like asking how it’s developing or how long he’s got or how the...I don’t feel I like to ask in front of him. But he says, ‘Oh, just ask.’ He doesn’t seem to mind.”

The clumsy way the bad news was broken seemed to have impacted Janet’s interactions with HCPs in such a way that she was not able to get her needs met.

In contrast to the other participants, Julie experienced the definitive diagnosis *after* Dave died, and had no idea it could be mesothelioma until two weeks beforehand. This meant it was very difficult *“to speak to anybody that had any detailed understanding and expertise around this illness.”* As someone with a health-related career, Julie’s instinct was to do *“research.”* She explained, *"I did it the same day because that's just me, I needed know what that [mesothelioma] meant, I needed to know how long we were talking about, I needed to know whether there were treatments, that kind of thing. And when I went to look it up, it kind of felt to me like a massive piece of the jigsaw had slotted into place that we'd never even known to look for."*

She found some studies that showed *"people that had been exposed to asbestos being more likely to die of stroke or cardiovascular issues."* Dave had been ill 18-months previously:

"Weirdly, that was with a fluid-related thing as well. So, this is why I wonder whether somebody should've picked it up before."

Now, she could suddenly make sense of Dave's on-going, unusual health issues. She found it *"frustrating"* because if they had known about Dave's asbestos exposure, they could have looked out for signs of related illness years earlier. Julie felt *"resentful"* because the MOD did not share information about his exposure:

"They seem to try to bury things like that rather than acknowledge them and tell people."

Once Julie had detailed information about mesothelioma, she chose to protect Dave from it, as he was already panicking (as we saw earlier). She had to explain to the HCPs how Dave was *"in denial"* and any difficult conversations would be *"doubly difficult"* as she thought he was *"blocking it out."* His avoidance could be another symptom of his PTSD.

Information exchange later in the mesothelioma journey

After the initial diagnosis, there were other points in the mesothelioma journey where participants reported issues to do with needing information. Having appropriate information offered in a thoughtful way at the right time meant a great deal to the patients and carers. Nicola appreciated being *"briefed beautifully"* in advance about the coroner's involvement. She was grateful to their CNS:

"She took time to explain it [chemotherapy] to us, and then I got the information from her so that [.] we were absolutely sure when he made that decision it was an informed decision."

She also was grateful to their GP (who had a palliative speciality) for how she talked with them about EOL:

"She was brilliant, she was so empathetic, and she was very good not to make any promises or guarantees. It's the honesty. [.] Dad responded really well to that."

Janet and Arthur appreciated having excellent contact with the ASG who were *"there at the end of the phone if we need anything."* They had also been briefed early on about palliative care services by their CNS, though they did not yet feel *"ready for anything like that."* Cerys found her relationship with the palliative care nurse *"very useful, especially regarding medication and talking about pain."*

As well as examples of helpful information exchange, the carers described instances where they did not get the information they needed, or when information was shared in upsetting ways, or when important information was not shared. For Vicky and Mike, who lived in a small town, meaning some treatment was provided in the nearest large city, it was very confusing trying to keep up with what appointments were happening where:

"It was just there were so many people involved. [.] If we'd have just had one person that we phoned to say, 'Now, this is happening this week, next week.'"

Vicky also struggled later on because she had to manage Mike's care herself by following instructions from HCPs:

"It got tougher, and I felt like a little hamster on a wheel trying to catch up with the pain control. I mean, I'm not a medical person so I was relying on what other people were telling me."

Her 'hamster' metaphor gives a sense of how small and powerless she felt, driven in a frenetic process which was not getting anywhere. Gary also sometimes felt helpless and frustrated when he was trying to get information. He described how he had been phoning the MOD every week for months about Marie's pension claim:

"They [MOD clerk] just lied to me each time. [.] I'm going, 'What's going on?'"

When he and Marie put in their formal complaint to the NHS trust, it took 18 months to get a response; waiting was *"a nightmare."* Len was twice treated in such a way that it led to him and Nicola making a complaint to the HCP team. Both incidents related to hospital staff refusing to take time to allow information to be shared with Nicola. In the first incident, Len was given a shortened prognosis. He was unhappy to share this devastating news with his daughter himself and asked HCPs to contact her, either to inform her or to arrange for them to be told together. However, this is what happened:

"The doctor turned round and said that they were too busy. Too busy that the call was never made."

Len did not understand and thought Nicola would be told. This was one of few times she saw him in tears. They considered complaining:

"He was very concerned that they [HCPs] didn't mark him and say, 'Right, that's it, you're not getting certain treatment.' But it was for the doctor to understand the consequences. And he said, 'You have to understand, these are my main two carers, my daughter and my son-in-law. If you don't keep them informed, they can't help you, and that means they can't help me.'"

A similar situation arose when his 'Do Not Resuscitate Form' was being completed. Len wanted Nicola involved, but the HCP's response was blunt: *"'No. Done.'"* Both father and daughter were *"set back"* by this incident; their military expectations of the NHS concerning, respect, teamwork, efficiency and trust were not met.

An emphasis on positivity

A final issue which showed how differently the participants could experience the exchange of information was the concept of 'positivity.' We saw in the section on '*Staying the same person'* how much the idea of having an optimistic mindset could be valued. Some participants drew hope from interacting with professional sources of information. (Among these sources I include the ASGs and charities, as they are organisations providing officially sanctioned information even though it may be provided by volunteers, patients and carers.) For example, Cerys *"caught onto that bit of hope"* when she heard at the ASG that some people survived for three or more years. Vicky was really grateful for the support she had received on mesothelioma social media groups during Mike's illness. After his death, she had *"a different perspective"*, so, when posting on the groups, she tried to *"put a positivity. I try and make the worst of times the best of times that it can be."* Although she felt sad each time another patient died, she said, *"I do find it does help me because I think I'm helping other people."*

For Gary and Marie, however, the emphasis on positivity had a different effect:

"People want you to be positive, 'Oh, stay positive, it'll be brilliant!' But that's a fallacy. [.] People saying, 'Oh, stay positive, you can beat this!' Mmm, well, we can't beat it, and every time she goes to the doctors, she either gets good news, relative good news or really rubbish news. So, she hated going."

When they attended a group event, Marie found it *"really hard".* This was because she was the only younger attendee, and others detailed the experiences of long-term survivors who had needed little treatment, unlike herself. When a speech was given, *"she did get angry"* because it was *"all about positivity. Positivity, blah, blah, blah, blah."*

Marie's experience highlights how for some people, attending a support group has challenges, such as feeling different. For her, this sense of feeling different plus the emphasis on positivity meant she could not feel the camaraderie that she and Gary, as veterans, might have expected and welcomed from a group situation. This mismatch left her feeling angry and disappointed.

From these differing reactions to the idea of positivity, we can see how different aspects of military culture came into play. Where a spirit of optimism and cheerfulness was predominant, added to an emphasis on helping the other, then positivity was experienced as having a beneficial psychological effect. However, where an atmosphere of honesty and facing the facts was expected, then being met with undiluted positivity led to feelings of anger and isolation.

Summary of sub-theme 'Information exchange and professionals'

In this section I explored carers and patients' experiences of exchanging information with professionals and witnessing professionals providing or withholding information. The military context led to expectations of communication regarding honesty, efficiency, planning ahead, trust, and protecting others. Again, the psychological effects could be highly beneficial, for example, in terms of feeling reassured, properly informed, included and cared for, but they could also be experienced as negative, with patients and carers feeling angry, ignored, frustrated, confused, helpless and traumatised.

'Raising awareness' sub-theme

This sub-theme was developed from the data of the four participants already bereaved. It related to carers' wishes to raise awareness about various topics. These included HCPs, the public and the military needing to know more about mesothelioma and asbestos risk; HCPs learning better ways of communicating with patients and carers; lack of knowledge about where veterans were in the UK; the MOD's attitude to asbestos risk and exposure; and public knowledge about hospice provision and grief. I begin by considering awareness-raising among HCPs. Next, I present awareness-raising concerning the MOD, followed by the idea of raising awareness more widely. Finally, I consider the experience of the two non-bereaved carers with respect to raising awareness.

Raising awareness among healthcare professionals

For the two carers whose spouses were younger, raising awareness amongst the medical profession about mesothelioma not only occurring in the elderly was important. Marie's misdiagnosis happened because of a lack of awareness:

"It was that perception by the consultant, 'No, no, you're too young. No, you're not in heavy industry.'"

Gary and Marie made the complaint to their local NHS trust because her diagnosis was so poorly handled. Gary explained:

"I'm in the [safety critical] industry. We always get told, if you make a mistake, put your hands up; it's a no blame environment. People learn from it."

When their complaint was not attended to, Gary said he "*had to just let it go for the sake of my health*." Gary was drawing on his experience of how safety critical incidents were handled in the military context. He expected teamwork and professionalism to contribute to the efficient operation of the whole organisation. In applying these standards to the NHS, his expectations were not met. The sense of being let down was very hard for him to bear.

Julie also highlighted the need for greater awareness amongst HCPs of mesothelioma in working-age people:

"There's something huge there around the whole raising awareness about the fact that it's not just people that are in their eighties now that may have worked on the railways. There are other groups of the population that are likely to have been exposed. And that for me I think is a biggie, because if we were looking for it, we might have even asked the question."

She felt *"frustration",* looking back at Dave's mesothelioma journey:

"I feel like perhaps I didn't bang tables hard enough. I would never have thought to ask the question. Nobody ever asked us about asbestos exposure."

Here she suggests she should somehow have tried harder to get him a diagnosis, but she simply did not have enough knowledge at the time. She was also particularly concerned that medical professionals should learn to look across their separate specialities in a more holistic way; because *"everything was being viewed through the lens"* of Dave's initial health problems, *"nobody ever had the whole picture."* HCPs needed to dig deeper:

"All of those symptoms and things that he was experiencing, the issues he had with fluid, nobody thought to look to see if it was anything other than just somebody gaining weight and not being very mobile."

The idea of lessons needing to be learned in the NHS also came up in Nicola's interview. We saw earlier how she and Len made a complaint about how they had been treated by HCPs in terms of communication. Nicola explained that they, like Gary, wanted staff to learn from it. Their supportive CNS provided a conduit: *"[CNS] took it on, to make it into a bit of a lesson learned, particularly with the doctors."* For Nicola and Len, various military values were in play: Len was anxious about challenging authority figures, and Nicola did not like being disloyal about fellow HCPs, but the importance of putting others first overrode these discomforts.

The MOD and awareness-raising

As well as wanting better awareness amongst HCPs, the participants were also concerned with the MOD's attitude to sharing asbestos risk information. Gary, who still worked for the military, said, *"it really makes me angry",* seeing 'beware asbestos' stickers in the workplace. He explained:

"They [MOD] knew the site that we worked in is laden with asbestos, but you've got 1,500 military guys there that don't get any education in it at all."

It was not enough for Gary that asbestos should be labelled. He thought the illness risks should be spelled out for personnel, who needed to know:

"We do online courses everyday about rubbish, but we could do an online course about mesothelioma. [.] I'd love the military to start educating their people. I bring it up every time we have a forum."

For Julie, the issue was about the MOD needing to share information when personnel had been exposed to asbestos. She had the same emotion as Gary:

"I feel really angry with the military, with the army. I feel angry that I think they don't share that kind of information with people, and I think they should."

She compared this issue to the experience of her first military husband in the Gulf War:

"He had things injected into him that we never even knew what they were, and those things do not appear on his medical record."

Veterans needed to know all relevant medical information from their time in service:

"Although that would've been awful to know that you'd been exposed, at least then if you started experiencing symptoms you would have an inkling that it could be something to do with that."

Julie was aware this added to frustration she already felt in her health-related job as veterans were "*let down"* after transition. She explained that service-delivery could be difficult:

"Nobody even knows where they are, so how can you target anything at them?"

Raising awareness more widely

Whilst Julie and Gary were particularly focused on improvements to information sharing in the NHS and the MOD, other participants had a wider view of which people 'needed to know' about mesothelioma. Nicola had been impacted by seeing on social media that people much younger than Len were being diagnosed:

"That's what's also kind of got to me. We're in 2020 and it's like, 'How is this still happening to people?'"

Nicola referred to raising awareness of mesothelioma as *"one of my ambitions",* giving herself a new focus for her military-style goal-setting. As we saw, she made a big effort to have mesothelioma noted as the cause of her father's death: "*I wanted to fight for my dad's name on this, and again, to raise awareness."* Awareness-raising could be done locally or at a wider level, so as well as helping with national campaigns, she had talked to local building contractors:

"I was on the phone finding out, 'Well, what are your plans if you find asbestos? What's going to be happening?' That sort of thing. Just so it's understood."

She was also motivated towards raising awareness of her local hospice, *"so that other families in the future don't [struggle]. Not everybody perhaps is in that situation to be able to provide 24/7 care as we are."*

Vicky shared Nicola's wider scope in terms of awareness-raising. Her focus was on providing bereaved people with what they were 'needing to know'. She had written a children's book about mesothelioma and was planning to work with local groups on *"doing something about grief."* Also, in her role within a local community organisation she had held meetings *"to find out how we tackle asbestos. [.] Are we aware and do we know where it all is?"* She saw this urge to make a difference for others as a part of her and Mike's identity as a couple:

"I suppose we're a bit odd really [laughs], we're more concerned about others and the impact that it has on others than the impact that it has on ourselves. We wanted to stop it [contamination]. We wanted to do something."

This motivation was expressed in similar ways by Gary and Julie:

"It was part of our ethos and values anyway. We are that kind of people. We believe in helping others." (Julie)

"With Marie doing all the trials and stuff, she wanted to help, and that's what we've always wanted to do". (Gary)

Being able to contribute in this way gave these bereaved carers something proactive to do when they might have felt helpless, and something positive to hold on to at a time of loss. Military culture emphasises goal-setting, and its influence can be seen here as positively impacting the bereaved veterans. In all three quotations above, each participant used the present/present perfect tense, showing how helping others who were 'needing to know' was a way of experiencing a continuing bond with their loved one, based in shared values. These values matched those of the military in terms of prioritising the protection of the community and focussing on the needs of the wider team, beyond just oneself.

The non-bereaved carers and awareness-raising

For two participants, Janet and Cerys, this sub-theme was not developed from their data. They were not at a stage where raising awareness was a priority. However, in Janet's data there was a hint that she wanted things to change regarding the breaking of bad news. She was so badly impacted by the *"abrupt"* doctor at Arthur's diagnosis that she tried to make sense of why he would deliver the news that way:

"I don't think he should have said, 'A year.' They're taught now to be open with people. And I think it could have been a bit more gentle, but I don't know. [.] Perhaps it was meant to come out like that. I don't know. But I mean, what suits one person doesn't suit another."

Janet clearly had a sense from her own lived experience that doctors ought to have better communication skills, and that their training might not be appropriate to meet different people's needs. However, her repetition of 'I don't know' showed a mistrust of her own judgement and knowledge in relation to the powerful medical profession. These two carers were also the ones with the lowest exposure to military culture, so perhaps were less motivated to raise awareness compared to the other carers.

Summary of sub-theme 'Raising awareness'

In this section I presented the sub-theme *'Raising awareness'* and highlighted the extent to which military culture influenced the carers. The four bereaved participants were strongly motivated to help others have access to what they 'were needing to know' in terms of information about asbestos risks to health. They wanted the MOD to raise awareness for serving personnel and veterans. They wanted medical professionals to have better understanding of mesothelioma's symptom pattern and affected population, as well as better communication skills. They wanted the general public to have better understanding about asbestos. Raising awareness about grief and about end-of-life support was also mentioned. Awareness raising was important to the carers on both a local and national scale. It provided a way for them to honour the veteran patient, which aligns with the importance in military culture of honouring the fallen. Awareness-raising helped the carers nurture an on-going bond with the deceased. It also provided a proactive outlet for feelings of anger and frustration. The military concept of 'lessons learned' was important to these carers, as it showed commitment to the welfare of others and to improving ways of working.

Summary of the super-ordinate theme 'Needing to know'

Military culture had an influence in terms of expectations about information exchange with and between professionals. These expectations related to honesty, efficiency, planning ahead, trust, and protecting others. If expectations were met, patients and carers felt reassured, properly informed, included and cared for, but if not, they were left feeling angry, ignored, frustrated, confused, helpless and traumatised. Military culture also had an influence in terms of expectations about information sharing within the dyad, resulting either in secrecy or in clear communicating as part of teamwork and planning. Where patient and carer strategies for getting their needs met were aligned, they felt connected, supported and safe. Where there was a mismatch, participants reported isolation, frustration, guilt and distress. Bereaved carers were strongly motivated to raise awareness about asbestos risks. The military concept of 'lessons learned' was important to these carers. They wanted the MOD to better inform serving personnel and veterans, and they wanted the general public to have better awareness, including about grief and end-of-life support. They wanted HCPs to better understand mesothelioma's symptom pattern and affected population, and to have improved communication skills.

6.3.6 Summary of cross-case analysis findings

Participants described a wide range of psychological impacts on themselves and on their loved ones. They made sense of their experiences in different ways. Positive psychological impacts reported by participants included hopefulness, a sense of achievement, feeling supported, closer relationships and finding positive meaning. Negative effects included low mood, isolation, disorientation, anger, exhaustion, losing trust, feeling unsupported and let down, and negative changes in sense of self.

The carers who appeared to experience the worst psychological impacts were Gary and Julie. They described negative changes to self-concept, lack of interest in living, guilt and trauma symptoms. The most adversely affected patients were Marie and Dave, who between them experienced abandonment, anger and fear. At the other end of the spectrum, Nicola and Mike were able to experience a sense of control and find meaning, retaining their positive self-concept. However, there was a mismatch between Mike and Vicky in terms of the psychological impact, with her experiencing more difficult feelings, such as guilt and failure. Aspects of military culture which were highlighted by the carers were stoicism and the use of humour. Humour encouraged close bonding and helped carers and patients to face adversity. Stoicism could help patients and carers make great efforts to keep going and deal with pain, but at times could lead to support and care needs not being met. Having high expectations of individuals and organisations making an effort brought distress to both patients and carers when they were let down, and half of participants felt they had let their relative down to some extent. The exchange of information, within the dyad and with others, was an area that had much potential for positive or negative psychological impacts.

The military context contributed to the psychological impact of the illness throughout the journey. Three of the carer-patient dyads were steeped in and identified themselves with military culture (Gary/Marie, Julie/Dave and Nicola/Len). One dyad comprised a long-serving veteran plus a carer who had a civilian identity (Vicky/Mike). Two dyads, where the patient had done just two years' military service long before the civilian carer was involved, showed less influence of military culture (Janet/Arthur and Cerys/Hywel). Military values, plus the expectations leading from these, contributed to heightened psychological effects, both positive (e.g., benefit-finding and closer bonding) and negative effects (e.g., feelings of betrayal, guilt and isolation).

6.4 Conclusion

In this chapter I presented the findings of the Stage Two main interview study with six carers of UK veterans with a diagnosis of mesothelioma. Three super-ordinate themes, developed by looking for patterns across the cases, were presented with supporting quotations from participants. These themes were: *'Going the extra mile'*; *'Staying the same person';* and *'Needing to know'*. The presentation of the themes was developed as a full narrative, with detailed commentary on extracts from the data. The findings showed similarities and differences between the carers' experiences of the mesothelioma journey and its psychological effects on themselves and the patients, and between how they made sense of these psychological effects. There were many instances of the impact of military culture, both on the patients and the carers themselves. In the next chapter I go on to discuss the findings of the secondary data analysis and the main interview study in combination, after providing a brief overview of the study so far. The findings are considered in relation to the existing research literature. The thesis's original contributions in terms of knowledge and methodology are presented, along with the strengths and limitations of the study. A closing reflexivity statement is provided. Implications for practice in the care and support of UK veterans and carers living with mesothelioma are suggested, and recommendations made for future research.

Chapter Seven: Discussion

7.1 Introduction

My doctoral study has generated unique, in-depth insight into the psychological effects of mesothelioma on patients and carers from a UK military background. In this chapter I discuss the findings of the study, combining the findings of the secondary data analysis and the main interview study. Firstly, an overview of the study is given, along with a summary of the key findings. Then the findings are considered in relation to the existing research literature. Next, the thesis's original contributions in terms of knowledge and methodology are presented. The strengths and limitations of the study are then considered. A closing reflexivity statement is provided next. Finally, implications for practice in the care and support of UK veterans and carers living with mesothelioma are suggested, and recommendations made for future research.

7.2 Overview of the study so far

7.2.1 Aims

The aims of this thesis were:

3) to contribute to international knowledge about the psychological effects of mesothelioma on patients and their carers
4) to contribute to understanding of the psychological impact of mesothelioma on UK military veterans, from the carers' perspective.

7.2.2 Objectives

The research following on from the conducting of a scoping review of the literature about the psychological effects of mesothelioma on patients and carers had two objectives. The first objective was to conduct a secondary data analysis (SDA) of transcripts of semi-structured interviews with carers of UK military veterans with mesothelioma. The second objective was to conduct a new qualitative empirical study collecting and analysing data from semi-structured interviews with carers of UK military veterans with mesothelioma.

7.2.3 Research questions

The study aimed to answer the following research questions:

Primary research question: "What are the psychological effects of mesothelioma from the perspective of family carers of UK military veterans?"

Secondary research questions:

a) "How do family carers of UK military veterans experience the psychological effects of mesothelioma on themselves?"

b) "How do family carers of UK military veterans make sense of the psychological effects of mesothelioma on themselves?"

c) "How do family carers of UK military veterans experience the psychological effects of mesothelioma on the patient?"

d) "How do family carers of UK military veterans make sense of the psychological effects of mesothelioma on the patient?"

7.2.4 Methods

Methods were chosen for the study which were appropriate for the research questions and aligned with IPA methodology. This methodology was suitable for my conceptual framework comprising the qualitative paradigm, with a critical realist epistemology and a feminist perspective. The study was carried out in two stages: first, a secondary data analysis of the MiMES transcripts, and second, the main interviews. Individual semi-structured audio-recorded interviews were conducted between 28/9/20 and 30/3/21 via videoconferencing with six carers of UK military veterans who had a diagnosis of mesothelioma. Attention was paid to appropriate quality guidelines at all stages of the study.

7.2.5 Key findings from the secondary data analysis

To facilitate comparison, the key findings from the secondary data analysis are presented in this section, followed by the key findings from the main interview study in the next section. An overview of the SDA's super-ordinate and sub-themes is given in Table 41.

Table 41: *Overview of SDA super-ordinate themes and sub-themes*

Super-ordinate themes	**Sub-themes**
Control and responsibility	The chain of command
	Controlling language and thinking

	The out-of-control body
	The proactive carer
Openness: is it safe?	Secrecy and intimacy
	Official secrets
	Becoming vulnerable
Human connections: getting support	n/a

The findings are summarised in the form of the following seven key findings:

1) Carers had high expectations of big organisations and institutions, such as the NHS and the MOD, particularly with respect to efficiency, communication and accountability. These expectations provided reassurance when things went well, with the carers often expressing high praise. These same high expectations of organisations caused distress and even traumatisation when the carers in my SDA felt let down. Carers were particularly distressed by the mishandling or hiding of information.

2) Carers and patients used control over language and thinking as a coping strategy, including humour and irony.

3) Control of physical pain was an important issue for carers. Also, carers' awareness of visible change and decline in the patient's body was hard to ignore. This could interfere with attempts to control thinking and feeling about the situation's severity.

4) All the participants appeared to accept their carer role without difficulty. Different patterns were identified across the participants[23] in terms of how proactive they were as carers and how comfortable they were with help seeking in the practical sphere:

   a) proactively attending to practicalities, planning ahead, doing it all yourself, and coping (Malcolm)

   b) following the lead of the veteran patient who proactively attends to practicalities and plans ahead, and accepts lots of external practical (and emotional) help (Graham)

   c) attending to practicalities *without* planning ahead, not asking for practical help, just getting on with it, doing it all yourself, and struggling or burning out (Andrea).

---

[23] The limited data from Janice meant a pattern could not be determined, though she said it was important to deal with each situation as it arose.

5) A habit of secrecy, ascribed explicitly to the military context, led to hiding of important information within the couple/family, including the sharing of feelings. ‘Protecting’ the partner/family was highly valued; this affected levels of intimacy. No carer said they felt closer to their partner over the course of the illness.

6) Carers and patients seemed to have limited awareness of their own feelings. Some talked in a *factual* way about topics which we might expect to be accompanied by expression of strong feelings (e.g., Damocles syndrome; guilt at contaminating family). For some, there was also a sense of shame and risk around certain types of emotional expression.

7) Some patients and carers showed discomfort or even lack of awareness about the possibility of emotional support, with little sense of mutuality within a supportive relationship. None of the carers emphasised family as a source of emotional support, and for some, interaction with family brought a sense of unease as it could lead to ‘risky’ emotions. Three carers did express strong appreciation of support from friends (both veteran and non-veteran), while one did not use the word ‘friends’, but talked glowingly of support from organisations (both military and civilian).

7.2.6 Key findings from the main interview study

The key findings from the main interview study are now summarised to allow comparison with the SDA findings. The main study’s super-ordinate and sub-themes are shown in Table 42.

Table 42: *Overview of Stage Two interview study themes*

Super-ordinate themes	*Sub-themes*
Going the extra mile	Just keeping on going
	Expecting and receiving committed back-up
Staying the same person	The recognisable patient
	The recognisable carer
Needing to know	Choosing what to share
	Information exchange and professionals
	Raising awareness

Three key findings are shown for each superordinate theme. Most of the carers ascribed to military culture certain aspects of their experience of mesothelioma’s psychological impact.

Other aspects were influenced by military culture but were not highlighted explicitly as such by participants. The key findings were as follows:

'Going the extra mile'

1) The carers and veteran patients had expectations about 'just keeping on going'. Stoic attitudes gave the veterans a feeling of control and self-reliance. Carers could be pushed beyond what they could manage by trying to keep going without enough support. The military code of 'service before self' was influential for two carers. The military's emphasis on physical fitness meant neglecting one's own bodily health could leave carers experiencing shame.

2) Expectations of the level of supporters' effort tended to be high, influenced by military values regarding teamwork, loyalty and selfless commitment. Carers and veteran patients receiving good support in line with expectations experienced relief, hope, elation, gratitude, comfort and being accepted. When their expectations of support were not met, negative impacts included experiencing guilt and anger, and feeling side-lined, let down and abandoned.

'Staying the same person'

1) The veteran patients wanted to stay essentially the same person and were impacted psychologically when this was impossible. The carers saw their veteran relatives as not fundamentally changed as people by their illness, though there was an extra dimension for the younger patients regarding shifting spousal identity.
2) Two carers saw themselves as basically having a familiar self but shifting between roles. Two had anxieties about whether, because they had experienced mental health issues previously, they could be robust enough to cope in their mesothelioma journey. The others experienced negative changes in how they saw themselves.
3) Military culture was relevant regarding identity consistency but was rarely highlighted by participants. Stoicism, selflessness, goal-orientation and humour brought psychological benefits. However, having high military standards, especially around loyalty, contributed to depression, despair, loss of trust and resentment.

'Needing to know'

1) Military culture had an influence in terms of expectations about information sharing within the dyad, resulting either in secrecy (e.g., about pain) or in clear communicating

as part of teamwork and planning. Where patient and carer strategies for getting their needs met were aligned, they felt connected, supported and safe. Where there was a mismatch, participants reported isolation, frustration, guilt and distress.

2) Military culture had an influence in terms of expectations about information exchange with and between professionals. These expectations related to honesty, efficiency, planning ahead, trust, and protecting others. If expectations were met, patients and carers felt reassured, properly informed, included and cared for. If expectations were not met, they were left feeling angry, ignored, frustrated, confused, helpless and/or traumatised.
3) Bereaved carers were strongly motivated to raise awareness about asbestos risks. The military concept of 'lessons learned' was important to them, as it showed commitment to the welfare of others and to improved ways of working. The carers wanted the MOD to better inform serving personnel and veterans, and the public to have better awareness, including about grief and end-of-life support. They wanted HCPs to have better understanding of mesothelioma's symptom pattern and affected population, as well as better communication skills.

7.3 The two sets of findings in relation to each other

Many similarities could be identified between the findings of the SDA and those of the main interview study. The SDA findings foreshadowed those of the main interviews, which then allowed the psychological issues to be explored more deeply. The main differences between the two sets of findings were associated with the following: developing closeness between the carer and the veteran patient; not being able to recognise/articulate emotions; and raising awareness. The fact that the main study participants appeared more emotionally literate could be explained by the nature of the study: they had signed up to talk about psychological impact, and the participant information sheet had made clear that the scope of the discussion included emotional responses; coping strategies; mental health; negative and positive changes; and relationships. The 'emotional closeness' difference may have arisen because changes to relationships were specifically asked about in my interview schedule and not in the SDA. The 'raising awareness' difference, however, is an example of my own influence on the study. By re-reading the SDA transcripts as part of the hermeneutic circle prior to writing this discussion, I realised just how prominent the idea of raising awareness was in the data of F2MM and F7MM (both male veterans). F2MM stated that his wife's dying words were to impress on him the need to *"do something"* about asbestos illness - it wouldn't help her but might help others. My initial interpretation had played down the issue of awareness raising which, in hindsight, I saw was vitally important to the bereaved carers. Perhaps from my civilian viewpoint I had not at first recognised the importance of awareness raising in this military context, with its dimension of honouring the fallen and veterans' contributions being remembered through "fictive kinship" (Brewster, McWade and Clark, 2021, p. 1996). It may also be a manifestation of a masculine tendency to direct one's emotions "into the wider public sphere" (Robertson, 2007, p. 97).

In Table 43 I bring together for the first time all the participants and veteran patients from the two stages, categorised by how much immersion they had experienced in the military and/or how far they identified themselves as 'military'. Categorising my study dyads in this way to emphasise the depth of their immersion in military culture was useful to help me make sense of my findings. I have not seen this type of categorisation elsewhere in the literature on military families. Group A comprises the dyads where both people were veterans. Group B comprises the dyads where the carer had been a military spouse while the veteran was serving in the Armed Forces, or had been a military spouse to another serving person, or had grown up in a military family and considered themself to have a military identity. Group C comprises the dyads where the carer was a civilian and did not have a military identity. The table makes clear how all three female veteran patients were cared for by a male veteran.

Table 43: *The participant dyads categorised by depth of immersion in military culture*

	Group A: **Veteran carers**	**Group B:** **'Military' carers**[24]	**Group C:** **Civilian carer**
SDA	Malcolm + Patricia	Andrea + Eric	Janice + Keith
	Graham + Dorothy		
Main study	Gary + Marie	Julie + Dave	Janet + Arthur
		Nicola + Len	Vicky + Mike
			Cerys + Hywel

In the following sections the SDA and main study findings are discussed in combination, to avoid repetition.

---

[24] The term 'military' carer denotes a carer who was a military spouse while the veteran was serving in the AF, or was a military spouse to another serving person, or grew up in a military family and considered themself to have a military identity.

7.4 The findings in relation to existing research literature

This study tells us a great deal about the psychological impact of mesothelioma on UK military veterans and their informal carers. Many of these findings will also apply to other patients with mesothelioma and their carers. However, I am going to focus on what my findings add specifically to the military context. In doing so, I will draw both on the findings of the SDA and of the main interview study, discussing them in relation to the articles in my scoping review and to those published later. For this reason, I next provide an overview of those research articles published since my review which would have met the inclusion criteria. I will then discuss the findings in relation to relevant research literature under the following headings: 'caring for and caring about'; 'the militarised body and pain'; 'sharing information'; and 'guilt, betrayal and traumatic stress'. I will highlight how my study adds new dimensions to the research literature in the military context, for example with regard to how internalised expectations may impact on female veterans and male carers, and how nuance in the dyad relationship may affect coping with pain. I will present my exploration of information sharing about diagnosis/prognosis and coping styles, which is novel in its use of the concept of degree of immersion in military culture for patient and carer dyads. I will also demonstrate how my study contributes new insight about the nature and extent of survivor guilt and moral injury in carers for veterans with mesothelioma.

7.4.1 Overview of recently published relevant articles on mesothelioma

Twelve relevant papers were published after the cut-off date of my scoping review which would have met the inclusion criteria. Also relevant to my discussion were two papers submitted for peer-review at the time of writing, October 2021, Ejegi-Memeh et al. (2021) and Harrison, Darlison and Gardiner (2021). These 14 papers are summarised in Table 44. The relatively large number of recent papers indicates that more attention is now being paid in the research community to the psychological impact of mesothelioma. The differing experience of males and females has been shown for the first time in one paper (Bonafede *et al.*, 2020).[25] The publication of a first study from a non-high income country, Brazil, is welcome (Padilha Baran *et al.*, 2019). The importance of nuance in this context for the understanding of psychological effects is highlighted by studies from different countries, e.g., the availability of legal euthanasia in the Netherlands (Prusak *et al.*, 2021); the reliance on traditional medicine in Brazil (Padilha Baran *et al.*, 2019).

---

[25] This new interest in gender in mesothelioma was also shown by Senek et al. (2021).

Table 44: *Recent relevant literature not included in the scoping review*

Reference	Publication status	Country	Aim	Contribution
Ejegi-Memeh, Taylor et al. (2020) *Military Experience of Mesothelioma Study (MiMES) - Mesothelioma UK*. Sheffield.	Project report	UK	To generate insights into the experience and health/support needs of British AF veterans with mesothelioma	Provides insight into four areas: 1) asbestos exposure 2) coping with diagnosis of mesothelioma 3) preferences for care & support 4) claiming compensation. Identifies how best HCPs & support agencies can help
Ejegi-Memeh, Darlison et al. (2020) 'Living with mesothelioma: a qualitative study of the experiences of male military veterans in the UK', *European Journal of Oncology Nursing*, 50, p. 101889.	Peer-reviewed article	UK	To understand the experience and health/support needs of British AF personnel/veterans with mesothelioma	Provides insight into how UK military veterans experience & cope with mesothelioma. Focuses on role HCPs & support agencies play in providing acceptable support.
Harrison, Darlison and Gardiner (2021)	Manuscript under review	UK	To explore the experiences of palliative end-of-life care for patients with mesothelioma from the perspective of bereaved family carers	Four themes: 1) understanding what lies ahead; 2) carer support; 3) care co-ordination; 4) managing after death: practicalities, inquests and abandonment. Caregivers need to understand what lies ahead to emotionally & practically prepare themselves for supporting the patient at end of life. Information & support needs of caregivers were often distinct from those of patients, including importance of information about coroner's involvement. Importance of care co-ordination was emphasised, with caregivers valuing on-going relationships & named individual taking responsibility for co-ordinating patient's care.

				Feelings of abandonment arose when there was no post-mortem contact with HCPs.
Taylor et al. (2021) ‘Effects of the COVID-19 pandemic on people with mesothelioma and their carers’, *Cancer Nursing Practice*, 20(4).	Peer-reviewed article	UK	To explore the effects of the COVID-19 pandemic on people with mesothelioma & their carers	Patients with mesothelioma & carers have been disproportionately affected by the pandemic, in 1) treatment & investigations 2) communication with healthcare teams 3) confusion concerning shielding 4) emotional & psychological burden.
Ejegi-Memeh, S. *et al.* (2021) ‘Patient and informal carers experience of living with mesothelioma: a systematic rapid review and synthesis of the literature’.	Manuscript under review	UK	To identify what is known about the experience of living with mesothelioma, from perspective of patients and their informal carers	Rapid Systematic Review - eight themes: 1) experience of diagnosis 2) physical impact of mesothelioma 3) psychological impact of mesothelioma 4) impact on informal carers, carers and relationships 5) self-management 6) health care professionals & systems 7) treatment and trials 8) asbestos exposure and compensation.
Harrison et al. (2021) ‘Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review’, *Palliative Medicine*, 35(6), pp. 1039–1051.	Peer-reviewed article	UK	To describe the palliative care needs and experiences of people with mesothelioma and their family carers	Integrative systematic review: cross-cutting theme of ‘unfathomable uncertainty’ with 5 themes: 1) organisation & co-ordination of services 2) communication & information needs 3) management of care needs & high symptom burden 4) impact of seeking compensation 5) family carers’ needs
Henshall et al. (2021) ‘Recommendations for improving follow-up care for patients with mesothelioma: a	Peer-reviewed article	UK	To explore experiences of patients with MPM of follow-up care in three NHS trusts	Identifies need for patients with MPM to access consistent, specialist, streamlined mesothelioma care, centred around specialist mesothelioma nurses & respiratory

qualitative study comprising documentary analysis, interviews and consultation meetings', *BMJ Open*, 11(1), p. e040679.				consultants, with input from wider multidisciplinary team.
Prusak et al. (2021) 'The psychosocial impact of living with mesothelioma: Experiences and needs of patients and their carers regarding supportive care', *European Journal of Cancer*, pp. e13498–e13498. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/ecc.13498.	Peer-reviewed article	The Nether-lands	To explore patients' & carers' needs & experiences regarding psychosocial support & their coping mechanisms	Patients' themes: 1) active coping 2) limited needs 3) limited knowledge & awareness about psychosocial support Carers' themes: 1) passive coping 2) 'it's all about the patient'
Di Basilio, Shigemura and Guglielmucci (2021) 'Commentary: SARS-CoV-2 and Asbestos Exposure: Can Our Experience With Mesothelioma Patients Help Us Understand the Psychological Consequences of COVID-19 and Develop Interventions?', *Frontiers in Psychology*, 12, p. 3719.	Peer-reviewed article	UK/ Italy/ Brazil	Commentary on Granieri et al. (2020)	Argues differences outweigh similarities. Suggests adopting ecological perspective focused on different levels where trauma occurs & intra/interpersonal dynamics involved.
Granieri et al. (2020) 'SARS-CoV-2 and Asbestos Exposure: Can Our Experience With Mesothelioma Patients Help Us Understand the	Peer-reviewed article	Italy	To identify knowledge on asbestos exposure & MM that provide insight into the psychological impact of the	Psychological impacts have common characteristics. In both cases, people experience similar effects. Individuals use similar defence mechanisms to contain overwhelming anxieties.

Psychological Consequences of COVID-19 and Develop Interventions?’, *Frontiers in psychology*, 11, p. 584320.			COVID-19 pandemic	
Bonafede et al. (2020) ‘Psychological Distress after a Diagnosis of Malignant Mesothelioma in a Group of Patients and Caregivers at the National Priority Contaminated Site of Casale Monferrato’, *International Journal of Environmental Research and Public Health*, 17(12), pp. 1–15.	Peer-reviewed article	Italy	To examine the emotional impact after diagnosis of MM in a group of patients and family carers in a National Priority Contaminated Site	For both patients & carers unconscious adaptive processes were central in dealing with overwhelming feelings related to mesothelioma. Carers were significantly more likely to have posttraumatic symptoms than patients. Female carers had elevated risk of depression.
Padilha Baran et al. (2019)) ‘Therapeutic itinerary revealed by the family members of individuals with mesothelioma: Multiple case studies’, *Texto e Contexto Enfermagem*, 28, p. e20170571.	Peer-reviewed article	Brazil	To describe the therapeutic itinerary revealed by the relatives of individuals with mesothelioma	Therapeutic itinerary was built from early symptoms detection & common sense practices. Family was central unit of care; professional subsystem, with challenge of diagnosing the disease, and religion, which represented the person’s and family members’ hope.
Warnock et al. (2019) ‘Patient experiences of participation in a radical thoracic surgical trial: findings from the Mesothelioma and Radical Surgery Trial 2 (MARS 2)’ *Trials*, 20, p. 598	Peer-reviewed article	UK	To improve understanding of patient experiences of trial procedures, trial treatments and factors influencing participation	Challenges: 1) volume & complexity of information given to participants 2) their understanding of clinical equipoise & randomisation. Factors influencing participation: 1) opportunity to undergo surgery, 2) a self-assessment of ability to

				cope with trial treatments, 3) maintaining a positive approach, 4) altruism. Obstacles: logistics of travelling for treatment in an unfamiliar setting. Negative consequences: 1) increased uncertainty amplified by multiple care providers, 2) unclear transition arrangements after trial.
Warby et al. (2019) 'Managing malignant pleural mesothelioma: experience and perceptions of health care professionals caring for people with mesothelioma', *Supportive Care in Cancer*, 27(9), pp. 3509–3519.	Peer-reviewed article	Austra-lia	To document the experience of MPM patients and their caregivers	Satisfaction with treatment was high. Participants identified need for improved communication & quality of information, discussion about treatments, end-of-life assistance, & caregiver support post-mortem.

In the following sections, I go on to consider my findings in relation to the published research literature under the following headings: 'caring for and caring about'; 'the militarised body and pain'; 'sharing information'; and 'guilt, betrayal and traumatic stress'. Although many of these findings will also apply to other patients with mesothelioma and their carers, I shall focus on what my findings add specifically to the military context.

7.4.2 Caring for and caring about

The patient and carer relationship is a fundamental part of the experience of being a human, with many ways of manifesting itself (Tomkins and Eatough, 2013). It involves both caring for and caring about: the latter relates to the existing relationship, and the former to physical care tasks and emotion work (Noddings, 2003). In phenomenological research, care has been presented as "a complex web of giving and receiving, joy and sorrow, and togetherness and solitude" (Tomkins and Eatough, 2013, p. 5). My findings show how the military context influenced many aspects of how the carers cared for and cared about the patient, other people, and themselves. I will consider this in the light of existing literature under the following headings: 'reluctance to seek help'; 'military masculinity and help-seeking'; and 'female veterans and male carers'.

Reluctance to seek help

It made sense to many of the carers to ‘go the extra mile’ and ‘just keep on going’ in terms of how they cared for their loved one. For some, this meant not asking for help, even when they were reaching crisis point. In my study, carers who reached crisis stage before accessing help spread across the three groups from Table 43 (p.237): Gary (A), Andrea (B) and Vicky (Mike). There is a sparse existing literature on informal carers in the military community, and my findings generally support the picture of reluctance in seeking help. A recent survey by the Royal British Legion (2021) of unpaid carers in the British Armed Force community found that veteran carers were 2.5 times more likely than civilians to care for a spouse or partner, and that *veteran* carers caring for a veteran were three times more likely than civilians to do so. Nearly half of carers for a veteran had not received any support in the last two years, double the proportion in the general population, and they were less likely to have had a recent carer’s assessment. Carers in the survey spoke of Armed Forces culture being a barrier to help-seeking. The Royal British Legion (2021, p. 43) recommended “a greater recognition of carers and their needs in their own right at a preventative rather than crisis stage”. Thandi et al. (2017) carried out a study on the experiences of spouses of UK military personnel in terms of informal caregiving and intimate relationships. They found that carers sometimes felt unable to cope with the demands of caregiving and the military partner’s lack of or delay in seeking help caused strain in the relationship. Williamson et al. (2019) looked at the impact of military service on physical heath in later life, comparing UK veterans with non-veterans. Their findings included carers reporting veterans as being extremely reluctant to accept informal care, ascribing it to embarrassment and pride; this could be distressing and frustrating for their close companions. Several patients in my study did not want the carer to tell other people, including family members, about their illness, putting pressure on the carer to manage on their own. This may reflect the veteran patient’s military background, where the emphasis is on an ‘us-us approach…we can hack it’ (Deakin, 2016, p. 27), a tight team working together and excluding outsiders (Brewster, McWade and Clark, 2021).

Military masculinity and help-seeking

In my sample, underpinning the issue of just keeping on going and not asking for help was the concept of military masculinity. The military has been described as a ‘hypermasculine’ culture (McAllister, Callaghan and Fellin, 2019; Alves-Costa *et al.*, 2021). It values toughness, stoicism, physical strength and emotional control, in a disciplined and hierarchical structure where “traditional expressions of hegemonic masculinity are presumed” (McAllister, Callaghan and Fellin, 2019, p. 258). Embodying masculinity is seen as a matter of survival, with rationality and calmness being valued; physical endurance and toughness are prioritised over self-care, with stoicism at the centre, i.e., “the capacity to endure and ‘crack on’ despite emotional and physical distress” (McAllister, Callaghan and Fellin, 2019, p. 263). Expressing empathy for those in distress may be framed as “enabling weakness” (McAllister, Callaghan and Fellin, 2019, p. 264). In my study, participants all invoked the concept of stoicism in the veterans as having come from their military background. They talked about the patients not wanting to seem vulnerable or weak, to not be seen ‘flinching’, and this supports Williamson et al.’s (2019, p. 6) report of older veterans wanting to appear “tough”. Older veterans value having a stoic attitude, appreciating the way they had been taught to accept unforeseen circumstances and carry on with determination, for example, when coping with the COVID-19 pandemic (Frondigoun *et al.*, 2021). Militarised masculinity has a long “after-life”, staying present in veterans’ lives long after they have left the AF, and it can have protective effects, e.g., via the sense of camaraderie encouraging social support (Bulmer and Eichler, 2017, p. 171).

Military masculinity necessarily involves a positioning of femininity as ‘other’, as “‘risky’ within the military environment, conflated with an essentialised emotional and physical delicacy that positions women as ‘unfit’ for military service” (McAllister, Callaghan and Fellin, 2019, p. 258). As well as making male veterans wary of being seen as vulnerable and therefore weak and not ‘manly’ enough, this has implications for female carers of military veterans in terms of help-seeking. In my sample, seven of the carers were female, five of whom were caring for their spouse. Military wives and female partners are positioned in contradictory ways. On the one hand, they are seen as being weaker physically and emotionally, and therefore in need of protection. In the British AF, family members are still known officially as ‘dependants’, irrespective of their individual circumstances (Ministry of Defence, 2014). On the other hand, they are required to show great practical and emotional resilience in their role supporting the military institution and their military partner (Keeling, Woodhead and Fear, 2016; Johnson, Ames and Lawson, 2021), e.g., managing frequent moves, running a household and family on their own while the partner is away, and possibly working in their own employment, without back-up from nearby family (Halvorson, 2010). Male serving personnel may alleviate their own guilt at being away from home by “drawing attention to their wives’ personal attributes of strength, independence, and ability to cope” (Keeling, Woodhead and Fear, 2016, p. 520). Military wives and partners find themselves in the service of the military by being “supportive and caring…‘not allowed’ to show emotion, dependence, vulnerability, fright and worry” (Johnson, Ames and Lawson, 2021). Perceptions of military partners are strongly gendered, with certain archetypal profiles being approved of, e.g., the resilient and independent ‘Perfect Partner’ and the ‘Suck It Up

Sunshine' who copes by 'just doing it' and expects this of others; other archetypes are frowned upon, e.g., the Whinger, who claims fair rights and is seen as too demanding (Johnson, Ames and Lawson, 2021). These militarised expectations are often internalised (Long, 2021) and can explain how carers in my sample, particularly those steeped in military culture (Groups A and B in Table 43), were more likely to just keep on going without seeking support, as they valued their own independence and ability to get on with things. Their veteran patient was also likely to expect them to cope well physically and emotionally if they assumed the view of the carer as resilient and independent. In the military, the needs of partners are put in second place to those of serving personnel and the institution (Catignani and Basham, 2021; Long, 2021), and it can seem natural, both to the carer and the veteran, to do this in later life when the veteran is ill.

Female veterans and male carers

My sample included carers for female as well as male veterans. My study's idiographic approach meant that I was able to present the experiences of these female veterans and their male carers. This new perspective builds upon the existing MiMES study, which focused on the experiences of *male* veterans with mesothelioma (Ejegi-Memeh, Darlison, *et al.*, 2020). For female veterans, their relationship with militarised masculinity is complicated, and they seem to have been marginalised in mainstream academic literature (Dodds and Kiernan, 2019; Godier-Mcbard, Gillin and Fossey, 2021; West and Antrobus, 2021). Women in the Armed Forces are situated within the different stories that may be told about women in the context of the military: they are vulnerable and need protecting; they are resources to be used to win wars; and (a newer story) they can be women soldiers, presented as feminine but militarised (Sjoberg, 2007). When female veterans transition from the Armed Forces, they not only have to recover a civilian identity, as males do, but also a female identity, as they are seen as having "honorary male status" and being "other" (West and Antrobus, 2021, p. 7). A recent study exploring the experience and needs of women veterans in the UK (Edwards and Wright, 2019) found that they were a hidden population: the civilian community had "difficulty recognising them as veterans" which led to them "becoming depressed, isolated and disconnected from services" (p.20). Another recent UK study (Godier-Mcbard, Gillin and Fossey, 2021) suggested that female veterans were more likely to access formal medical support compared to males. However, Godier-McBard et al. (2021, p. 4) reported that female veterans wanted to be seen as "strong", with illness of any sort being seen as weakness, and women's mental health seen as negatively stereotyped; participants ascribed their "stiff upper lip mentality" to their service, and described barriers to help-seeking.

In my own study, Malcolm took pride in Patricia's courage in the face of painful interventions and valued how she approached everything with humour; Gary was concerned that Marie was not "robust" enough. The two female carers who showed anxiety about their own mental ability to cope were civilians, who may have been influenced by their veteran husband's expectations about women being 'weaker'. Andrea, a military wife, in particular, embodied an ingrained expectation of independence and not asking for help, of getting on with it and being strong. However, her husband clearly felt that wives and families needed protecting, hence his decision to circumvent having an 'upsetting' funeral, and not letting anyone know he was close to death. My findings add to the limited existing picture of the complexities for women veterans, and women caring for male veterans, regarding attitudes to help-seeking. This is needed as it is important to beware of militarised masculinity being "the only lens through which we understand veterans' experiences" (Bulmer and Eichler, 2017, p. 173).

The three male carers for a female veteran with mesothelioma in my study were taking on a supportive, caring role. To my knowledge, there is no existing research literature looking at male veterans as carers. I therefore now consider my participants' experiences in relation to the general literature on male carers, which itself is not copious.[26] Caring is a gendered activity because it is more usually carried out by women and because it involves nurturing (Spendelow, Adam and Fairhurst, 2017; Mott, Schmidt and MacWilliams, 2019). Hegemonic masculinity has been used as a concept to explain how men may cope with a caring role; alternative literature has focussed on how men are able to think and behave in a flexible way, combining traditional masculinity with nurturing caregiving (Spendelow, Adam and Fairhurst, 2017). Mott, Schmidt and MacWilliams (2019) found that male caregivers "demonstrated caring by highlighting the practical tasks they perform, the technical skills they possess, and their ability to take control of the situation" (p. E18). They also preferred to have autonomy and independence in the role, to take a problem-centred approach, and to see the role "in terms of being a protector or provider" (p. E18). They tended not to seek social support, although findings were mixed. Finally, they reported less role-strain than women; this may be due to their problem-solving approach, or to under-reporting in order to show they "can handle anything" (p. E22). Judd, Guy and Howard (2019) explored the lived experiences of UK men caring for a dying spouse/partner and their help-seeking for themselves. Their participants saw their caring tasks as providing a source of purpose and responsibility, like having a job. Seeking help seemed to be "incompatible with everything…their experience of caring for their dying partners, the carer role itself, their

---

[26] A recent literature review of male caregiving in western cultures (Mott, Schmidt and MacWilliams, 2019) identified 40 articles, of which only five related to men providing care for cancer patients.

relationship with their partner, the fact that their partners were terminally ill, and them as men" (p.8). Their participants' data suggested that for the carer to access support, "there is a need to turn towards one's own pain, resulting in a perception of turning away from others, that is, their dying partner" (p. 8). It was important to protect their partners from their own distress, and to seek help only as a last resort (p. 9). In a study exploring Australian men's experiences of informal cancer care, Kenny et al. (2020) found that participants wanted to avoid the powerlessness and vulnerability that came with witnessing illness and talking about death; they therefore tended to avoid talking about mortality. Ussher et al. (2013), in a study of the gendered difficulties and rewards in cancer care, identified that men were more likely to report increased relational closeness with the patient, and the burden of extra responsibilities within the home as a difficult aspect.

We might expect the male carers in my study to have a double dose of masculinity in relation to their caring role, thanks to their military background, and to follow the pattern described by Mott, Schmidt and MacWilliams (2019) and Judd, Guy and Howard (2019). This was true for Malcolm, who was focussed on the practical, responsible, and protective side of his role, seeing it as a job to be done well, and to be done on his own. He explained how he and his wife had chosen not to talk about her death until the night before she died. It was also true for Gary, who took so many tasks into his 'square' of responsibility that he was unable to cope. He described not being able to pay attention to his own self-care because it would have meant him leaving his wife's side; he was aware that paying attention to his own needs in this high-stakes situation was incompatible with his identity as "a grown man." Gary was a younger carer and was able to recognise and articulate his emotions in the interview, suggesting that there was some "softening" of hegemonic masculinity for him (Kenny *et al.*, 2020, p. 493). This may have been due to a generational effect (Robinson and Robertson, 2014), yet he was still in its grip when it came to his embodied experience. The third male carer, Graham, showed a different pattern. He seemed to be positioned more as an ally and helper rather than the main carer, as if his wife herself was the carer. He described how she had taken charge of adjustments to the house, for example, and had accessed plenty of emotional support for herself. As she was a veteran, this could be an example of *her* military background coming through in a proactive, problem-solving, 'can do' attitude, with Graham positioned as part of her team, her expected back up. Nicola's approach to the carer role had all the hallmarks of a typical male pattern: a proactive, problem-solving style, with an emphasis on positivity and not dwelling on things, plus a discomfort with seeking support for her own emotions. She was also one of only two carers to report feeling closer to the veteran patient. However, she also showed an aspect typical of female carers, i.e., positioning caring as a privilege (Ussher *et al.*, 2013). Malcolm also expressed this aspect of his role. None of my three male carer participants reported any issues for them with taking on household responsibilities, unlike Ussher et al.'s male carers (2013). This may be explained by the fact that military training in the British Armed Forces instils skills and pride in keeping a smart appearance and a shipshape environment, so these household tasks were within my participants' experience and capabilities. Therefore, it seems that the findings of my study support to some extent the existing research literature in terms of the carer's role. However, new insight has been provided into how a military background may affect carers' experience of doing care and caring about their loved one, with some atypical manifestations in terms of gender.

7.4.3 The militarised body and pain

One particular aspect of my participants' experience stood out as being affected by military culture: the response to pain from both the carer and the veteran with mesothelioma. Pain is a significant part of mesothelioma's heavy symptom burden (Dickinson, Labuc and Bracegirdle, 2021; Hoon *et al.*, 2021; Khan *et al.*, 2021). Pain can come both from the cancer itself and from procedures, e.g., thoracentesis and cytoreductive surgery, and it may not be clear to the patient which of these is causing the pain (Ream *et al.*, 2021).

When Armed Forces personnel transition to civilian life they may be reluctant to abandon their militarised body (Grimell, 2019). As Grimell (2019, pp. 107–8) explains, "the bodies of service members are one of the most important aspects of creating and maintaining military identities…The strengths of the body are saluted and promoted…Conversely, the weakness of the body is one of the most feared and unaccepted conditions of military cultures." In fact, to undo the transformation that took place, "inscribed on the body", when the military uniform was first put on, may be impossible (McSorley and Maltby, 2012, p. 4). Training of the body "fosters a capacity to 'soldier on' in the face of corporeal adversity" (Hockey, 2012, p. 9). Many veterans, as well as having undergone basic training, will also have completed Survival, Evasion, Resistance and Escape (SERE) training, which aims to "develop and nurture coping skills by means of gradual exposure and mastery of increasingly challenging stressors; it thus acts as a proactive defence against future stressful situations" (Matthew *et al.*, 2015, p. 168). This training will include coping with pain, promoting a belief in the power of the mind to help deal with it. Such a response was illustrated by Vicky's husband, Mike.

Another embodied aspect of military service is the relationship with food: it is "an institutionalised, bizarre relationship" which may lead to food being an unrecognised stress factor for veterans, with potential for eating disorders and body dysmorphia (Mobbs, 2018, p.

1). Also, wounding may occur to the body during military service, with a hierarchy of wounding being identified. The MOD classifies injuries as either ‘battle’ or ‘non-battle’ injuries; the media reports these injuries differently, with accounts of heroism, sacrifice and masculinity attached to those from combat (Caddick *et al.*, 2020). It is interesting to consider where mesothelioma should be positioned in these categories, as it could be caused either from exposure during combat or from the environment. Within the military, there may be stigma associated with an injury which is not visible and obvious; having a sick note and light duties can lead to ridicule. Dodson (2020, p. 2) explained: “I had become what I despised…To the naked eye there was nothing wrong with me. Internally, my body was buggered”. This matched the experience of Len in my study, who was distressed by the fact his condition was hidden from view.

Life in the military generally involves a great deal of physical exercise and strenuous activity. Williamson et al. (2019) found that many UK veterans continued to exercise after leaving the AF. Staying physically active was central to their retirement, more so than for civilians. The veteran patient’s level of physical fitness prior to the occurrence of mesothelioma was mentioned by many of my participants, along with the pride they felt in being fit and active. There is also an aspect of hegemonic masculinity with regards to health which is a sense of ‘don’t care’, i.e., a degree of risk and danger is acceptable (Robertson, 2007, p. 61). This could be seen in my data in the accounts of Len learning to ski in his 70s and Hywel taking his boat out alone (despite a heart condition) in his mid-80s. It was not surprising, then, to find in my study some sense of shame in veterans, like Hywel, who were no longer able to maintain their self-image of being fit and physically strong, and for whom mesothelioma’s unpredictable rate of deterioration may have made it hard to adjust. This supports the findings on physicality in Bibby et al.’s (2021, p. 6) study on mesothelioma trial participation, where men with mesothelioma “often emphasised their prior fitness and strength” and some “expressed sadness and regret” when they recognised their strength was deteriorating. In a recent review of health disparities associated with malignant pleural mesothelioma in the USA, Freudenberger and Shah (2021) found that elderly patients were less likely to receive any treatment, despite MPM being a disease of old age. They suggested that ‘clinical nihilism’[27] from HCPs might be a factor in this disparity. Warby et al. (2019) also identified medical nihilism as a reason for chemotherapy being underused to treat MPM. To elderly veterans who are actually physically stronger and more active than civilians, it may seem unreasonable when they are not offered active treatment. This certainly chimes with how

---

[27] Clinical/medical/therapeutic nihilism is when a clinician thinks that an intervention is unlikely to do any good (Mamede and Schmidt, 2014).

Hywel and Cerys experienced him being ‘written off’. My findings show a general pattern of both patients and carers being positive about clinical trial participation. This may have been because they had a sense of the patient’s physical fitness being good enough to handle the effects. This supports a finding by Warnock et al. (2019, p. 5) that the decision-making of many mesothelioma patients to take part in the MARS 2 trial was influenced by “their own assessment of their ability to cope physically with treatment, particularly surgery”. It may also point to the carer’s own wish to ‘just keep on going’ and support the patient in whatever needed to be done. This is a novel finding which does not concur with Bibby et al.’s (2021) finding regarding patient and carers’ attitudes to trial participation in the general British mesothelioma population. They found that these carers were less enthusiastic about research than the patients, which they suggested could reflect higher anxiety among these relatives, or advocacy “on behalf of stoical patients” (p. 15).

As well as the veteran patient, a carer who is steeped in the military way of life may also feel shame if they do not keep up their own physical fitness, as was the case for Gary. The Royal British Legion (2021) identified that the health of carers for veterans who were veterans themselves was worse than other carers, and that this group took fewer breaks from caring. Other carers in my study described how they had not attended to their own physical health needs, e.g., Janet, who was aware that her diabetes nurse would be displeased with her weight-gain. Both the Royal British Legion (2021) and Post et al. (2021) pointed out the adverse relationship for carers of veterans between their health behaviours and psychological well-being, with these carers tending to put their physical and psychological well-being needs in second place. Post et al. (2021) recommended considering the ill veteran’s whole family unit when targeting healthcare.

Recent research literature has considered how military veterans deal with pain from chronic conditions, rather than from illnesses such as cancer. Engward, Fleuty and Fossey (2018, p. 41) found that “some veterans with limb loss will try to tolerate high levels of pain without asking for help.” An exploration of female veterans’ chronic pain (Denke and Barnes, 2013) showed that they were very keen to avoid being labelled as weak, and therefore did not seek help for their pain until it was unbearable. The authors said it was important for HCPs to understand this, otherwise pain assessment would be inaccurate and pain relief sub-optimal for female veterans. Hitch et al. (2020) identified that veterans used different pain management methods to civilians and might only seek help when the pain was completely debilitating. They found that using military techniques to cope gave veterans a feeling of control. Veterans felt anger and frustration at the loss of favoured activities and their former identity, and guilt about not being able to keep on going and thus disappointing others. Pride was a barrier to help-seeking, as was the use of humour which could mask their needs from services. The authors pointed out that avoidance as a strategy may actually lead to excessive pain levels, with long-term maladaptive consequences, and therefore recommended a “veteran-civilian” approach to pain management (p. 122). All the participants in my study referred to pain as an issue for their loved one, and it could be difficult to control. However, the carers described a variety of experiences with handling pain. Cerys had to work hard to encourage Hywel to admit to his pain and take medication. Dorothy had her pain helped by a hospice, and Nicola was able to access immediate help for Len when his pain escalated at home at the end of life. However, Andrea and Vicky reported their own distress at pain that was not well-managed.

Vicky’s husband was ill during COVID-19 restrictions, which may have made his situation worse. This supports Taylor et al.’s (2021) findings from a study on the effects of the COVID-19 pandemic on people with mesothelioma and their carers, showing that they were disproportionately affected including in terms of the psychological and emotional burden. Another study on the impact of COVID-19 on cancer patients and carers reported reduced quality of life among carers (Hulbert-Williams *et al.*, 2021). Bowers et al. (2020) reported that during the pandemic, family caregivers were being asked to administer end of life drugs where previously these would have been given by HCPs; this may have caused carers to feel under pressure due to feeling unconfident and also may have caused anxiety about hastening death. Both these issues may have applied to my participant Vicky. Wilson, Caswell and Pollock (2021, p. 1), in a study of the ‘work’ of managing medications at home, identified that “the management of medications can substantially add to the burden placed on patients and families…especially when fatigued, distressed and under pressure”. This seems to have been the case for Gary and Marie. Their experience also showed a complex interaction between militarised expectations around pain, being ‘robust’ and accessing help, which was difficult for the couple to handle. Overall, my study has added to the research literature on veterans and pain with its presentation of nuance within the relationship between patient and carer.

7.4.4 Sharing information

Sharing information at diagnosis

The findings from my study showed that receiving a diagnosis of mesothelioma was usually a shocking and devastating event for both patients and carers. Only Andrea and Eric lacked surprise: his involvement in the naval community and knowledge of historical asbestos exposure meant they were well aware that this disease was a possibility for him. My other participants were mainly caring for veterans from the army and air force, and the shocking impact on them of the unexpected bad news supports the findings of the MiMES study (Ejegi-Memeh, Taylor, *et al.*, 2020). Bonafede et al.'s (2020) study was the first quantitative study published which presented the psychological impact of diagnosis on carers separately from patients. They showed that carers were significantly more likely to exhibit post-traumatic symptoms than patients, that women showed higher levels of depressive and post-traumatic symptoms, and that women carers were more at risk than men of developing depression. The idiographic dimension of my study allowed the drawing out of differences between carers and patients in how they experienced the diagnosis, as well as differences between male and female participants.

One of the key aspects of differing experience identified from my data related to the wish for information about prognosis. Several participants quoted the actual words said by the patient when they asked the HCP how long they had left to live. Malcolm stated confidently that asking this question is what anyone would do in that situation. There seemed to be a pattern of the veteran patients' stoic outlook immediately coming into play alongside their problem-solving, task-oriented coping style. This supports the findings of the MiMES study regarding patients' coping efforts in reaction to the diagnosis and prognosis (Ejegi-Memeh, Darlison, *et al.*, 2020). In my study, the dyads who particularly took this approach were all of those in Group A and Nicola and Len from Group B[28]. Both patient and carer wanted to know what they were dealing with and appreciated honesty and directness from the HCP. However, other patterns could also be observed. Eric (Group B) preferred to go to appointments alone, a practice with which his wife concurred, as it would allow him to "focus". He chose to know prognostic information but hide it from his family, prioritising protecting them from distress over empowering them to make preparations. Arthur (Group C) asked outright for his prognosis whilst his wife was present, leading to great and on-going distress for her.

Military systems are designed to provide a framework of certainty in the face of unpredictable and life-threatening events. The experience of mesothelioma has often been documented in the research literature in terms of overwhelming uncertainty, e.g., Harrison et al. (2021), Walker et al. (2019). Getting the diagnosis may even mark the end of a period of uncertainty and signal the start of active responses via treatment (Kirby *et al.*, 2020). It makes sense, then, that military veterans should gain security in a similar situation of uncertainty by deploying task-oriented strategies of fact-finding and planning. However,

---

[28] Group A = veteran carer; Group B = carer who was a military spouse/grew up in a military family; Group C = civilian carer.

civilians may have a different coping style - avoidant coping. In my study, Dave (a veteran) and Janet had this avoidant coping style. He remained in denial about his mesothelioma diagnosis, and his avoidance may have been linked to his PTSD. Janet's needs were not met at the diagnosis appointment. Lelorain (2021) considered the most helpful way for HCPs to discuss prognosis with cancer patients. Whilst her paper referred to patients, she added that the needs of relatives in this context required further research. She noted (p. 5) that "patients with avoidant coping, i.e., patients who do not face problems and instead try distractions to avoid thinking of them, prefer non-disclosure" of a poor prognosis. Her recommendations to HCPs were firstly to establish rapport with the patient to assess their needs at this point; they should not engage in prognosis discussion with those they do not know (which is what happened to Janet); if high distress was detected, the discussion should be postponed. The patients' *and carers'* wishes about the amount and type of information they want regarding prognosis should be discovered: this would "help in the ethical dilemma of hope as opposed to knowing and autonomy" (p. 5). Fostering hope is possible, even with a disease such as mesothelioma, if it is framed as being about reaching short term goals, "the belief that each day has potential, the feeling that life has value and feeling connected with others" (p. 5). Mori et al. (2019) made similar recommendations, and added that a specific way of phrasing bad news was preferred by patients, with a wider range of survival time being given along with a 'hope for the best, prepare for the worst' statement. In another paper, Lelorain (2018) suggested that the manner of breaking the bad news to mesothelioma patients was less harmful if it combined positive and active empathy with an orientation towards an action plan. Taylor, Warnock and Tod (2019) stressed the importance of getting the balance right when communicating a mesothelioma diagnosis and giving bad news during the pathway because of the lasting impact this can have on the patient experience.

One reason why fostering hope is important when diagnosing mesothelioma is that a problem-solving, task-orientated coping style could lead to a patient taking their own life. The topic of suicide did not come up in my study's data, except when Vicky talked about Mike's wish to avoid it for faith reasons. However, the choice to participate in my study may not have seemed appropriate for any carers whose loved one had taken their own life after receiving the diagnosis. I mention suicide here because suicide risk in the initial time-period after diagnosis of mesothelioma featured in my scoping review. Henson et al. (2019) found that out of all cancer types mesothelioma patients had the highest risk of suicide in the first six months (an 8.61-fold risk compared to the general population), and Ball, Moore and Leary (2016) and Girgis et al. (2019) identified hopelessness resulting from HCPs' negative messages. McFarland et al. (2019, p. 224) listed the following as associated with suicide:

“depression, hopelessness, demoralization, pain, lack of social support, feeling like a burden to others, a strong need to control circumstances, and existential concerns”. The overlap is clear with the typical psychological effects of mesothelioma. Prusak et al. (2021) described how one ‘active coping’ action taken immediately after diagnosis by patients with mesothelioma in The Netherlands was to arrange euthanasia. Hegemonic masculinity scripts have been suggested as a reason for older men to be vulnerable to suicide (Canetto, 2017). A recent study of suicide among Scottish military veterans (Bergman, Mackay and Pell, 2021) found an increased risk in older female veterans compared to civilians. Therefore, skilled delivery of a mesothelioma diagnosis by HCPs may be particularly important for military veterans.

During her interview, Janet also mentioned that she would like to have more opportunity to talk privately to HCPs, rather than in front of her husband. This would have given her the chance to ‘pace herself’ in terms of gradually finding out more about his prognosis. This finding aligns with Harrison, Darlison and Gardiner’s (2021) recommendation that provision should be made for carers of mesothelioma patients to have separate one-to-one discussions about end of life matters. Research by Swetenham et al. (2015) regarding palliative care suggested that carers and patients had differing needs for information, which could be catered for if they were seen separately by HCPs; patients wanted to explore more emotional topics away from the carer, whilst the carers wanted more information. The importance of a personalised approach to the imparting of information about the curability, prognosis and progression of mesothelioma was stressed by Harrison et al. (2021), and the difference between the needs of patients and carers was highlighted in Prusak et al.’s (2021) study on supportive care in mesothelioma. The authors reported that whereas patients tended to have an active coping style, carers had a passive style. This meant they “put themselves and their emotional needs aside. They did not want to affect their loved ones with their feelings as – in their opinion – it would not be supportive” (p. 7), and in fact the carers had a strong need for psychosocial support and sometimes felt forgotten by HCPs. During the COVID-19 pandemic, a challenge of breaking bad news about mesothelioma in a sensitive way was the switch to remote consultations. This change meant that it could be harder to involve family members and to handle difficult emotions (Taylor, Tod, *et al.*, 2021). In my study, Cerys wanted more face-to-face appointments, yet Janet found that remote appointments allowed her to titrate her exposure to the news. In their study about communicating a mesothelioma diagnosis in the UK, Taylor, Warnock and Tod (2019, p. 7) noted that the majority of patient participants wanted information to be given “in a direct and honest way while maintaining hope”. My study therefore reinforces the importance of the manner in which the diagnosis and prognosis are communicated and draws new attention to the needs of the carer in this process.

Sharing information within the dyad

Amongst the dyads in my study there were varied levels of intimacy in terms of sharing information with each other. At one end of the spectrum, Gary and Marie talked about everything. In fact, he gradually lost his 'filter' and felt compelled to give raw information about Marie's condition to their children and work colleagues. Nicola and Len found a shared metaphor for talking about his death and became closer than ever. At the other end of the spectrum, Eric almost completely stopped talking to Andrea at the end of life, having hidden from her the fact he was near to death. Vicky and Mike both employed talking with each other as a coping strategy, yet hid certain aspects of their experience from the other (Mike's anxieties and Vicky's anger at the unfairness of his illness.) Military culture may have been having an effect on communication within the dyad. The military is a secretive organisation (Catignani and Basham, 2021), and habits of secrecy were mentioned by Andrea and Graham in terms of what was shared about worries and feelings in their couples. However, the military may also be a site of "intense intimacy", where there are no secrets between comrades (Brewster, McWade and Clark, 2021, p. 13) and men could be "so close" (Robertson, 2007, p. 118). It seemed plausible, therefore, that a dyad might experience great intimacy when the carer was experienced by the veteran as part of the same 'team'. This was my impression of the relationship between Nicola and Len. This intimacy allowed for good planning and adjustment to each new phase of the illness. This aligns with Thandi et al.'s (2017, p. 268) findings that some carers and the veterans they cared for overcame challenges by working together, seeing illness or injuries as "obstacles to defeat together".

The concept of 'protective buffering' has been used to describe the process where one person avoids open communication with the aim of avoiding distress in another person (Revenson, Wollman and Felton, 1983). Protective buffering was identified as a strategy used in military couples dealing with illness (Thandi *et al.*, 2017) and by dyads coping with uncertainty in advanced cancer (Shilling *et al.*, 2017). Protective buffering could have adverse effects, such as isolating the patient from a partner who could likely offer support, and leading to poorer mental health (Langer, Brown and Syrjala, 2009; Thandi *et al.*, 2017; Tan, Sharpe and Russell, 2021). My study has highlighted the different degrees of openness that carers and the veteran with mesothelioma may experience when communicating with each other, and how this may impact psychologically on them both. My study has also indicated how the participants' experiences differed according to whether both partners were military or not.

7.4.5 Guilt, betrayal and traumatic stress

Half of the carers who were my participants talked about feeling guilty or about feeling let down by others. Both of these feelings were the consequence of having expectations and assumptions about how people and organisations should behave. In my data were examples of guilt at not continuing to help the patient fight to live, guilt at being a healthy ex-smoker, anger at the Ministry of Defence for not providing the expected support and information, and anger at the NHS for not working efficiently and taking responsibility when things went wrong. I will now consider these findings in relation to the existing literature.

Feeling guilty

In my study, Vicky explained how she felt guilty for having smoked but staying well, whilst her husband, who had made sure to live a healthy lifestyle, died from mesothelioma. This type of guilt can be termed 'survivor guilt'. Fimiani et al. (2021, p. 1) explained thus:

> "This construct includes not only *the guilt about being spared from harm that others incurred*, but also the feeling of guilt that people may experience when they believe themselves *to have had any kind of advantage compared with others*, such as having more success, greater abilities, better health, greater wealth, a better job, or more satisfying relationships." [italics in original]

According to Glaser, Knowles and Damaskos (2019, p. 766), survivor guilt can lead to "anxiety, sleep disturbances, excessive vigilance or feelings of depression, hopelessness or self-blame". Although survivor guilt has featured in the general research literature on cancer, e.g., Perloff et al. (2019), Glaser, Knowles and Damaskos et (2019), Viswanath (2019), it has rarely featured in the mesothelioma research literature, though it appears in the grey literature more often, e.g., Kember (2014); Von St. James (2016). Bonafede et al. (2020) suggested that the reason for caregivers to have more severe traumatisation than patients was due to survivor guilt; all the caregivers in their study were also exposed to asbestos due to their contaminated local environment. Survivor guilt could be relevant to the mesothelioma experience in different ways: caregivers who have been exposed but do not become ill (including those who may have inadvertently caused the patient's contamination); patients who are long-term survivors and outlive other patients; and carers like Vicky who feel that they have unfairly been spared. Vicky reported challenging feelings when she experienced the death of other mesothelioma patients in online support groups, an issue identified by Glaser, Knowles and Damaskos (2019). The increase in numbers of long-term survivors due to more effective treatments such as immunotherapy may mean that survivor guilt becomes a more common phenomenon. In my sample, the three male veteran carers, Malcolm, Graham and Gary, all knew that they could also have been exposed to asbestos, but they did not express any feelings of survivor guilt. They saw the MOD as ‘the guilty party’ which may explain the lack of survivor guilt in their experience.

As well as survivor guilt, Vicky also expressed guilt at having let Mike down by not physically being able to keep on going with his intimate care and needing other people to come in. The other participant in my study who expressed guilt was Julie, who felt she had let Dave down by allowing his life support to be taken away whilst he still wanted to keep ‘fighting’. Such guilty feelings were explained by Bennett (2017) as making sense from the spouse’s point of view because they “may feel that failing to make good on their commitment to care is a betrayal”, and that they have not met their expectations of how to be a loving partner. Guilt can be a defence against feelings of “helplessness, death anxiety and grief” (Glaser, Knowles and Damaskos, 2019, p. 767), all of which are likely to be activated by the experience of mesothelioma. Holding on to guilt may also provide a way to be loyal to the dead, fulfilling a commemorative function (Glaser, Knowles and Damaskos, 2019); this may chime with the strong emphasis in military culture on loyalty and commemoration. Another effect of survivor guilt identified by Perloff et al. (2019) is that it can motivate people to feel an obligation to help others, and this may have contributed to the strong wish amongst my participants to ‘raise awareness’ about the risks of asbestos exposure. The extent and nature of survivor guilt in carers for a veteran with a diagnosis of mesothelioma is a novel finding from my study.

Traumatic stress

The sense of powerlessness inherent in receiving a diagnosis of an incurable illness like mesothelioma can negatively impact someone’s belief systems regarding control, justice, predictability and self-image (Glaser, Knowles and Damaskos, 2019). Both Vicky and Julie showed these negative impacts in their data. In fact, Julie also showed signs of traumatic stress, e.g., her flashbacks. This aligns with the picture of female carers being at higher risk for posttraumatic stress symptoms drawn by Bonafede et al. (2020). Walmsley and McCormack (2021), in an IPA study on dementia families, showed that traumatic distress was linked with events that were perceived as threatening to loved ones in a hierarchical care system.

Julie's husband, Dave, had been diagnosed with PTSD many years before his death, and this condition may have been exacerbated by his experience of mesothelioma. Traumatic stress symptoms have been linked in the research literature to the experience of being diagnosed with and treated for cancer, e.g., Cunningham et al. (2020), Sumner and Edmondson (2018). Swartzman et al.'s (2017) meta-analysis showed that cancer survivors who had experienced a prior trauma were more likely to exhibit traumatic stress symptoms, and that carers had similar proportions of trauma symptoms to patients; this was despite the fact that according to the DSM-V (American Psychiatric Association, 2013), cancer is no longer considered a potentially traumatic event. In military veterans, a cancer diagnosis can have a variety of impacts, including traumatic stress and positive growth (Jahn *et al.*, 2012; Martin *et al.*, 2014). Writing about PTSD in veterans and palliative care, Way et al. (2019) explained that a veteran's original trauma could be mimicked by the threat to life from their illness and so could amplify their PTSD. Mulligan et al. (2014) identified younger veterans, those with active PTSD from combat, and those with an uncertain prognosis as more likely to perceive cancer as a traumatic stressor. All these criteria applied to Dave in my study, and we saw how PTSD in his case could obstruct decision-making about treatment. The MiMES study (Ejegi-Memeh, Darlison, *et al.*, 2020; Ejegi-Memeh, Taylor, *et al.*, 2020) did not refer to the combination of mesothelioma in veterans and traumatic stress, apart from suggesting that occupational history-taking could trigger emotional distress. My study therefore adds additional understanding of how traumatic stress may affect British veterans with mesothelioma and their caregivers.

Moral injury

The term 'moral injury' was first used by Shay and Munro (1999) to describe the psychological distress armed forces personnel and veterans experienced after witnessing injustice caused by malpractice from their leadership. Shay later (2011, p. 183) defined moral injury as "betrayal of 'what's right' in a high-stakes situation by someone who holds power". Two further definitions may be useful in this discussion. These are:

> "The lasting psychological, biological, spiritual, behavioral and social impact of perpetrating, failing to prevent, bearing witness to, or learning about acts that transgress deeply held moral beliefs and expectations." (Litz *et al.*, 2009, p. 695)

> "Moral injury is a negative self-judgement [due to] having transgressed core moral beliefs and values or feeling betrayed by authorities. It is reflected in the destruction of moral identity

> and loss of meaning. Its symptoms include shame, survivor guilt, depression, despair, addiction, distrust, anger, a need to make amends and the loss of a desire to live." (Brock, 2011, p. 1)

Therefore, moral injury may be about something a person has done, or something they have witnessed being done by others. The effects of moral injury can include lingering ruminations focusing on unresolved anger/blame; negative self-evaluation (from the perspective of the self and others); breakdown in spiritual beliefs/negative view of God; and trust issues (Anderson, 2021).

The concept of moral injury has been researched in various contexts as well as the military, e.g., workplace bullying (Anderson, 2021), healthcare professionals (Čartolovni *et al.*, 2021), refugees (Nickerson *et al.*, 2015). At its heart, moral injury is about a loss of trust "about one's own or other's ability to keep our shared moral covenant" (Nash and Litz, 2013, p. 368). It is interesting to notice the word 'covenant' in this description, the word used in the British military context to sum up the obligation and agreement to care for AF personnel, veterans and their families as a result of their service. The MOD itself has talked of the "moral" component of fighting power as related to the care given to wounded personnel (Ministry of Defence, 2011, p. v). We can therefore see the links between expectations of those in the British military community about being loyally backed up by the MOD, expectations which have a moral quality, and the possibility of moral injury if those expectations are not met, in an example of "institutional betrayal" (Thompson, 2021, p. 111).

The participants in my study whose experience matched the parameters of moral injury were Graham, Gary and Julie (let down by the MOD), Malcolm (let down by the NHS) and Julie (transgressing by not allowing Dave to remain 'a soldier' at the end of his life). Between them, we can find many reports in their data of the symptoms listed by Brock (above). Also recognised as a component of moral injury is a spiritual element (Hodgson and Carey, 2017), which can be seen in Julie's struggles. The existing literature on mesothelioma has often referred to patients and carers feeling angry at previous employers, an emotion complicated sometimes by loyalty (Di Basilio, Shigemura and Guglielmucci, 2021; Harrison *et al.*, 2021). The MiMES report (Ejegi-Memeh, Taylor, *et al.*, 2020) described participants feeling frustrated about perceived inequalities, with some saying that the MOD had not fulfilled its duty of care. In the article about MiMES, Ejegi-Memeh, Darlison et al. (2020) told of frustration arising from the NHS being less efficient than the military system and harder to navigate. The published literature on mesothelioma in the UK often documents such difficulty in navigating fragmented services, where communication with HCPs is disjointed, e.g., Henshall et al. (2021), Taylor et al. (2021), Harrison et al. (2021). My study adds a new dimension to the literature, by showing that the distress caused to some carers of veterans with mesothelioma goes beyond frustration and anger and can be conceptualised as moral injury. I suggest that this happens because expectations arising from deeply held values about loyalty, respect, efficiency and honesty are broken. These could be expectations either about oneself, or in dealings with the MOD, or with the NHS. The NHS has been termed a British national “masculine” institution (Robertson, 2007, p. 33), which the AF community may expect to live up to the same military values. Individual members of the military community may be unaware of the expectations the deep-seated legacy has given them. The sociologist Pierre Bourdieu (1990) developed concepts including *habitus, field, capital* and *doxa* to help explain the dynamics of power in society. The meanings of these terms are given in Box 5.

Box 5: *Bourdieu’s* (1990) *terms and their meanings*

Habitus: dispositions/behaviours accepted in a particular social/cultural setting

Field: a social structure with its own set of rules and level of authority

Capital: sums of particular assets put to productive use - economic, cultural or social

Doxa: ways of being that are taken for granted; the unquestioned shared beliefs of a field

Bourdieusian theory has been used to explain the effects of transitioning from the military to the civilian field (Cooper *et al.*, 2017, 2018). Perhaps the difficulties of negotiating the field of the NHS institution whilst expecting a continuity with the military field result in “‘hysteresis’: the discord occurring when the new field is too different from the field to which one’s habitus is previously adjusted” (Cooper *et al.*, 2018, p. 164). As Robinson and Robertson pointed out (2014, p. 356), it is “no easy task” to have a more flexible habitus whilst keeping a durable core identity. Thus, Bourdieusian theory could be used to describe the experience of Gary and Malcolm, both ‘military men’, as they attempted to handle the transition between the military field and the field of the NHS as carers.

In this section, I have discussed my findings in relation to the published research literature under the following headings: ‘caring for and caring about’; ‘the militarised body and pain’;

‘sharing information’; and ‘guilt, betrayal and traumatic stress’. In the following section, I set out the original contribution to knowledge made by this thesis.

7.5 Original contribution to knowledge

This study is the first to explore the psychological impact of living with a diagnosis of mesothelioma in the UK military context. It is also the first study to explore the experience of the whole mesothelioma journey from the unique perspective of the informal carer. The focus on carers for a set of patients from a particular workplace is also novel in the mesothelioma literature. Whilst my findings add strength to the findings from the MiMES study, they add an extra dimension by highlighting the different experiences of female veterans and their male carers, and of non-naval veterans.

The UK military veteran community is heterogeneous (Finnegan *et al.*, 2020). This study highlights how carer and veteran dyads, who differ in terms of their saturation in military culture, may experience the effects of the military legacy to greater or lesser degrees and in different ways. Using the concept of degree of immersion in military culture is a novel contribution to the literature, as far as I am aware.

This study highlights for the first time the issue of moral injury for carers in relation to the interface between the UK military context and the National Health Service. It is also the first study to apply the term moral injury to the psychological impact of asbestos-related illness on a group of former employees in relation to their employer. The study has also shown for the first time the extent and nature of survivor guilt in carers for a veteran with a diagnosis of mesothelioma.

The study adds to existing knowledge on how British military veterans and their carers respond to pain. To my knowledge, research in the UK military context has previously been limited to considering pain from amputations, combat injuries and musculo-skeletal conditions.

Although Bourdieusian theory has been applied to the transition from the military to the civilian field, e.g., Cooper et al. (2018), it does not appear from the literature to have been applied to the transition from the military field to the field of the NHS as experienced by an informal carer.

The timing of my study in relation to the COVID-19 pandemic means that the issues raised for many of my participants were heightened. This study therefore contributes knowledge as to how a global pandemic might make things worse for a set of people with strong expectations about how the world should work.

7.6 Original contribution to methodology

Since its initial development, IPA methodology has proved popular for researching the experience of illness (Smith, 2011b), from the perspective of the patient, e.g., Guité-Verret and Vachon (2021), Kruger et al. (2021); and also from that of the carer, e.g., Atout et al. (2021), Scerri, Borg Xuereb and Scerri (2021); and other stakeholders, e.g., Maya et al. (2021); Melis et al. (2021)**;** Hadjittofi, Gleeson and Arber (2021). However, to my knowledge, IPA has not previously been used to explore the experience of mesothelioma from the patient's perspective or from that of the carer or stakeholder. My study therefore presents a novel use of IPA in this population. With its focus on the individual participant's experience and on convergence and divergence between participants' data, my use of IPA has contributed a nuanced understanding of how both patients and carers are impacted psychologically by the illness. This matched a need for more nuanced understanding about mesothelioma's psychological effects identified by my scoping review (see page 66). IPA's idiographic emphasis also meant my study was able to illuminate the range of different experiences, challenges and responses within the veteran community due to intersectionality. Attention has been drawn in recent literature to the importance of acknowledging these differences (Brewster, McWade and Clark, 2021; Gonzalez and Simpson, 2021). IPA's interest in participants' sense-making about the illness experience allowed insights to be gained which will be useful in helping HCPs and other professionals tailor their interventions and approaches (Kennedy *et al.*, 2017). See Section 7.9 for consideration of the implications for practice.

Methodological innovation in IPA has been welcomed by its original developers, who did not intend it to be used in a rigid, inflexible way (Smith, Flowers and Larkin, 2009; Smith and Eatough, 2019). My study was constructed in two stages, a secondary data analysis followed by individual interviews, with IPA used for both stages. Whilst IPA has been used previously for secondary analysis of existing data, my search of the methodological literature revealed no use of IPA in a two-stage study such as mine. I argue that the way the SDA findings foreshadowed the main study findings showed this approach was fruitful. Recruitment to mesothelioma studies can be challenging as it is a rare illness and has such a poor prognosis (Prusak *et al.*, 2021). Using IPA to make efficient use of existing data to inform an empirical IPA interview study in this small population is therefore a methodological innovation, albeit one of the "gentle waves" rather than the "seismic shifts" (Clarke and Braun, 2018, p. 21).

7.7 Strengths and limitations of the study

7.7.1 Strengths of the study

How the study met different sets of quality criteria

Throughout the development and conduct of my study, I paid attention to relevant quality criteria. For the scoping review I used Tricco et al.'s (2018) reporting guideline. I conducted the scoping review in a systematic way, using the staged method described by Arksey and O'Malley (2005) and Levac, Colquhoun and O'Brien (2010). For the two IPA stages I looked to Yardley's (2000) general quality criteria for qualitative research, plus Smith's (2011b, 2011a) and Nizza, Farr and Smith's (2021) criteria designed for IPA (see Table 45).

Table 45: *Quality criteria relevant to IPA*

Reference	Purpose of framework	Summarised Criteria
Yardley (2000)	To assess the quality of qualitative health research	sensitivity to context
		commitment and rigour
		transparency and coherence
		impact and importance
Smith (2011b, 2011a)	To assess the quality of IPA work	clearly subscribes to theoretical principles of IPA
		sufficiently transparent
		coherent, plausible & interesting analysis
		sufficient sampling from corpus
		well focused
		strong data & interpretation
		engaging and enlightening
Nizza, Farr and Smith (2021)	To achieve excellence in IPA	constructing a compelling, unfolding narrative
		developing a vigorous experiential and/or existential account
		close analytic reading of participants' words
		attending to convergence and divergence

Yardley's (2000) first quality criterion is *sensitivity to context.* I aimed to demonstrate sensitivity to context at all stages of my IPA. My initial choice of the methodology was appropriate because the project concerned exploring subjective experience from the carer's perspective. I then paid particular attention to the military socio-cultural context and considered how this might affect my relationship with the participants. My feminist perspective also helped me to acknowledge and identify issues of power. During the steps of analysis, I gave attention to each individual participant's data, grounding my interpretations in what they said, and I later contextualised my findings against the existing academic literature.

Yardley's next quality criterion is *rigour.* I showed commitment by engaging with relevant topics frequently throughout the PhD by meeting with patients, carers and professionals from the mesothelioma community and with researchers from the Armed Forces community, for example via the Defence Research Network. My own experience of having lung cancer and of being a carer for a loved one with cancer whilst working towards my PhD also showed my engagement with the topic. To enhance the rigour of my IPA, I immersed myself deeply in the data from each interview, taking time to carry out the iterative process of the hermeneutic circle. I kept records which were complete and systematic, providing a clear audit trail (see Appendix U for examples of these records).

Yardley's third criterion is *transparency and coherence.* Langdridge (2007, p. 157) sees this criterion as one of the most important for validity; "interpretations of the text are not limitless", therefore a strong, persuasive case needs to be made for what the researcher presents as the most plausible account. Clear presentation of the methods, supporting data and the researcher's influence all help to build a persuasive case. In this thesis I aimed to give a detailed and clear account of my project, showing how IPA methodology aligned with my conceptual framework and how my usage of IPA in practice cohered with its theory. Examples of documents from my audit trail are given in Appendix U. Reflexivity statements were included so the reader could gain a sense of my influence on different stages of the study. I presented the findings of my scoping review both at a Mesothelioma UK Patient and Carer Day and in my published article. I received feedback in an email from a bereaved carer of a mesothelioma patient saying that my findings resonated with her experience, thus demonstrating the coherence of my work (see Appendix V).

The final criterion in Yardley's list is *impact and importance.* There are indications that my study will have impact. My published scoping review was included in a recent Research Prioritisation Exercise (Taylor, Gardiner, *et al.*, 2021). This exercise identified issues which were in urgent need of further research. The issues raised in my study resonated with some of these, particularly symptom management; receiving a mesothelioma diagnosis; palliative and end-of-life care; and barriers and facilitators to joined-up service provision. My scoping review has also been used as a rationale for further studies by the Mesothelioma UK Research Centre - Sheffield. It has been cited in academic papers (Altmetric, 2021). Also, I was able to submit evidence based on my preliminary findings to a UK Parliamentary Select Committee, which was included in their report on Women in the Armed Forces (UK Parliament Defence Committee, 2021) (see Appendix W).

I met Smith's (2011b, 2011a) and Nizza, Farr and Smith's (2021) various criteria for quality in IPA as follows. I focussed on individual carers' experiences and their sense-making, looking at the specific topic of psychological effects. My interviews were carefully planned and conducted to provide rich data including existential material. I provided detailed examples of my analysis process for transparency. My interpretation was presented in a coherent narrative, which went beyond description to develop deeper meanings below the surface. A close analytic reading of my participants' words was carried out. Sufficient extracts were presented from the data (from at least three participants for each theme) to demonstrate density of evidence. Each theme included convergence and divergence between the participants' experiences, thus capturing nuance. Focusing on compelling experiential and existential meaning in the participants' accounts gave my analysis depth. I hoped to provide an analysis which told a compelling and persuasive story; the individual reader will judge how far I have fulfilled this aim.

Other strengths of the study

From my scoping review I identified that there was a lack of nuance in the literature about the psychological impact of mesothelioma on both patients and carers. My study adds a more nuanced view of the mesothelioma experience in different populations: British people, and within that, the military community. My sample was suitably homogenous for IPA methodology and within it there was also variation: three female patients; two middle-aged patients rather than elderly; one person with peritoneal mesothelioma; one dyad living in rural Wales, where access to services could be more difficult; one patient with complex existing physical and mental health needs; several carers were in employment as well as caring; three carers were not bereaved at the time of interview. The study's sample was small, as is appropriate for IPA. Such qualitative research cannot be used to make statistical generalisations as would be done in quantitative studies. However, studies such as mine can be used to make suggestions of internal generalisation within the setting, group or population, i.e., to people, events or activities that are not directly represented in the data collected (Maxwell, 2020). The diversity within my small sample enhances the possibility of some internal generalisability. Lincoln and Guba (cited Schwandt (1997, p. 58) recommended that qualitative researchers should "provide sufficient details . . . so that readers can engage in reasonable but modest speculation about whether the findings are applicable to other cases", i.e., have transferability. Levitt (2021) suggests that practising methodological integrity and paying attention to variation within qualitative data help a reader to understand the boundaries around the phenomenon under discussion in a study and thus to see what might fit to a different context of interest. I have endeavoured to give as many details about the context of my data, about my methods and methodology, and about myself as researcher as possible with these aims concerning transferability in mind.

7.7.2 Limitations of the study

The sample was limited in terms of various participant characteristics. Although attempts were made to recruit to this study from the wider UK population, including those living in Northern Ireland and abroad, none was successful. The participants and their veteran relatives were all White British. All the participants identified their own and their participant's gender in binary terms, although the relevant demographic question required a free text answer, and all were/had been in a heterosexual marriage. No participants reported economic disadvantage such as homelessness or financial worries. The final sample size was smaller than originally planned. Anecdotal reports were received from representatives of both military partners and informal carers explaining that there was a level of disillusion in terms of frequent requests for research participation which never led to practical improvements. This applied both to military partners and to informal carers. Two issues to do with the wording of study materials may have contributed to recruitment difficulties. Firstly, it became clear during recruitment that many stakeholders did not realise someone who had done National Service counted as a veteran. Secondly, I should have clarified that my recruitment criteria included all veterans of the British Armed Forces, including non-UK nationals.

There may have been gatekeeping by patients which stopped some carers from being represented in my sample. Anecdotally, I heard that some veterans with mesothelioma would mention to professionals that their female partner was 'not coping'. It is possible that assumptions were being made about who was a suitable participant for my study. Masculinist assumptions about what was appropriate in research may have led to the marginalisation of certain women's voices (Catignani and Basham, 2021). The participants in my study were willing to talk about psychological issues and to be open about their emotions. The experience of carers who were less comfortable with emotional topics may not have been reflected in my study.

Aspects of myself as the interviewer will undoubtedly have influenced how the participants interacted with me prior to and during the interviews. My gender and my outsider status as non-military meant that participants are likely to have communicated with me differently than if, for example, I had been a male veteran. As a civilian ‘outsider’, the “experiential gap” may have meant I was able to conduct a deeper exploration of the participants’ own phenomenological experiences (Smith, 2014, p. 130). On the other hand, my embodied insider knowledge of lung cancer meant I had shared many experiences described by my participants, e.g., Video Assisted Thoracic Surgery procedures, pre-operative anxiety, drug side-effects, recovery from an operation, scanxiety. I even realised I had been inside the same scanner as one of the veteran patients in my study! My interpretation of the participants’ data was also influenced by my intersectionality. A different researcher would have produced different interpretations. My focus on reflexivity and transparency throughout should help readers to gain enough context to help them interpret my thesis for themselves.

7.7.3 The COVID-19 pandemic

The COVID-19 pandemic affected many different aspects of life in the UK and worldwide from March 2020 onwards and was still on-going as I finished my thesis (December 2021). The cancer journeys of myself and my husband were affected by the pandemic in terms of our follow-up care being generally conducted remotely. The COVID-19 pandemic coincided with the mesothelioma journey of several of my participants (see Figure 15 p. 173). This gave a different context to the one I was anticipating. It is impossible to know how much the participants’ experiences were affected. The pandemic possibly heightened experiences that might have happened anyway. The pressures of the COVID-19 pandemic meant people were less likely to step forward to participate in my study. It made recruitment more difficult as I was not able to attend support groups or other activities to recruit. Some people may not have wished to be interviewed virtually, though others may have felt more comfortable taking part in this way. Throughout this thesis I have highlighted where any decisions had to be made which were due to the pandemic.

7.8 Closing reflexivity statement

In this section I will give a brief reflexive overview of my study as I look back over the whole process of preparing for and conducting it. I had originally rejected a transformative/emancipatory paradigm for my study. However, over the three years of my PhD, I came to find that critical military studies provided an illuminating perspective, and I understood better how all research was political. Submitting evidence from my study to a UK parliamentary committee felt empowering, as did identifying issues that needed to be addressed to improve the experience of veterans with mesothelioma and their carers.

As I approached the end of writing my thesis, I attended and participated in the opening of the *Cancer Revolution* exhibition at the Manchester Museum of Science and Industry. This exhibition included an object I had submitted representing my own cancer journey (see Appendix Z). For the first time, I met with other cancer patients *as a patient* (outside of medical settings). I was aware that I had avoided joining support groups and forums for myself; this was my own choice of how to cope with my cancer journey. The unexpected, instant intimacy and warmth that came from talking to other cancer survivors with whom I shared an experience was amazing. There was a joyful aspect, with no sense of stigma. This visit brought home to me how much I had compartmentalised my own identity as a cancer patient from my researcher identity. I will probably understand more only after my PhD is finished about my own journey and about the effect of my three identities intersecting: cancer researcher, cancer patient and cancer carer.

As a counsellor, I know that it is part of the therapeutic process for the therapist to be changed by the encounter with the client (Kottler and Hunter, 2010). Over the course of my PhD, I found that I had been positively influenced by my encounter with military culture, noticing how much it helped me as I laboured to complete my thesis to tell myself, “Just keep on going! Crack on!”

7.9 Implications for practice

This thesis has highlighted various areas in which clinical practice could be enhanced. These areas are considered in this section.

The way that news of the mesothelioma diagnosis and prognosis is delivered can have a huge impact on the experience of both patients and carers. It is therefore important for HCPs to be as skilled and as sensitive as possible when meeting patients and carers to break bad news. Assessment should be made regarding patients’ *and carers’* wishes about the amount and type of information they want, and, if possible, their individual needs in terms of coping styles should be addressed. Carers may benefit from being offered on-going opportunities to talk with HCPs without the patient being present.

Rehabilitation can provide benefit to people living with incurable cancer at all stages of their illness, increasing independence, confidence, hope, coping and physical function (Loughran, Rice and Robinson, 2017). A recent UK retrospective notes review of patients with a diagnosis of mesothelioma found most had symptoms that would benefit from intervention from an Allied Health Professional at diagnosis; the authors recommended offering early rehabilitation as it is key to reducing the impact of such symptoms (Dickinson, Labuc and Bracegirdle, 2021).

The study highlighted how veterans are challenged in recognising, assessing and reporting pain. Veterans should be actively encouraged to report pain levels accurately in terms of this being useful information. Veterans, who may be wary of accessing palliative care and who may under-report symptom severity, could be encouraged to see early rehabilitation as a proactive way to improve their physical performance and retain independence for longer. This would also benefit their carers.

Healthcare professionals should make a point of asking every mesothelioma patient and carer whether they, a member of their family, or the person they care for have served in the UK Armed Forces. The Royal British Legion reported that only 11% of carers in the AF community had been asked this question by services they used (2021). The word ‘veteran’ is not helpful to use in this question as many veterans do not recognise this term as applicable to themselves, or do not like it (Edwards and Wright, 2019). Asking this question could identify more ‘hidden’ female veteran patients and male veteran carers.

The Royal British Legion (2021, p. 37) also reported that carers in the military community “appeared to feel less valued than carers in the general population do” and were feeling “invisible”. Healthcare professionals should aim to help them feel recognised and included. Using language referring to being ‘part of a team’ may be helpful as it aligns with military culture. This may help veteran patients to see the carer as an ally who needs to have relevant information to function well within the team, encouraging communication. Carers from the military community may need to be told how important it is to get their own needs met to support the patient’s well-being. ‘Relationship-centred care’ has been recommended by Taylor et al. (2018) to enhance communication between healthcare staff and patients living with mesothelioma and their family carers. This type of care facilitates everyone involved to experience the “Six Senses” (Taylor *et al.*, 2018, p. 24): Security, Belonging, Continuity, Purpose, Achievement and Significance. I suggest that these six senses align very closely with military values and expectations. Therefore, attending to these aspects of health care could provide a highly supportive environment for military patients with mesothelioma and their carers, protecting them against the negative psychological effects documented in my study. The ‘Continuity’ sense involves ensuring “seamless and consistent” communication (Taylor *et al.*, 2018, p. 24). Having a single point of communication to help navigate the journey would have been welcomed by the participants in my study. Easy access is required to HCPs for carers to obtain advice and reassurance. Lack of such access contributes to “isolation, fear and low confidence in care-giving” (Ream *et al.*, 2021, p. 8).

Carers’ needs may change over the course of the patient’s illness. Ream et al. (2021) reported how the experience of carers for patients undergoing chemotherapy was essentially dynamic: carers may at times be very positive and upbeat and at other times may be at risk of overburden. Therefore, the carer’s needs should be periodically assessed, not only at the beginning of the illness. This assessment would include whether they are managing medical interventions at home, as they may need extra support (Wilson, Caswell and Pollock, 2021) but not ask for help. As part of on-going assessment of their needs, carers’ and patients’ psychological health should be assessed. For those from the military community, attention should be paid to the possibility of existing/newly arising PTSD and of moral injury.

7.10 Recommendations for future research

There are many unanswered questions remaining about the psychological effects of mesothelioma on people living with the disease and their carers, and on veterans and their carers in particular.

The veterans and their carers in my study had mixed experiences of accessing and being supported by counselling services. A specialist counselling service has been set up by HASAG in the UK, offering counselling to people diagnosed with mesothelioma and their loved ones across the South of England, London and the Home Counties, with support also offered to the military community nationwide (HASAG, 2021). Research is needed on access to and the appropriateness of such counselling and other psychological support for those in the military community affected by mesothelioma.

Moral injury has been identified by my study as a serious negative psychological impact on carers for UK veterans with a diagnosis of mesothelioma. Further research is suggested into this aspect of their experience. Research is also needed into possible moral injury arising in veterans and carers affected by other medical conditions caused by service in the Armed Forces, and/or stemming from their interactions with the National Health Service.

My study has demonstrated the reluctance of veteran patients to disclose their levels of pain and distress, and the negative impact this reluctance can have on their carers. Electronic symptom reporting has been trialled recently in the UK for mesothelioma patients (Roma *et al.*, 2020). This could prove especially beneficial for veteran patients by providing a regular, structured, unobtrusive and impersonal way to track symptoms and report them to HCPs. Research exploring the appropriateness and usefulness of such a system for veterans with mesothelioma is suggested.

The needs of carers regarding the breaking of bad news throughout the mesothelioma journey require further investigation (Lelorain, 2021).

My study was unable to recruit participants from outside England and Wales. Further research is needed into the psychological effects of mesothelioma on veteran patients from the British Armed Forces and their carers who live in other regions of the UK and abroad. This may highlight how cultural differences affect their experiences. For example, in Northern Ireland, veterans have high unreported levels of PTSD and may choose to hide their ex-military identity (Armour, McGlinchey and Ross, 2021); Gurkhas who served before 1997 for less than 4 years do not have the right to live in the UK (Home Office, 2021), so are likely to be living in Nepal. As my study only related to veterans of the British Armed Forces, research is recommended into the impact of mesothelioma on veterans and their carers from other countries, as no such studies have been conducted to date.

The importance of physical activity and fitness for the UK military veteran community has been highlighted in my study. My findings showed how carers put aside their own physical health needs and the impact this had on them. Horne et al. (2021) called attention to the lack of research about the barriers and facilitators to UK carers' physical activity in a range of conditions. A recent UK survey of GPs (Spiers *et al.*, 2021, p. 4) found that "carers are at increased risk of illness, and specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function, and poor sleep." Therefore, research into physical fitness and activity levels for carers of people with mesothelioma in the UK is suggested.

My study participants only included one carer for a person with peritoneal mesothelioma. The experience of this dyad was different to that of the dyads where the diagnosis was pleural mesothelioma. In fact, there was a striking similarity to the impact on patients and carers which has been described for *ovarian* cancer - Marie's original misdiagnosis (Tan, Sharpe and Russell, 2021). Possibly research into this similarity would provide benefits for peritoneal patients and their carers via cross-fertilisation of knowledge.

The findings of my study showed how keeping up with the latest developments in mesothelioma treatments and trials could involve a great deal of work and stress for a carer. Kerr et al. (2021, p. 9) pointed out the current lack of knowledge about “how contemporary cancer patients…engage with, take up or repudiate dominant expectations of prediction, personalisation, prevention and participation in this genomics era.” Research is therefore suggested into how patients and carers respond to and are affected psychologically by awareness of and access to the newest advances in mesothelioma clinical research.

7.11 Conclusion

Informal carers have been described as “the hidden patients” (Kristjanson and Aoun, 2004, p. 359). My thesis has shed new light onto the experience of a particular group of carers who had not been represented in their own right in the research literature: carers for UK military veterans with a diagnosis of mesothelioma. This is the first study to have explored the psychological effects of mesothelioma on patients and carers from the carers’ perspective, adding nuance to a sparse body of literature. An interpretative phenomenological approach was chosen for the study as it was appropriate for exploring this experience which had an existential, meaningful dimension for the patients and the carers.

The findings of the secondary data analysis and the main interview study revealed the different ways that the carers and veteran patients were impacted psychologically and how the military context influenced this impact. The participants had high expectations of big organisations and institutions, such as the NHS and the MOD, particularly with respect to efficiency, communication and accountability. The importance of expectations about keeping on going in the face of adversity was highlighted. A reluctance to show perceived weakness and to ask for help had implications for both patients and carers in terms of accessing appropriate and timely support. Communication was a key factor in producing positive or negative psychological effects. Underpinning the experience of the mesothelioma journey were military values regarding efficiency, responsibility, teamwork, service to others and loyalty.

The thesis has shown for the first time the issue of moral injury relating to the interface between the UK military context and the National Health Service and has also applied the term moral injury to the psychological impact of asbestos-related illness on a group of former employees in relation to their employer. It has also added new knowledge on how British military veterans and their carers respond to pain. The thesis has also presented methodological innovation: IPA was used for the first time to explore the experience of mesothelioma and was used in a novel two-stage model where secondary data analysis informed an empirical interview study.

Various implications for practice have been suggested. These include encouraging veterans to view early rehabilitation positively; identifying all veteran patients and carers and using language about teamwork to help them get support; using the Senses Framework and relationship-centred care to help carers feel included and recognised and enhance communication; and regularly assessing carers' and patients' psychological state.

Recommendations have been made for future research including about the experience of counselling for carers and patients with mesothelioma; electronic symptom reporting for veterans with mesothelioma; and moral injury in this new context.

The carrying out of a qualitative study on the psychological effects of mesothelioma has contributed much needed nuance to the limited existing research. My hope is that this will help to develop service delivery for UK military veterans and their carers and to illuminate further areas for research which in time may benefit the whole community of people living with mesothelioma.

References

Abdel-Rahman, O. (2018) ‘Global trends in mortality from malignant mesothelioma: Analysis of WHO mortality database (1994-2013)’, *The Clinical Respiratory Journal*, 12(6), pp. 2090–2100. doi: 10.1111/crj.12778.

Ackroyd, S. and Karlsson, J. (2014) ‘Critical Realism, Research Techniques, and Research Designs’, in Edwards, P. K., O’Mahoney, J., and Vincent, S. (eds) *Studying organizations using critical realism: a practical guide*. Oxford: Oxford University Press, pp. 21–46. doi: 10.1093/acprof:oso/9780199665525.001.0001.

Action on Asbestos (2021) *Armed Forces & Asbestos Compensation*. Available at: https://www.clydesideactiononasbestos.org.uk/compensation-and-benefits/asbestos-related-disease-compensation-and-the-armed-forces (Accessed: 18 June 2021).

Addington-Hall, J. and McPherson, C. (2001) ‘After-Death Interviews with Surrogates/Bereaved Family Members: Some Issues of Validity’, *Journal of Pain and Symptom Management*, 22(3), pp. 784–790. doi: 10.1016/S0885-3924(01)00330-X.

Albertson, K., Taylor, P. and Murray, E. (2019) ‘Place, space and identity: the manifold experience of transition in and after the military’, *Illness, Crisis & Loss*, 27(4), pp. 1–4.

Alexander, S., Pillay, R. and Smith, B. (2018) ‘A systematic review of the experiences of vulnerable people participating in research on sensitive topics’, *International Journal of Nursing Studies*, 88, pp. 85–96. doi: 10.1016/j.ijnurstu.2018.08.013.

Allmark, P. *et al.* (2009) ‘Ethical Issues in the Use of In-Depth Interviews: Literature Review and Discussion’, *Research Ethics*, 5(2), pp. 48–54. doi: 10.1177/174701610900500203.

Altmetric (2021) *Overview of attention for article published in Psycho-oncology, July 2020, Wiley Online Library*. Available at: https://wiley.altmetric.com/details/84955616#twitter-demographics (Accessed: 14 June 2021).

Alves-Costa, F. *et al.* (2021) *Experiences of Intimate Partner Violence and Abuse among Civilian Partners of UK Military Personnel: Perceptions of the Impact of Military Life and Experiences of Help-seeking and Support*. London. Available at: https://s31949.pcdn.co/wp-content/uploads/KCL-FiMT-REPORT-2021-FULL-REPORT-DIGITAL-AW.pdf (Accessed: 30 October 2021).

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders: DSM-5*. 5th edn. Washington D.C.: American Psychiatric Publishing.

Anderson, J. (2021) ‘Clash of Values: Workplace Bullying and Moral Injury’, *Counseling and Family Therapy Scholarship Review*, 3(2), pp. 1–8.

Angood, P. *et al.* (2010) ‘Patient and family involvement in contemporary health care’, *Journal of Patient Safety*, 6(1), pp. 38–42.

Arber, A. and Spencer, L. (2013) ‘“It’s all bad news”: the first 3 months following a diagnosis of malignant pleural mesothelioma’, *Psycho-oncology*, 22(7), pp. 1528–1533. doi: 10.1002/pon.3162.

Archer, M. *et al.* (2016) *What is Critical Realism?* Available at: http://www.asatheory.org/current-newsletter-online/what-is-critical-realism (Accessed: 3 November 2019).

Archibald, M. M. *et al.* (2019) ‘Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants’, *International Journal of Qualitative Methods*, 18, pp. 1–8. doi: 10.1177/1609406919874596.

Arksey, H. and O’Malley, L. (2005) ‘Scoping studies: towards a methodological framework’, *International Journal of Social Research Methodology*, 8(1), pp. 19–32. doi: 10.1080/1364557032000119616.

Armour, C., McGlinchey, E. and Ross, J. (2021) *The Health and Wellbeing of Armed Forces Veterans in Northern Ireland*. Belfast. Available at: https://nivso.org.uk/wp-content/uploads/2021/04/NI-Veterans-Health-Wellbeing-Study-Psychological-Wellbeing-Survey-Report.pdf.

Ashcroft, M. (2014) *The Veterans’ Transition Review*. London. Available at: http://www.veteranstransition.co.uk/vtrreport.pdf (Accessed: 11 November 2019).

Aspers, P. and Corte, U. (2019) ‘What is Qualitative in Qualitative Research’, *Qualitative Sociology*, 42, pp. 139–160.

Atkinson, P. (1997) ‘Narrative turn or blind alley’, *Qualitative Health Research*, 7, pp. 325–344.

Atout, M. *et al.* (2021) ‘The lived experience of family members who care for children with cancer: An interpretative phenomenological approach’, *European Journal of Oncology Nursing*, 52, p. 101978. Available at: https://pubmed.ncbi.nlm.nih.gov/34090147/ (Accessed: 14 October 2021).

Atuel, H. R. and Castro, C. A. (2018) ‘Military Cultural Competence’, *Clinical Social Work Journal*, 46, pp. 74–82.

Baker, C. *et al.* (2016) ‘Encounters with the Military’, *International Feminist Journal of Politics*. Routledge, 18(1), pp. 140–154. doi: 10.1080/14616742.2015.1106102.

Ball, H., Moore, S. and Leary, A. (2016) ‘A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer’, *European Journal of Oncology Nursing*, 25, pp. 62–67. doi: 10.1016/j.ejon.2016.09.007.

Bamberg, M. (2011) ‘“Who am I?” Narration and its contribution to self and identity’, *Theory & Psychology*, 21(1), pp. 3–24. doi: 10.1177/0959354309355852.

Bamberg, M., De Fina, A. and Schiffrin, D. (2011) ‘Discourse and Identity Construction’, in Schwartz, S. J., Luyckx, K., and Vignoles, V. (eds) *Handbook of Identity Theory and Research Volume 1*. New York: Springer, pp. 177–199.

Di Basilio, D., Shigemura, J. and Guglielmucci, F. (2021) ‘Commentary: SARS-CoV-2 and Asbestos Exposure: Can Our Experience With Mesothelioma Patients Help Us Understand the Psychological Consequences of COVID-19 and Develop Interventions?’, *Frontiers in Psychology*, 12, pp. 1–12. doi: 10.3389/FPSYG.2021.720160.

Baxter, P. and Jack, S. (2008) ‘Qualitative case study methodology: study design and implementation for novice researchers’, *The Qualitative Report*, 13(4), pp. 544–559.

Beauchamp, T. and Childress, J. (2001) *Principles of biomedical ethics*. 5th edn. New York: Oxford University Press.

Bennett, M. (2017) ‘Blameless Guilt: The Case of Carer Guilt and Chronic and Terminal Illness’, *International Journal of Philosophical Studies*, 26(1), pp. 72–89. doi: 10.1080/09672559.2017.1416422.

Bentley, B. and O’Connor, M. (2015) ‘Conducting Research Interviews with Bereaved Family Carers: When Do We Ask?’, *Journal of palliative medicine*, 18(3), pp. 241–245. doi: 10.1089/JPM.2014.0320.

Bergeron, S. (2016) ‘Formal, informal and care economies’, in Disch, L. and Hawkesworth, M. (eds) *The Oxford Handbook of Feminist Theory*. New York: Oxford University Press, pp. 179–206.

Bergman, B. P., Burdett, H. J. and Greenberg, N. (2014) ‘Service Life and Beyond – Institution or Culture?’, *The RUSI Journal*, 159(5), pp. 60–68. doi: 10.1080/03071847.2014.969946.

Bergman, B. P., Mackay, D. F. and Pell, J. P. (2021) ‘Suicide among Scottish military veterans: follow-up and trends’, *Occupational and Environmental Medicine*, [preprint]. doi: 10.1136/OEMED-2021-107713.

Bhaskar, R. (1998) ‘General introduction’, in Archer, M. et al. (eds) *Critical realism: essential readings*. Abingdon: Taylor & Francis Group, pp. ix–xxiv.

Bhaskar, R. (2005) *The Possibility of Naturalism*. 3rd edn. London and New York: Routledge.

Bhaskar, R. (2008) *A Realist Theory of Science*. 3rd edn. London and New York: Verso.

Bhaskar, R. (2016) *Enlightened Common Sense: the Philosophy of Critical Realism*. Abingdon: Routledge.

Bhaskar, R. and Lawson, T. (1998) ‘Transcendental realism and science’, in Archer, M. et al. (eds) *Critical realism: essential readings*. Abingdon: Taylor & Francis Group, pp. 3–186.

Bibby, A. *et al.* (2021) ‘The Priorities of People with Mesothelioma: A Qualitative Study of Trial Participation and Treatment Decisions’, *Research Square*, [preprint]. Available at: https://www.researchsquare.com/article/rs-721316/v1 (Accessed: 29 September 2021).

Biggerstaff, D. and Thompson, A. R. (2008) ‘Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research’, *Qualitative Research in Psychology*, 5, pp. 214–224.

Binks, E. and Cambridge, S. (2018) ‘The Transition Experiences of British Military Veterans’, *Political Psychology*, 39(1), pp. 125–142. doi: 10.1111/pops.12399.

Boddy, C. R. (2016) ‘Sample size for qualitative research’, *Qualitative Market Research: An International Journal*, 19(4), pp. 426–432. doi: 10.1108/QMR-06-2016-0053.

Bogdan, R. and Biklin, S. (1998) *Qualitative research for education: an introduction to theory and methods*. 3rd edn. Boston: Allyn and Bacon.

Bonafede, M. *et al.* (2018) ‘The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: A systematic review of published studies’, *American Journal of Industrial Medicine*, 61(5), pp. 400–412. doi: 10.1002/ajim.22831.

Bonafede, M. *et al.* (2020) 'Psychological Distress after a Diagnosis of Malignant Mesothelioma in a Group of Patients and Caregivers at the National Priority Contaminated Site of Casale Monferrato', *International Journal of Environmental Research and Public Health*, 17(12), pp. 1–15. doi: 10.3390/ijerph17124353.

Booth, A., Sutton, A. and Papaioannou, D. (2016) *Systematic approaches to a successful literature review*. 2nd edn. Los Angeles: SAGE Publications Inc.

Bourdieu, P. (1990) *The logic of practice*. Cambridge: Polity Press.

Bowers, B., Pollock, K. and Barclay, S. (2020) 'Administration of end-of-life drugs by family caregivers during covid-19 pandemic', *The BMJ*, 369, p. 1615. doi: 10.1136/bmj.m1615.

Braun, V. *et al.* (2019) 'Thematic Analysis', in Liamputtong, P. (ed.) *Handbook of research methods in health social sciences*. Singapore: Springer Singapore, pp. 843–860. doi: 10.1007/978-981-10-5251-4_103.

Braun, V. and Clarke, V. (2019) 'Reflecting on reflexive thematic analysis', *Qualitative Research in Sport, Exercise and Health*, 11(4), pp. 589–597. doi: 10.1080/2159676X.2019.1628806.

Braun, V. and Clarke, V. (2020a) 'Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches', *Counselling and Psychotherapy Research*, 21(1), pp. 37–47. doi: 10.1002/capr.12360.

Braun, V. and Clarke, V. (2020b) 'One size fits all? What counts as quality practice in (reflexive) thematic analysis?', *Qualitative Research in Psychology*, 18(3), pp. 328–352. doi: 10.1080/14780887.2020.1769238.

Braun, V. and Clarke, V. (2021) *Answers to frequently asked questions about thematic analysis*. Available at: https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html#7f465f88ad64a879655581789558d01 (Accessed: 1 March 2021).

Brett, J. *et al.* (2014) 'Mapping the impact of patient and public involvement on health and social care research: a systematic review', *Health Expectations*, 17(5), pp. 637–650. doi: 10.1111/j.1369-7625.2012.00795.x.

Brewin, C. R., Garnett, R. and Andrews, B. (2011) 'Trauma, identity and mental health in UK military veterans', *Psychological Medicine*, 41(8), pp. 1733–1740. doi: 10.1017/S003329171000231X.

Brewster, L., McWade, B. and Clark, S. J. A. (2021) 'A point of connection? Wellbeing, the veteran identity and older adults', *Ageing & Society*, 41(9), pp. 1984–2005. doi: 10.1017/S0144686X20000161.

Brims, F. J. H. (2009) 'Asbestos – a legacy and a persistent problem', *Journal of the Royal Naval Medical Service*, 95(1), pp. 4–11.

British Army, The (2020) *Army Core Values*. Available at: https://apply.army.mod.uk/what-we-offer/what-we-stand-for (Accessed: 19 June 2020).

Brock, R. (2011) *How Do We Repair the Souls of Those Returning from Iraq?*, *Huffpost Communities*. Available at: https://www.huffpost.com/entry/the-war-is-coming-home-so_b_1027499 (Accessed: 1 November 2021).

Broderick, F., Deignan, T. and Combes, H. (2017) ‘An exploratory study into the traumatic impact of advanced cancer among patients and partners’, *Operant Subjectivity: the International Journal of Q Methodology*, 39, pp. 1–24.

Bulmer, S. and Eichler, M. (2017) ‘Unmaking militarized masculinity: Veterans and the project of military-to-civilian transition’, *Critical Military Studies*, 3(2), pp. 161–181. doi: 10.1080/23337486.2017.1320055.

Bulmer, S. and Jackson, D. (2016) ‘“You do not live in my skin”: embodiment, voice, and the veteran’, *Critical Military Studies*, 2(1–2), pp. 25–40.

Burdett, H. *et al.* (2013) ‘“Are You a Veteran?” Understanding of the Term "Veteran” among UK Ex-Service Personnel: A Research Note’, *Armed Forces & Society*, 39(4), pp. 751–759. doi: 10.1177/0095327X12452033.

Burnell, K., Crossland, J. and Greenberg, N. (2017) ‘The health and social care of older veterans in the UK: Raising awareness of needs in later life’, in Hughes, J. H. (ed.) *Military Veteran Mental Health and Social Care: Contemporary Perspectives*. Abingdon: Routledge, pp. 81–95. doi: 10.4324/9781315195117.

Burnell, K., Needs, A. and Gordon, K. (2017) ‘Exploring the suitability and acceptability of peer support for older veterans’, *Quality in Ageing and Older Adults*, 18(2), pp. 120–130. doi: 10.1108/QAOA-09-2016-0036.

Caddick, N. *et al.* (2020) ‘Hierarchies of wounding: Media framings of “combat” and “non-combat” injury’, *Media, War & Conflict*, 14(4), pp. 503–521. doi: 10.1177/1750635219899110.

Cancer Research UK (2021) *Mesothelioma incidence statistics*. Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/mesothelioma/incidence#heading-One (Accessed: 23 June 2021).

Canetto, S. S. (2017) ‘Suicide: Why Are Older Men So Vulnerable?’, *Men and Masculinities*, 20(1), pp. 49–70. doi: 10.1177/1097184X15613832.

Careers Research and Advisory Centre (2011) *The Vitae Researcher Development Framework*. Available at: https://www.vitae.ac.uk/researchers-professional-development/about-the-vitae-researcher-development-framework/developing-the-vitae-researcher-development-framework (Accessed: 15 November 2021).

Carel, H. (2016) *Phenomenology of Illness*. Oxford: Oxford University Press. doi: 10.1093/acprof:oso/9780199669653.001.0001.

Carroll, K. (2013) ‘Infertile? The emotional labour of sensitive and feminist research methodologies’, *Qualitative Research*, 13(5), pp. 546–561. doi: 10.1177/1468794112455039.

Carter, S. M. *et al.* (2008) ‘You Have to Make Something of All That Rubbish, Do You? An Empirical Investigation of the Social Process of Qualitative Research’, *Qualitative Health Research*, 18(9), pp. 1264–1276. doi: 10.1177/1049732308321753.

Carter, S. M. and Little, M. (2007) ‘Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research’, *Qualitative Health Research*, 17(10), pp. 1316–328.

Čartolovni, A. *et al.* (2021) 'Moral injury in healthcare professionals: A scoping review and discussion', *Nursing Ethics*, 28(5), pp. 590–602. doi: 10.1177/0969733020966776.

Casellas-Grau, A., Ochoa, C. and Ruini, C. (2017) 'Psychological and clinical correlates of posttraumatic growth in cancer: A systematic and critical review', *Psycho-oncology*, 26(12), pp. 2007–2018. doi: 10.1002/pon.4426.

Catignani, S. and Basham, V. M. (2021) 'The gendered politics of researching military policy in the age of the "knowledge economy"', *Review of International Studies*, 47(2), pp. 211–230. doi: 10.1017/S0260210521000036.

Charity Commission for England and Wales (2017) *Military charities: group case report*. London. Available at: https://www.gov.uk/government/publications/military-charities-group-case-report/military-charities-group-case-report.

Charmaz, K., Thornberg, R. and Keane, E. (2018) 'Evolving Grounded Theory and social justice inquiry', in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks: SAGE Publications Inc, pp. 411–443.

Chase, S. E. (2011) 'Narrative Inquiry: Still a field in the making', in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 4th edn. Thousand Oaks, CA: SAGE Publications Inc, pp. 421–434.

Chase, S. E. (2018) 'Narrative Inquiry: toward theoretical and methodological maturity', in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks: SAGE Publications Inc, pp. 546–560.

Chauvette, A., Schick-Makaroff, K. and Molzahn, A. E. (2019) 'Open Data in Qualitative Research', *International Journal of Qualitative Methods*, 18, pp. 1–6. doi: 10.1177/1609406918823863.

De Chesnay, M. and Banner, D. (2015) *Nursing research using grounded theory : qualitative designs and methods*. New York: Springer Publishing Company.

Chilisa, B. and Kawulich, B. (2012) 'Selecting a research approach: Paradigm, methodology and methods', in Wagner, C., Kawulich, B., and Garner, M. (eds) *Doing social research: A global context*. New York: McGraw Hill, pp. 51–61.

Clarke, V. and Braun, V. (2018) 'Feminist qualitative methods and methodologies in psychology: A review and reflection', *Psychology of Women & Equalities Section Review*, 2(1), pp. 13–28.

Clayson, H., Seymour, J. and Noble, B. (2005) 'Mesothelioma from the patient's perspective', *Hematology/Oncology Clinics of North America*, 19(6), pp. 1175–90. doi: 10.1016/j.hoc.2005.09.003.

Colaizzi, P. (1978) 'Psychological research as the phenomenologist views it', in Valle, R. and King, M. (eds) *Existential phenomenological alternatives for psychology*. New York: Oxford University Press, pp. 48–71.

Colarusso, G. *et al.* (2019) 'The role of immunotherapy in mesothelioma', *Precision Cancer Medicine*, 2(21), pp. 1–10.

Collins, C. and Cooper, J. (2014) 'Emotional Intelligence and the Qualitative Researcher', *International Journal of Qualitative Methods*, 13(1), pp. 88–103.

Cooper, L. *et al.* (2017) ‘A model of military to civilian transition: Bourdieu in action’, *Journal of Military, Veteran and Family Health*, 3(2), pp. 53–60.

Cooper, L. *et al.* (2018) ‘Transition From the Military Into Civilian Life: An Exploration of Cultural Competence’, *Armed Forces & Society*, 44(1), pp. 156–177. doi: 10.1177/0095327X16675965.

Cresswell, J. (2003) *Research design: qualitative, quantitative and mixed methods approaches*. Thousand Oaks, CA: SAGE Publications Inc.

Creswell, J. and Poth, C. (2017) *Qualitative Inquiry and Research Design*. 4th edn. Thousand Oaks, CA: SAGE Publications Inc.

Critical Appraisal Skills Programme (2021) *CASP Checklists - CASP - Critical Appraisal Skills Programme*. Available at: https://casp-uk.net/casp-tools-checklists/ (Accessed: 14 February 2020).

Cronin, C. J. and Lowes, J. (2016) ‘Brief encounters with qualitative methods in health research: Phenomenology and interpretative phenomenological analysis’, *Cumbria Partnership Journal of Research Practice and Learning*, 5(1), pp. 8–12.

Crowe, S. *et al.* (2011) ‘The case study approach’, *BMC Medical Research Methodology*, 11(1), pp. 1–9. doi: 10.1186/1471-2288-11-100.

Cunningham, S. C. *et al.* (2020) ‘Influence of psychosocial distress on traumatic stress symptoms among oncology patients in clinical trials’, *Journal of Psychosocial Oncology Research & Practice*, 2(2), p. e21. doi: 10.1097/OR9.0000000000000021.

D’Agostino, R. and Wilson, R. (1999) ‘Asbestos: the hazard, the risk, and public policy’, in Foster, K., Bernstein, D., and Huber, P. (eds) *Phantom Risk: Scientific Inference and the Law*. Cambridge, MA: MIT Press Ltd, pp. 183–209.

Dahlberg, H. and Dahlberg, K. (2020) ‘Open and Reflective Lifeworld Research: A Third Way’, *Qualitative Inquiry*, 26(5), pp. 458–464. doi: 10.1177/1077800419836696.

Dannatt, R. (2016) *Boots on the Ground: Britain and her Army since 1945*. London: Profile Books.

Daudt, H. M. L., Van Mossel, C. and Scott, S. J. (2013) ‘Enhancing the scoping study methodology: A large, inter-professional team’s experience with Arksey and O’Malley’s framework’, *BMC Medical Research Methodology*, pp. 48–57. doi: 10.1186/1471-2288-13-48.

Davis, J. (2002) ‘Narrative and social movements: the power of stories’, in Davis, J. (ed.) *Stories of change: Narrative and Social Movements*. New York: State University of New York Press, pp. 3–29.

Davison, E. H. *et al.* (2016) ‘From Late-Onset Stress Symptomatology to Later-Adulthood Trauma Reengagement in Aging Combat Veterans: Taking a Broader View’, *The Gerontologist*, 56(1), pp. 14–21. doi: 10.1093/geront/gnv097.

Deakin, S. (2016) ‘Education in an Ethos at the Royal Military Academy Sandhurst’, in Robinson, P., De Lee, N., and Carrick, D. (eds) *Ethics Education in the Military*. Abingdon: Routledge, pp. 29–44. doi: 10.4324/9781315256078-10.

Denke, L. and Barnes, D. M. (2013) ‘An ethnography of chronic pain in veteran enlisted women’, *Pain Management Nursing*, 14(4), pp. e189–e195. doi: 10.1016/J.PMN.2011.10.004.

Denzin, N. K. and Lincoln, Y. S. (2018) ‘Introduction’, in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE Handbook of qualitative research*. 5th edn. Los Angeles: SAGE Publications Inc.

Department of Health (2016) *Care and support statutory guidance issued under the Care Act 2014*. 2nd edn. London: The Stationery Office.

DeVault, M. L. and Gross, G. (2012) ‘Feminist Qualitative Interviewing: Experience, Talk, and Knowledge’, in Hesse-Biber, S. N. (ed.) *Handbook of Feminist Research: Theory and Praxis*. 2nd edn. Thousand Oaks, CA: SAGE Publications Inc.

Dickinson, F., Labuc, P. and Bracegirdle, R. (2021) ‘Symptom Burden and Referral to Allied Health Professionals at time of Diagnosis for Patients with Malignant Pleural Mesothelioma’, *Journal of Thoracic Oncology*, 16(3), p. S391.

Dodds, C. D. and Kiernan, M. D. (2019) ‘Hidden Veterans: A Review of the Literature on Women Veterans in Contemporary Society’, *Illness, Crisis & Loss*, 27(4), pp. 293-310. doi: 10.1177/1054137319834775.

Dodgson, J. (2019) ‘Reflexivity in qualitative research’, *Journal of Human Lactation*, 35(2), pp. 220–222.

Dodson, A. (2020) *Biff! A Personal Reflection on Supporting the Wounded, Injured and Sick*. Available at: https://thearmyleader.co.uk/wounded-injured-and-sick/ (Accessed: 8 January 2021).

Doherty, R., Cole, S. and Robson, A. (2019) *Focus on: armed forces charities’ housing provision*. London. Available at: https://www.scie-socialcareonline.org.uk/focus-on-armed-forces-charities-housing-provision/r/a110f00000TDBXgAAP.

Dooley, J. J., Wilson, J. P. and Anderson, V. A. (2010) ‘Stress and depression of facing death: Investigation of psychological symptoms in patients with mesothelioma’, *Australian Journal of Psychology*, 62(3), pp. 160–168.

Douglas, T. and Van Den Borre, L. (2019) ‘Asbestos neglect: Why asbestos exposure deserves greater policy attention’, *Health policy*, 123(5), pp. 516–519. doi: 10.1016/j.healthpol.2019.02.001.

Eatough, V. and Smith, J. A. (2017) ‘Interpretative Phenomenological Analysis’, in Willig, C. and Stainton-Rogers, W. (eds) *The SAGE Handbook of Qualitative Psychology*. 2nd edn. London: Sage Publications, pp. 179–194.

Edwards, P. and Wright, T. (2019) *No Man’s Land*. Dudley. Available at: https://www.forward-assist.com/salute-her-research (Accessed: 28 October 2020).

Eichler, M. (2017) ‘Add female veterans and stir? a feminist perspective on gendering veterans research’, *Armed Forces & Society*, 43(4), pp. 674–694.

Eifert, E. K. *et al.* (2015) ‘Family Caregiver Identity: A Literature Review’, *American Journal of Health Education*, 46(6), pp. 357–367. doi: 10.1080/19325037.2015.1099482.

Ejegi-Memeh, S., Darlison, L., *et al.* (2020) ‘Living with mesothelioma: a qualitative study of the experiences of male military veterans in the UK’, *European Journal of Oncology Nursing*, 50, p. 101889. doi: 10.1016/j.ejon.2020.101889.

Ejegi-Memeh, S., Taylor, B., *et al.* (2020) *Military Experience of Mesothelioma Study (MiMES) - Mesothelioma UK*. Sheffield. Available at: https://www.mesothelioma.uk.com/wp-content/uploads/dlm_uploads/2021/02/MiMES_Report_FINAL.pdf.

Ejegi-Memeh, S. *et al.* (2021) ‘Patients’ and informal carers’ experience of living with mesothelioma: a systematic rapid review and synthesis of the literature’, *manuscript under review*.

Engward, H., Fleuty, K. and Fossey, M. (2018) *Blesma Families Study*. London. Available at: https://aru.ac.uk/veterans-and-families-institute/blesma-families (Accessed: 7 September 2020).

Erickson, F. (2018) ‘A history of qualitative inquiry in social and educational research’, in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks, CA: SAGE Publications Inc, pp. 36–65.

Erikson, E. H. (1994) *Identity and the life cycle*. New York: W.W. Norton & Company.

Faretta, E. and Civilotti, C. (2016) ‘EMDR therapy in psycho-oncology: A bridge between mind and body’, *Journal of EMDR Practice and Research*, 10(3), pp. 138–152.

Farr, J. and Nizza, I. E. (2019) ‘Longitudinal Interpretative Phenomenological Analysis (LIPA): A review of studies and methodological considerations’, *Qualitative Research in Psychology*, 16(2), pp. 199–217. doi: 10.1080/14780887.2018.1540677.

Feldman, D. B. and Periyakoil, V. S. (2006) ‘Posttraumatic stress disorder at the end of life’, *Journal of palliative medicine*, 9(1), pp. 213–218. doi: 10.1089/jpm.2006.9.213.

Feltham, C. and Horton, I. (2006) ‘Therapeutic skills and clinical practice’, in Feltham, C. and Horton, I. (eds) *The SAGE Handbook of Counselling and Psychotherapy*. 2nd edn. London: SAGE Publications Ltd, pp. 73–153.

Fernandez, A. V. (2020) ‘Embodiment and Objectification in Illness and Health Care: Taking Phenomenology from Theory to Practice’, *Journal of Clinical Nursing*, 29(21–22), pp. 4403–4412. doi: 10.1111/jocn.15431.

Fimiani, R. *et al.* (2021) ‘Survivor guilt: Theoretical, empirical, and clinical features’, *International Forum of Psychoanalysis*, 30(3). doi: 10.1080/0803706X.2021.1941246.

Finlay, L. (2009) ‘Debating phenomenological research methods’, *Phenomenology and Practice*, 3(1), pp. 6–25.

Finlay, L. (2015) ‘Qualitative methods’, in Vossler, A. and Moller, N. (eds) *The Counselling and Psychotherapy Research Handbook*. Thousand Oaks, CA: SAGE Publications Inc, pp. 164–182.

Finnegan, A., Jackson, R. and Simpson, R. (2018) ‘Finding the Forgotten: Motivating Military Veterans to Register with a Primary Healthcare Practice’, *Military medicine*, 183(11–12), p. e509. doi: 10.1093/milmed/usy086.

Finnegan, A. P. *et al.* (2020) ‘Educating nurses to deliver optimum care to military veterans and their families', *Nurse Education in Practice*, 42, p. 102654. doi: 10.1016/J.NEPR.2019.102654.

Fox, J. and Diab, P. (2013) 'An exploration of the perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an Eating Disorders Unit: An Interpretative Phenomenological Analysis (IPA) study', *Journal of Health Psychology*, 20(1), pp. 27–36.

Frank, A. W. (2010) 'In defence of narrative exceptionalism', *Sociology of Health & Illness*, 32(4), pp. 665–667. doi: 10.1111/j.1467-9566.2010.01240_3.x.

Freeman, L. (2018) 'Introduction: feminist phenomenology, medicine, bioethics, and health', *International Journal of Feminist Approaches to Bioethics*, 11(2), pp. 1–13.

Freudenberger, D. C. and Shah, R. D. (2021) 'A narrative review of the health disparities associated with malignant pleural mesothelioma', *Journal of Thoracic Disease*, 13(6), p. 3809. doi: 10.21037/JTD-20-3516.

Frondigoun, L. *et al.* (2021) *The Unforgotten Forces Project Final Report: An Evaluation of Support for Older Veterans in Scotland*. Glasgow. Available at: https://www.vfrhub.com/wp-content/uploads/2021/05/UF-Final-Report-Colour-2021.pdf (Accessed: 14 October 2021).

Furuya, S. *et al.* (2018) 'Global Asbestos Disaster', *International Journal of Environmental Research and Public Health*, 15(5), pp. 1000–1011. doi: 10.3390/ijerph15051000.

Gadamer, H. (1990) *Truth and Method*. 2nd edn. New York: Crossroad.

Gieseler, F. *et al.* (2018) 'Cancer Diagnosis: A Trauma for Patients and Doctors Alike', *Oncologist*, 23(7), pp. 752–754. doi: 10.1634/theoncologist.2017-0478.

Gilligan, C. (1982) *In a different voice : psychological theory and women's development*. Cambridge, Mass.: Harvard University Press.

Giorgi, A. (2012) 'The Descriptive Phenomenological Psychological Method', *Journal of phenomenological psychology*, 43(1), pp. 3–12.

Girgis, S. *et al.* (2019) '"It sort of hit me like a baseball bat between the eyes": a qualitative study of the psychosocial experiences of mesothelioma patients and carers', *Supportive Care in Cancer*, 27(2), pp. 631–638. doi: 10.1007/s00520-018-4357-0.

Glaser, B. G. and Strauss, A. (1966) *Awareness of dying*, *Weidenfeld and Nicolson*. London.

Glaser, B. and Holton, J. (2004) 'Remodeling Grounded Theory', *Qualitative Marketing, Media and Opinion Research*, 5(2), pp. 1–23.

Glaser, S., Knowles, K. and Damaskos, P. (2019) 'Survivor guilt in cancer survivorship', *Social Work in Health Care*, 58(8), pp. 764–775. doi: 10.1080/00981389.2019.1640337.

Godier-Mcbard, L., Gillin, N. and Fossey, M. (2021) *We also served - the health and well-being of female veterans in the UK*. Cambridge. Available at: https://www.vfrhub.com/wp-content/uploads/2021/06/WeAlsoServed_Electronic.pdf (Accessed: 22 June 2021).

Godier-McBard, L. R. *et al.* (2021) 'Gender differences in barriers to mental healthcare for UK military veterans: a preliminary investigation', *BMJ Military Health*, [preprint]. doi: 10.1136/BMJMILITARY-2020-001754.

Golsteijn, C. and Wright, S. (2013) 'Using narrative research and portraiture to inform design research', in Kotzé, P. et al. (eds) *Human-Computer Interaction – INTERACT 2013*. Berlin/Heidelberg: Springer, Berlin, Heidelberg, pp. 298–315. doi: 10.1007/978-3-642-40477-1_19.

Gonzalez, J. A. and Simpson, J. (2021) 'The workplace integration of veterans: Applying diversity and fit perspectives', *Human Resource Management Review*, 31(2), p. 100775. doi: 10.1016/J.HRMR.2020.100775.

Goswami, E. *et al.* (2013) 'Domestic Asbestos Exposure: A Review of Epidemiologic and Exposure Data', *International Journal of Environmental Research and Public Health*, 10(11), pp. 5629–5670.

Granieri, A. *et al.* (2020) 'SARS-CoV-2 and Asbestos Exposure: Can Our Experience With Mesothelioma Patients Help Us Understand the Psychological Consequences of COVID-19 and Develop Interventions?', *Frontiers in psychology*, 11, p. 584320. doi: 10.3389/fpsyg.2020.584320.

Grant, M. J. and Booth, A. (2009) 'A typology of reviews: an analysis of 14 review types and associated methodologies', *Health information and libraries journal*, 26(2), pp. 91–108. doi: 10.1111/j.1471-1842.2009.00848.x.

Gray, H. (2017) 'Domestic Abuse and the Reproduction of the Idealised "Military Wife"', in Woodward, R. and Duncanson, C. (eds) *The Palgrave International Handbook of Gender and the Military*. London: Palgrave Macmillan, pp. 227–240. doi: 10.1057/978-1-137-51677-0_14.

Grimell, J. (2019) 'Leaving Military Service with a Military Body: Insights for Pastoral Care and Counseling', *The journal of pastoral care & counseling*, 73(2), pp. 106–114. doi: 10.1177/1542305019848436.

Guglielmucci, F., Bonafede, M., *et al.* (2018) 'Research and malignant mesothelioma: lines of action for clinical psychology', *Annali dell'Istituto superiore di sanità*, 54(2), pp. 149–159. doi: 10.4415/ann_18_02_11.

Guglielmucci, F., Franzoi, I. G., *et al.* (2018) '"The less I think about it, the better I feel": A thematic analysis of the subjective experience of Malignant Mesothelioma patients and their caregivers', *Frontiers in Psychology*, 9, p. 205. doi: 10.3389/fpsyg.2018.00205.

Guité-Verret, A. and Vachon, M. (2021) 'The incurable metastatic breast cancer experience through metaphors: the fight and the unveiling', *International Journal of Qualitative Studies on Health and Well-being*, 16(1), pp. 1–14. doi: 10.1080/17482631.2021.1971597.

de Haan, S. (2020) 'An enactive approach to psychiatry', *Philosophy, Psychiatry & Psychology*, 27(1), pp. 3–25.

Habib, A. *et al.* (2018) 'Post-traumatic growth in (ex-) military personnel: review and qualitative synthesis', *Occupational Medicine*, 68(9), pp. 617–625. doi: 10.1093/occmed/kqy140.

Hadjittofi, M., Gleeson, K. and Arber, A. (2021) 'The experience of disgust by nursing and midwifery students: An interpretative phenomenological approach study', *Nursing Inquiry*, 110, p. 103720. doi: 10.1111/NIN.12427.

Hai, B. *et al.* (2012) 'Diagnosis and prognosis of malignant mesothelioma of the tunica vaginalis testis', *Canadian Urological Association Journal*, 6, pp. E238–E241. doi:

10.5489/cuaj.10200.

Haigh, F. *et al.* (2019) ‘Developing a critical realist informed framework to explain how the human rights and social determinants of health relationship works’, *BMC Public Health*, 19(1), pp. 1571–1583. doi: 10.1186/s12889-019-7760-7.

Hakim, C. (1982) *Secondary analysis in social research : a guide to data sources and methods with examples*. London: Allen & Unwin.

Halling, S. (2020) ‘Phenomenology as fidelity to phenomena: Moving beyond the Van Manen, Smith, and Zahavi debate’, *The Humanistic Psychologist*, 49(2), pp. 342–353. doi: http://dx.doi.org/10.1037/hum0000195.

Halvorson, A. (2010) *Understanding the Military: The Institution, the Culture, and the People*. Rockville. Available at: https://www.samhsa.gov/sites/default/files/military_white_paper_final.pdf (Accessed: 20 September 2021).

Hammersley, M. (2007) ‘The issue of quality in qualitative research’, *International Journal of Research & Method in Education*, 30(3), pp. 287–305. doi: 10.1080/17437270701614782.

Hammersley, M. (2018) ‘What is ethnography? Can it survive? Should it?’, *Ethnography and Education*. Routledge, 13(1), pp. 1–17. doi: 10.1080/17457823.2017.1298458.

Hanley, T., Jordan, C. and Wilk, C. (2015) ‘Planning your research: design, method and sample’, in Vossler, A. and Moller, N. (eds) *The Counselling and Psychotherapy Research Handbook*. Thousand Oaks, CA: SAGE Publications Inc, pp. 88–100.

Hannes, K. and Bennett, S. (2017) ‘Understanding evidence from qualitative research’, in Hoffman, T., Bennett, S., and Del Mar, C. (eds) *Evidence-Based Practice Across the Health Professions*. 3rd edn. Melbourne: Elsevier Australia, pp. 226–247.

Harding, N. and Kostera, M. (2021) ‘Doing Ethnography: introduction’, in Harding, N. and Kostera, M. (eds) *Organizational Ethnography*. Cheltenham: Edward Elgar Pulishing Limited, pp. 1–17.

Harries, P. G. (1971) ‘Asbestos Dust Concentrations in Ship Repairing: A Practical Approach to Improving Asbestos Hygiene in Naval Dockyards’, *The Annals of Occupational Hygiene*, 4(3), pp. 241–254.

Harrison, M. *et al.* (2021) ‘Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review’, *Palliative Medicine*, 35(6), pp. 1039–1051.

Harrison, M., Darlison, L. and Gardiner, C. (2021) ‘A qualitative study exploring the experiences of end of life care for patients with mesothelioma from the perspective of bereaved family caregivers in the UK’, *manuscript under review*.

Hart, C. (2018) *Doing a literature review : releasing the research imagination*. 2nd edn. London: SAGE Publications.

HASAG (2021) *Free Asbestos & Mesothelioma Counselling Service - HASAG*. Available at: https://hasag.co.uk/support/counselling-service/ (Accessed: 26 October 2021).

Hawkesworth, M. and Disch, L. (2016) ‘Feminist Theory: Transforming the Known World’, in

Disch, L. and Hawkesworth, M. (eds) *The Oxford Handbook of Feminist Theory*. Oxford: Oxford University Press, pp. 1–15.

Haydon, G., Browne, G. and Van Der Riet, P. (2018) ‘Narrative Inquiry as a Research Methodology: Exploring Person Centred Care in Nursing’, *Collegian (Royal College of Nursing, Australia)*, 25(1), pp. 125–29.

Health and Safety Executive (2012) *Control of Asbestos Regulations 2012*. Available at: https://www.hse.gov.uk/asbestos/regulations.htm (Accessed: 18 June 2021).

Health and Safety Executive (2018) *Mesothelioma in Great Britain*. London. Available at: www.hse.gov.uk/statistics/tables/meso03.xlsx (Accessed: 14 February 2020).

Health and Safety Executive (2020) *Mesothelioma statistics for Great Britain, 2020*. Available at: www.hse.gov.uk/statistics/tables/meso03.xlsx (Accessed: 1 March 2021).

Health and Safety Executive (2021) *Asbestos - FAQs*. Available at: https://www.hse.gov.uk/asbestos/faq.htm (Accessed: 18 June 2021).

Heidegger, M. (1962) *Being and Time*. Oxford: Blackwell.

Heinonen, E. and Nissen-Lie, H. (2020) ‘The professional and personal characteristics of effective psychotherapists: a systematic review’, *Psychotherapy Research*, 30(4), pp. 417–432.

Henshall, C. *et al.* (2021) ‘Recommendations for improving follow-up care for patients with mesothelioma: a qualitative study comprising documentary analysis, interviews and consultation meetings’, *BMJ Open*, 11(1), p. e040679. doi: 10.1136/bmjopen-2020-040679.

Henson, K. E. *et al.* (2019) ‘Risk of suicide after cancer diagnosis in England’, *JAMA Psychiatry*, 76(1), pp. 51–60.

Higate, P. *et al.* (2019) ‘Militarization, stigma, and resistance: negotiating military reservist identity in the civilian workplace’, *Critical Military Studies*, pp. 1–19. doi: 10.1080/23337486.2018.1554941.

Hitch, C. M. *et al.* (2020) ‘How Army Veterans Cope with Chronic Pain: A Grounded Theory Approach’, *Journal of Veterans Studies*, 6(1), pp. 122–134. doi: 10.21061/JVS.V6I1.125.

Hockey, J. (2012) ‘On patrol: The embodied phenomenology of infantry’, in McSorley, K. (ed.) *War and the Body: Militarisation, Practice and Experience*. London: Routledge, pp. 92–105.

Hodgson, T. and Carey, L. (2017) ‘Moral Injury and Definitional Clarity: Betrayal, Spirituality and the Role of Chaplains’, *Journal of religion and health*, 56(4), pp. 1212–1228. doi: 10.1007/S10943-017-0407-Z.

Home Office (2021) *Gurkhas discharged before 1 July 1997 and their family members*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/750344/persons-seeking-settlements-on-discharge-gurkhas-v2.0ext.pdf (Accessed: 25 October 2021).

Hoon, S. N. *et al.* (2021) ‘Symptom Burden and Unmet Needs in Malignant Pleural Mesothelioma: Exploratory Analyses From the RESPECT-Meso Study’, *Journal of Palliative*

Care, 36(2), pp. 113–120. doi: 10.1177/0825859720948975.

Horne, J. *et al.* (2021) ‘A Systematic Review on the Prevalence of Physical Activity, and Barriers and Facilitators to Physical Activity, in Informal Carers in the United Kingdom’, *Journal of Physical Activity and Health*, 18(2), pp. 212–218. doi: 10.1123/JPAH.2020-0526.

Huang, X., Lin, J. and Demner-Fushman, D. (2006) ‘Evaluation of PICO as a Knowledge Representation for Clinical Questions’, in *AMIA Annual Symposium*. Washington, DC, pp. 359–363.

Hughes, N. and Arber, A. (2008) ‘The lived experience of patients with pleural mesothelioma’, *International Journal of Palliative Nursing*, 14(2), pp. 66–71.

Hulbert-Williams, N. *et al.* (2021) ‘Evaluating the impact of COVID-19 on supportive care needs, psychological distress and quality of life in UK cancer survivors and their support network’, *European Journal of Cancer Care*, 30(5), p. e13442. doi: 10.1111/ECC.13442.

Hunt, E. J. F. *et al.* (2014) ‘The mental health of the UK Armed Forces: where facts meet fiction’, *European journal of psychotraumatology*, 5(1), p. 23617. doi: 10.3402/ejpt.v5.23617.

Husserl, E. (1970) *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy*. Evanston, IL: Northwestern University Press.

Husserl, E. (2001) *Logical Investigations I-II*. London: Routledge.

Hynes, C. and Thomas, M. (2016) *What does the literature say about the needs of veterans in the areas of health?* Available at: http://usir.salford.ac.uk/id/eprint/40047/8/tablesfinalvs4.pdf:public (Accessed: 16 November 2021).

Hynson, J. *et al.* (2006) ‘Research with bereaved parents: a question of how not why’, *Palliative Medicine*, 20, pp. 805–811.

Institute for Government (2021) *Timeline of UK coronavirus lockdowns, March 2020 to March 2021*. Available at: https://www.instituteforgovernment.org.uk/sites/default/files/timeline-lockdown-web.pdf (Accessed: 23 August 2021).

Jahn, A. L. *et al.* (2012) ‘Distress and Resilience After Cancer in Veterans’, *Research in Human Development*, 9(3), pp. 229–247. doi: 10.1080/15427609.2012.705555.

Johnson, A., Ames, K. and Lawson, C. (2021) ‘Archetype Profiles of Military Spouses in Australia – Identifying Perfect Partners and Mean Girls’, *Armed Forces & Society*. doi: 10.1177/0095327X211029318.

Johnstone, L. and Boyle, M. (2018) ‘The Power Threat Meaning Framework: An Alternative Nondiagnostic Conceptual System’, *Journal of Humanistic Psychology*, 58. doi: 10.1177/0022167818793289.

Judd, R., Guy, H. and Howard, R. A. (2019) ‘Caring for a dying partner: The male experience’, *Journal of Palliative Care*, 34(1), pp. 5–11. doi: 10.1177/0825859718774679.

Kaplan, A. (1964) *The conduct of enquiry: methodology for behavioral science*. San Francisco: Chandler.

Karp, D. (1996) *Speaking of sadness. Depression, disconnection and the meaning of illness*. New York: Oxford University Press.

Kasai, Y. and Hino, O. (2018) ‘Psychological Transition Characteristics of Patients Diagnosed with Asbestos-Related Mesothelioma’, *Juntendo Medical Journal*, 64(2), pp. 114–121. doi: 10.14789/jmj.2018.64.JMJ17-OA09.

Keeling, M., Woodhead, C. and Fear, N. T. (2016) ‘Interpretative Phenomenological Analysis of Soldiers’ Experiences of Being Married and Serving in the British Army’, *Marriage & Family Review*, 52(6), pp. 511–534. doi: 10.1080/01494929.2015.1124353.

Kember, L. (2014) *Helping Caregivers Cope with Feelings of Guilt*. Available at: https://www.asbestos.com/blog/2014/04/11/coping-with-guilt/ (Accessed: 15 November 2021).

Kennedy, B. M. *et al.* (2017) ‘Healthcare Providers versus Patients’ Understanding of Health Beliefs and Values’, *Patient experience journal*, 4(3), pp. 29–37. Available at: /pmc/articles/PMC5751953/ (Accessed: 14 October 2021).

Kenny, K. *et al.* (2020) ‘Reciprocity, Autonomy, and Vulnerability in Men’s Experiences of Informal Cancer Care’, *Qualitative health research*, 30(4), pp. 491–503. doi: 10.1177/1049732319855962.

Kerr, A. *et al.* (2021) ‘Exploring personalised cancer medicine’, in Kerr, A. et al. (eds) *Personalised Cancer Medicine*. Manchester: Manchester University Press, pp. 1–21.

Khan, K. *et al.* (2021) ‘Assessing Supportive Care Needs in a Highly Specialized Mesothelioma Surgical Treatment Program’, *American Journal of Respiratory Critical Care Medicine*, 203, p. A4761. doi: 10.1164/AJRCCM-CONFERENCE.2021.203.1_MEETINGABSTRACTS.A4761.

Kidder, L. H. and Fine, M. (1987) ‘Qualitative and quantitative methods: When stories converge’, *New Directions for Program Evaluation*, 1987(35), pp. 57–75. doi: 10.1002/ev.1459.

King, A. (2004) *The Ethos of the Royal Marines: The Precise Application of Will*. Available at: https://ore.exeter.ac.uk/repository/bitstream/handle/10036/58653/RMethos4.pdf (Accessed: 19 June 2020).

Kirby, E. R. *et al.* (2020) ‘Responses to a cancer diagnosis: a qualitative patient-centred interview study’, *Supportive Care in Cancer*, 28, pp. 229–238. doi: 10.1007/s00520-019-04796-z.

Kirkham, J., Smith, J. A. and Havsteen-Franklin, D. (2015) ‘Painting Pain: An Interpretative Phenomenological Analysis of Representations of Living With Chronic Pain’, *Health Psychology*, 34(4), pp. 398 – 406.

Kirksey, E. and Helmreich, S. (2010) ‘The emergence of multispecies ethnography’, *Cultural Anthropology*, 25(4), pp. 545–576. doi: 10.1111/j.1548-1360.2010.01069.x.

Kitchen, V. (2018) ‘Veterans and military masculinity in popular romance fiction’, *Critical Military Studies*, 4(1), pp. 34–51. doi: 10.1080/23337486.2016.1235761.

Køster, A. and Fernandez, A. V. (2021) ‘Investigating modes of being in the world: an introduction to Phenomenologically grounded qualitative research’, *Phenomenology and*

Cognitive Science, 20(5), pp. 1–21. doi: DOI: 10.1007/s11097-020-09723-w.

Kottler, J. A. and Hunter, S. V. (2010) ‘Clients as teachers: Reciprocal influences in therapy relationships’, *Australian and New Zealand Journal of Family Therapy*, 31(1), pp. 4–12. doi: 10.1375/ANFT.31.1.4.

Kovach, M. (2018) ‘Doing indigenous methodologies’, in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks, CA: SAGE Publications Inc, pp. 214–234.

Kristjanson, L. J. and Aoun, S. (2004) ‘Palliative Care for Families: Remembering the Hidden Patients’, *The Canadian Journal of Psychiatry*, 49(6), pp. 359–365. doi: 10.1177/070674370404900604.

Kruger, S. *et al.* (2021) ‘Young adult women’s meaning-making of living with type 1 diabetes: towards growth and optimism’, *Psychology & Health*, 36(11), pp. 1–18. doi: 10.1080/08870446.2021.1977303.

Kübler-Ross, E. (1970) *On death and dying*. London: Tavistock.

Kuhn, T. (1970) *The Structure of Scientific Revolutions*. 2nd edn. Chicago: University of Chicago Press.

Kumar, S. and Cavallaro, L. (2018) ‘Researcher Self-Care in Emotionally Demanding Research: A Proposed Conceptual Framework’, *Qualitative Health Research*, 28(4), pp. 648–658. doi: 10.1177/1049732317746377.

Labov, W. and Waletzky, J. (1967) ‘Narrative analysis: Oral versions of personal experience’, in Helm, J. (ed.) *Essays on the Verbal and Visual Arts*. Seattle: University of Washington Press, pp. 12–44.

Lafrance, M. N. and Wigginton, B. (2019) ‘Doing critical feminist research: A Feminism & Psychology reader’, *Feminism and Psychology*, 29(4), pp. 534–552. doi: 10.1177/0959353519863075.

Laidsaar-Powell, R., Butow, P. and Juraskova, I. (2019) ‘Recognising and managing the psychosocial needs of family carers: It’s time for change’, *Patient Education and Counseling*, 102(3), pp. 401–403. doi: 10.1016/j.pec.2019.02.016.

Langdridge, D. (2007) *Phenomenological psychology : theory, research, and method*. Harlow: Prentice Hall.

Langer, S. L., Brown, J. D. and Syrjala, K. L. (2009) ‘Intra- and Inter-personal Consequences of Protective Buffering among Cancer Patients and Caregivers’, *Cancer*, 115(18), pp. 4311–4325. doi: 10.1002/CNCR.24586.

Larkin, M. (2021a) ‘Email to ipaqualitative@groups.io, 18th January 2021’.

Larkin, M. (2021b) ‘Email to ipaqualitative@groups.io, 24th February 2021’.

Larkin, M., Shaw, R. and Flowers, P. (2019) ‘Multiperspectival designs and processes in interpretative phenomenological analysis research’, *Qualitative Research in Psychology*, 16(2), pp. 182–198. doi: 10.1080/14780887.2018.1540655.

Larkin, M., Watts, S. and Clifton, E. (2006) ‘Giving voice and making sense in interpretative phenomenological analysis', *Qualitative Research in Psychology*, 3(2), pp. 102–120.

Larner, B. and Blow, A. (2011) 'A Model of Meaning-Making, Coping and Growth in Combat Veterans', *Review of General Psychology*, 15(3), pp. 187–197. doi: 10.1037/a0024810.

Lazard, L. and McAvoy, J. (2020) 'Doing reflexivity in psychological research: What's the point? What's the practice?', *Qualitative Research in Psychology*, 17(2), pp. 159–177.

Leavy, P. and Harris, A. (2018) *Contemporary feminist research from theory to practice*. New York: Guilford Publications.

Lebovits, A. H. *et al.* (1981) 'Psychological aspects of asbestos-related mesothelioma and knowledge of high risk for cancer', *Cancer Detection and Prevention Prev*. 1981/01/01, 4(1–4), pp. 181–184.

Lebovits, A. H., Chahinian, A. P. and Holland, J. C. (1983) 'Exposure to asbestos - psychological responses of mesothelioma patients', *American Journal of Industrial Medicine*, 4(3), pp. 459–466. doi: 10.1002/ajim.4700040306.

Leder, D. (1990) 'Whose body? What body? The metaphysics of organ transplantation', in Cherry, M. (ed.) *Persons and their bodies: rights, responsibilities, relationships*. Dordrecht, NL: Kluwer, pp. 233–264.

Lee, C. S. and Lyons, K. S. (2019) 'Patterns, relevance, and predictors of dyadic mental health over time in lung cancer', *Psycho-oncology*, 28(8), pp. 1721–1727. doi: 10.1002/pon.5153.

Lelorain, S. *et al.* (2018) 'Physician Empathy Interacts with Breaking Bad News in Predicting Lung Cancer and Pleural Mesothelioma Patient Survival: Timing May Be Crucial', *Journal of Clinical Medicine*, 7(10), pp. 364–378. doi: 10.3390/jcm7100364.

Lelorain, S. (2021) 'Discussing Prognosis with Empathy to Cancer Patients', *Current Oncology Reports*, 23(4), pp. 42–52. doi: 10.1007/S11912-021-01027-9.

Lester, J. N. and O'Reilly, M. (2021) 'Quality in Qualitative Approaches: Celebrating Heterogeneity', *Qualitative Research in Psychology*, 18(3), pp. 295–304. doi: 10.1080/14780887.2021.1931734.

Levac, D., Colquhoun, H. and O'Brien, K. K. (2010) 'Scoping studies: advancing the methodology', *Implementation Science*, 5(69), pp. 1–9. doi: 10.1186/1748-5908-5-69.

Levi-Strauss, C. (1994) *The Savage Mind*. Oxford: Oxford University Press.

Levitt, H. M. *et al.* (2017) 'Recommendations for designing and reviewing qualitative research in psychology: Promoting methodological integrity', *Qualitative Psychology*, 4(1), pp. 2–22. doi: 10.1037/qup0000082.

Levitt, H. M. (2021) 'Qualitative generalization, not to the population but to the phenomenon: Reconceptualizing variation in qualitative research', *Qualitative Psychology*, 8(1), pp. 95–110. doi: 10.1037/QUP0000184.

Li, Q. P. and Loke, A. Y. (2013) 'The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research', *Psycho-oncology*, 22(11), pp. 2399–2407. doi: 10.1002/pon.3311.

Liljestrom, M. (2016) ‘Affect’, in Disch, L. and Hawksworth, M. (eds) *The Oxford Handbook of Feminist Theory*. New York: Oxford University Press, pp. 16–38.

Lincoln, Y. S., Lynham, S. and Guba, E. (2018) ‘Paradigmatic controversies, contradictions, and emerging confluences, revisited’, in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks, CA: SAGE Publications Inc.

Lindsay, G. M. and Schwind, J. K. (2016) ‘Narrative Inquiry: Experience Matters’, *Canadian journal of nursing research*, 48(1), pp. 14–20. doi: 10.1177/0844562116652230.

Litz, B. *et al.* (2009) ‘Moral injury and moral repair in war veterans: A preliminary model and intervention strategy’, *Clinical Psychology Review*, 29(8), pp. 695–706.

London, A. S. and Wilmoth, J. M. (2016) ‘Military Service in Lives: Where Do We Go From Here?’, in Shanahan, M. J., Mortimer, J. T., and Kirkpatrick Johnson, M. (eds) *Handbook of the Life Course: Volume II*. Cham: Springer International Publishing, pp. 277–300. doi: 10.1007/978-3-319-20880-0_12.

Long-Sutehall, T., Sque, M. and Addington-Hall, J. (2011) ‘Secondary analysis of qualitative data: A valuable method for exploring sensitive issues with an elusive population?’, *Journal of Research in Nursing*, 16(4), pp. 335–344. doi: 10.1177/1744987110381553.

Long, E. (2021) ‘Living Liminal Lives: Army Partners’ Spatiotemporal Experiences of Deployment:’, *Armed Forces and Society*, March 2021, p. 95327. doi: 10.1177/0095327X21995966.

Loughran, K., Rice, S. and Robinson, L. (2017) ‘Living with incurable cancer: what are the rehabilitation needs in a palliative setting?’, *Disability and Rehabilitation*, 41(7), pp. 770–78. doi: 10.1080/09638288.2017.1408709.

Mackenzie, N. and Knipe, S. (2006) ‘Research Dilemmas: Paradigms, Methods and Methodology’, *Issues in Educational Research*, 16(2), pp. 193–205.

Mallon, S. and Elliott, I. (2019) ‘The Emotional Risks of Turning Stories into Data: An Exploration of the Experiences of Qualitative Researchers Working on Sensitive Topics’, 9(3), p. 62. doi: 10.3390/soc9030062.

Mamede, S. and Schmidt, H. G. (2014) ‘The twin traps of overtreatment and therapeutic nihilism in clinical practice’, *Medical Education*, 48(1), pp. 34–43. doi: 10.1111/MEDU.12264.

van Manen, M. (1990) *Researching lived experience: human science for an action sensitive pedagogy*. London and Ontario: Althouse Press.

van Manen, M. (2017) ‘But is it phenomenology?’, *Qualitative Health Research*, 27, pp. 775–779.

Mann, S. *et al.* (2019) ‘Revisiting localized malignant mesothelioma’, *Annals of Diagnostic Pathology*, 39, pp. 74–77. doi: 10.1016/j.anndiagpath.2019.02.014.

Markham, A. (2018) ‘Ethnography in the digital internet era’, in Denzin, N. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks, CA: SAGE Publications Inc, pp. 650–668.

Marshall, B. *et al.* (2013) ‘Does Sample Size Matter in Qualitative Research?: a Review of Qualitative Interviews in IS Research’, *The journal of computer information systems.*, 54(1), pp. 11–22.

Martin, L. A. *et al.* (2014) ‘Re-conceptualizing Cancer Survivorship through Veterans’ Lived Experiences’, *Journal of Psychosocial Oncology*, 32(3), pp. 289–309. doi: 10.1080/07347332.2014.897782.

Matthew, G. *et al.* (2015) ‘What Are the Psychological Effects of Delivering and Receiving “High-Risk” Survival Resistance Training?’, *Military Medicine*, 180(2), pp. 168–177. doi: 10.7205/MILMED-D-14-00285.

Maxwell, J. A. (2013) *Qualitative research design : an interactive approach*. 3rd edn. Los Angeles, California: Sage Publications.

Maxwell, J. A. (2020) ‘Why Qualitative Methods Are Necessary for Generalization’, *Qualitative Psychology*, 8(1), pp. 111–118. doi: 10.1037/QUP0000173.

Maya, S. *et al.* (2021) ‘Oncologists’ experience with discussing cancer prognosis with patients and families: perspectives from India’, *Translational Behavioral Medicine*, 11(10), pp. 1896–1904. doi: 10.1093/TBM/IBAB070.

Mbozi, P., Ratcliff, C. and Roberts, D. (2020) ‘Challenges Facing Women Caring for a Spouse Having Cancer Treatment: A Critical Literature Review’, *Open Journal of Nursing*, 10, pp. 34–68. doi: 10.4236/ojn.2020.101003.

McAllister, L., Callaghan, J. E. M. and Fellin, L. C. (2019) ‘Masculinities and emotional expression in UK servicemen: “Big boys don’t cry”?’, *Journal of Gender Studies*, 28(3), pp. 257–270. doi: 10.1080/09589236.2018.1429898.

McCoyd, J. and Schwaber Kerson, T. (2006) ‘Conducting Intensive Interviews Using Email’, *Qualitative Social Work*, 5(3), pp. 389–406.

McFarland, D. C. *et al.* (2019) ‘Suicide in patients with cancer: Identifying the risk factors’, *Oncology*, 33(6), pp. 221–226.

McGregor, L. *et al.* (2014) ‘Reclaiming their lives: the decision-making process in living liver donation - an interpretative phenomenological case study analysis of one couple’, *Psychology & Health*, 29(12), pp. 1373–1387.

McHugh, M. (2014) ‘Feminist Qualitative Research: Toward Transformation of Science and Society’, in Leavy, P. (ed.) *The Oxford Handbook of Qualitative Research*. Oxford: Oxford University Press.

McSorley, K. and Maltby, S. (2012) ‘War and the Body: Cultural and military practices’, *Journal of War & Culture Studies*, 5(1), pp. 3–6. doi: 10.1386/jwcs.5.1.3_7.

Mead, G. (1934) *Mind, Self and Society*. Chicago: University of Chicago Press.

Melis, P. *et al.* (2021) ‘Experiencing communication related to knowing the cancer diagnosis and prognosis: A multi-perspective interpretative phenomenological study’, *European Journal of Oncology Nursing*, 51, p. 101904. doi: 10.1016/J.EJON.2021.101904.

Merleau-Ponty (2012) *Phenomenology of Perception*. London: Routledge.

Merleau-Ponty, M. (1964) *The Primacy of Perception*. Evanston, IL: Northwestern University Press.

Mertens, D. (2005) *Research methods in education and psychology: integrating diversity with quantitative and qualitative approaches*. 2nd edn. Thousand Oaks: SAGE Publications Inc.

Mertens, D. (2009) *Transformative research and evaluation*. New York: The Guildford Press.

Mesothelioma Applied Research Foundation (2015) *Asbestos Exposure in the Military*. Available at: https://www.curemeso.org/2015/11/10/asbestos-exposure-military/ (Accessed: 5 November 2019).

Mileham, P. (2016) 'Teaching Military Ethics in the British Armed Forces', in Robinson, P., De Lee, N., and Carrick, D. (eds) *Ethics Education in the Military*. Abingdon: Routledge, pp. 43–56.

Ministry of Defence (2011) *Joint Medical Doctrine*. London. Available at: http://defenceintranet.diif.r.mil/Organisations/Orgs/JFC/Organisations/Orgs/DC (Accessed: 1 November 2021).

Ministry of Defence (2014) *A Guide for Army Families*. London: Ministry of Defence. Available at: https://www.army.mod.uk (Accessed: 30 October 2021).

Ministry of Defence (2016a) *An explanation of the Armed Forces Covenant*. Available at: https://www.gov.uk/government/publications/an-explanation-of-the-armed-forces-covenant (Accessed: 11 October 2019).

Ministry of Defence (2016b) *Fair compensation for veterans with cancer caused by asbestos*. Available at: https://www.gov.uk/government/news/fair-compensation-for-veterans-with-cancer-caused-by-asbestos (Accessed: 18 May 2020).

Ministry of Defence (2016c) *Veterans Key Facts*. Available at: https://www.armedforcescovenant.gov.uk/wp-content/uploads/2016/02/Veterans-Key-Facts.pdf (Accessed: 11 October 2019).

Ministry of Defence (2018) *The Strategy for our Veterans*. Available at: https://www.gov.uk/government/publications/strategy-for-our-veterans/ (Accessed: 11 October 2019).

Ministry of Defence (2019a) *Asbestos in defence equipment platforms, buildings and infrastructure*. Available at: https://www.gov.uk/government/publications/asbestos-in-defence-equipment-platforms-buildings-and-infrastructure (Accessed: 18 June 2019).

Ministry of Defence (2019b) *Population projections: UK Armed Forces veterans residing in Great Britain, 2016 to 2028*. Available at: https://www.gov.uk/government/publications/population-projections-uk-armed-forces-veterans-residing-in-great-britain-2016-to-2028 (Accessed: 16 October 2019).

Ministry of Defence (2021) *Who can join the UK armed forces? Nationality and residence requirements*. Available at: https://commonslibrary.parliament.uk/research-briefings/cbp-8625/ (Accessed: 17 May 2021).

Mobbs, M. (2018) *What's Eating Our Veterans?* Available at: https://www.psychologytoday.com/gb/blog/the-debrief/201811/whats-eating-our-veterans (Accessed: 2 March 2021).

Moher, D. *et al.* (2010) 'Guidance for Developers of Health Research Reporting Guidelines', *PLoS Medicine*, 7(2), p. e1000217. doi: 10.1371/journal.pmed.1000217.

Moore, S., Darlison, L. and Tod, A. M. (2010) ‘Living with mesothelioma. A literature review’, *European Journal of Cancer Care*, 19(4), pp. 458–468. doi: 10.1111/j.1365-2354.2009.01162.x.

Morgan, D. L. (2014) ‘Pragmatism as a Paradigm for Social Research’, *Qualitative Inquiry*, 20(8), pp. 1045–1053.

Mori, M. *et al.* (2019) ‘Adding a Wider Range and “Hope for the Best, and Prepare for the Worst” Statement: Preferences of Patients with Cancer for Prognostic Communication’, *The Oncologist*, 24(9), pp. E943-952. doi: 10.1634/THEONCOLOGIST.2018-0643.

Morrow, R., Rodriguez, A. and King, N. (2015) ‘Colaizzi’s descriptive phenomenological method’, *The Psychologist*, 28(8), pp. 643–644.

Mott, J., Schmidt, B. and MacWilliams, B. (2019) ‘Male caregivers: Shifting roles among family caregivers’, *Clinical Journal of Oncology Nursing*, 23(1), pp. E17–E24. doi: 10.1188/19.CJON.E17-E24.

Moye, J. and Rouse, S. J. (2015) ‘Posttraumatic Stress in Older Adults: When Medical Diagnoses or Treatments Cause Traumatic Stress’, *Psychiatric Clinics of North America*, 38(1), pp. 45–57. doi: 10.1016/j.psc.2014.11.003.

Mulligan, E. *et al.* (2011) ‘Do military veterans identify cancer as a traumatic stressor?’, *Gerontologist*, 51, pp. 458–459.

Mulligan, E. A. *et al.* (2014) ‘Cancer as a Criterion A Traumatic Stressor for Veterans: Prevalence and Correlates’, *Psychological Trauma: Theory, Research, Practice, and Policy*, 6(S1), pp. S73–S81. doi: 10.1037/a0033721.

Mumford, A. (2012) ‘Veteran Care in the United Kingdom and the Sustainability of the “Military Covenant”’, *Political Quarterly*, 83(4), pp. 820–826. doi: 10.1111/j.1467-923X.2012.02358.x.

Murphy, D. *et al.* (2019) ‘A latent profile analysis of PTSD symptoms among UK treatment seeking veterans’, *European journal of psychotraumatology*. Edited by D. Murphy, 10(1), p. 1558706. doi: 10.1080/20008198.2018.1558706.

Nagamatsu, Y. *et al.* (2019) ‘Physician requests by patients with malignant pleural mesothelioma in Japan’, *BMC cancer*, 19(1), pp. 383–390. doi: 10.1186/s12885-019-5591-7.

Nash, W. P. and Litz, B. T. (2013) ‘Moral Injury: A Mechanism for War-Related Psychological Trauma in Military Family Members’, *Clinical Child and Family Psychology Review*, 16(4), pp. 365–375. doi: 10.1007/S10567-013-0146-Y.

National Rural Bioethics Project University of Montana (2007) *Ethics and environmental health*. Available at: http://www.umt.edu/bioethics/libbyhealth/introduction/background/asbestos_timeline.aspx (Accessed: 18 June 2021).

Nelms, T. (2015) ‘Phenomenological Philosophy and Research’, in de Chesnay, M. (ed.) *Nursing Research Using Phenomenology*. New York: Springer Publishing Company.

Newing, H. (2010) *Conducting Research in Conservation: Social Science Methods and*

Practice. New York: Routledge.

NHS Health Education for England (2019) *NHS Healthcare for the Armed Forces*. Available at: https://www.e-lfh.org.uk/programmes/nhs-healthcare-for-the-armed-forces/ (Accessed: 16 October 2019).

Nickerson, A. *et al.* (2015) ‘Moral injury in traumatized refugees’, *Psychotherapy and Psychosomatics*, 84(2), pp. 122–123. doi: 10.1159/000369353.

Nikischer, A. (2019) ‘Vicarious trauma inside the academe: understanding the impact of teaching, researching and writing violence’, *The International Journal of Higher Education Research*, 77(5), pp. 905–916. doi: 10.1007/s10734-018-0308-4.

Nizza, I., Farr, J. and Smith, J. A. (2021) ‘Achieving excellence in interpretative phenomenological analysis (IPA): four markers of high quality’, *Qualitative Research in Psychology*, 18(3), pp. 369–386.

Noddings, N. (2003) *Caring: a feminine approach to ethics and moral education*. 2nd edn. Oakland: University of California Press.

Nuyts, V. *et al.* (2018) ‘Hotspots of malignant pleural mesothelioma in Western Europe’, *Translational Lung Cancer Research*, pp. 516–519. doi: 10.21037/tlcr.2018.10.01.

O’Connor, M. *et al.* (2014) ‘Vulnerability at the End of Life: Australian Veterans Requiring Home- Based Palliative Care’, *Home Health Care Management and Practice*, 26(3), pp. 134–140. doi: 10.1177/1084822313514978.

O’Leary, Z. (2004) *The essential guide to doing research*. London: Sage Publications.

Olesen, V. (2018) ‘Feminist qualitative research in the millenium’s first decade’, in Denzin, N. K. and Lincoln, Y. S. (eds) *The SAGE handbook of qualitative research*. 5th edn. Thousand Oaks, CA: SAGE Publications Inc, pp. 151–175.

Opsal, T. *et al.* (2016) ‘“There Are No Known Benefits . . .”: Considering the Risk/ Benefit Ratio of Qualitative Research’, *Qualitative Health Research*, 26(8), pp. 1137–1150. doi: 10.1177/1049732315580109.

Ozen, B., Ceyhan, O. and Büyükcelik, A. (2019) ‘Hope and perspective on death in patients with cancer’, *Death Studies*, pp. 1–7. doi: 10.1080/07481187.2019.1626942.

Padilha Baran, F. D. *et al.* (2019) ‘Therapeutic itinerary revealed by the family members of individuals with mesothelioma: Multiple case studies’, *Texto e Contexto Enfermagem*, 28, p. e20170571. doi: 10.1590/1980-265X-TCE-2017-0571.

Paley, J. (2017) *Phenomenology as Qualitative Research: a critical analysis of meaning attribution*. London: Routledge.

Palmer, M. *et al.* (2010) ‘Developing an Interpretative Phenomenological Approach to Focus Group Data’, *Qualitative Research in Psychology*, 7(2), pp. 99–121. doi: 10.1080/14780880802513194.

Palmer, R. (1971) ‘“Phenomenology” Edmund Husserl’s Article for the Encyclopaedia Britannica (1927): New Complete Translation by Richard E. Palmer’, *Journal of the British Society for Phenomenology*, 2(2), pp. 77–90.

Parr, S. (2020) ‘Integrating critical realist and feminist methodologies’, in Van Grohmann, I. and Gunnarson, L. (eds) *Critical realism, feminism and gender: a reader*. Abingdon: Routledge, pp. 253–267.

Paulus, T. *et al.* (2017) ‘The discourse of QDAS: reporting practices of ATLAS.ti and NVivo users with implications for best practices’, *International Journal of Social Research Methodology*, 20(1), pp. 35–47. doi: 10.1080/13645579.2015.1102454.

Pearson, C. and Caddick, N. (2018) *Meeting the needs of Commonwealth personnel and families: a map of service provision*. London.

Perloff, T. *et al.* (2019) ‘Survivor guilt: The secret burden of lung cancer survivorship’, *Journal of Psychosocial Oncology*, 37(5), pp. 573–585. doi: 10.1080/07347332.2019.1569191.

Perreira, J. (2020) *Armed Forces Veteran Transition And Survival Guide*. Available at: https://www.forces.net/military-life/veterans/armed-forces-veteran-transition-and-survival-guide (Accessed: 19 June 2020).

Perversi, P. *et al.* (2018) ‘Exploring reasoning mechanisms in ward rounds: a critical realist multiple case study’, *BMC Health Services Research*, 18, pp. 643–654.

Peters, M. D. J. *et al.* (2020) ‘Updated methodological guidance for the conduct of scoping reviews’, *JBI evidence synthesis*, 18(10), pp. 2119–2126. doi: 10.11124/JBIES-20-00167.

Pezalla, A., Pettigrew, J. and Miller-Day, M. (2012) ‘Researching the researcher-as-instrument: an exercise in interviewer self-reflexivity’, *Qualitative Research*, 12(2), pp. 165–185.

Pham, M. T. *et al.* (2014) ‘A scoping review of scoping reviews: Advancing the approach and enhancing the consistency’, *Research Synthesis Methods*, 5(4), pp. 371–385. doi: 10.1002/jrsm.1123.

Phelps, J. (2020) ‘The Transformative Paradigm: Equipping Technical Communication Researchers for Socially Just Work’, *Technical Communication Quarterly*, 30(2), pp. 204–215. doi: 10.1080/10572252.2020.1803412.

Philip, G. and Bell, L. (2017) ‘Thinking critically about rapport and collusion in feminist research: Relationships, contexts and ethical practice’, *Women’s Studies International Forum*, 61, pp. 71–74.

Pietkiewicz, I. and Smith, J. A. (2014) ‘A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology’, *Czasopismo Psychologiczne - Psychological Journal*, 20(1), pp. 7–14. doi: 10.14691/CPPJ.20.1.7.

Pike, A. (2016) *Deployment to employment: exploring the veteran employment gap in the UK*. London. Available at: https://media.britishlegion.org.uk/Media/5035/deployment-to-employment.pdf.

Post, D. *et al.* (2021) ‘Caring for carers: Understanding the physical and psychological well-being of carers of veterans in Australia’, *Health & Social Care in the Community*, [Preprint]. doi: 10.1111/HSC.13449.

Preston, A. (2021) ‘Robert Harris “I start a book on 15 January and finish on 15 June”’, *The Observer*, July, p. 45.

Prusak, A. *et al.* (2021) ‘The psychosocial impact of living with mesothelioma: Experiences and needs of patients and their carers regarding supportive care’, *European Journal of Cancer*, 30(6), p. e13498. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/ecc.13498.

Psycho-oncology (2021) *About this journal. Psycho-oncology*. Available at: https://onlinelibrary.wiley.com/journal/10991611 (Accessed: 23 January 2021).

Public Health England (2017) *Asbestos: general information*. Available at: https://www.gov.uk/government/publications/asbestos-properties-incident-management-and-toxicology/asbestos-general-information (Accessed: 20 October 2018).

Quincey, K., Williamson, I. and Wildbur, D. (2021) ‘Men with breast cancer and their encounters with masculinity: An interpretative phenomenological analysis using photography’, *Psychology of Men & Masculinities*, 22(4), pp. 690–703.

Quirkos Limited (2020) *Quirkos Full Manual (v2.4) November 2020*. Available at: https://www.quirkos.com/manual.pdf (Accessed: 22 July 2021).

Ream, E. *et al.* (2021) ‘Understanding the support needs of family members of people undergoing chemotherapy: A longitudinal qualitative study’, *European Journal of Oncology Nursing*, 50, p. 101861. doi: 10.1016/J.EJON.2020.101861.

Reid, K., Flowers, P. and Larkin, M. (2005) ‘Exploring lived experience’, *Psychologist*, 18(1), pp. 20–23.

Revenson, T., Wollman, C. and Felton, B. (1983) ‘Social supports as stress buffers for adult cancer patients’, *Psychosomatic Medicine*, 45(4), pp. 321–331.

Reynolds, C. J. *et al.* (2019) ‘Mesothelioma mortality in great Britain: How much longer will dockyards dominate?’, *Occupational and Environmental Medicine*. BMJ Publishing Group, 76(12), pp. 908–912. doi: 10.1136/oemed-2019-105878.

Reynolds, J., Ogden, M. and Beresford, R. (2021) ‘Conceptualising and constructing “diversity” through experiences of public and patient involvement in health research’, *Research Involvement and Engagement 2021 7:1*, 7(1), pp. 1–11. doi: 10.1186/S40900-021-00296-9.

Ricouer, P. (1970) *Freud and Philosophy: an essay on interpretation*. New Haven: Yale University Press.

Riesman, D. *et al.* (1965) *The Lonely Crowd: A Study of the Changing American Character*. 2nd edn. New Haven: Yale University Press.

Robertson, S. (2007) *Understanding Men and Health*. Maidenhead: Open University Press.

Robinson, M. and Robertson, S. (2014) ‘Challenging the field: Bourdieu and men’s health’, *Social Theory and Health*, 12(4), pp. 339–360. doi: 10.1057/STH.2014.8.

Robinson, O. C. (2014) ‘Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide’, *Qualitative Research in Psychology*. Routledge, 11(1), pp. 25–41. doi: 10.1080/14780887.2013.801543.

Rodham, K., Fox, F. and Doran, N. (2015) ‘Exploring analytical trustworthiness and the process of reaching consensus in interpretative phenomenological analysis: lost in transcription’, *International Journal of Social Research Methodology*, 18(1), pp. 59–71. doi: 10.1080/13645579.2013.852368.

Rogers, C. (2020) ‘Just mothers: criminal justice, care ethics and “disabled” offenders’, *Disability and Society*. Routledge, 35(6), pp. 926–948. doi: 10.1080/09687599.2019.1655711.

Rogers, C. R. (1978) *The Foundations of the Person-Centred Approach*. Available at: http://www.elementsuk.com/libraryofarticles/foundations.pdf (Accessed: 25 January 2021).

Roma *et al.* (2020) ‘Advanced Symptom Management System for Patients with Malignant Pleural Mesothelioma (ASyMSmeso): Mixed Methods Study’, *Journal of Medical Internet Research*, 22(11), p. e19180. doi: 10.2196/19180.

Rowling, L. (1999) ‘Being in, being out, being with: Affect and the role of the qualitative researcher in loss and grief research’, *Mortality*, 4(2), pp. 167–181.

Royal Air Force (2020) *RAF Core Values*. Available at: https://www.raf.mod.uk/aircadets/raf-aircadets/assets/File/RAF Values %26 Ethos posters.pdf (Accessed: 18 June 2020).

Royal British Legion (2021) *Unpaid Carers in the Armed Forces Community*. London. Available at: https://www.britishlegion.org.uk/get-involved/things-to-do/campaigns-policy-and-research/unpaid-carers-in-the-armed-forces-community?utm_source=twitter&utm_medium=organicsocial&utm_campaign=carersreport (Accessed: 14 September 2021).

Royal College of Physicians (2018) *National Mesothelioma Audit Report (for the audit period 2014-16)*. London.

Ruggiano, N. and Perry, T. E. (2019) ‘Conducting secondary analysis of qualitative data: Should we, can we, and how?’, *Qualitative Social Work*. London, England, 18(1), pp. 81–97. doi: 10.1177/1473325017700701.

Russon, J. and Jacobson, K. (2018) ‘Existential Medicine and the Intersubjective Body’, in Aho, K. (ed.) *Existential Medicine*. London and New York: Rowman & Littlefield International, pp. 191–204.

Saldana, J. (2018) ‘Researcher, Analyze Thyself’, *International Journal of Qualitative Methods*, 17(1). doi: 10.1177/1609406918801717.

Sartre, J.-P. (1948) *Existentialism and Humanism*. London: Haskell House Publishers.

Scerri, D., Borg Xuereb, C. and Scerri, J. (2021) ‘Caring for a parent with pulmonary fibrosis in Malta: The lived experiences of daughters in mid-adulthood’, *Health & Social Care in the Community*, [preprint]. doi: 10.1111/HSC.13426.

Schleiermacher, F. (1998) *Hermeneutics and Criticism and other Writings*. Cambridge: Cambridge University Press.

Schwandt, T. (1997) *The SAGE dictionary of qualitative inquiry.* Thousand Oaks, CA: SAGE Publications.

Seale, C. (1999) ‘Quality in qualitative research’, *Qualitative Inquiry*, 5(4), pp. 465–78.

Senek, M. *et al.* (2021) ‘Mesothelioma: exploring gender differences in time to diagnosis, seeking legal advice and occupational risk', *Cancer Nursing Practice*, 20(2), pp. 1–7.

Shaw, R. L. (2011) 'The future's bright: celebrating its achievements and preparing for the challenges ahead in IPA research', *Health Psychology Review*. Taylor & Francis Group, 5(1), pp. 28–33. doi: 10.1080/17437199.2010.524808.

Shay, J. (2011) 'The Modern American Military', *Daedalus*, 140(3), pp. 179–188.

Shay, J. and Munroe, J. (1999) 'Group and milieu therapy for veterans with complex posttraumatic stress disorder', in Saigh, P. A. and Bremner, J. D. (eds) *Posttraumatic stress disorder: A comprehensive text*. Boston: Allyn & Bacon, pp. 391–413.

Sherborne, V. *et al.* (2020) 'What are the psychological effects of mesothelioma on patients and their carers? A scoping review', *Psycho-Oncology*, 29(10), pp. 1464–1473. doi: 10.1002/pon.5454.

Sherif, V. (2018) 'Evaluating Preexisting Qualitative Research Data for Secondary Analysis', *Forum: Qualitative Social Research*, 19(2), pp. 1–17. doi: 10.17169/fqs-19.2.2821.

Sherman, N. (2004) 'Educating the Stoic warrior', *Whitehall Papers*, 61(1), pp. 105–126. doi: 10.1080/02681300408523011.

Shildrick, M. (1999) 'The body which is not one: dealing with difference', *Body & Society*, 5(2–3), pp. 77–92.

Shilling, V. *et al.* (2017) 'The pervasive nature of uncertainty—a qualitative study of patients with advanced cancer and their informal caregivers', *Journal of Cancer Survivorship*, 11(5), pp. 590–603. doi: 10.1007/s11764-017-0628-x.

Shinebourne, P. (2011) 'The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA)', *Existential Analysis: Journal of the Society for Existential Analysis*, 22(1), pp. 16–31.

Sjoberg, L. (2007) 'Agency, Militarized Femininity and Enemy Others: Observations From The War In Iraq', *International Feminist Journal of Politics*, 9(1), pp. 82–101. doi: 10.1080/14616740601066408.

Slatman, J. (2012) 'Phenomenology of bodily integrity in disfiguring breast cancer', *Hypatia*, 27(2), pp. 281–300.

Smith, A. J. (2014) 'Culturally competent therapy with military veterans: Identifying and overcoming issues facing providers', *Journal of Military and Government Counseling*, 2(2), pp. 119–135.

Smith, J. A. (1996) 'Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology', *Psychology & Health*, 11(2), pp. 261–271.

Smith, J. A. (2011a) 'Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria', *Health Psychology Review*, 5(1), pp. 55–61. doi: 10.1080/17437199.2010.541743.

Smith, J. A. (2011b) 'Evaluating the contribution of interpretative phenomenological analysis', *Health Psychology Review*, 5(1), pp. 9–27. doi: 10.1080/17437199.2010.510659.

Smith, J. A. (2018) '"Yes, it is phenomenological": A reply to Max van Manen's crtitique of interpretative phenomenological analysis', *Qualitative Health Research*, 28, pp. 1955–1958.

Smith, J. A. (2019) 'Participants and researchers searching for meaning: conceptual developments for interpretative phenomenlogical analysis', *Qualitative Research in Psychology*, 16(2), pp. 166–181.

Smith, J. A. and Eatough, V. (2019) 'Looking Forward: Conceptual and Methodological Developments in Interpretative Phenomenological Analysis: Introduction to the Special Issue', *Qualitative Research in Psychology*, 16(2), pp. 163–165. doi: 10.1080/14780887.2018.1540620.

Smith, J. A., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis : theory, method and research*. Los Angeles: SAGE Publications Inc.

Smith, J. A. and Nizza, I. (2021) *Essentials of Interpretative Phenomenological Analysis*. Washington D.C.: APA.

Smith, J. A. and Osborn, M. (2003) 'Interpretative phenomenological analysis', in Smith, J. A. (ed.) *Qualitative psychology: a practical guide to research methods*. London: SAGE Publications, pp. 51–80.

Smith, J. A. and Osborn, M. (2015) 'Interpretative Phenomenological Analysis', in Smith, J. A. (ed.) *Qualitative psychology : a practical guide to research methods*. 3rd edn. London: Sage Publications, pp. 25–52.

Social Sciences Centre for Education Studies (2019) *Critical Realism*. University of Warwick. Available at: https://warwick.ac.uk/fac/soc/ces/research/current/socialtheory/maps/critical/ (Accessed: 11 November 2019).

Sparrow, K. *et al.* (2020) 'The experience of health and welfare workers in identifying and responding to domestic abuse among military personnel in the UK', *BMC Health Services Research*, 20, p. 947. doi: https://doi.org/10.1186/s12913-020-05672-x.

Spendelow, J. S., Adam, L. A. and Fairhurst, B. R. (2017) 'Coping and adjustment in informal male carers: A systematic review of qualitative studies', *Psychology of Men and Masculinity*, 18(2), pp. 134–143. doi: 10.1037/MEN0000049.

Spiers, G. *et al.* (2021) *Caring as a social determinant of health*. London. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf (Accessed: 25 October 2021).

Spiers, J. (2021) 'Email to ipaqualitative@groups.io 19 Jan 2021'.

Spiers, J. and Riley, R. (2019) 'Analysing one dataset with two qualitative methods: The distress of general practitioners, a thematic and interpretative phenomenological analysis', *Qualitative Research in Psychology*, 16(2), pp. 276–290. doi: 10.1080/14780887.2018.1543099.

Spiro, A., Settersten, R. A. and Aldwin, C. M. (2016) 'Long-term Outcomes of Military Service in Aging and the Life Course: A Positive Re-envisioning', *The Gerontologist*, 56(1), pp. 5–13. doi: 10.1093/geront/gnv093.

Sque, M., Walker, W. and Long-Sutehall, T. (2014) 'Research with bereaved families: A framework for ethical decision-making', *Nursing Ethics*, 21(8), pp. 946–55. doi: 10.1177/0969733014521097.

Von St. James, H. (2016) *How One Mesothelioma Survivor Deals With Survivor's Guilt*. Available at: https://www.mesothelioma.com/blog/how-one-mesothelioma-survivor-deals-with-survivors-guilt/ (Accessed: 15 November 2021).

Stein, J. *et al.* (2018) 'Growing Apart: A Longitudinal Assessment of the Relation Between Post-traumatic Growth and Loneliness Among Combat Veterans', *Frontiers in Psychology*, 9, p. 893. doi: 10.3389/fpsyg.2018.00893.

Stewart, M. (2017) 'A sense of betrayal', *Journal of Public Mental Health*, 16(1), pp. 6–8. doi: 10.1108/JPMH-05-2016-0023.

Stibbe, A. (1997) 'Fighting, Warfare and the Discourse of Cancer', *South African Journal of Linguistics*, 15(2), pp. 65–70.

Stilwell, P. and Harman, K. (2021) 'Phenomenological research needs to be renewed: time to integrate enactivism as a flexible resource', *International Journal of Qualitative Methods*, 20, pp. 1–15.

Strand, L. A. *et al.* (2010) 'Asbestos-related cancers among 28,300 military servicemen in the Royal Norwegian Navy', *American Journal of Industrial Medicine*, 53(1), pp. 64–71.

Stutey, D. M. *et al.* (2020) 'The Practice of Bridling: Maintaining Openness in Phenomenological Research', *The Journal of Humanistic Counseling*, 59(2), pp. 144–156. doi: 10.1002/johc.12135.

Sumner, J. and Edmondson, D. (2018) 'Refining our understanding of PTSD in medical settings', *General Hospital Psychiatry*, 53, pp. 86–87. doi: 10.1016/J.GENHOSPPSYCH.2018.05.001.

Svenaeus, F. (2018) 'Phenomenology of pregnancy and the ethics of abortion', *Medicine, Health Care and Philosophy*, 21(1), pp. 77–87.

Swain, J. (2016) 'Changing the identities of young army recruits and new ways of looking at hegemonic forms of military masculinity', *Culture, Society and Masculinities*, 8(1), pp. 1–19. doi: 10.3149/CSM.0801.1.

Swanborn, P. (2010) *Case Study Research: What, Why and How?* London: SAGE Publications, Inc.

Swartzman, S. *et al.* (2017) 'Posttraumatic stress disorder after cancer diagnosis in adults', *Depression and Anxiety*, 34(4), pp. 327–339. doi: 10.1002/da.22542.

Swetenham, K. *et al.* (2015) 'Communication differences when patients and caregivers are seen separately or together', *International Journal of Palliative Nursing*, 21(11), pp. 557–563. doi: 10.12968/ijpn.2015.21.11.557.

Sword, W. *et al.* (2012) 'The complexity of postpartum mental health and illness: a critical realist study', *Nursing Inquiry*, 19(1), pp. 51–62.

Tan, J. H., Sharpe, L. and Russell, H. (2021) 'The impact of ovarian cancer on individuals and their caregivers: A qualitative analysis', *Psycho-oncology*, 30(2), pp. 212–220.

Taylor, B. *et al.* (2018) *Communicating a diagnosis of mesothelioma: Findings and Recommendations from the Radio Meso study*. Sheffield. Available at: https://www.sheffield.ac.uk/polopoly_fs/1.795982!/file/RADIOMesofinalreport.pdf (Accessed:

2 November 2021).

Taylor, B., Tod, A., *et al.* (2021) ‘Effects of the COVID-19 pandemic on people with mesothelioma and their carers’, *Cancer Nursing Practice*, 20(4), pp. 1–16.

Taylor, B., Gardiner, G., *et al.* (2021) ‘Mesothelioma patient and carer experience research: a Research Prioritisation Exercise’, in *NCR Cancer Conference Abstracts*. London. Available at: https://abstracts.ncri.org.uk/abstract/mesothelioma-patient-and-carer-experience-research-a-research-prioritisation-exercise/ (Accessed: 10 December 2021).

Taylor, B. H., Warnock, C. and Tod, A. (2019) ‘Communication of a mesothelioma diagnosis: developing recommendations to improve the patient experience’, *BMJ Open Respiratory Research*, 6(1), p. e000413. doi: 10.1136/bmjresp-2019-000413 %J BMJ Open Respiratory Research.

Thandi, G. *et al.* (2017) ‘Informal caregiving and intimate relationships: the experiences of spouses of UK military personnel’, *Journal of the Royal Army Medical Corps*, 163(4), pp. 266–272. doi: 10.1136/jramc-2016-000679.

Thomas, C. (2010) ‘Negotiating the contested terrain of narrative methods in illness contexts’, *Sociology of Health & Illness*, 32(4), pp. 647–660. doi: 10.1111/j.1467-9566.2010.01239.x.

Thompson, L. (2021) ‘Toward a feminist psychological theory of “institutional trauma”’, *Feminism & Psychology*, 31(1), pp. 99–118. doi: 10.1177/0959353520968374.

Threader, J. and McCormack, L. (2016) ‘Cancer-related trauma, stigma and growth: the “lived” experience of head and neck cancer’, *European Journal of Cancer Care*, 25(1), pp. 157–169.

Tight, M. (2020) *Understanding Case Study Research: Small-scale Research with Meaning*. Thousand Oaks, CA: SAGE Publications Inc.

Timonen, V., Foley, G. and Conlon, C. (2018) ‘Challenges When Using Grounded Theory’, *International Journal of Qualitative Methods*, 17, pp. 1–10. doi: 10.1177/1609406918758086.

Tomkins, L. and Eatough, V. (2013) ‘Meanings and Manifestations of Care: A Celebration of Hermeneutic Multiplicity in Heidegger’, *Humanistic Psychologist*, 41(1), pp. 4–24. doi: 10.1080/08873267.2012.694123.

Toombs, S. K. (1992) *The meaning of illness: a phenomenological account of the different perspectives of physician and patient*. New York: Springer.

Torrance, H. (2018) ‘Evidence, criteria, policy, and politics’, in Denzin, N. K. and Lincoln, Y. S. (eds) *The Sage handbook of qualitative research*. 5th edn. Thousand Oaks, CA: SAGE Publications Inc, pp. 766–795.

Trainor, L. and Bundon, A. (2020) ‘Developing the craft: reflexive accounts of doing reflexive thematic analysis’, *Qualitative Research in Sport, Exercise and Health*, 13(5), pp. 705–726.

Tricco, A. *et al.* (2018) ‘PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation’, *Annals of internal medicine*, 169(7), pp. 467–473.

Turner, D. (2020) *Tips for conducting online interviews and focus groups for qualitative research*. Available at: https://www.quirkos.com/blog/post/online-interviews-focus-groups-qualitative-research (Accessed: 17 June 2020).

UK Parliament Defence Committee (2021) *Protecting those who protect us: Women in the Armed Forces from Recruitment to Civilian Life*. London. Available at: www.parliament.uk/copyright. (Accessed: 26 July 2021).

UK Research and Innovation (2015) *Guidance on best practice in the management of research data*. Available at: http://www.oecd.org/sti/sci-tech/38500813.pdf (Accessed: 21 July 2021).

University of Sheffield (2019a) *Assessing ethical risk*. Available at: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure/proceduralelements (Accessed: 30 November 2019).

University of Sheffield (2019b) *Emotionally demanding research: risks to the researcher*. Available at: https://www.sheffield.ac.uk/polopoly_fs/1.834056!/file/SREGP-EmotionallyDemandingResearch.pdf (Accessed: 30 November 2019).

Ussher, J. M. *et al.* (2013) ‘The Gendered Construction and Experience of Difficulties and Rewards in Cancer Care’, *Qualitative Health Research*, 23(7), pp. 900–915. doi: 10.1177/1049732313484197.

Vagle, M. D. (2010) ‘Re-framing Schön’s call for a phenomenology of practice: A post-intentional approach’, *Reflective Practice*, 11(3), pp. 393–407. doi: 10.1080/14623943.2010.487375.

VandenBos, G. R. and American Psychological Association (2020) *APA Dictionary of Psychology*. 2nd edn. Washington D.C.: American Psychological Association.

Verhage, A. and Boels, D. (2017) ‘Critical appraisal of mixed methods research studies in a systematic scoping review on plural policing: assessing the impact of excluding inadequately reported studies by means of a sensitivity analysis’, *Quality & Quantity*, 51(4), pp. 1449–1468.

Veterans’ Gateway (2019) *Veterans’ Gateway*. Available at: https://www.veteransgateway.org.uk/ (Accessed: 16 October 2019).

Vicary, S., Young, A. and Hicks, S. (2016) ‘A reflective journal as learning process and contribution to quality and validity in interpretative phenomenological analysis’, *Qualitative Social Work*, 16(4), pp. 550–565. doi: 10.1177/1473325016635244.

Viswanath, V. (2019) *Bereavement and its Impact on Family Caregivers*, *todaysclinician.com*. Available at: https://todaysclinician.com/bereavement-and-its-impact-on-family-caregivers/ (Accessed: 21 October 2021).

Walker, E. and Collier, E. (2016) ‘Hidden in plain sight; the reality for older military veterans’, *Journal of Psychiatric and Mental Health Nursing*, 23(3–4), pp. 143–144. doi: 10.1111/jpm.12292.

Walker, M. (2007) *Moral understandings: a feminist study in ethics*. 2nd edn. Oxford: Oxford University Press.

Walker, S. L. *et al.* (2019) ‘The Lived Experience of Persons With Malignant Pleural Mesothelioma in the United States’, *Cancer Nursing*, 44(2), pp. E90–E98. doi: 10.1097/NCC.0000000000000770.

Walmsley, B. D. and McCormack, L. (2021) ‘Dementia families: Relinquishing home care to aged care services: Guilt, traumatic loss and growth’, *Dementia*, 20(5), pp. 1814–1831. doi: 10.1177/1471301220970784.

Warby, A., Dhillon, H. M., *et al.* (2019) ‘A survey of patient and caregiver experience with malignant pleural mesothelioma’, *Supportive Care in Cancer*, 27(12), pp. 4675–4686. doi: 10.1007/s00520-019-04760-x.

Warby, A., Dhillon, H., *et al.* (2019) ‘Managing malignant pleural mesothelioma: experience and perceptions of health care professionals caring for people with mesothelioma’, *Supportive Care in Cancer*, 27(9), pp. 3509–3519. doi: 10.1007/s00520-019-4648-0.

Warnock, C. *et al.* (2019) ‘Patient experiences of participation in a radical thoracic surgical trial: findings from the Mesothelioma and Radical Surgery Trial 2 (MARS 2)’, *Trials*, 20, p. 598. doi: 10.1186/s13063-019-3692-x.

Wawrziczny, E. *et al.* (2014) ‘Couples’ experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics’, *Dementia*, 15(5), pp. 1082–1099.

Way, D. *et al.* (2019) ‘Top Ten Tips Palliative Care Providers Should Know About Caring for Veterans’, *Journal of Palliative Medicine*, 22(6), pp. 708–713. doi: 10.1089/JPM.2019.0190.

West, H. and Antrobus, S. (2021) ‘“Deeply odd”: women veterans as critical feminist scholars’, *Critical Military Studies*, [preprint]. doi: 10.1080/23337486.2021.1907020.

Whitehead, P. B. and Clark, R. C. (2016) ‘Addressing the challenges of conducting research with end-of-life populations in the acute care setting’, *Applied Nursing Research*, 30, pp. 12–15. doi: 10.1016/j.apnr.2015.08.006.

Van Wijngaarden, E., Van Der Meide, H. and Dahlberg, K. (2017) ‘Researching Health Care as a Meaningful Practice: Toward a Nondualistic View on Evidence for Qualitative Research’, *Qualitative Health Research*, 27(11), pp. 1738–1747. doi: 10.1177/1049732317711133.

Williams, B. *et al.* (2008) ‘Identifying and Responding to Ethical and Methodological Issues in After-Death Interviews with Next-of-Kin’, *Death Studies*, 32(3), pp. 197–236.

Williams, K., Morrison, V. and Robinson, C. (2014) ‘Exploring caregiving experiences: caregiver coping and making sense of illness’, *Aging & Mental Health*, 18(5), pp. 600–609.

Williams, T. and Carel, H. (2018) ‘Breathlessness: from bodily symptom to existential experience’, in Aho, K. (ed.) *Existential Medicine*. London: Rowman & Littlefield International, pp. 145–160.

Williamson, V. *et al.* (2019) ‘Impact of military service on physical health later in life: a qualitative study of geriatric UK veterans and non-veterans’, *BMJ Open*, 9(7), p. e028189. doi: 10.1136/bmjopen-2018-028189.

Willig, C. (2016) ‘Constructivism and “The Real World”: Can they co-exist?’, *QMiP Bulletin*, (21). Available at: https://openaccess.city.ac.uk/id/eprint/13576/1/.

Wilson, E., Caswell, G. and Pollock, K. (2021) ‘The “work” of managing medications when someone is seriously ill and dying at home: A longitudinal qualitative case study of patient and family perspectives’, *Palliative Medicine*, [preprint]. doi: 10.1177/02692163211030113.

Wilson, S. (2008) *Research as ceremony: indigenous research methods*. Nova Scotia: Fernwood Press.

Windelband, W. (1893) *History of Philosophy*. New York: Macmillan.

Wolgemuth, J. *et al.* (2015) 'Participants' experiences of the qualitative interview: considering the importance of research paradigms', *Qualitative Research*, 15(3), pp. 351–372. doi: 10.1177/1468794114524222.

Wood, N. (2019) *The Military Human*. York: York St John University.

Wood, N., Cotterill, D. and Cronin-Davis, J. (2017) 'Veterans: understanding military culture and the possible effects on engagement', in Long, C., Cronin-Davis, J., and Cotterill, D. (eds) *Occupational Therapy Evidence in Practice for Mental Health*. 2nd edn. Chichester: Wiley-Blackwell, pp. 191–222.

Woods, B. A. (2003) 'The Terror of the Night: Posttraumatic Stress Disorder at the End of Life', *Journal of Hospice & Palliative Nursing*, 5(4), pp. 196–204. doi: 10.1097/00129191-200310000-00012.

Woodward, R. and Jenkings, N. K. (2012) 'Military memoirs, their covers and the reproduction of public narratives of war', *Journal of War & Culture Studies*, 5(3), pp. 349–369. doi: 10.1386/jwcs.5.3.349_1.

Yardley, L. (2000) 'Dilemmas in qualitative health research', *Psychology & Health*, 15(2), pp. 215–228. doi: 10.1080/08870440008400302.

Yin, R. (2017) *Case Study Research and Applications: Design and Methods*. 6th edn. Thousand Oaks, CA: SAGE Publications Inc.

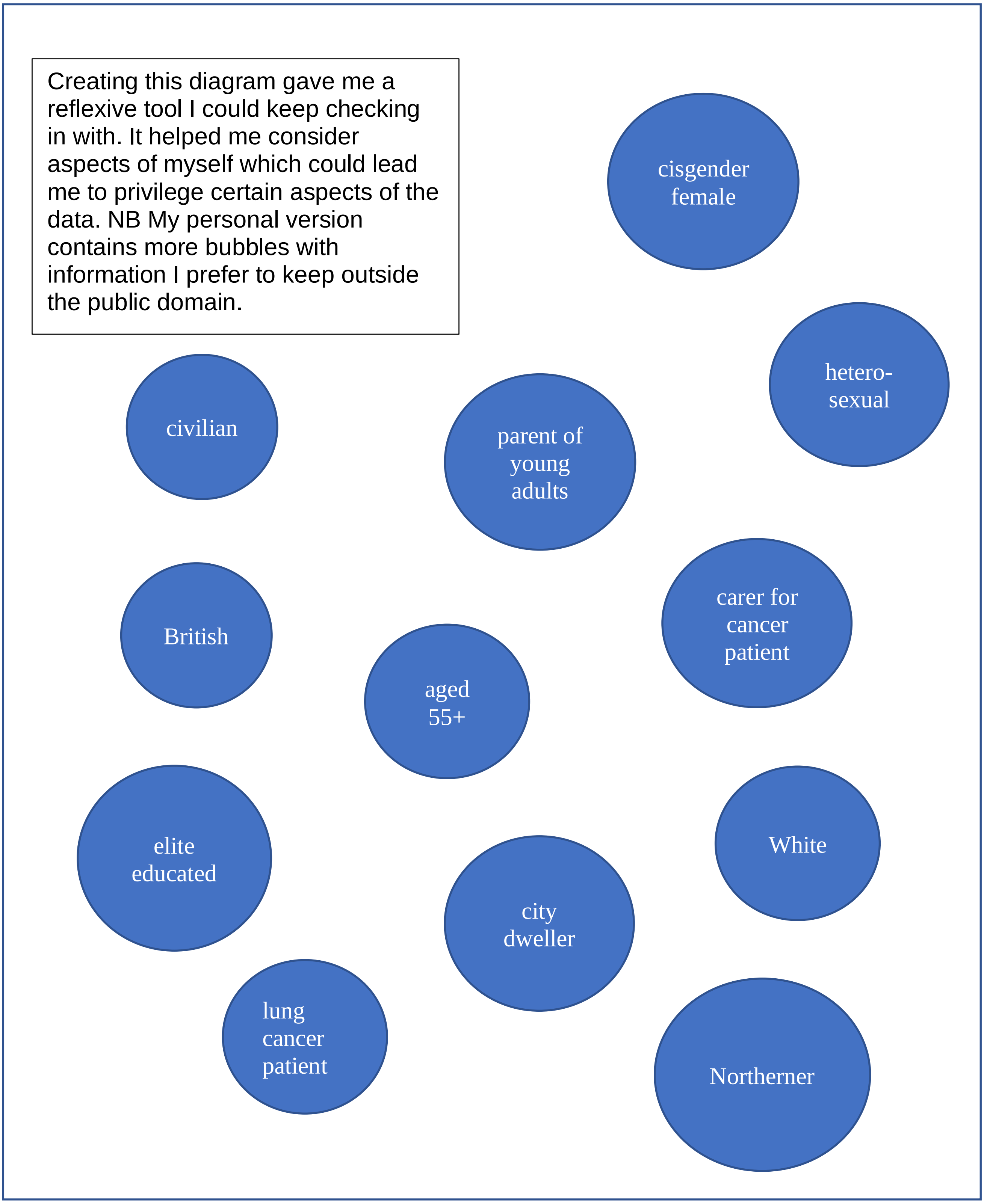
Zahavi, D. (2019) *Phenomenology: the basics*. Abingdon: Routledge.

Zeiler, K. (2014) 'A philosophical defense of the idea that we can hold each other in personhood: intercorporeal personhood in dementia care', *Medicine, Health Care and Philosophy*, 17(1), pp. 131–141.

Zinkhan, G. M. and Hayes, L. A. (1989) 'Changing patterns of other-directedness: A content analysis of women's magazines', *Journal of Social Psychology*, 129(6), pp. 825–831. doi: 10.1080/00224545.1989.9712091.

Appendices

Appendix A: Reflexive consideration of my intersectional identities



Creating this diagram gave me a reflexive tool I could keep checking in with. It helped me consider aspects of myself which could lead me to privilege certain aspects of the data. NB My personal version contains more bubbles with information I prefer to keep outside the public domain.

Appendix B: Scoping review published in *Psycho-oncology*

Check for updates

Received: 30 March 2020 | Revised: 5 June 2020 | Accepted: 21 June 2020

DOI: 10.1002/pon.5454

REVIEW

WILEY

What are the psychological effects of mesothelioma on patients and their carers? A scoping review

Virginia Sherborne | **Jane Seymour** | **Bethany Taylor** | **Angela Tod**

Division of Nursing and Midwifery, The University of Sheffield, Sheffield, UK

Correspondence
Virginia Sherborne, Division of Nursing and Midwifery, The University of Sheffield, Barber House, 387 Glossop Road, Sheffield S10 2HQ, UK.
Email: hvsherborne1@sheffield.ac.uk

Funding information
Mesothelioma UK, Grant/Award Number: R/153919

Abstract

Objective: Despite recent advances in research, malignant mesothelioma remains an incurable and devastating disease, typically bringing shock and emotional distress to patients and carers. Little research has addressed the psychological impact on either group. This scoping review examines the current state of evidence on the psychological effects of mesothelioma on patients and carers, and identifies areas for further research.

Methods: We searched PubMed, PsychINFO, CINAHL, the Cochrane Library and Web of Science for English-language peer-reviewed research articles published 1981 to 2019 reporting studies focussing on the psychological effects of mesothelioma on patients and carers. Following data extraction and quality appraisal, reflexive thematic analysis was used to identify themes.

Results: Seventeen articles met the inclusion criteria. Carers' experiences were generally amalgamated with patients'. Three themes were developed. *The Passing of Time* included the importance of timing of interventions; delays in the medical journey; awareness of different time-phases in mesothelioma; and uncertainty/certainty. *Dealing with Difficult Feelings* reflected ubiquitous negative emotions, feelings about identity and states of being and associated coping strategies. *Craving Good Communication* covered issues related to sharing of information and to positive/negative aspects of communication.

Conclusions: Though limited, the evidence indicates that mesothelioma, with its high symptom-burden, incurability, rarity and asbestos-related causation, leads to complex and inter-relating psychological effects on patients and carers. These effects are both negative and positive. The sparse literature gives a partial picture and demonstrates an urgent need for more nuanced research. Studies exploring the experiences of specific groups are recommended, with particular attention required to carers.

KEYWORDS
cancer, caregivers, communication, diagnosis, mesothelioma, oncology, palliative care, psychological distress, psycho-oncology, review

1 | INTRODUCTION

Malignant mesothelioma (MM) is an incurable disease usually linked to asbestos exposure.[1] There are two main types: the most common, malignant pleural mesothelioma (MPM), affecting the membrane lining the lungs and chest wall, and peritoneal mesothelioma (PM), affecting the abdominal lining.[2] Symptoms appear after a long latency period (20-50 years), with the disease often progressing very quickly.[3] Mesothelioma is usually diagnosed in older people.[1] Survival rates are poor: for 2014 to 2016 the percentage of patients in England and Wales surviving 1 year post-diagnosis was 38%, and 3 years post-diagnosis was 7%.[1] Within these figures, there is a significant difference in survival times for different subtypes. In mesothelioma's initial stages, symptoms tend to be non-specific, meaning it is often diagnosed at a late stage.[4] However, occasionally, mesothelioma is diagnosed at an asymptomatic stage after an incidental finding.[5] Once disease is advanced, the symptom burden is severe, including breathlessness, chest wall pain, weight loss, sweating and fatigue, with severity increasing and sometimes proving difficult to palliate.[6]

Research into the lived experience of mesothelioma patients has been sparse. Cancer patients in general experience psychological distress, including anxiety, depression, existential concerns and post-traumatic stress.[7-9] They may also experience posttraumatic growth.[10] Carers of cancer patients in turn are more likely to experience depression, anxiety, hopelessness, isolation, somatic symptoms and financial issues.[11] Mesothelioma, with its high symptom burden, incurability, rarity and asbestos-related causation, has a unique psychosocial impact.[12]

Although mesothelioma remains incurable, recent advances in clinical research are providing more treatment options, such as immunotherapy.[13] Further research into the psychological aspects of mesothelioma is required to map any changes that may be occurring alongside the changes in medical treatment and prognosis. This applies to carers as well as patients, as their wellbeing is an important part of the picture.[13,14] However, the experience of carers has not been a particular focus of mesothelioma research to date.[15] Therefore, the aim of this scoping review was to examine the current state of evidence on the psychological effects of mesothelioma on patients and carers, and identify areas for further research.[16]

2 | METHODS

In line with scoping review methodology, the search question was suitably broad, but had clarity regarding the scope of inquiry[17]: what is the current state of the evidence on the psychological effects of mesothelioma on patients and their carers? The population was 'patients and carers', the intervention was 'mesothelioma' (covering all disease types), and the outcome was 'psychological effects' (positive and negative).

A scoping review does not aim to be exhaustive, but to give an initial assessment of the available literature.[18] Therefore, any potentially relevant articles identified from the reference lists of the retrieved articles or from Google Scholar were included, but grey literature was not, nor were attempts made to locate on-going, unpublished research in the field. This decision, made for feasibility reasons, provided a limitation to comprehensiveness.

The review was conducted using the staged method described by Arksey and O'Malley[16] and Levac et al.[17] It was reported following the PRISMA Extension for Scoping Reviews Checklist,[19] with the aim of being systematic, transparent and replicable.[20] A protocol was not registered.

Keywords from published relevant articles were reviewed to inform this process (see Figure 1). Searches took place in May 2019 of these bibliographic databases: PubMed, PsychINFO via OvidSP, CINAHL, the Cochrane Library and Web of Science. Search parameters were adjusted to match individual database requirements.

An example search strategy (CINAHL) is given in the Appendix. The results for each database search were exported into EndNote and duplicates removed. A flowchart of the search strategy is given in Figure 2

For inclusion, articles had to be peer-reviewed research articles (reporting empirical qualitative, quantitative, or mixed methods studies and literature reviews). Other inclusion criteria were:

- in English (practical reasons);
- involving adult humans (mesothelioma extremely rare in children);
- dating from 1981 (seminal Lebovits article published[21]) to May 2019;
- focussing on psychological effects (not physical aspects of symptoms/treatment);
- focussing on mesothelioma (mentioned in title or abstract).

Population (all fields)	patients/carers	patient* families family caregiver* carer*
Intervention (title/abstract)	mesothelioma	mesothelioma
Outcome (all fields)	psychological effects**	psychological psychoncology psychooncology psycho-oncology psychosocial support* social uncertainty hope* anxiety depression coping

** Definition of psychological effects = psychological symptoms; emotional responses; coping strategies/mechanisms.

FIGURE 1 Relevant keywords identified

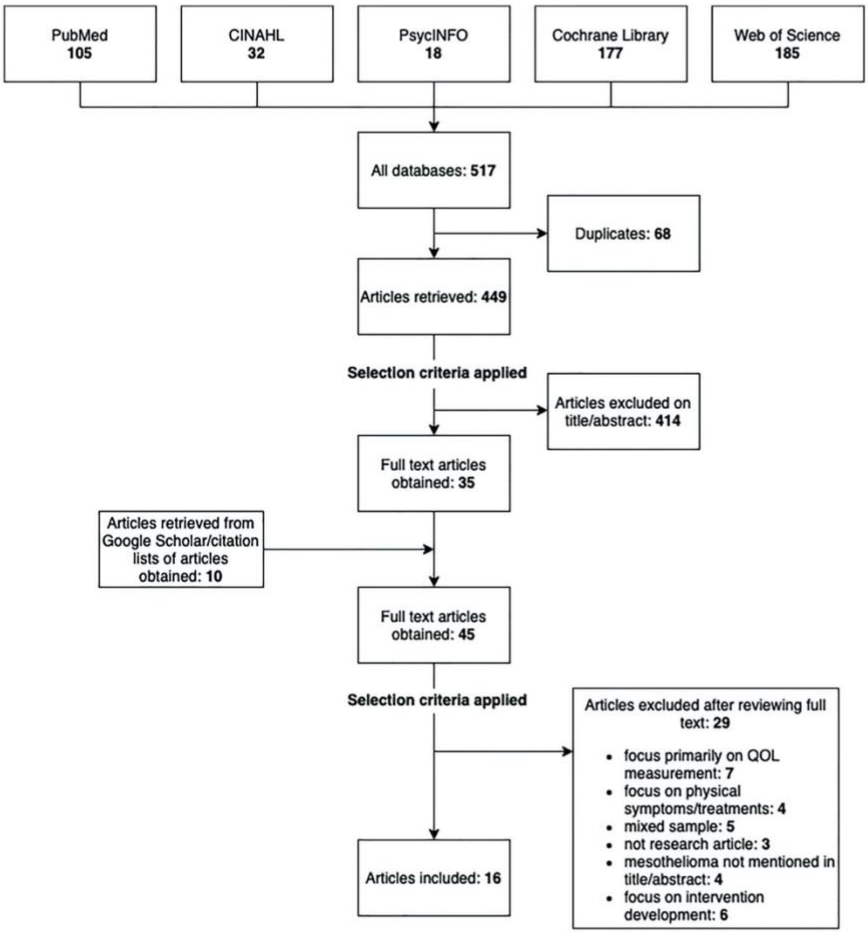


FIGURE 2 Possibly relevant articles identified from electronic searches

Exclusion criteria applied were:

- not in English;
- not involving adults;
- focussing on clinician's perspective, rather than patient's/carer's;
- about questionnaire development or focussing primarily on quality of life (QOL) measurement (eg, part of a clinical trial or QOL tool development), as these would not focus on content but on the tool's validity and reliability;
- about physical symptoms, treatments or epidemiology;
- focussing on intervention development;
- conference abstracts, dissertations, editorials, book reviews, individual case reports;
- concerning lung and pleural cancers (ie, mixed sample).

A single reviewer (VS) applied the inclusion and exclusion criteria to the retrieved articles after duplicate removal. Titles and abstracts were screened for relevance and irrelevant articles excluded. The remaining articles were obtained in full text and exclusion criteria were applied. Broadly following the team approach recommended to aid rigour,[17] the authors met to discuss eligibility decisions at the beginning of the process. The team also discussed and agreed inclusion/exclusion after the full text studies were obtained. Further interrater reliability measures were not undertaken for practical reasons and due to time constraints.

Data were extracted by VS from the articles into forms based on examples provided by Booth et al[18] for qualitative and quantitative articles. No testing or calibration of the forms was conducted. The following items were extracted: citation; location; research objectives;

participant details; recruitment and sampling methods; data collection and analysis methods; relevant findings and results; authors' conclusions; possible new relevant articles from references. To identify findings and results relevant to the research question, VS reviewed each article's abstract and results sections. Discussion sections were also scrutinised in case any extra findings had been presented here rather than in the results section.

We wanted to understand the range and quality of the existing evidence. While there is debate about quality appraisal in scoping reviews,[20,22,23] we decided to follow a quality appraisal process. The aim was to inform the review by giving an overview of the quality of the existing literature as a whole, including the quality of reporting, but without excluding any of the identified articles. (The authors noted quality appraisal was conducted by Ball et al.[6]) For our review, after data extraction the articles were critically appraised using CASP checklists.[24]

As is recommended to aid rigour,[16,17] our *Results* section included a descriptive numerical summary and qualitative thematic analysis of key relevant findings. Braun and Clarke's[25,26] reflexive thematic analysis was employed, using *Quirkos* QDA software. Steps completed were:

1. familiarization with the data: reading and re-reading, noticing interesting features, making notes and asking reflexive questions;
2. generating codes: inductively identifying clear labels for important features throughout the dataset and collating relevant extracts;
3. generating candidate themes: identifying meaning-based patterns in the codes and data:
4. reviewing themes: checking the candidate themes against the dataset, ensuring each relates to a central concept, and sensing how each theme relates to the others;
5. defining themes: naming and developing a detailed analysis of each.

To stay close to the data, VS generated semantic, rather than latent, codes, which stay at the surface of the data,[26] for example, loyalty; stigma; future. Developing the themes was a consciously creative process, requiring reflection and thoughtfulness.[27] Reflexive questions were useful throughout the analysis process, for example, 'Am I making assumptions about loyalty to former employers?' *Quirkos* enabled codes to be clustered and combined, helping VS identify meaning-based patterns. For example, clusters named 'difficult feelings', 'positivity' and 'coping strategies' combined, becoming the theme *Dealing with Difficult Feelings*.

3 | RESULTS

After duplicate removal, 449 articles were retrieved from searching the databases. Of these, 414 were excluded after review of title or abstract. The remaining 35 articles' full text was obtained, and their citation lists reviewed for possibly relevant articles. Along with Google Scholar searches, this process resulted in 10 further potentially relevant articles being obtained in full text. Eligibility criteria were applied, leading to exclusion of 29: seven focussed primarily on QOL measurement, four focussed on physical symptoms/treatments, five used mixed samples, three were not research articles, four did not mention mesothelioma in title or abstract, and six focussed on intervention development. This left 16 articles eligible for review (see Figure 2). VS subsequently learned from a nurse specialist (CNS) about an article[28] published December 2019, which met our search criteria. We included this.

The review's findings are presented in two ways: a basic analysis of the characteristics of the included studies, and a report of the themes developed from the data.[16]

3.1 | Characteristics of the included studies

An overview of the charted characteristics and critical appraisal data for each included article is presented in Supporting Information S1. The 17 articles comprised 11 qualitative, two quantitative and three literature reviews Moore et al,[29] Bonafede et al,[12] Ball et al[6] and one article[30] combining the reporting of a qualitative study with a literature review (see Supporting Information S2 for details). The precise definition of mesothelioma varied across the articles (see Supporting Information S2).

Considering the qualitative studies first, four were conducted in the UK, one in Australia, two in Italy, two in Japan, and three in the USA. Nine articles aimed to explore the subjective experience of mesothelioma and identify care and support needs. Two studies explored psychological issues around risk awareness.[21,31] One developed recommendations to improve the diagnosis experience.[32] The majority investigated MPM, while four looked at MPM plus peritoneal. The range of participants was 5 to 112. Eight studies were situated in large teaching hospitals. Two recruited via local specialist nurse referrals, and two via nationwide hospitals, groups and networks. The qualitative studies commonly excluded anyone judged 'not well enough' to participate, or who had a psychiatric diagnosis, or who might experience aggravated emotional distress. Only three included carers and relatives in their design.[30,32,33] In a few articles attention was paid to teasing out patient and carer experiences at different time-points in the disease's course: at diagnosis,[32,34] and in the first 6 months.[30] Kasai and Hino[35] conducted the first longitudinal qualitative study in this field, examining five transition points in disease progression with participants diagnosed 5 to 8 years previously. Whilst the majority of cases of mesothelioma in the literature were men who had been exposed occupationally, the Italian articles[12,15,30] included a higher proportion of females, as they studied people exposed by living in or near National Priority Contamination Sites (rather than occupationally exposed males as is typical).

Of the quantitative studies, one was conducted in the UK (with no specified mesothelioma type), one in Australia (MPM). Dooley et al[36] assessed 49 patients who were suing their employer, aiming to investigate stress and depression symptoms in men with mesothelioma. Henson et al[37] aimed to quantify suicide risk in patients with cancer and identify risk factors to help with psychological assessment. They covered the whole population of people who died by suicide after cancer diagnosis in England. Their statistical study allowed comparison of the first 6 months after diagnosis to the rest of the patient's life. For the handling of missing data in the quantitative articles, see Supporting Information S2.

In the three literature reviews, studies conducted in the UK, Europe, the USA and Australia predominated (see Supporting Information S2). Moore et al[29] aimed to identify what was known about the experience of living with mesothelioma. Bonafede et al[12] reviewed the research on psychological aspects of MM patients and asbestos-exposed people. Ball et al[6] evaluated if MPM and advanced lung cancer patients' psychological care needs differed. The number of participants ranged from 6 to 63,[12] 2 to 15[6] and 5 to 409.[29] Ball et al's[6] review only covered MPM, whereas the others looked at all mesothelioma types. Only Moore et al[1] included the experience of carers or families.

3.2 | Quality appraisal

The critical appraisal carried out informs the following overview of the field's quality. Of the qualitative articles, three were rated as low risk of bias[28,32,38]; the rest were rated unclear. Of the quantitative, Henson et al[37] was rated low, and Dooley et al[36] unclear. All three reviews[6,12,29] were rated unclear.

A limitation commonly reported was generalisability: numbers of participants were small, due to mesothelioma's rarity and recruitment difficulties caused by its debilitating nature. The only large-scale study was Henson et al,[37] which added a new dimension to the field by uncovering suicide risk. Kasai and Hino,[35] in the only longitudinal study, marked out the illness into five time-periods and provided a useful new framework, but could only follow five participants. All three literature reviews[6,12,29] highlighted the paucity of studies on psychological aspects and lived experiences of mesothelioma patients and carers. They also usefully drew out differences between the experience of mesothelioma patients and those with lung cancer or asbestos-exposed people. The reviews together gave a wider reach across the field, each having a different emphasis and scope of their search (see Supporting Information S2). The Italian group added a new psychoanalytical perspective.[12,15,30] Along with Dooley et al,[36] their articles were the only ones to refer specifically to trauma theory. Overall, the studies presented clear rationales, used appropriate methods, and gained appropriate ethical approval. They related their findings to practice and relevant research-based literature, suggesting areas for future research (eg, developing needs-assessment tools) and practice improvements. However, there was sometimes a lack of clarity around the purpose and extent of involvement of carers and family members in the interviews.

In terms of the standard of reporting, as assessed by the critical appraisal checklists,[24] only four articles could be considered excellent.[28,32,37,38] Amongst the others, there was some lack of transparency regarding reporting of methods. It is possible the journals' limited word counts had an effect. The most noticeable area of omission was detailing the relationship between researcher and participants. There was little critical examination of the researcher's own role, with potential for bias and influence, both in the formulation of questions and in data collection, and there was sometimes lack of clarity around the role of the patient's own medical team. However, more consideration was given to potential bias in the analysis process. In terms of representation, the voices of participants were heard more easily, and showed more range, in some studies than others.

This section has presented the findings relating to the characteristics of the 17 identified articles. Next, this review summarises the findings relating to key themes developed, which captured the range of data in the articles.

3.3 | Themes

Three themes relating to the research question were developed from the data: 'The Passing of Time', 'Dealing with Difficult Feelings' and 'Craving Good Communication'.

3.4 | The passing of time

This theme appeared in all 17 articles, in different guises: the importance of timing for various interventions; delays in the medical journey; awareness of different time-phases in mesothelioma; and the uncertainty/certainty axis (Table 1).

Four studies[6,12,15,30] identified the first time-period: pre-diagnosis. For mesothelioma, there is an extra dimension around causality, and the 'Damocles syndrome' (retrospective awareness of personal risk from asbestos exposure was identified as a cause of anxiety and distress.[6,12,15,30] These feelings could also be generated by awareness that the patient's own contact with asbestos may have led to the second-hand exposure of family members, for example, by washing work clothes.[12]

Two studies[15,32] highlighted another difficult aspect of this initial period: the long, frustrating journey to a definitive diagnosis. Diagnosis was a significant time-point in 14 articles, bringing shock, anger, anguish, numbness, anxiety and depression. The fact that the patient's time was now limited brought a terrible certainty. However, alongside the certainty came distressing *uncertainty* about disease progression and the future.[6,35] Issues of timing caused distress at diagnosis, for example, the appointment not being long enough; inappropriate levels of information about the illness and compensation.[32,33,40]

The initial phase of the illness is critical in terms of suicidality. 'Henson et al[37] showed that, when considering variation in suicide risk by years since diagnosis, out of all cancer types mesothelioma patients had the highest risk of suicide in the first 6 months, with an 8.61-fold risk compared with the general population'. Hopelessness was identified as a result of negative messages from healthcare professionals by Ball et al[6] and Girgis et al.[33]

TABLE 1 Participant quotations

Theme	Quotation	Source
The passing of time	Many friends of mine died because of mesothelioma. This makes you wonder who will be the next one. When the ultimate diagnosis arrived, it killed me in a moment […] I've been killed that day. I do not know what tomorrow will bring or next month. I do not even know if I can look to Christmas…really, I do not know the speed of these things. You need a little bit of time just to discuss or talk about it. You go away, you know nothing. You do not even know what mesothelioma is. We filled all the forms in…and we have not received anything yet. […] I'm still waiting for some crazy doctor to come to disprove what the hospital proved. And that's my worry, that's my biggest worry.	Patient, Guglielmucci et al[15] Patient, Guglielmucci et al[15] Patient, Ball et al[6] Patient, Taylor et al[32] Patient, Clayson et al[38]
Dealing with difficult feelings	It was a terrible ordeal. No pain, no. Not painful at all, but it's the weirdest experience [pleural drainage]. It's like living as rats in the hole. He gets very frustrated and irritable [and] then he cries because he wants to be doing things. […] it's very hard, I feel like a punch bag. There is a lot of anger, and it's not my fault. It does not pay to think too far down the road because that's bad news. As you say, head in the sand. He [husband] does not want to talk about my disease […] He does not talk with anybody. […] he is annoyed, because he says this is our business. I ain't going away without a fight! I'm not just going to carry on. I'm going to crack on. Well what we are going to do is to enjoy each day. I hope I've walked well in my life, to have spent it well and that's it. If [the treatments] will go well, I am really happy, because I still have some ambitions to realize. If it will go bad, it does not matter.	Patient, Moore et al[2] Carer, Guglielmucci et al[15] Carer, Hughes and Arber[39] Patient, Arber and Spencer[34] Patient, Guglielmucci et al[15] Patient, Girgis et al[33] Patient, Moore et al[29] Patient, Guglielmucci et al[15]
Craving good communication	She was able to explain a lot of it and she used drawings and pictures and things to show me because I had not even got a clue. Being well-informed and knowing my results eases my anxiety and gives me a sense of control. I want my doctor to tell me everything, including bad news. Do not tell me the bad news. Just let me know something good. I knew that she [CNS] would be there, she told me, she'd be on the phone, and I could ring her any time. I hope my doctor not only treats my tumour but also takes care of me. I am not a box with cancer; but a living person. I do not have a companion. At night, I find myself alone. You cannot say: 'I have someone to whom I can talk about that'. I wanted to talk to people, but they were [not] going through the same thing. And there was no one there for me.	Carer, Taylor et al[32] Patient, Nagamatsu et al[40] Patient, Nagamatsu et al[40] Patient, Nagamatsu et al[40] Carer, Taylor et al[32] Patient, Nagamatsu et al[40] Patient, Guglielmucci et al[15] Carer, Girgis et al[33]

After the initial period, the speed and unpredictability of disease progression caused intense anxiety, as three studies showed.[6,12,30] Sometimes, lack of continuity with medical staff left patients unsure about the next treatment steps, with an inability to plan ahead accompanied by distrust of medical interventions and HPCs.[12,15] In a study examining the communication of a mesothelioma diagnosis Taylor et al[32] aimed to understand how a diagnosis can be communicated well and distress can be minimised. They highlighted that breaking bad news (BBN) could occur at many different time-points. Within the mesothelioma patient journey there were multiple episodes of bad news: although diagnosis was the main one, there were others, such as not being eligible for a trial.

'The future' as a stimulus for worry about loved ones was a time-related feature reported by several articles.[6,15,36] Clinically significant posttraumatic stress symptoms were linked by Dooley et al[36] to physical symptoms, reminding patients they were going to die and making them think about their families' future. Legal and financial issues took up frustrating amounts of precious time, and the patient's death was not the end-point of the journey, as legal/financial matters dragged on further.[6,15,30,39]

3.5 | Dealing with difficult feelings

All 17 articles presented difficult feelings and allied coping strategies. 'Difficult feelings' includes negative emotions, and also feelings around identity and states of being (Table 1). These had a range of causes, some described above. Physical symptoms, for example, pain and sweating, were inherently upsetting or frightening, and also frustrating in their impact on independence and social roles.[6,12,34,39] Feeling socially isolated was mentioned in several articles, resulting from depression, apathy and stigma.[15,30,39]

The physical burden took its toll on carers, and patients worried about being a burden[6] or agreed to treatment to keep relatives happy[35] who in turn could feel guilty.[29,33]

Distress sometimes resulted from the effect of professionals' activities. It was caused by medical treatments[29,30]; lack of continuity[6,32]; feeling abandoned if chemotherapy was not an option[39]; and feeling like guinea pigs during trials.[15] The anger that was identified was linked to two causes. The first was patients' frustration at not being able to do ordinary activities, with carers also feeling helpless or angry about changes in the patients, such as their sense of identity, willingness to live a normal life, or their irritability.[15,39] Second, complex medico-legal matters led, for some, to feelings of anger and betrayal towards employers. For others, conflicted loyalty towards former employers meant anger was redirected towards families or doctors.[6,12,39]

These many difficult feelings led patients and carers to experience a lack of control. This could include feeling powerless over the disease; having to relinquish family responsibilities; fearing total loss of agency at end-of-life; and insecurity about how to live and who could help.[28,34]To cope, they engaged in a wide range of strategies. Avoidance/denial was identified as the main mechanism.[12] Strategies included deciding that statistics do not apply; limiting information[33]; trying to live normally[6]; and denying negative emotions.[15] Refusing to talk or think about things was frequently used both by patients and carers.[15,30,39] However, this tended to increase social isolation, brought relationship difficulties, and came at a cost to the individual.

A fighting spirit was identified as helping to protect a sense of control.[33,35] Other factors giving a sense of control were accessing complementary/alternative medicine, support groups, palliative care, physiotherapy and maintaining fulfilling social and family roles.[6,12]

Some participants had an accepting attitude, reviewed their lives, mourned their losses and looked for the positive.[15,29,33,35] Patients were more likely to report acceptance than carers.[29]

Only the quantitative studies[36,37] highlighted suicide as a coping strategy. Henson et al[37] showed patients with mesothelioma had the highest suicide risk of all English cancer patients. All participants in Dooley et al's study[36] reported significant traumatic stress symptoms co-morbid with increased depression and anxiety, which could put them at risk of suicide. Hopelessness appeared as an important aspect of the mesothelioma experience compared with that of lung cancer,[6] with the difference explained by mesothelioma's incurability, poor prognosis and lack of treatment options.

3.6 | Craving good communication

Issues around the sharing of information and positive/negative aspects of communication (Table 1) were reported by 16 articles. In Nagamatsu et al's[40] study of patients' requests to doctors, most focused on communication. Inept or thoughtless information delivery caused huge distress and hopelessness. This happened at diagnosis,[6,32,33] when shock affected capacity to absorb information, or later, regarding specialist supportive care services and responsibility for treatment decisions.[6,39] The timing of compensation/benefits information needed special care.[6] Participants wanted clear, understandable explanations, with opportunity to ask questions.[32,40] Getting accurate information at the right time could be very helpful, for example, by lessening worries about progression, or giving comfort and a feeling of agency about finances.[6,30,40]

The importance of getting the balance right for each individual was stressed, using a customised, patient-centred approach to reflect the huge variation in what people want and can take in Reference 32,33,40. Whilst the majority of Nagamatsu et al's[40] participants wanted honesty, a significant minority preferred only good news.

As well as difficulties with doctor-patient information transfer, there were issues within families. Carers struggled to decide who to share with,[33] and worried about upsetting others.[6] Some patients were overwhelmed with shame and guilt which they could not verbalise.[15] The issue of risk information coming haphazardly, from non-employer sources, was highlighted.[12]

Participants clearly valued good communication skills and practices in health care professionals (HCPs). Effective multi-disciplinary team-working meant informing specialist nurses immediately mesothelioma was suspected; BBN was shared across the team; participants knew what to expect; and hope could be maintained.[12,32] A kind, warm, inclusive way of talking was appreciated.[32,40] Caseworkers were useful for communicating across the gap between physicians and patients/carers, and providing much needed individual emotional support.[15,33]

Several studies presented the need of carers and patients for communication with others who had the same experience and understood the nuances of this rare disease.[33,35,39] They valued the emotional support, and some patients found it helped them prepare for dying.[35] For some families, talking to each other about mesothelioma and its effects was extremely difficult, and they wanted to be helped by psychologists to find new ways to communicate.[15] Skilled listeners, for example, psychologists were identified as able to provide valuable emotional support.[15]

Hughes and Arber[39] found their participants were grateful for being heard, telling their stories urgently despite becoming very distressed. They also reported their participants had issues with sex and intimacy, as did Dooley et al,[36] though this was only alluded to in other studies.

4 | DISCUSSION

This review has provided insight into the literature of the psychological effects of mesothelioma on patients and carers. The characteristics of the studies were presented, along with quality appraisal. The majority of our 17 included articles were qualitative. Only two were quantitative. Studies conducted in Europe, North America and Australia predominated. Most of the literature related to the overall experience of mesothelioma over the course of the disease from the patient's perspective. The majority of our included studies were assessed as having unclear risk of bias, with only four having low risk. Three themes relating to the research question were developed from the data. The first showed aspects regarding time passing, which are specific to the mesothelioma journey. The second indicated the difficult feelings and allied coping strategies experienced by patients and carers. The third provided a picture of communication issues.

Until relatively recently, researchers did not place emphasis on psychological effects at different stages of the disease, or consider the variety of prognoses, treating the mesothelioma journey as uniform.[29] The general need for more nuance has been recognised and is starting to be addressed, for example, by Ball et al's[6] differentiation of mesothelioma from lung cancer. With attention now paid to the early stages of the disease, there is a need for focus on the impact of progression, taking into account the difference between indolent and aggressive types of mesothelioma.[29] This is important as new treatments come on line, and survival times vary even more.

The sparse nature of the field of evidence means there are many research gaps. Few studies included patients with PM. Where included, their experience was not differentiated from MPM, so more research is needed. The majority of qualitative studies had exclusion criteria such as existing psychiatric diagnosis, risk of aggravating distress, or being considered 'well enough'. In addition, mainly hospital patients were studied, omitting those receiving only supportive care.[6] Therefore, it is likely people who have more psychological difficulties (such as PTSD and dementia) or distress are missing from the picture, except in the quantitative data. There is potential for qualitative research to be opened up to such people, for example, those affected by military experiences, with sufficient ethical safeguards in place. Studies show that vulnerable participants can find benefit from participating, even if it is a distressing experience.[41,42] There is an important question about psychological trauma being caused by catastrophic diagnosis, frightening medical treatments, and symptoms such as breathlessness[32,43,44] which requires investigation in regard to mesothelioma.

Despite the review's search terms allowing for positive effects to be reported, the emphasis in the studies was mostly on the negative. The most recent article, by Walker et al,[28] was an exception, with its finding that participants frequently expressed hope and optimism. The wider cancer literature includes studies on posttraumatic growth, benefit-finding and hope.[10,45-47] There is therefore scope to explore positive aspects of the mesothelioma experience, which might help counter the hopelessness often transmitted by HCPs.

None of the studies explored the unique experience of carers. If included at all, they were mixed in with patients, so their particular concerns and needs were muted and overlooked. This lack of inclusion may in part be due to lack of recognition by carers themselves, since many relatives, friends or partners of patients might reject the term 'carer' as not applying to them.[48] It may also reflect a lack of recognition by researchers and healthcare systems.[49-51] A nuanced exploration of the psychological effects on this group is needed. The studies hint that there are issues related to intimacy and sex for people with mesothelioma and their partners, which could be explored in future research.

The studies included in the review came from a limited number of developed countries. The findings from Italy, which particularly showed stigma and social isolation where a whole community was contaminated, suggest that local variations in circumstance can bring different effects. It is important therefore to research the experience of mesothelioma in other countries, such as South Africa, where incidence is under-reported and healthcare is limited.[52]

So far, no studies have reported the effects on populations who differ by type of workplace (eg, education, healthcare), causation (eg, secondary exposure, unidentified), gender, social class or age.

4.1 | Study limitations

This review was conducted in partial fulfilment of a doctorate. A single researcher carried out the majority of the review using a reflexive process. However, the process and the themes identified were extensively discussed in doctoral supervision with the other authors. Existing studies with psychological effects as secondary outcomes could include valuable relevant information. Our decision not to include these was therefore a limitation. The scope of our search could have been wider (no inclusion of grey literature or attempt to find on-going research). In mitigation, the aim was to be reproducible through transparency in conduct and reporting, with provision of good documentation.[18]

4.2 | Clinical implications

This review has highlighted the importance of clinical practitioners being aware of the complex psychological impact and sequelae of mesothelioma. The findings indicate currently there is little evidence to inform clinical practice related to the psychological impact of mesothelioma, especially with regard to carers. However, our findings could inform the development of an assessment tool to identify psychological issues and address risk. They could also impress upon HCPs the importance of communication skills training.

5 | CONCLUSIONS

Though limited, the evidence indicates that mesothelioma, with its high symptom-burden, incurability, rarity and asbestos-related causation, leads to complex and inter-relating psychological effects on patients and carers. These effects are both negative and positive. The sparse literature gives a limited picture and demonstrates an urgent need for more nuanced research. Studies exploring the experiences of specific groups are recommended, such as people exposed in different workplaces. No study has addressed the unique experience of carers, so this is suggested.

ACKNOWLEDGEMENTS

This study was conducted within a PhD funded by Mesothelioma UK within their Supporting Our Armed Services project.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

ETHICAL BACKGROUND STATEMENT

Ethical clearance was not required. A preliminary version was accepted for presentation at iMig2020.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created/analysed.

ORCID

Virginia Sherborne https://orcid.org/0000-0003-1106-765X
Angela Tod https://orcid.org/0000-0001-6336-3747

REFERENCES

1. Royal College of Physicians. *National Mesothelioma Audit Report (for the Audit Period 2014–16)*. London: RCP; 2018.
2. Hai B, Yang Y, Xiao Y, Li B, Chen C. Diagnosis and prognosis of malignant mesothelioma of the tunica vaginalis testis [Internet]. *Can Urol Assoc J*. 2012;6:E238-E241. https://doi.org/10.5489/cuaj.10200.
3. Nuyts V, Vanhooren H, Begyn S, Nackaerts K, Nemery B. Asbestos bodies in bronchoalveolar lavage in the 21st century: a time-trend analysis in a clinical population. *Occup Environ Med*. 2017;74(1):59-65.
4. Health and Safety Executive. *Mesothelioma in Great Britain [Internet]*. London: Health and Safety Executive; 2020: https://www.hse.gov.uk/statistics/causdis/mesothelioma/mesoarea-20.pdf
5. Giraudo C, Fraia AS, Bellini A, Fortarezza F, Rea F, Calabrese F. Unexpected pleural finding after a fall [Internet]; 2019; www.thelancet.com/oncology.
6. Ball H, Moore S, Leary A. A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer. *Eur J Oncol Nurs*. 2016;25:62-67.
7. Curran L, Sharpe L, Butow P. Anxiety in the context of cancer: a systematic review and development of an integrated model. *Clin Psychol Rev*. 2017;56:40-54.
8. Swartzman S, Booth JN, Munro A, Sani F. Posttraumatic stress disorder after cancer diagnosis in adults: a meta-analysis. 2017;34:327-339.
9. Linden W, Vodermaier A, Mackenzie R, Greig D. Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender, and age. *J Affect Disord*. 2012;141(2–3):343-351.
10. Casellas-Grau A, Ochoa C, Ruini C. Psychological and clinical correlates of posttraumatic growth in cancer: a systematic and critical review. *Psycho-Oncol*. 2017;26(12):2007-2018.
11. Kleine A-K, Hallensleben N, Mehnert A, Hönig K, Ernst J. Psychological interventions targeting partners of cancer patients: a systematic review. *Crit Rev Oncol/Hematol*. 2019;140:52-66.
12. Bonafede M, Ghelli M, Corfiati M, et al. The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: a systematic review of published studies [Internet]. *Am J Ind Med*. 2018;61(5):400-412. https://doi.org/10.1002/ajim.22831.
13. Colarusso G, Terzic J, Achard V, Friedlaender A. The role of immunotherapy in mesothelioma. *Precis Cancer Med*. 2019;2(21):1–10.
14. Lee CS, Lyons KS. Patterns, relevance, and predictors of dyadic mental health over time in lung cancer. *Psychooncology*. 2019;28(8):1721-1727.
15. Guglielmucci F, Franzoi IG, Bonafede M, Borgogno FV, Grosso F, Granieri A. "The less I think about it, the better I feel": a thematic analysis of the subjective experience of Malignant Mesothelioma patients and their caregivers [Internet]. *Front Psychol*. 2018;9:205. http://www.ncbi.nlm.nih.gov/pubmed/29515509.
16. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19-32.
17. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;5(1):69.
18. Booth A, Sutton A, Papaioannou D. *Systematic Approaches to a Successful Literature Review*. 2nd ed. Los Angeles: SAGE; 2016.
19. Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018;169(7):467-473.
20. Grant MJ, Booth A. A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Info Libr J*. 2009;26:91-108.
21. Lebovits AH, Chahinian AP, Gorzynski JG, Holland JC. Psychological aspects of asbestos-related mesothelioma and knowledge of high risk for cancer. *Cancer Detect Prev*. 1981;4(1–4):181-184.
22. Brien S, Lorenzetti DL, Lewis S, Kennedy J, Ghali W. Overview of a formal scoping review on health system report cards. *J Gen Intern Med*. 2008;23:355.
23. Verhage A, Boels D. Critical appraisal of mixed methods research studies in a systematic scoping review on plural policing: assessing the impact of excluding inadequately reported studies by means of a sensitivity analysis. *Qual Quant*. 2017;51(4):1449-1468.
24. Critical Appraisal Skills Programme. CASP Checklists - CASP - Critical Appraisal Skills Programme [Internet]. https://casp-uk.net/casp-tools-checklists/ [Accessed 1/6/2020].
25. Braun V, Clarke V. Thematic analysis - The University of Auckland [Internet]. https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html#fe0e29aab58caef8a1ae830d8e370fb0
26. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. *Handb Res Methods Heal Soc Sci*. 2018;843-860.
27. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Heal*. 2019;11(4):589-597.

28. Walker SL, Crist JD, Shea K, Holland S, Cacchione PZ. The lived experience of persons with malignant pleural mesothelioma in the United States. *Cancer Nurs*. 2019;1.
29. Moore S, Darlison L, Tod AM. Living with mesothelioma. A literature review. *Eur J Cancer Care (Engl)*. 2010;19(4):458-468.
30. Guglielmucci F, Bonafede M, Franzoi IG, Granieri A. Research and malignant mesothelioma: lines of action for clinical psychology. *Ann Ist Super Sanita*. 2018;54(2):149-159.
31. Lebovits AH, Chahinian AP, Holland JC. Exposure to asbestos - psychological responses of mesothelioma patients. *Am J Ind Med*. 1983;4(3):459-466.
32. Taylor BH, Warnock C, Tod A. Communication of a mesothelioma diagnosis: developing recommendations to improve the patient experience. 2019;6(1):e000413. https://bmjopenrespres.bmj.com/content/bmjresp/6/1/e000413.full.pdf.
33. Girgis S, Smith A, Lambert S, Waller A, Girgis A. "It sort of hit me like a baseball bat between the eyes": a qualitative study of the psychosocial experiences of mesothelioma patients and carers. *Support Care Cancer*. 2019;27(2):631-638.
34. Arber A, Spencer L. 'It's all bad news': the first 3 months following a diagnosis of malignant pleural mesothelioma. *Psychooncology*. 2013;22(7):1528-1533.
35. Kasai Y, Hino O. Psychological transition characteristics of patients diagnosed with Asbestos-related mesothelioma. *Juntendo Med J*. 2018;64(2):114-121.
36. Dooley JJ, Wilson JP, Anderson VA. Stress and depression of facing death: investigation of psychological symptoms in patients with mesothelioma [Internet]. *Aust J Psychol*. 2010;62(3):160-168. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc7&AN=2010-17610-006.
37. Henson KE, Brock R, Charnock J, Wickramasinghe B, Will O, Pitman A. Risk of suicide after cancer diagnosis in England [Internet]. *JAMA Psychiatry*. 2019;76(1):51-60. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc14&AN=2019-07149-005.
38. Clayson H, Seymour J, Noble B. Mesothelioma from the patient's perspective. *Hematol Oncol Clin North Am*. 2005;19(6):1175-1190.
39. Hughes N, Arber A. The lived experience of patients with pleural mesothelioma [Internet]. *Int J Palliat Nurs*. 2008;14(2):66-71. http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=105898753&site=ehost-live.
40. Nagamatsu Y, Oze I, Aoe K, et al. Physician requests by patients with malignant pleural mesothelioma in Japan. *BMC Cancer*. 2019;19:383.
41. Wolgemuth J, Erdil-Moody Z, Opsal T, et al. Participants' experiences of the qualitative interview: considering the importance of research paradigms. *Qual Res*. 2015;15(3):351-372.
42. Alexander S, Pillay R, Smith B. A systematic review of the experiences of vulnerable people participating in research on sensitive topics. *Int J Nurs Stud*. 2018;88:85-96.
43. Gieseler F, Gaertner L, Thaden E, Theobald W. Cancer diagnosis: a trauma for patients and doctors alike. *Oncologist*. 2018;23(7):752-754.
44. Faretta E, Civilotti C. EMDR therapy in psycho-oncology: a bridge between mind and body [Internet]. *J EMDR Pract Res*. 2016;10(3):138-152. http://resolver.shef.ac.uk/?http://find.shef.ac.uk/openurl/44SFD/44SFD_services_page?sid=OVID:psycdb&id=pmid:&id=doi:10.1891%2F1933-3196.10.3.138&issn=1933-3196&isbn=&volume=10&issue=3&spage=138&pages=138-152&date=2016&title=Journal+of+EMDR+Practice+and+R.
45. Broderick F, Deignan T, Combes H. An exploratory study into the traumatic impact of advanced cancer among patients and partners. *Operant Subj Int J Q Methodol*. 2017;39:1-24.
46. Ozen B, Ceyhan O, Büyükcelik A. Hope and perspective on death in patients with cancer [Internet]. *Death Stud*. 2019;44:1-7. https://doi.org/10.1080/07481187.2019.1626942.
47. Li QP, Loke AY. The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. 2013;22.
48. Eifert EK, Adams R, Dudley W, Perko M. Family caregiver identity: a literature review [Internet]. *Am J Heal Educ*. 2015;46(6):357-367. https://www.tandfonline.com/action/journalInformation?journalCode=ujhe20.
49. Angood P, Dingman J, Foley M, et al. Patient and family involvement in contemporary health care [Internet]. *J Patient Safety*. 2010;6(1):38–42. https://journals.lww.com/journalpatientsafety/fulltext/2010/03000/Patient_and_Family_Involvement_in_Contemporary.6.aspx.
50. Mbozi P, Ratcliff C, Roberts D. Challenges facing women caring for a spouse having cancer treatment: a critical literature review [Internet]. *Open J Nurs*. 2020;10:34-68. https://doi.org/10.4236/ojn.2020.101003.
51. Laidsaar-Powell R, Butow P, Juraskova I. Recognising and managing the psychosocial needs of family carers: it's time for change. *Patient Educ Couns*. 2019;102(3):401-403.
52. Abdel-Rahman O. Global trends in mortality from malignant mesothelioma: analysis of WHO mortality database (1994-2013) [Internet]. *Clin Respir J*. 2018;12(6):2090-2100. https://doi.org/10.1111/crj.12778.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: Sherborne V, Seymour J, Taylor B, Tod A. What are the psychological effects of mesothelioma on patients and their carers? A scoping review. *Psycho-Oncology*. 2020;29:1464–1473. https://doi.org/10.1002/pon.5454

Appendix C: Example search strategy (CINAHL)

Tuesday, May 21, 2019 6:55:40 AM
Query
AB mesothelioma AND ((psychological OR psychoncology OR psychooncology OR psycho-oncology OR psychosocial OR support* OR social OR uncertainty OR hope* OR anxiety OR depression OR coping)) AND ((patient* OR families OR family OR caregiver* OR carer*))
Limiters/Expanders
Limiters - Published Date: 19810101-20191231; English Language; Peer Reviewed; Research Article; Age Groups: All Adult
Search modes - Boolean/Phrase
Last Run Via
Interface - EBSCOhost Research Databases
Search Screen - Advanced Search
Database – CINAHL
Results
32

Appendix D: Data extraction form examples

Data extraction form – qualitative

Adapted from Booth et al (2016) p. 220-222

Data extracted by:	**Date:**	**Ref ID:**

Full paper screen:

Question		**If yes**	**If no**
1	Does the title/abstract include mesothelioma?	Continue	Exclude
2	Is the sample mixed?	Exclude	Continue
3	Is this a research article?	Continue	Exclude
4	Is the focus on intervention development?	Exclude	Continue
5	Is the focus primarily on QOL measurement?	Exclude	Continue
6	Is the focus on physical symptoms/treatment?	Exclude	Continue

Title of article		
Author(s)		
Title of journal		Year
Volume	Issue	Pages

Study details	**Location/country**			
	Research question/objectives			
Participants	**Population**			
	Age			
	Age (Mean/Range)	Mean	Range	
	Gender	Male (N)	Female (N)	Not specified (N)

	Ethnicity
	Recruitment/sampling

Data collection	**Method**
	Validation and recording

Data analysis	**Method**

Findings	
How are results presented?	*Verbatim Quotes [italics]* Author Statements [Normal] **Author statements supported by Verbatim quotes [Bold]**
Theme 1	
Theme 2	
Theme 3	
Theme 4	

Authors' conclusions		
Comments	*Limitations, reviewer comments, etc.*	
References	**Possible new includes**	
	Background papers	

Data extraction form – quantitative

Adapted from Booth et al (2016) p. 176-177

Data extracted by:	**Date:**	**Ref ID:**

Full paper screen:

Question		**If yes**	**If no**
1	Does the title/abstract include mesothelioma?	Continue	Exclude
2	Is the sample mixed?	Continue	Exclude
3	Is this a research article?	Continue	Exclude
4	Is the focus on intervention development?	Continue	Exclude
5	Is the focus primarily on QOL measurement?	Continue	Exclude
6	Is the focus on physical symptoms/treatment?	Continue	Exclude

Title of article		
Author(s)		
Title of journal		Year
Volume	Issue	Pages

Study details	**Location/country**			
	Study type/design			
	User/carer stakeholder involvement in design/conduct of study			
	Research question/objectives			
Participants	**Population**			
	Age			
	Age (Mean/Range)	Mean		Range
	Gender	Male (N)	Female (N)	Not specified (N)
	Characteristics			

	Ethnicity
	Recruitment/sampling
	Details of any theory/conceptual models used

Study date and duration	

Data collection	**Method**
	Who collected by
Data analysis	**Method**

Intervention	
Who provided intervention?	
Description of intervention	
How was intervention/service delivered?	

Duration & intensity	
How & why was intervention delivered?	
Any theoretical framework used to develop intervention	
Results	
Outcome measures used	
Details of outcomes/findings	
Strengths/limitations of study (including sample diversity)	

Author’s conclusions:

Reviewer’s notes/comments:

Appendix E: Screenshot of *Quirkos* in use during Step 3 of analysis

Appendix F: Research paradigms and philosophical assumptions

Whilst there are many definitions of *methodology,* the general understanding of the term is "the overall approach to research linked to the paradigm or theoretical framework" (Mackenzie and Knipe, 2006, p. 5). Methodology aims to explain and justify methods (Kaplan, 1964). It is important for researchers when they are trying to develop knowledge on a phenomenon to be explicit about their paradigm positioning, i.e., their own particular world view (Haigh *et al.*, 2019). Thomas Kuhn (1970, p. 175), who was influential in developing the concept of the paradigm, defined it as "the entire constellation of beliefs, values, techniques, and so on shared by the members of a given community." This world view will "guide our thinking, our beliefs, and our assumptions about society and ourselves" (Chilisa and Kawulich, 2012, p. 1). The paradigm therefore "orients" the research (Bogdan and Biklin, 1998, p. 22), and must be made overt as the essential first step, because without it "there is no basis for subsequent choices regarding methodology, methods, literature or research design" (Mackenzie and Knipe, 2006, p. 2). To enhance studies' trustworthiness, Levitt et al. (2017, pp. 9–10) recommend the concept of 'methodological integrity', with its two core constituents, *fidelity* and *utility*:

> "Integrity is established when research designs and procedures (e.g., autoethnography, discursive analysis) support the research goals (i.e., the research problems/ questions); respect the researcher's approaches to inquiry (i.e., research traditions sometimes described as world views, paradigms, or philosophical/epistemological assumptions); and are tailored for fundamental characteristics of the subject matter and the investigators."

The paradigm is based on various philosophical assumptions about knowledge and knowing (Haigh *et al.*, 2019):

- ontology (what the nature of reality is and what can be known about it)
- epistemology (the nature of knowledge and the process of getting to know)
- methodology (the approach to knowledge construction)
- axiology (the influence of values on knowledge and its acquisition).

It was therefore essential to state explicitly my own philosophical assumptions to orient my research study and to enhance its credibility. Presenting a set of internally consistent research elements (epistemology, methodology and method) would be a "key marker of quality" (Carter and Little, 2007, p. 1326).

Research paradigms can be presented at two levels: an abstract/general level of philosophical positions (e.g. positivism), and a more specific level (e.g. queer theory)

(Maxwell, 2013). When paradigms are discussed in the literature, there are differences in how many paradigms are counted, with different terms being used to describe them, which can be confusing (Mackenzie and Knipe, 2006). Indeed, Denzin and Lincoln (2018, p. 1) assert that “older paradigms are being reconfigured…hybrid paradigms are emerging.” Paradigms “are beginning to ‘interbreed’” (Lincoln, Lynham and Guba, 2018, p. 109). Therefore, in the following consideration, I chose to use the categories set out by Mackenzie and Knipe (2006) as being the most common (postpositivist/positivist, interpretivist/constructivist, transformative, and pragmatic), plus an additional newer postcolonial/indigenous paradigm (Chilisa and Kawulich, 2012).

Positivism is what is sometimes referred to as the ‘scientific method’, which aims to establish objective truth via generalisable natural laws (Mackenzie and Knipe, 2006; Chilisa and Kawulich, 2012). The ontological position is that reality is “‘out there’ and discoverable through the research process” (Braun *et al.*, 2019, p. 7). Positivism could study the social world in the same way as the natural world, looking for causal explanations and testing theories (Mertens, 2005). In the mid-twentieth century, a distinction was made between positivism and post-positivism, a “less strict form” (Chilisa and Kawulich, 2012). Post-positivists believe that there is an independent reality which science could study, but that observations could not be guaranteed to be error-free, and theories might need to change (Chilisa and Kawulich, 2012). Socio-cultural meanings mediated how reality could be accessed (O’Leary, 2004). In terms of epistemology, post-positivists think that “perfect objectivity cannot be achieved but is approachable” (Chilisa and Kawulich, 2012, p. 9). Positivist/post-positivist research generally uses quantitative methods for collecting and analysing data, using precise observation and replicable measurement (Mackenzie and Knipe, 2006).

The *interpretivist/constructivist* paradigm is concerned with “understanding the world as others experience it” (Chilisa and Kawulich, 2012, p. 9), and sees reality as socially constructed and dependent on the mind of the individual person (Mertens, 2005). This approach dates back to the work of the German philosophers Husserl (1859-1938) and Dilthey (1833-1911), on phenomenology and hermeneutics respectively (Mackenzie and Knipe, 2006). Phenomenology has been variously described as “the study of the mind-world dyad, or…the self-other-world triad” (Zahavi, 2019, p. 15), and the study of “what the experience of being human is *like,* in all of its various aspects” (Smith, Flowers and Larkin, 2009, p. 11). Hermeneutics is the study of interpretation, especially of texts (Finlay, 2015, p. 80). For constructivists, knowledge is subjective, and truth depends on cultural and historical context (Chilisa and Kawulich, 2012). This means that a researcher’s own background and experiences will influence how they interact with a study (Mackenzie and Knipe, 2006) and therefore need to be acknowledged and reported within research (Chilisa and Kawulich, 2012). Whereas positivists begin with a theory which they test, interpretivist/constructivists usually develop patterns of meaning or theories as they go through the research process (Mackenzie and Knipe, 2006), sometimes letting research questions evolve during the study (Mertens, 2009). Qualitative data collection methods and analysis are favoured by this approach, though quantitative data may be used in combination (mixed methods) to deepen the qualitative description (Mackenzie and Knipe, 2006).

The *transformative* paradigm emerged in the first decade of the 21st century, credited to the work of Donna Mertens (Phelps, 2020). Scholars such as Gilligan (1982) had been critical of the positivist/postpositivist and interpretivist/constructivist paradigms. They viewed them as grounded in theories developed by and about white men. African scholars and indigenous scholars in the West held that these paradigms had marginalised other ways of knowing and produced irrelevant research projects (Chilisa and Kawulich, 2012). The transformative paradigm placed social justice at the heart of research, as both its origin and its goal (Phelps, 2020). Mertens (2009, p. 2) originally named the paradigm *transformative-emancipatory,* but later changed it to *transformative* “to emphasize the role of the people involved in the research. Rather than being emancipated, we work together for personal and social transformation.” Transformative researchers assume there are “multiple realities shaped by social, political, cultural, economic, race, ethnic, gender and disability values”, where some values are right and some wrong (Chilisa and Kawulich, 2012, p. 6). Any transformative research program has to contain a group action agenda to change the participants’ lives (Mackenzie and Knipe, 2006; Mertens, 2009). The researcher’s life is also expected to be transformed, as the researcher-participant relationship is not based on a power hierarchy the way it is in the aforementioned paradigms (Chilisa and Kawulich, 2012). Transformative researchers make commitments which are based on non-paternalistic supporting of the public good (Phelps, 2020). Their aim in research is “to destroy myth, illusions, and false knowledge and empower people to act to transform society” (Chilisa and Kawulich, 2012, p. 13).

Within the *postcolonial indigenous* paradigm, Chilisa and Kawulich (2012, p. 5) give the aim of research as being,

> “to challenge deficit thinking and pathological descriptions of the former colonized and reconstruct a body of knowledge that carries hope and promotes transformation and social change among the historically oppressed.”

The paradigm has been developed in the 21st century. In this paradigm, researchers see "the formulaic, antirelational approach to research as a neocolonial proposition" (Kovach, 2018, p. 215). Knowledge is understood as relational, and is shared with all creation, including non-human sources (Wilson, 2008; Kovach, 2018). Both quantitative and qualitative methodologies may be used (Kovach, 2018). Cultural ways of understanding the world are valued, such as songs and storytelling (Chilisa and Kawulich, 2012; Kovach, 2018).

The *pragmatist* paradigm does not make a commitment to any particular philosophical system or reality (Mackenzie and Knipe, 2006). It thus allows for "multiple methods, different worldviews, and different assumptions" (Cresswell, 2003, p. 12). It has a practical emphasis, with researchers focussing on the 'what' and 'how' of the problem being considered (Cresswell, 2003, p. 11). The research problem is positioned as central, and methods are picked which seem most likely to furnish insights (Mackenzie and Knipe, 2006). Pragmatism particularly appeals to mixed methods researchers, where "most of the focus…was on practical, procedural issues about how to combine the strengths of qualitative and quantitative methods rather than philosophical claims" (Morgan, 2014, p. 1051). The pragmatist paradigm seems similar to the idea of 'bricolage' as an approach to research; Levi-Strauss (1994) used the term 'bricoleur' to mean a person who uses whatever materials and tools are available. In the research process, the bricoleur does not follow a prescribed plan, but "spontaneously adapts to the situation, creatively employing the available tools and materials to come up with unique solutions to a problem" (Maxwell, 2013, p. 42). I had already ruled out the postcolonial/indigenous paradigm as not appropriate to the population of my project, the UK military community, as they do not constitute a formerly colonised social group (apart from those Commonwealth troops such as Gurkhas). The pragmatist paradigm did not seem helpful: it did not provide a set of internally consistent elements, and would not give me an "accepted and well-developed approach" to build on (Maxwell, 2013, p. 43).

Appendix G: Reasons for rejecting alternative qualitative approaches

Within the qualitative paradigm, there are various different ‘approaches to’ (Creswell and Poth, 2018) or ‘strategies of’ (Denzin and Lincoln, 2018) inquiry that can be taken. Creswell and Poth (2017) consider the five main approaches to be narrative, phenomenology, grounded theory, ethnography, and case study, from which researchers need to choose the best option to fit their own research questions and interests, in keeping with methodological integrity (Levitt *et al.*, 2017). These five approaches are those which are most often seen in the social, behavioural and health sciences literature (Creswell and Poth, 2017). There are other possible strategies aligned to the qualitative paradigm, such as discourse analysis, but for practical reasons I confined my consideration of alternative approaches to these five. In this appendix I describe in detail narrative, grounded theory, ethnography and case study approaches and set out my reasons for rejecting them.

Narrative

Narrative was originally conceived of in the research field as quite narrowly defined as oral linguistic discourse (Labov and Waletzky, 1967). Over time, the definition widened considerably, moving beyond written accounts of the past to include, for example, imagined future experiences, and embroideries that convey collective embodied suffering (Chase, 2018). Narratives can be viewed as factual representations of what happened; as scripts to aid understanding of events; and as commemorative performances (Davis, 2002). Susan Chase attempted to give an up-to-date working definition of narrative (2018, p. 549):

> “A personal narrative is a distinct form of *communication*; it is meaning making through the shaping of experience; a way of understanding one’s own or others’ actions; of organizing events, objects, *feelings, or thoughts in relation to each other*; of connecting and seeing the consequences of actions, events, *feelings, or thoughts* over time (*in the past, present, and/or future*)[29].

There has been a debate about ‘narrative essentialism/exceptionalism’, that is, the idea that narrative has inherent “primacy and good” (Chase, 2018, p. 548). For example, Paul Atkinson (1997, p. 343) considered narrative “but one form of social action” which should not be “granted priority”. Arthur Frank (2010, p. 665), on the other hand, with his particular focus on illness narratives, argued that “narrative is distinctive among human capacities and distinctively necessary for human flourishing”, and that his own ethics-first rather than methodology-first stance would be “better understood as narrative-first, because anyone’s

---

[29] Italics in the original denote the changes to her previous definition (Chase, 2011, p. 421).

sense of what counts as ethical is derived, first and often most pervasively, from the stories that a person knows." Carol Thomas (2010, p. 657) developed this debate by suggesting, in relation to her cancer patients' study, that narrative researchers need to be more open about their methodological and ethical stance to promote an "ethic of human care". Narrative has also been seen as privileged in that storytelling is a means for people to create and recreate their own identities (Bamberg, De Fina and Schiffrin, 2011). Narrative inquiry can therefore be particularly appropriate for exploring experiences of identity continuity or change (Bamberg, 2011).

In a narrative research study, the researcher asks participants "to tell their stories and presents them, using a framework of temporality, sociality and spatiality, to allow a deeper understanding of their experience" (Haydon, Browne and Van Der Riet, 2018). Narrative inquiry has been much used for research in the field of illness, with its potential for changes in identity, and the importance of events and feelings over time. So, I needed to consider carefully whether this methodology would suit my own illness experience study. Narrative researchers are interested in the content of stories, or their structure, or how cultural stories relate to those stories people tell themselves about their own experiences (Smith, Flowers and Larkin, 2009, p. 44). Therefore, a narrative approach would be useful for a study focussing on *how* narrative relates to sense-making (Smith, Flowers and Larkin, 2009, p. 45). The distinctive feature of narrative analysis is "a focus on each account in its entirety and integration among its parts, rather than on discursive or thematic parts per se", which attends "to layers of meaning within a single narrative: multiple voices and dialogues" (Chase, 2018, p. 552).

A practical and ethical issue of the narrative approach is that it entails multiple meetings between researcher and participant for data collection, with the aim of collecting a "richer and deeper story", with opportunities for "regular checking of stories" (Haydon, Browne and Van Der Riet, 2018, p. 128). The co-created, relational aspect is seen as very important:

> "We become co-participants in this endeavor. We observe, listen, and live alongside our participants, which allows us a deeper insight into the research phenomenon. As the stories are lived and told in a given place and in relationship, we co-construct the emerging knowledge" (Lindsay and Schwind, 2016, p. 15)

As my participants would be the carers of people with a terminal diagnosis, where prognosis is highly uncertain, it made sense to choose a research approach which minimised the burden on them in terms of time. It might not be possible to arrange more than one interview appointment. Also, my original aim was to include carers from around the UK, which would make multiple visits potentially difficult in terms of travel time and expense during my PhD. Therefore, for both theoretical and practical/ethical reasons, I rejected a narrative approach for my empirical study.

Grounded theory

Grounded theory (GT) is possibly the interpretive strategy that is most widely used currently in the social sciences (Denzin and Lincoln, 2018). It was "discovered, not invented" (Glaser and Holton, 2004, p. 20) by Glaser and Strauss, initially being known as the *constant comparative method* (Glaser and Strauss, 1966). In its classic form, GT is "a set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area", with data collection and analysis processes which are "simultaneous, sequential, subsequent, scheduled and serendipitous" (Glaser and Holton, 2004, p. 3). Glaser saw GT as very flexible, a "transcending research methodology", such that he objected to Creswell's "lumping" of GT in with other qualitative methods (Glaser and Holton, 2004, p. 5).

In its classic form, GT's first step was to enter into the research *without* doing a literature review, so as to avoid having predetermined ideas or even a preconceived problem to investigate (Glaser and Holton, 2004, p. 11). This objectivist position later came to be viewed as problematic, with Charmaz developing a constructivist version of GT, which emphasised keeping an open mind in approaching data whilst acknowledging preconceptions (Charmaz, Thornberg and Keane, 2018, p. 414). Greater attention needed to be paid to researcher reflexivity and researcher-participant relationships (Charmaz, Thornberg and Keane, 2018, p. 414). Charmaz et al. (2018, p. 412) gave the following summary of GT's defining characteristics:

- begins with inductive data
- involves simultaneous data collection and analysis
- relies on comparative methods
- explicitly focuses on analysis and theory construction
- provides tools to study action and process
- contains strategies for developing, checking and strengthening an original analysis.

Grounded theory provides an iterative, inductive approach to qualitative data analysis, aiming to be systematic and rigorous. It seeks to categorise behaviours (Finlay, 2015), and is "fundamentally aimed at explaining and rendering convincing portrayals of social processes” (Timonen, Foley and Conlon, 2018, p. 8). Since my research aim is not to theorise about the social world, but to explore the individual experiences of a particular participant group, GT is not an appropriate methodology for me to use.

Ethnography

Frederick Erickson’s (2018, p. 39) suggestion that “the best definition for ethnography is ‘writing about other people’” is based in its etymology and its roots in late 19th century exploration of the lifeways of people living in colonial settings. After initial efforts to collect accurate facts and provide comprehensive descriptions of non-Western people, ethnography began to be used not just to describe, but to “advocate for and inform social change” (Erickson, 2018, p. 39). Then, moving beyond description of behaviour, ethnography became more holistic by reporting social action, including the actors’ meaning-perspectives (Erickson, 2018). By the mid-20th century, ‘realist’ ethnography was being conducted, increasingly via film recording, to explore for example labour relations in the USA, and Kalahari Bushmen in Africa (Erickson, 2018). More attention subsequently began to be paid to the importance of systematic methods, the significance of the researcher’s personal perspective, and the power relations inherent in the observer-participant relationship (Erickson, 2018). ‘Critical ethnography’ developed, where researchers “stepped out of a defended position of value neutrality to one of vulnerability, shifting from distanced relations with informants to relations of solidarity” (Erickson, 2018, p. 49). With late-20th century postmodernism and its challenge to the basic authority of any text, ‘autoethnography’ emerged as an approach, which included the researcher as present in fieldwork, and in the 21st century, ‘performance ethnography’ brought vivid accounts via arts-based representation (Erickson, 2018). Ethnography has an increasingly wide variety of sub-divisions, e.g., ‘multispecies ethnography’ (Kirksey and Helmreich, 2010); ‘netnography’ (Harding and Kostera, 2021).

Hammersley (2018, p. 5) gives an overview of various definitions of ethnography, leading to the following list of typical features:

- relatively long-term data collection process,
- taking place in naturally occurring settings,
- relying on participant observation, or personal engagement more generally,
- employing a range of types of data,
- aimed at documenting what actually goes on,
- emphasises the significance of the meanings people give to objects, including themselves, in the course of their activities, in other words culture, and
- holistic in focus.

However, Hammersley also shows that coming to a precise agreement on ethnography's definition is very difficult. He also highlights the challenges for carrying out ethnographic studies in the current climate of demands for accountability, the shift towards quantitative methods as a funding requirement, and the time-pressures on postgraduate students (2018). Hanley et al. explain that this methodology involves researchers "sharing a lot of time with" participants (2015, p. 93), and Linda Finlay (2015, p. 167) describes how the researcher "immerses him/herself in a cultural context as a participant-observer aiming to understand local rules, practices and shared knowledge."

Ethnography is an approach which fits within a constructivist/interpretivist paradigm, where the purpose of research is to understand people's experiences (Chilisa and Kawulich, 2012). When classifying approaches, it may be positioned under a heading 'Investigating social settings and culture' rather than 'Exploring lived experience' (Finlay, 2015). My empirical study seeks to explore the lived experience of people who do not live in the same location, and it is not looking at the "meanings of cultural phenomena" (Markham, 2018, p. 653). Therefore, ethnography is not a suitable choice of methodology for my own project.

Case study

There are many different and evolving definitions of case study: Tight (2020) provides no fewer than 11. He also explains (2020, p. 8) that it is a "holistic strategy. We study…the entirety of the case, not selected aspects." Case studies are useful when the requirement is for "in-depth, multi-faceted explorations of complex issues in their real-life settings" (Crowe *et al.*, 2011). They can be used for explaining, describing or exploring objects of research in everyday contexts (Yin, 2017). This sort of exploration entails "interviewing, observing, and document analysis" (Creswell and Poth, 2017, p. 313). Swanborn (2010) suggests that case study is the strategy of choice when information is needed about people's perceptions and decision-making in a particular time-frame and interaction. Baxter and Jack (2008, p. 544) consider it valuable to "develop theory, evaluate programs, and develop interventions". Case studies may be descriptive, sticking to detailing the 'how, when, and why' of a phenomenon, or they may be aiming to generate and test theory. Bearing all this in mind, I rejected case study as an appropriate strategy for my study for the following reasons. My research questions were asking about the experiential and sense-making aspects of mesothelioma, rather than perceptions and decision-making. I was not intending to test an existing hypothesis. My participant population was geographically spread in many different areas, rather than one particular context, and it would be impractical for me to attempt to observe them in a real-life setting. My focus is on the experience of the carer, rather than the holistic picture of interactions from many angles.

Appendix H: Phenomenology – the philosophical tradition

Phenomenology, the philosophical tradition focussing on the study of experience, was originally developed by Husserl (see my section above on the *interpretivist/constructivist paradigm,* page 77). Husserl was responding to the increasingly mechanistic worldview of scientific endeavour in his lifetime; he wanted science to have a respectful and constructive attitude towards human experience (Van Wijngaarden, Van Der Meide and Dahlberg, 2017). He showed that the positivist paradigm's idea of objectivity as detached and value-free was impossible; humans were always in a lifeworld which provided the foundation of all understanding (Husserl, 1970). Individual psychological processes, such as perception and consciousness, were Husserl's main philosophical concern (Smith, Flowers and Larkin, 2009). He asserted it was necessary to move from the 'natural attitude', where we take for granted our everyday experience, and to take on a 'phenomenological attitude', focussing in a reflective way on our inner perception of what we encounter (Smith, Flowers and Larkin, 2009; Van Wijngaarden, Van Der Meide and Dahlberg, 2017). This reflection led to awareness of the subjective experience of becoming conscious of specific things as they appear, hence the term *phenomena,* from the Ancient Greek verb *phainomai,* to appear or seem (Palmer, 1971). For Husserl, the concept of 'intentionality' was very important; this is the idea that consciousness is always *of* something, that it is directed and points beyond itself, and thus consciousness is always from a particular perspective (Zahavi, 2019). It was necessary to go back to the *things themselves* (Husserl, 2001). This involved a process of 'bracketing', i.e., turning away from any interpretations, theories and prejudices, to have an open mind, experience objects as they reveal themselves, and thus gain new insights (Zahavi, 2019). The next stage was a process of 'transcendental reduction', which meant identifying the essential qualities of an experience through a series of reductions (looking through different lenses), to look at the *content* of experience (Smith, Flowers and Larkin, 2009), i.e., its common "whatness" (Eatough and Smith, 2017, p. 3). Husserl's approach was essentially descriptive and eidetic[30].

Phenomenological philosophy was developed by Husserl's student, Heidegger, in a move towards a hermeneutic and existential emphasis (Smith, Flowers and Larkin, 2009). He stated that "the meaning of phenomenological description as a method lies in interpretation" (1962, p. 37). His conceptualisation (Heidegger, 1962) of a human being as 'Dasein', meaning 'there-being' or 'Being-in-the-world', paid attention to existence as related to and involved with the world (Eatough and Smith, 2017). "Dasein is 'always already' *thrown* into

---

[30] 'Eidetic' means interested in the universal essence or 'eidos'.

this pre-existing world of people and objects, language and culture, and cannot be meaningfully detached from it" (Smith, Flowers and Larkin, 2009, p. 17). The concept of 'intersubjectivity' is key: humans have a shared and relational existence in the world which means we can understand and communicate with each other (Zahavi, 2019). Dasein is multi-modal, in the sense that it includes practical, reflexive, social, emotional and temporal aspects (Smith, Flowers and Larkin, 2009). Heidegger engaged a hermeneutic lens because he understood appearance as having two aspects, visible meanings and latent or disguised meanings, which can be facilitated and made sense of (Heidegger, 1962). To interpret a phenomenon which appears, it was essential to be aware fore-conceptions would always be there, and, to stop them getting in the way, we should prioritise the new object (Heidegger, 1962).

Merleau-Ponty developed Husserl's account of human experience as rooted in perception, describing perception as an *embodied* process (Merleau-Ponty, 2012). This meant that a human had an individually situated, subjective perspective on the world, so their knowledge of it was interpretative (Smith, Flowers and Larkin, 2009). The subject and the world were intertwined: "the world is entirely on the inside, and I am entirely outside of myself" (Merleau-Ponty, 2012, p. 430). Subjectivity, embodiment and perception could not be separated, so bodily changes often led to changes in the sense of self (Carel, 2016). Humans were essentially 'body-subjects', with their relationship to others stemming from their own embodied perspective, i.e., from a position of difference (Smith, Flowers and Larkin, 2009). The body had a dual role: firstly, a physical object that could be viewed from a third-person perspective, and secondly, the site of consciousness and subjectivity, experienced in the first-person (Carel, 2016). Merleau-Ponty stated, "the body is much more than an instrument or a means; it is our expression in the world, the visible form of our intentions" (1964, p. 5), and, because the body is embedded in a moral, existential setting, (2012, p. xix) "we are condemned to meaning."

Sartre's work also involved existential phenomenology. He saw human beings as in a process of becoming and developing, rather than having a fixed, unified self (Sartre, 1948). Their perception of the world depended on the presence or absence of things and of other people, and experiences took place in an interpersonal context (Smith, Flowers and Larkin, 2009). Sartre highlighted the difference between self and other, with an awareness of 'radical otherness' (Zahavi, 2019). He analysed the body as having three orders: the objective (the physical), the subjective (first-person experienced), and the intersubjective, i.e., the individual's body experienced as reflected by the other's experience of it (Carel, 2016). He stressed that, because humans were in an evolving and unfixed state, they had freedom to choose and were responsible for their own actions, within the constraints of the context in which they found themselves (Sartre, 1948).

Since the late 20th century, others have built on the work of these four philosophers to bring phenomenological approaches to bear on medicine and health. For example, Leder (1990) looked at the experience of organ transplants; Svenaeus (2018) explored the experience of pregnancy and abortion (2018); and Toombs (1992) considered the different perspectives of patients and physicians. An advantage of taking a phenomenological approach in this way is that it narrows the gap between objective, medical assessments of illness and its effects, and individual, subjective experiences, thus enabling better patient-HCP communication and better understanding of impacts on well-being (Freeman, 2018). Feminist phenomenology has also made a contribution to the study of medicine and health, e.g., Shildrick (1999); Slatman (2012); Zeiler (2014). This contribution includes aiming "to dismantle what is generally considered to be universal and essential to human experience and to broaden our familiarity with and understanding of the scope, structures, and varieties of human experiences" and showing "how themes of difference, vulnerability, and volatility are central to, rather than deviations from, human experiences, and moreover, that they have important implications within the sphere of medicine" (Freeman, 2018, p. 2).

The work of philosopher Havi Carel has particular relevance to my research project. In *Phenomenology of Illness* (2016), Carel develops the work of Merleau-Ponty and Sartre, as have other philosophers such as Russon and Jacobson (2018). Carel draws on the existing phenomenological literature about illness, such as Toombs' (1992, p. 229) explication of five essential losses. Carel considers the important differences between disease and illness (2016, p. 15), between the objective body and the body as lived (2016, p. 53), and between health and illness (2016, p. 58). Using her own experience as a respiratory patient, she develops a 'phenomenology of breathlessness' (2016, pp. 106–129), an account which has potential to illuminate my enquiry into the experience of mesothelioma. Her chapters 'Illness as Being-towards Death' (2016, pp. 150–179) and 'Is well-being possible in illness?' (2016, pp. 130–149), which include considerations of post-traumatic growth and the personal/cultural interface with death, again have relevance to my project on this incurable and fatal illness.

Appendix I: Consideration of alternative phenomenological approaches

Phenomenological philosophy has led to an awareness that “the complex understanding of ‘experience’ invokes a lived process, an unfurling of perspectives and meanings, which are unique to the person’s embodied and situated relationship to the world” (Smith, Flowers and Larkin, 2009, p. 21). Since the late 20th century, qualitative researchers have been drawn to use this phenomenological perspective as a research approach; examples include Giorgi’s descriptive phenomenological method; van Manen’s hermeneutic phenomenology; Smith’s IPA; and Colaizzi’s descriptive phenomenological method (Zahavi, 2019). Phenomenology has been seen as an attractive research approach because it was “genuinely open-ended and did justice to experience as it is lived” (Halling, 2020, p. 2), which seemed particularly important when researchers were “engaged in the study of phenomena of great importance in terms of fostering human well-being” (Halling, 2020, p. 2).

Giorgi, drawing on Husserl’s concepts of reduction, description and the search for essences, was the first to bring a phenomenological approach to psychology (Morrow, Rodriguez and King, 2015). Giorgi set out his method in the following steps (Giorgi, 2012):

- take up an initial position of phenomenological reduction;
- read the whole description to get a holistic sense of the data;
- reread the description, noting down constituting parts (meaning units);
- use free imaginative variation to transform the data to show their psychological value;
- write an essential structure of the experience;
- use the essential structure to clarify and interpret the raw data.

The aim of this method was to produce “a description of the world of the other, not an interpretation” (Giorgi, 2012, p. 7). Colaizzi’s descriptive method was different from Giorgi’s in being thematic rather than ‘distilling’, and also had a final step of seeking verification of the fundamental structure from the participants (Morrow, Rodriguez and King, 2015). The third step involved bracketing pre-suppositions “in order to stick closely to the phenomenon as experienced” (Morrow, Rodriguez and King, 2015, p. 644). I chose to reject this descriptive phenomenological approach because I do not believe it is possible to carry out the reduction stage completely, achieving some kind of non-influence or neutrality (Nelms, 2015). I concur with Finlay (2009), who sees a continuum between description and interpretation, with attempts to draw strict boundaries being counterproductive. My own experiences and understandings can be valuable:

> “the best path is a critical awareness of the researcher’s preconceived biases and presuppositions in an attempt to separate them from participants’ descriptions; striving for openness to the other while acknowledging biases” (Nelms, 2015, p. 19).

In contrast to Giorgi and Colaizzi, van Manen (1990) followed a hermeneutic phenomenological approach, explicitly staying true to Heidegger’s philosophy, valuing the practice of being philosophical as a researcher. He rejected bracketing in favour of explaining his existing beliefs and bias, as this would allow him to evaluate their strengths and weaknesses (Zahavi, 2019). His approach involved using diaries and other written accounts of experience, and sometimes made reference to artistic media (Nelms, 2015). He stated that phenomenology was like poetry, aiming for “an incantative, evocative speaking, a primal telling” (1990, p. 13). Van Manen restricted his phenomenological task to looking at the *pre-reflective* experience of the world, which leaves to one side the important transition to conscious conceptualisation (Zahavi, 2019). There is also the question of the “strongly normative and at times even moralizing character of his approach” (Zahavi, 2019, p. 125). I rejected van Manen’s approach, despite its interpretative orientation, because of its restricted range of interest and its potentially unethical moralising aspect. From the four phenomenological research approaches given above, I rejected Giorgi’s, Colaizzi’s and van Manen’s, but chose Smith’s (IPA).

I now briefly look at a few of the more recent developments in phenomenological research approaches. Stilwell and Harman (2021, p. 1) argue that “qualitative research approaches under the umbrella of phenomenology are becoming overly prescriptive and dogmatic”, and need to be “renewed and refreshed with opportunities for methodological flexibility”. They suggest (2021, p. 3) broadening out from just using individual interviews and “a narrow view of sense-making that *only* focuses on *what it is like* to have an experience”. They propose an enactivist approach, using a ‘5E model’ of sense-making (2021, p. 5): “embodied, embedded, enactive, emotive, and extended”. This pays attention to relational dynamics e.g., between a patient and a healthcare professional, and to the environment. Their approach involves semi-structured interviews, real-time observations, and exploration of participants’ engagement with relevant objects, such as medical devices. It provides the potential to draw up a ‘personalized network model’, integrating four dimensions: the physiological, experiential, sociocultural and existential (de Haan, 2020). Whilst this approach looks potentially very fruitful in giving a rounded, extended picture of patient or carer experience, it is still in the early stages of being developed, and also in practical terms would not be possible for my PhD project.

In a contrasting approach, Køster and Fernandez's (2021) 'Phenomenologically Grounded Qualitative Research' (PGQR) uses philosophical phenomenology's concept of 'existentials' to create an initial framework for exploring a particular feature of human being in the world. The authors envisage research studies thus grounded as being intensely focused, with a hermeneutic attitude, and drawing on extensive advance familiarity with the existential under investigation. The interview explores the interviewee's experiential content, using an interview guide as "a broad hermeneutic roadmap" which "steers the interview through a few predefined focus points, which ensure that the research question is explored in a thorough manner" (Køster and Fernandez, 2021, p. 11). As an example, they describe (2021, p. 8) interviewing participants about early parental bereavement for "a total of 6-8 hours over the course of 3-4 interviews." An advantage of this very deep exploration is that it allows participants to talk about pre-reflective and embodied modes of being in the world in a fresh, culturally unscripted way (Køster and Fernandez, 2021). However, the authors state (Køster and Fernandez, 2021) that "PGQR does not typically inquire into interviewee's opinions, beliefs, or values", and that the intense and prolonged focusing may feel uncomfortable and strange to participants (2020, p. 12). This approach is therefore unsuitable for my research study, as it would give such a narrow focus as to likely be less than helpful for informing practice, and it would not be appropriate for patients and carers already under pressure from this incurable disease.

Appendix J: Example of reflexive notes (SDA)

[These notes – originally handwritten - were made while listening to the recording of an interview.]

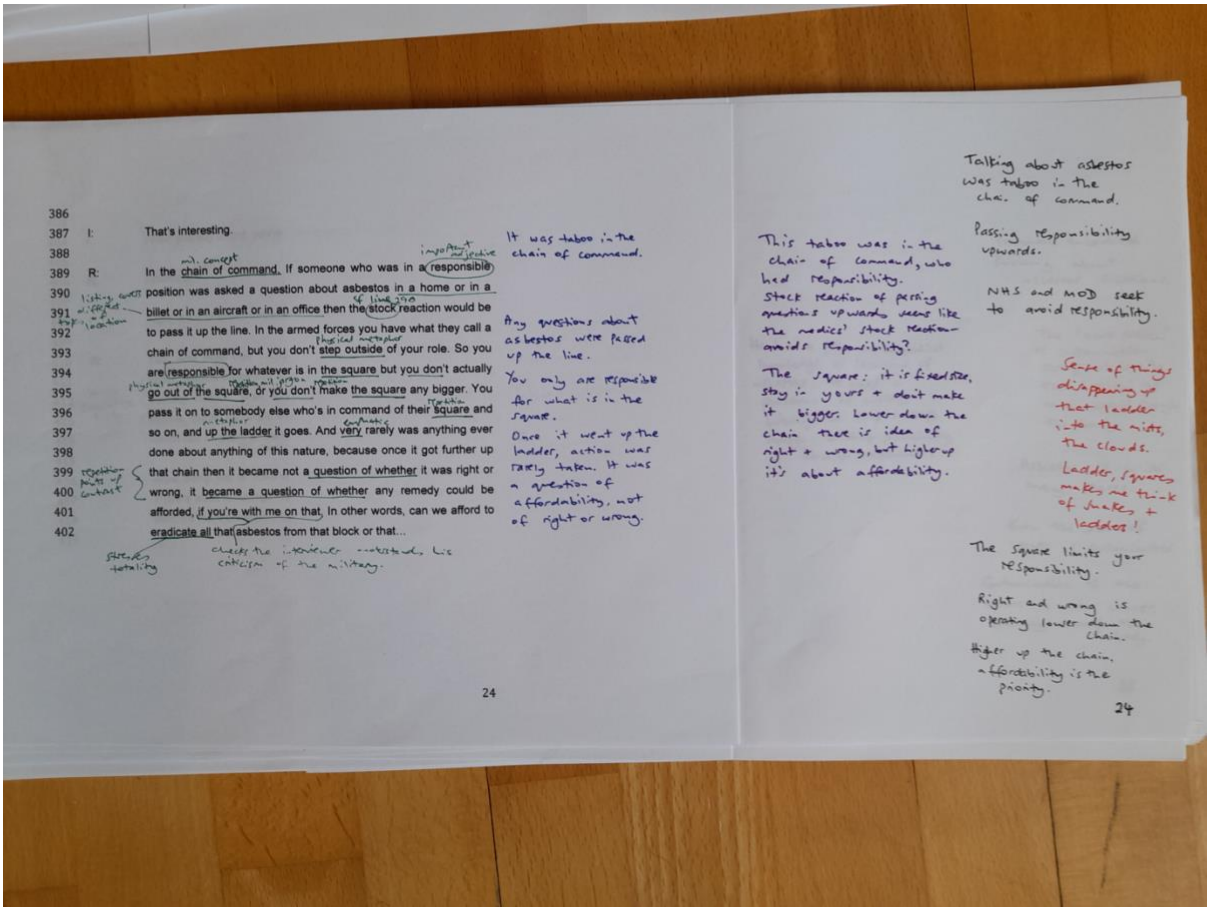
He refers to ‘post trauma’. Not sure what he means by this, but he seems confident using the term? Or is he? So, is he unusual as an older veteran being OK with talking about psychological trauma from losing his wife to meso? Are my participants actually going to be more comfortable with this stuff than I expect?? Also ‘my therapy’ – not a word I would expect from this man.

He appeals to interviewer’s nursing experience when describing nasty needle procedure. Cf my counselling experience – could be useful if they know?

Hardest bit to understand is where he asks to know [prognosis] first to spare her the ‘pressure.’ Hard to tease out the meaning… Feels very mixed up and maybe even he doesn’t really get what happened. Or is trying to explain it afterwards. Or I just can’t get my head around this…Have I been in this situation? No! Or maybe…I did get my rib pain checked but didn’t want to worry Sam any more – he was so anxious about his own health. But that’s not the same. This scenario feels old-fashioned. Had she in fact agreed/asked not to know? Can’t marry that with her straight-out question earlier on.

BTW I think this is the first time I’ve heard the word ‘love’ in any of the interviews!!!

Appendix K: Photo of an example transcript page



I: That's interesting.

R: In the chain of command. If someone who was in a responsible position was asked a question about asbestos in a home or in a billet or in an aircraft or in an office then the stock reaction would be to pass it up the line. In the armed forces you have what they call a chain of command, but you don't step outside of your role. So you are responsible for whatever is in the square but you don't actually go out of the square, or you don't make the square any bigger. You pass it on to somebody else who's in command of their square and so on, and up the ladder it goes. And very rarely was anything ever done about anything of this nature, because once it got further up that chain then it became not a question of whether it was right or wrong, it became a question of whether any remedy could be afforded, if you're with me on that. In other words, can we afford to eradicate all that asbestos from that block or that...

24

mil. concept

important adjective

listing different types of location

of line 390

physical metaphor

physical metaphor

repetition

mil jargon

repetition

repetition

metaphor

emphatic

repetition points of contrast

stresses totality

checks the interviewer understands his criticism of the military.

It was taboo in the chain of command.

Any questions about asbestos were passed up the line.

You only are responsible for what is in the square.

Once it went up the ladder, action was rarely taken. It was a question of affordability, not of right or wrong.

This taboo was in the chain of command, who had responsibility.
Stock reaction of passing questions upwards seems like the medics' stock reaction – avoids responsibility?

The square: it is fixed size, stay in yours + don't make it bigger. Lower down the chain there is idea of right + wrong, but higher up it's about affordability.

Talking about asbestos was taboo in the chain of command.

Passing responsibility upwards.

NHS and MOD seek to avoid responsibility.

Sense of things disappearing up that ladder into the mists, the clouds.

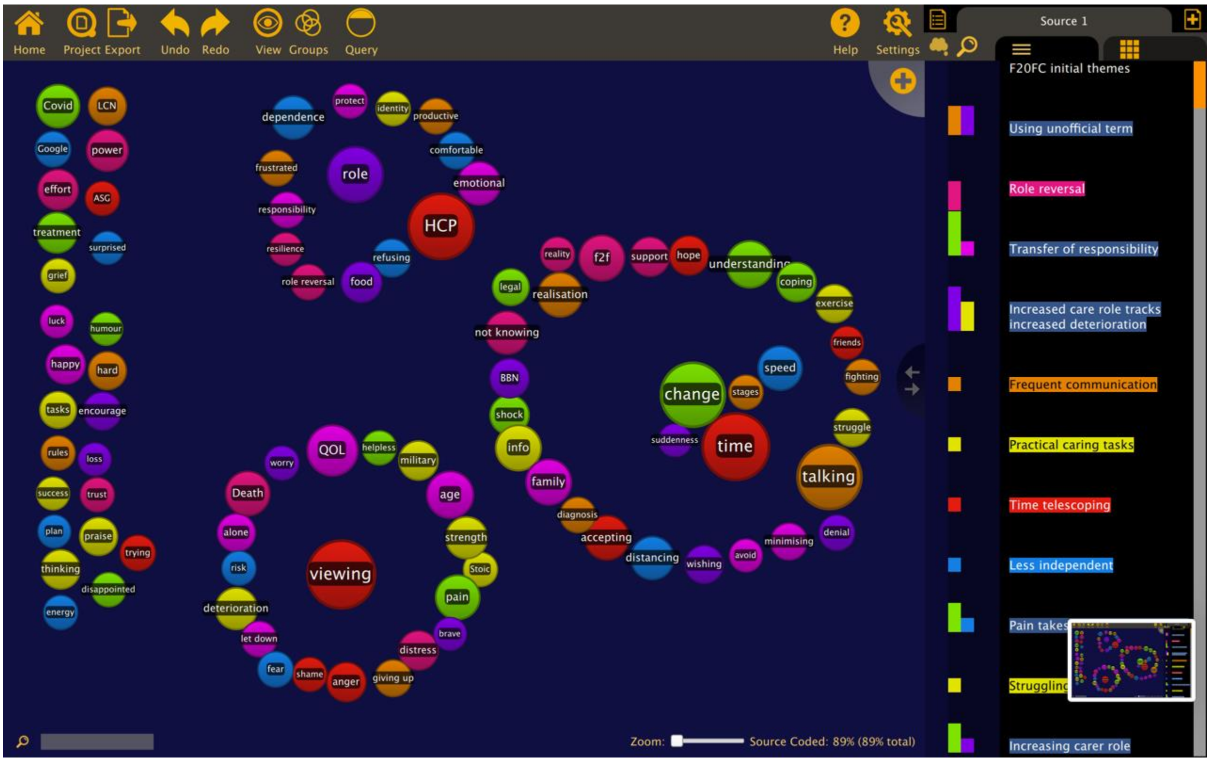
Ladder, squares makes me think of snakes + ladders!

The square limits your responsibility.

Right and wrong is operating lower down the chain.
Higher up the chain, affordability is the priority.

24

Appendix L: Photo of an example *Quirkos* map of emergent themes



Appendix M: Main study individual participants' themes with quotations

F15MM

Super-ordinate theme	Sub-theme	Illustrative quotations
Who cares?	*Only I can do it*	• I had to get used to dealing with needles and all that stuff and I'm not a great fan, but so, you'd learn to be a medic in a way. • I felt …disappointed at times with some of the options that she wasn't offered, which I had to research and offer, get her onboard with myself because I thought she was being a bit let down at times. • She [counsellor] put us in touch with a lawyer and we just handed everything over to them and left it. And that was, that was important because that made a huge impact on our quality of life at the time. We weren't dealing with phone calls; we weren't dealing with letters all the time. And for me, I could just concentrate fully on looking after my wife and I didn't have to fight anybody anymore, someone else, someone was doing it for me, and they were doing it really well. • I went to see the nurse and I said, is that person right, she's a doctor and she's talking about clotting drugs when she's on anti-clotting drugs, that just wouldn't work would it?
	Being abandoned	• Marie fell into this hole of limbo, and nobody wanted to touch it but left her in pain and agony. • After a full career in the RAF and the army and we've lived out lives travelling around with the MOD and I was like, "What is the, what is the problem?" • Her best friend, who claims still to have been her best friend, never came to see her for 18 months and she's only six miles away and it's just, it was crazy. • I suppose I felt helpless...I felt angry because of the misdiagnosis that she received for a whole year.
	Caring about others	• I'm in the [safety critical] industry, we always get told if you make a mistake, put your hands up, it's a no blame environment, people learn from it, your mistakes get shared equally across every part of [safety critical industry], there's no borders or barriers or anything. • They (MOD) knew the site that we worked in is laden with asbestos, but you've got 1,500 military guys there that don't get any education in at all. • I just dumped them [friends who never visited] and Marie still kept in touch but she just did it, she's like a puppy sometimes, she was just doing it to help them.

		• There was only about five times that she really broke down ……but [distressed sound] most of the time it was worrying about me, that's the way she was.
	Not being bothered	• I'm ready to go. I can't put it any other way, I've had a great life. I probably am depressed but I'm not going to kill myself or anything, but if I died of something, I'm not that bothered. • I don't polish my shoes as regular as I used to [slight laugh], all those little signs. [.] That's not me at all, but I don't care anymore. • They [MOD] just then said, we're not paying out and that's it, so we just left it, we were like, pff, whatever, no problem. • I'm fine, I'm fine, I'm fine [voice drops]. I've just got to get fit again [ppfff]. I've got to want to get fit again [laughs]. • My wife minded it, me being her carer, having to do it but I didn't mind it at all.
Going the extra mile	*Being physically and mentally robust*	• Ah yes, you've brought me onto a good thing there: the military, I never go to a doctor, I just never do, I just, not that I don't like doctors, I just don't think they help me. • I wasn't as robust then as I became. I never used to challenge doctors and stuff like that, I'd rather be in the hospital and out the hospital because I thought they were all just talking rubbish anyway. • I think I influenced her at times not to go to the doctor [.] in the early stages, because I thought, "Why go to a doctor if you've just got a little pain in the tummy? I get pains in my tummy all the time," and that's just my military upbringing. • I just thought she could be maybe a little bit more robust, but that was my military thinking projected onto her. • I was notoriously, still to this day, don't take any medication, apart from those stupid happy pills. • She should have been more proactive at taking pain relief before the pain occurred because the pain was so severe. [.] Maybe she was just thinking that I, even though we talked about everything, was worried about her just taking drugs for drugs' sake and I wasn't. I was just trying to make sure that she was taking the right ones. • I know what I need to do, I'm a grown man. I know what I need to do, but it's just moving on. I've got to find something to move on to. • I was fighting really, making myself ill because I was getting, I was driving to work…because I was still having to go to work all the time with this and I was crying in the car on the way to work, just not sleeping.

		• The girl [counsellor] said, "Why are you dealing with all this stuff, you've got enough on your plate?" [.] and I said, "Well, who else is going to deal with it?" and she said, "Just get a lawyer." • I'm totally unhealthy now, I've got about five stone that I don't need just because I never wanted to leave her side. • I needed her [counsellor] to say something like, I know you're tired, you're really tired, that's a normal thing, you're going to be really tired, your work'll understand if you can't come to work, that sort of thing, your wife'll understand if you just want to go to bed [laughs] because it's a bit tiring. [.] I wanted them to come up with a golden solution to my problems, something to go, have you thought about this and me go, no I haven't and them go, well do that.
	A "can do" attitude	• Trying to get hold of the [drain] parts initially via the chemist or from the district nurse, to sort of put in a prescription was just mental [.] My wife felt uncomfortable, so I wasn't going to hang around, so I just drove everywhere to get these things. • I used to love hard work and I used to go, right, I'll do it, I'll do it, and I'll start a job and I just won't stop until it's finished. • I used to be 'get up and go'. Now I'm not.
	Expectations are high	• I would challenge things and some of the answers I wasn't happy with because that's not the environment I work in. • I thought, "Well, these people [MOD] should be…they should know what they're talking about, surely to God?" • I know I was pushing the boundaries, people have got their lives and that, but within half an hour, he emailed me back.
Communication of the facts	*Telling the facts*	• People would say to me, how's Marie, I'd just broadcast everything. I didn't even listen to what I was saying. • I didn't care what people thought any more, I just thought: I'll tell you how it is. • We've always said from that day forward, that we will not…try and…candy-coat the truth. • That affected the relationship with the kids, maybe, because at times they'd say, don't tell me, and I'd say, and I'd say, I've got to. • She [Marie] did get angry, but one of the biggest things of that was one of the fellows gave a brief and he was one of these…he was suffering as well, but

		he was all about positivity. Positivity, blah, blah, blah, blah. - You end up going, well I've got this niggling ankle pain again, you then self-diagnose, you say, I'm just going to try and ride through it. [.] There's no point in even saying anything because no one is going to listen, you just crack on with it.
	Getting all the facts	- They [MOD clerk] just lied to me each time. - Very rarely would she [Marie] look it up on the internet or anything like that, on source information like the, the Mesothelioma UK [.] bulletin, she would hardly ever read that. But I'd read everything, I'd try and discover everything.
	Perception versus reality	- I was [.] dealing with the incompetence of [local NHS trust], the incompetence of the Veterans UK and the incompetence of sometimes the health professionals that I met, my perceived incompetence, by the way, you know, they might know better. - I think maybe she delayed the period of going onto stronger pain relief because she might have thought that I…she might have had a misconceived idea that I didn't approve of drugs, I don't know but we both we quickly we talked about everything, absolutely everything and we'd never leave anything behind.

F16FC

Super-ordinate theme	Sub-theme	Illustrative quotations
Being together or alone	*What brings comfort*	- We have a laugh and a hug and then I more or less forget about it. - I put my nose in a book or play on my tablet. I've got a um…like Solitaire. - We nibble more than we should, at least I should, on the wrong things. And it's just one way of dealing with things really. - I suppose I do it [nibbling] to keep him company as much as anything. We just sit and I think, "Well, why not?" 'Cos I might not have him for ever. I don't know what my nurse will say when I see her, but er that's me at the minute. - We're closer if anything. - And I've got someone [God/Jesus] to talk to before I go to sleep at night and when I wake up in the morning, and you feel better if you've had a little prayer and a little hope. And then you just try to do the best you can. - It was meeting other people that had the same thing. That was so wonderful.

	Someone there to support you	- She [specialist nurse] was absolutely wonderful. She really was. She really made a difference. - He's never been like it since. It was just everything to do with the operation and being away from me. We're not really apart much. - One of them [neighbours] is already a widow, so she's quite…you know, it's quite uplifting listening to her talk. - I said [to 13- year old granddaughter] "What on earth am I going to do without Granddad?" She says, "Don't you worry, Grandma, you've got us." - They [church] keep ringing up and finding out how we are and how we're doing and everything. - When he went to the eye hospital about his glaucoma, they wouldn't let my daughter in with him. He only had to go in on his own and I think he was a bit bewildered. [.] That was a bit hard. - They [Macmillan Centre] were very, very good, but we didn't feel we were ready for anything like that. - They [ASG] have been absolutely wonderful and they're there at the end of the phone if we need anything. They really are.
	Meeting face-to-face	- They've been having a service on Youtube on a Sunday. And they're going to carry on with that even though they're back in church now, so we'll have some contact. - We've missed their coffee mornings [ASG]. They do it on Zoom. [.] We do enjoy the contact there. - Arthur likes the idea of going into the hospital and seeing someone face-to-face to talk about things. Not the phone. But I'm happier not to go. - Sometimes you feel like, you know, asking how it's developing or how long he's got or how the….I don't feel I like to ask in front of him. But he says, "Oh, just ask." He doesn't seem to mind.
Knowing her own mind	*Being self-critical*	- It was to begin with very, very hard and I had to, I'm one of these people that if anything happens, I have to talk about it. And I did talk about it, anyone I saw practically. They were probably fed up with me. - I find I am very impatient. [.] I'm ready to do it [eyedrops] and he's faffing about, and I keep going 'Grr', and I've got to really say to myself, 'Come on, Janet, patience, patience.' - I feel as if…I've got lazy, I think. I don't do so much around the house as I did. I keep looking and thinking, "Ooh, gosh, I need to do some cleaning today and that," and I never get it done. It's always tomorrow [laughs]. - I said to my son when I saw him, "I just want it all to be over. I just want it all to be over. I can't cope with this."

	The back of her mind	• I'm one of these that tries to put it to the back of my mind. If anything crops up, I stick my nose in a book. • It was that doctor that said….was quite abrupt with it. And I think that's at the back of my mind, that's what upset me more than anything. [.] Perhaps it was meant to come out like that. I don't know. But I mean, what suits one person doesn't suit another. • The biggest thing that stands out in my mind is the fact that, well, Arthur asked, "How long?" and he said, "Well, about a year."
	When it goes wrong	• If I think about it too hard, I think I'd howl all the time…It's a funny feeling. • It [Alzheimer's] runs in the family, unfortunately. That's what worries me, I'm going to get. • Someone asked me afterwards, at the beginning, "What's it like?" I said, "My mind's like a washing machine. It's just going round and round and round." • For a long, long time, I've been taking an anti-depressant – just a small one – for years. I think it's right from oo, not long after the menopause, I suppose. And it just keeps me on an even keel.
	Confused and needing guidance	• I really don't know. I've got to be guided by what other people say. And what *his* decision is. It's not my decision if anything happens, it's his. • Apparently, there is an operation you can have, but I said, "I don't see how you can. It'll be like taking a potato peeler and trying to peel." If it's growing round the lungs, the outside, what can you do? • He's always dealt with the money, which is a bit frightening really. And everything's on the computer.
	Using strategies	• They'll ring him up for the x-ray he had last week. And I'll probably go out the room and just let him talk and let him tell me about it afterwards. I suppose it could be a way of…blanking it out. • I think he [middle son] is a bit like me, actually, bury his head in the sand a bit. • Our daughter will take us shopping and he'll come back and that's him for the rest of the day. He'll just sleep. And that's the only time I really think about it, but then I try to joke about it and not think about it. • We're very, very lucky. Very, very lucky. So that's what you've got to do, is thank you, thank for what you've got. • I'm fine. I stick my nose in a book [laughing].
Being more aware of time	*So much time has passed*	• He can remember things from when he was in the RAF. [.] There was all bits floating in the air and there was lots of things it could be. But he still

		doesn't understand how it can be, but I mean, he's [age] now. How long does it take to come out? • He's lucky he's lived to how the age he is. And we've just got to be thankful for what we've had.
	The unbearable (un)certainty	• The way the doctor more or less said, "Well, that's it. You've got a year." • I sometimes feel as if I want the next couple of years or however long just to be over. I'm wishing my life away because I feel sometimes, I don't want to cope with this. • I think it's the undecision [sic]. You don't know how far advanced it is. You don't know how long. You don't know how it's going to be. [.] I mean, he must have had it for years, but you don't know how long, it suddenly started changing. But that's the biggest thing. • I think I'd have been upset anyway, but it was just those words that stayed in my mind. And then Arthur tried to get him [doctor] down to something, he said, "How long's a piece of string?"
	Temporary lulls in speeding time	• I'm more aware…of *time*. • A year was January 20th, I think. So, the year's flying by and he's not really any worse. Unless he takes a dip, but he's fine. • Then, after time, it all changed and I realised, well, he wasn't really as …disappearing just yet.
His changing self?	*Upset by the unexpected*	• They asked us [family] not to go in and he was expecting us, and he really took…I'd never heard him shout at me like it. • Sometimes I think, "Ooh, do I know you as well as I think I do?" and then other times it's just fine. • I don't think Arthur's got a coping strategy. He just takes things as it comes. • To begin with, he was angry. He was, you know, very upset and angry, and then he'd more or less say, "Well, I'm going to fight this." • He'd been to have a chest x-ray, and somebody had cancelled his appointment. And he was really, really upset and it really got him down.
	A quiet, inward gentleman	• He's what's called a gentleman really. He doesn't sort of shout, he just goes quiet. • There are people out there, I know, but until…he really feels…he's a bit sort of private like that. He doesn't always want a lot of people around. But I think, if necessary, they'll be there. • He's not so outgoing. He can't talk about things quite the same as what I do. I find that it's my way of releasing things. I can talk.

	Getting tighter with money	• I think he's a bit tighter! • He's frightened he's going to leave me with…he wants to leave me as much as possible. I know why he's doing it. And he won't spend out if he can't.

F17FC

Super-ordinate theme	Sub-theme	Illustrative quotations
(Dis)connection and withdrawal	*To have and to hold*	• Being a carer and a wife is really hard because sometimes you lose… that…being that person's emotional partner, soulmate, love, you know, that gets lost in amongst all of the stress of caring for someone with such a complex illness. • It was really hard because I was having to hold it all, in order to not panic him any further. • And we *were* fine because we were an extremely strong couple and we were an amazing team. • He still wanted to be self-sufficient; he did not want me to be caring for him in that respect. • He he wanted me to do that [washing him] because it helped him to maintain his dignity. • His biggest fear was dying on his own; that had always been his fear. • We had no opportunity to have any deep and meaningful discussions or anything like that, or to, for us to come to terms with what was happening together. • Through his strength and through looking after him I grew a lot as a person. • The best thing for Dave was perhaps not the best thing for me, but he had to be their (HCPs) priority. • How my needs have been met by my GP, I'm extremely disappointed in that. [.] They've not rung me once, they've not followed up to see if I'm okay.
	Choosing to withdraw	• A busy respiratory ward with nurses that…it was just not conducive for a man who was in the last days of his life, you know, where he could've used some peace and some calm. • I think I've withdrawn because it's just almost too difficult to… You feel as though if you tell people and you don't get much back from them, er [outbreath] you feel a bit disregarded, so it's almost easier not to. • I like laughter, I like fun. I I think it's dangerous for me to withdraw. Dangerous? I suppose, dangerous is a bit of a strong term but I I think I think if I…you know, I have to make a new start in my life now. • From the minute that that the consultant came into our cubicle and drew the curtain around and told us, I felt him withdraw from me. And I think that was

		because he was afraid but also he didn't he didn't want to scare me. • My relationship with them [her parents] has changed, in as much as I'm….I'm kind of I'm not letting them see what's really going on. • I don't trust people in the same way. I don't I don't [outbreath] …because, I guess, I don't trust people to like me for me. • It felt at the time like the priority was discharging him and getting him out of hospital.
	Connecting to support	• Because of COVID so again, it's a bit difficult to know whether this would've been my experience had it not been for all of this, you know, needing to be distanced. I've I've just felt like I could do with somebody somebody face to face, somebody to actually come and sit with me and go through the form. • It all happened so fast that there wasn't time to access any of that [cancer support], so I felt like I didn't know where to turn, I felt quite unsupported. • Generally, I think the care's out there, I think it's just finding the right care at the right time and the right support at the right time that's difficult. • It was very difficult for me to be able to speak to anybody that had any understanding, detailed understanding and expertise, around this illness. • I've got somebody I can ring [mesothelioma charity] and I've got somebody…if I've got questions about the disease, there are two people there who have said that I can contact them any time.
Viewing through a different lens	*A different view of past and future*	• For me, I think that's one of the most difficult about it is that [outbreath] he'd been carrying this thing around with him. • I don't want that to define me going forward or to define our life, so that's that's quite…that's something I'm still having to come to terms with. • I already felt to an extent like um by ex-service people are quite let down by by the services, by the MOD, by by whichever service they were in. And actually now I think I feel that even stronger and and, again, I don't want that sense of resentment to build up. I don't think he he he cast any blame on the on the army for that [exposure] at all. My feeling is that he he was so passionate about his his service and about what the army gave to him, I don't think he'd had time to compute it enough. • And then, at the end it just felt like *everything* had been snatched out from underneath us, *everything*. • The fact that this has come from an an unnatural cause and the fact that it's come from…the most likely source of the exposure was when he was serving his country, something that he…he was *always* a soldier,

		in his heart and in his soul. [.]So I think for me, that's that's really hard. • I owe it to him and to us and to everything that we were about to make sure that however long I'm still here for, I make the most of it. • I find my new place in the world. It's really hard; shaping that is really hard. • The COVID world just adds to the complexity of it; how you shape that is very difficult.
	Seeing the bigger picture	• The previous time he was ill, which was 18 months pr- before, weirdly, that was with a fluid-related thing as well. So, this is kind kind of why I wonder whether somebody should've picked it up before. • In hindsight there were probably lots of opportunities for somebody to have just said, hold on a minute… • There are other groups of the population that are likely to have been exposed. And that for me I think is a biggie, because if were looking for it we might have even we might have even asked the question. • It kind of felt to me like a massive piece of the jigsaw had slotted into place that we'd never even known to look for. • Everything is being viewed through the lens of [cardiovascular condition] and and and then they were all separate problems – so different specialists dealing with all of those different things. And and actually, I guess, nobody ever had the whole picture. • He was still saying, I think they've got it wrong, Julie, I think they've got it wrong, you know, because I'm not feeling any… [outbreath]. He had a really high pain threshold, so him saying he wasn't feeling any pain er was probably a bit meaningless really [laughs].
	The narrow focus of trauma	• I have flashbacks where I'm back there in that hospital ward, and particularly around some of the more distressing things that were happening to his body. • I watched him slip on the bed and he slipped on the bed and just landed on the mattress and broke his arm, and that was because the cancer had gone into his bones, you know, *in that short space of time.* And [sigh] that's having an effect on my mental health in as much as….it's it's traumatic. • I then had to go and watch him fighting for breath and …have him asking me for his BiPAP machine back; that's the last words he said to me, BiPAP. He was so desperate to still be able to breathe; he was so desperate to still be able to fight it. • I had to stand and watch while they decided not to give it back to him because it was doing him…more harm than good.

		• He thought COVID was going to kill him. That was what he kept saying, if this COVID thing gets me, it'll kill me.
	What is hidden from view	• These things happen – but it's about the fact that they are not acknowledged. They [MOD] seem to try to bury things like that. • I feel really angry with the military, with the army. I feel angry that I think they don't share that kind of information with people, and I think they should. • He [her first military husband] had injections, he had things injected into him that we never even knew what they were, and those things do not appear on his medical record.
Moving versus taking a fixed position as a response to challenge	*Openness to fluidity and change*	• I think he just, kind of, kind of wanted to to sweep all of those potential issues under the carpet and just, you know, we were fine. • I don't just want to… survive and tread water. • I went back to work really quickly. And so, I think I, kind of, shoved it all in the cupboard and shut the door and it's all now coming out. • The fact that he was in denial; it was one of the things that that I warned the medical staff about straightaway. • I think how I've changed is is that I've just I'm a lot less able to deal with my emotions. And I don't quite know *how* to deal with them; I don't know how to process some of this, it's all so big. • I still think in his head it was if, not when, …which in a way was probably a benefit for him but it made it more difficult for me. • He was he was much more stoic about the pain he experienced [from cardiovascular condition], about the the difficulties it caused him, because he wasn't very mobile. I think he just accepted that and just got on with it, accepted that as his lot, because that's what's that's what's drilled into them [Armed Forces] – you deal with whatever's thrown at you.
	What keeps you steady	• I've lost the person who was my reference point for everything, so I feel as though I'm losing some confidence in myself. • He was still a rock for me even right up till the end. • I think he was just trying to, sort of, reseat himself in his faith. • During those those final days in hospital he very much…he wanted to believe that I believed the same as him. • We had so much thrown at us in our lives, and…[slight outbreath] if there was a God why would God do that?

		• I make sure I eat well. I try to make sure I get as much sleep as possible but also, not stress on any day – I I I can't. Fresh air, hugely. And just keeping busy. • For him, so his coping strategy, I think his single biggest coping strategy was his faith. And looking out for other people. • Even on the worst days when we'd been shared the worst news, he would tell the consultant or the nurses a joke. • I've also lost a huge part of what was my sense of purpose because I've been a carer for the last 11 years and now I'm on my own.
	Digging in for a fight	• He had to fight every day, he had to wake up in the morning and and every day was was a battle for him. And I remember vividly him saying that – every day was a series of paving slabs to be moved to get to the one thing he needed to do that day. • He thought we would fight it and, you know, he'd come home and we'd we'd prove them wrong. • I feel as though I didn't let him carry on fighting, I just I just allowed them to…to just let him go [outbreath]. And I know that….that's…that's that kind of guilt is not helpful and it's not real, because he he had mesothelioma, he had weeks or months at the most.

F18FC

Super-ordinate theme	Sub-theme	Illustrative quotations
The Well-oiled machine – Onwards and Upwards!	*Planning for a goal* ***and*** *adapting to circumstances*	• It was kind of, OK, we've been dealt with this [diagnosis] and, right, we've got to move on. • Probably also from my background as a [health-related role], is that I was very much a facilitator, and having worked in palliative care myself, it was kind of my personal goal to achieve a good death for dad. • When we were talking about as and when the time comes for him to head off and stuff, he chose from the start that he was going to be going to the caravan site in the sky. • Our coping strategies adjusted at each time that we stepped down in the condition. • I crack on at times, and then I guess as long as I've always got something to aim for and aspire for, you've got to have a goal. I've always been very goal-driven and my dad was. • He wasn't going to give in, absolutely not. I mean, straight after the clinic appointment, he described it to me as a bloody nuisance [laughs]. He went, 'Right, well, we're going to go and get the caravan, get it back on the road.' He was not going to let things get in his way.

		• Afterwards, I was a bit sort of up and down with triggers for sudden….I was reading somewhere, I think they call them ‘grief attacks’. • She [GP] was brilliant, she was so empathetic, and she was very good not to make any promises or guarantees. It’s the honesty. Dad responded really well to that [honesty], because as soon as he’s got that, straightaway he gave me a list of things. “Right, this is what I want to do, this is who I want to see.” Clear, done. • It got to the point where, say, dad wasn’t physically strong enough perhaps to use some of the machines. But say, my husband would help him with it and bring him in, so he was still doing a part of it, so you know so um he wasn’t seen that he couldn’t do certain stuff.
	Always being active and busy	• My parents were extremely active. You could count dad’s sick days in his entire working career on one hand, it just didn’t come into his mind. • I’m thinking, “Oh, what do I do with my time?” Which is a really weird thing for me, because like my mum and dad, I’m not one to sit down and do nothing. • It’s kind of that, “Oh, sit down and breathe.” And then sometimes I do find that’s when sometimes thoughts come into my head and then I get quite down. • We have such lovely memories of days out and weekends away, we just absolutely maxed it. • It’s kind of mind over matter and physical fitness, and maybe also a bit of luck [laugh] of how long his body managed to fend it off. • It wouldn’t have been quality of life for him [.] because he was rapidly losing his independence and that’s not him. • I think the other element of the devastation was just, this is your lot, that’s it, and he still had things to do, which was backed up by the coroner.
	Continuity is valuable	• Dad still wanted to be known as that he was a dad, that he was a husband, he was a neighbour, he was a best mate, he was a friend. And yes, you’ve got this awful diagnosis and prognosis, but he [.] is still Len. • A bit like my dad dealt with my mum, just crack on and do it, and that’s how I dealt with it. • We had continuity of people coming in and out of the house, which was really settling for him. It was settling for me because I didn’t have to start re-inducting people [laugh]. • I purposely got rid of all that [medical] stuff into another room, so that to anybody it looked like a normal front room. [.] “Right, who’s up for the brews?” • Quite stoic, and I guess probably some of that [military influence] did have an impact on how he

		dealt with processing the prognosis. [.] "Bloody nuisance, this" and "Crack on". • I see myself as more military than civilian. • We got the funding, the fast-track funding from the hospital and the palliative care service were seamless. That was really good. • Even in the last few days, he was still, where possible, wanting to get properly dressed [laugh]. Shirt and tie man [laugh]. Shirt and tie man. • He wanted that sort of normality right to the end. He didn't even say goodbye to her [wife] on the last time, he just said, 'Well, I think it's time you headed back [to respite] and off you go and find that pussy cat.' • He never really left the military. [.] He was always sort of, "Stand by your beds!" I wouldn't say strict, but just very, very disciplined.
The Well-oiled Machine – Eyes Right!	*Looking to the positive*	• Humour is so important, and it never left my dad. • There's a reason for everything and those last few days allowed dad and I, and for my husband, to provide that most intimate of care really, which is a times, quite…oh gosh, what's the word? Quite an honour, really, it's a very special thing. • So, I have sad days sometimes, but I have a lot of happy days. • I'm quite a positive person and I always look at the glass half full, of Pimm's, if possible. • It pushes out the negative stuff really because you just think there are some very kind-hearted people out there. • I'm very much like my dad, I try not to take life too seriously. I only try and be grown-up on a number of occasions. • If you work in the health service, sometimes you've got a bit of a dark humour, and it's just to get you through sometimes some really awful situations. And probably with the military, with what's involved, girls and boys go through. • Hopefully it's that lesson learned thing, which was very much my dad's take on things. It's not to never make a mistake, but as long as you've learnt from it, it's almost the bigger thing. • Half of it was a bit numb [at certifying GP's comments], half of it was a bit comedy. [.] Then there was an element where I thought, "If I start to get angry, I'm going to get very angry." And I thought, "I don't really want to do that."
	Focusing on other people	• Even in his last couple of days, he was writing little notes to say, 'I'm sorry if I've put you out', bless him [laugh]. • He was always very much a person of checking other people. [.] When we were told the news in the

		clinic [diagnosis], he had three questions first off. [.] ‘What will happen to my wife? What will happen to my daughter? How long have I got to live?’ In that order. • There are people that are being diagnosed with this much younger. I think that’s what‘s also kind of got to me, we’re in 2020 and it’s like, ‘How is this still happening to people?’ • Underneath, though, as he said it a number of times to me, he was utterly devastated. I’ve [sigh] thought about it and I did wonder whether it was because it wasn’t something that could be *seen,* if you see what I mean.
The Well-oiled Machine – All together now!	*Having back-up from the team*	• Also having my husband there as well, having that male person as well [laugh] sometimes for some of those other bits that he could get on and crack on and do, bloke to bloke. • My husband’s in the AF and I’m now retired from the [health-related role] but I work for the MOD. [.] As soon as people heard, like our chain of commands and our bosses, I mean, they just pulled together. • Luckily the coroner was extremely helpful and was very clear. • That was probably one of the first times after the diagnosis I saw my dad in tears. [.] He was upset obviously that he’s been told, well, the rough time we had, which was initially a year, well, it might be half that. [.] But I think it was more the fact that they did not tell me, and that *he* had to tell me. • He said, “You have to understand these are my two main carers. [.] If you don’t keep them informed, they can’t help you, and that means they can’t help me.” • I can only describe it as super-cool that everybody in our care team that was involved got on board with that as well. That was really lovely, because then he could open up a bit more. • It was just that extra drain on us, whilst trying to process that you’re in those last final days, I did have a slight breakdown wibble one evening. • We’d been there [hospice] a few times for lunch in their café. [.] He used to get some of his symptoms, like a really bad cough, or [.] lots of burping, [.] but there, it didn’t matter. • He didn’t want to get on the bad side of the doctor, and he was very concerned that they didn’t mark him and say, “Right, that’s it, you’re not getting certain treatment,” type thing.
	Togetherness and bonding	• Towards the end, he thought, “Well, my time’s almost up, I’m going to start swearing!” [.] Some of the stuff, it was just hilarious! [.] It brought us very much closer.

		• We'd always had a close relationship and it just closened it even more • He's still very, you know, a proud gentleman and it took a little bit just for him to get used to his daughter having to undertake some of that [personal] care, but I think it brought us even closer.
	Putting in the effort	• A majority of my friends are military. So again, when they first heard about dad being ill, they were ploughing in with offers of help. • I ploughed a lot of efforts into that as well as the physical care. And I guess also the emotional and spiritual care. • We were quite open to tell people in due course of what was going on, and I mean the offers of help, it was really lovely and beautiful to see. • We did achieve a good death, that everybody's efforts, and I was really eager that almost anybody that was coming in from our care team, coming through the door, like thanking each and every one of them for the part, big or small, that they played in achieving a good death. • When they sorted out his DNR form, and he asked, and I felt it was, given the situation, extremely understandable, and he said, "Right, well, could I speak to my daughter, or could you talk this through with my daughter?" "No, done."

F19FC

Super-ordinate theme	Sub-theme	Illustrative quotations
Travelling the right way	*Needing direction*	• It got tougher, and I felt a little hamster on a wheel trying to catch up with the pain control, trying… I mean, I'm not a medical person so I was relying on what other people were telling me. • He wanted to make sure that it was acceptable to his faith to have the [syringe] driver before he had it because he didn't want it to be classed as um taking his own life. • It wasn't always clear which…who we should be phoning. So, [laugh] we tended to phone the Macmillan nurses at [local hospital], they tended to put us on the right track. Yeah. It was just there were so many people involved. If we'd have just had one central person, which [laughs] it's impossible, isn't it, but that would have been lovely. If we'd have just had one person that we phoned to say now, you know, this is happening this week, next week. • The most important point was getting the diagnosis, yeah, August 13th. Because until that point, we didn't know what we were dealing with and we didn't know where we were going. We felt really lost.

	Keeping the body pure	• He doesn't he didn't like taking painkillers. All his life, he'd tried not to abuse his body with chemicals or anything, he detested anybody who smokes. • He wouldn't take painkillers for his arthritis or when he did take them, he said they didn't work, so he'd just use his mind, he said. Because he was a big believer in the power of the mind. • Like Michael, I'm not one for medication [laugh] if I can help it.
	A positive life	• They [people he'd helped over the years] would come, and they'd talk to him and they'd thank him for what he'd done for them. So, and that was lovely, I'd see this smile come on his face and he he knew that his life hadn't been wasted. • I think I'm wanting people to value me, yeah. That's odd… I feel like…I know Michael's made his mark …um…[tearful]…and I don't want my life to be… wasted…um [tearful]. • His biggest one [coping strategy] was his religion though, yeah. Yeah. He never got angry, not once. I was furious at times, really cross, you know, why, why Michael, the kindest man ever? • I'm coming from a different perspective and I'm now seeing people in there [online group] and I'm thinking, oh, they're at that stage where Michael was, what can I tell them that's going to give them some positive support? I try and put a positivity. I try and make the, the worst of times the best of times that it can be. • Because Michael was always positive, he was he was never negative, he always…we did think that the chemo was going to work, we really did, so that was a huge disappointment when it hadn't worked. • The knitting comes out, [laugh] copious knitting, and people are benefiting. • I've always got in the back of my mind, and it won't go away, if the government hadn't laid down such strict rules for the doctors at the beginning, if he'd have been seen sooner, would he have…would the chemo have been able to have worked on him?
Turning towards others	*Positive and negative positioning in relation to others*	• I suppose we're a bit odd really [laugh], we're more more concerned about others and the impact that it has on others than the impact that it has on ourselves. You know, we want, we wanted to stop it [contamination], we wanted to do something. • It's been particularly hard because of COVID. Because when Michael was classed as terminal, people could come and visit. And they always did it safely, they wore masks and, you know, we were extremely careful. Um but the day that he died, that all had to stop. And it was like going from this

		wonderful bubble of love, lots and lots of love, to, oh… - My mental health, yeah [laugh] yeah, I think it has affected me quite a lot. I did have the support beforehand. I do…people are probably bored silly of me, but I keep posting pictures on Facebook to bring back happy memories. I'm sure they'll tell me when they're fed up. - I sometimes think I'm more…I can't think of the word. Sometimes I read things into situations that maybe aren't there, find I'm a bit sensitive over…if people criticise, not criticise in a nasty way but just say something, I think it's personal to me. - I used to say it's not fair that you've got this, it should have been me [.] because I used to smoke…..[.] Yeah. It just seemed so unfair that somebody who had never abused his body in any way, shape or form should should be suffering. - [Name of campaigner]. She's an absolute gem, isn't she? She's my woman of the year, [name of campaigner] is! Yeah, what a what a gem she is!
	Asking for and accepting help	- We thought we could manage it ourselves without having extra carers in. And I think again we made a mistake. I should have asked for help sooner. I didn't ask for help in the home until five days before he died. - I did some…a few years ago, have a bit of a meltdown, about five years ago, um when I asked for some help and I did get help. Um and I was concerned after Michael died that I might find myself in the same situation again where I didn't want to get out of bed. Um but no, I've not reached that far yet. And I keep remembering er some of the strategies that I used to use then because I I wasn't sleeping in the night then, and so I used some of the relaxation techniques that I remember. - It was that moment when he'd had a shower and he couldn't get out of the shower and that was the the point when I realised, I …can't do this on… my own. And he literally had to drape himself over my shoulders so I could help him back to bed. That was that was that was the crux for me when I thought I'm not physically able…mentally I was able, just just about, but it was like I hit a brick wall. - I don't know how I got there [hospice] to be honest, I was in a bit of a state, I shouldn't really have driven, thinking back. And she [consultant] made me sit down and talk for a while. And I'm so glad she did.

	Thoughtful-ness towards others	• I've written a little book um to help youngsters who might be experiencing um somebody dying around them, it might be their grandad or whoever, who's got mesothelioma. • He wasn't afraid to die. He was more bothered about leaving me and others behind. • Katy said, should you come out of there [Facebook group] now, mum? Because sometimes I'll say, ah, it's really sad, another mesothelioma warrior's died. And she'll say, but you should you be in there, is that helping you? And I'll, I said, well, I won't go in as often. But I do find it does help me because I think I'm helping other people. • She's [daughter] been my rock, she has. I do worry about her now, though, I think I think it's time that she looked after herself a bit more and didn't keep coming up and down from [distant city] twice a week just to make sure poor old mum's alright [laugh]. 'Cos poor old mum is alright, I'm getting there. • One of the first things I've done since Michael died is to go into [community organisation]…not go in physically but via Zoom and everything, have meetings to find out how *we* tackle asbestos and how we make our residents and schools and everything, are we aware and do we know where it all is? • [Name of young relative] drew a picture of his earliest memory and Michael drew a picture of his earliest memory. And then they got talking about memories and everything. And eventually, these sheets of paper became a special memory card that they could give each other, which was lovely. And and that helped [child] a lot, um yeah.
Sharing is sweet	*Sharing intimately*	• Talking to Michael was the [my] biggest coping strategy because we *could* share how we felt with each other. And that was one of his. • His sense of humour never went, you know. He'd got he'd got a wicked look in his eyes sometimes and sense of humour. Even on the last day when he couldn't take water and I was dabbing him with a little sponge, so he was getting some some comfort, and my finger just went in his mouth. And he bit it and this grin [laugh] came on his face. Oh dear! But I knew that was him just telling me that he loved me. • Once he was diagnosed, I think he told me every day at least once a day that he loved me, yeah. So, that was the biggest change in our relationship, that he could say that. • We weren't able to, to share the same bed anymore because he found he was in a lot of pain. So, I, I moved into the other bedroom but usually at around five o'clock in the morning, I'd open the door and say, can I come in for a little bit? And he'd say, of course

		you can. And that's the time when we used to talk, do a lot of talking then.
	Keeping things private	• Michael was quite strong mentally. Um but I have found a couple of little notes that he probably wrote down to himself um that show that… he was worried about some things, um …about where he would die um and…um that he would have sorted everything out before he died. • Michael initially didn't want people outside of really just me and Katy knowing that he'd got cancer because he didn't want them to look at him as 'Michael with cancer'. And that was tough because I wanted to go out and say to everybody, he's got cancer. So, I found that really hard. • I like to know everything, right, I really do [laugh]. And he wouldn't tell me a [laugh] lot of what he'd done [in the military]. I picked up snippets from him. • Sometimes I wanted to just get out, um so, I might just go and hang the washing out for five minutes and have a bit of a rant at myself and then come back in. • I felt like I'd failed him [voice breaking]. Because he was a very personal man and er having to have other people wash him and care for him [tearful]. But um [tearful] he right to the end, he didn't he didn't let anybody else pass him his urine bottle except for one carer on the the third night before he died. Yeah. So that was hard.

F20FC

Super-ordinate theme	Sub-theme	Illustrative quotations
Swopping roles is uncomfort-able	*Parent and child reversal*	• The roles have definitely reversed, you know, and and um I think Dad looks to me for everything now. • You hold it together for everybody else, don't you, as the the woman in the family, the mother, the daughter, the sister, everybody comes to me, and um so you you hold it together for them. But in between I've had my odd little moments where I think, "Oh," [sharp intake of breath] you know, "this is my dad." • He loves sweet things so, you know, little bits of trifle and um but now he's going, "No, no, don't want it, don't feel like it." It's um so, that's difficult, sitting watching them when they can't put anything in their mouth. • My daughters, um although there's a part of me trying to protect them as well, they're, you know, two of them particularly are older and and they're very caring and things towards me. • He doesn't want help with being washed and dressed yet, but it's fast approaching. She doesn't

		know if he'd be happy with *her* doing that. It was different with her mum (physical washing, toilet). Her anxiety: he's struggling, but not accepting any physical help at the moment.
	Stepping in and out of HCP role	• My [health-related] career, you know, I think, yeah, you deal with lots of things that you you build that resilience to deal with, um but I have my weeping moments in between, you know. • With mesothelioma, you know, I I didn't know that much about it beforehand, um so obviously you go, you turn to things like Google now, don't we, we all look things up. • He [consultant] then also spoke to me about um, "I'll send you a list of solicitors. We can't recommend but this is something that you probably need to pursue because it's an industrial um thing, so it's best if you speak to one of them," um which at at that time, I didn't know *anything* about all this, so that was all a minefield really. • That's hard because I can feel me, as that [healthcare role] particularly, sort of, wanting [laugh]...he said to me yesterday, "Stop pushing food at me!" [laugh] and I thought, "No, I know I am," but you just want to, you're wanting to encourage, you're wanting to...Because you can see the weight dropping off him and you can see him getting weaker by every day, you know. And… that's the struggle, I think.
Seeing a frail elderly gentleman	*How he sees himself*	• He'll say, you know, "I'm, I'm concentrating on trying to live, not bothered about dying." It's *that* attitude. • He is quite stoic. He's very um…doesn't want to give in to pain relief. He is taking pain relief now, but that's taken quite a while to get him to that point. • On the other hand, I'm saying, "Now, Dad, if you've got pain, please take something. Nobody's going to dish out any medals, you know. Stop, don't fight it. • He said, "The thing is, [.] we're not the type, Cerys," he said, "to just sit in a chair and curl up and die."
	How HCPs see him	• He kept saying to me, "Well, nobody's really talked to us about it and what about treatment? Aren't I getting any treatment?" And um yeah, so I think er that probably hasn't helped the situation. • And Dad said um, "I said to him, what do we do about this, then"? And he said, "Well, to be honest, you know, it's probably best nothing at your age now," sort of thing. "It's, sort of..." um Dad said, "What, just get on with it, is it?" And he said, "Yes." • Previously, a little abandoned, no, that's too strong a word, but no faces to names. "Oh well, he's 87", feeling of he's not being dealt with as robustly.

	The daughter's view	- Seeing him so frail now, it's *that* that gets me I think when you think, gosh, you know, Dad was so strong. - We wouldn't have known had he not gone into A&E and had a scan. Um so… yeah, we wouldn't have known any different. And to look at him then I would've thought we'd have a good few years left with him, but it's actually quite rapid how things have been changing. - Because he's been quite young for an [age]-year-old, you know, he hasn't been a frail…gentleman. - He's got a stent fitted. It was that that was in my mind, "Oh, what if he has a heart attack?" But the other part of me was saying, "Well, you know, he's doing what he wants to do [sailing], he's happy, and it's great that he's doing it, so there's no way I'm going to stop him." - Now, looking at him, I think he's, sort of, more resigning himself to the fact, I see some of that anger going. It's that more, "I'm too weak to bother," you know. - With the pain, he is a little snappy, cantankerous. And he feels frustration with the pain and that he can't do his activities. - I think some of that stoic bit, that's you know yeah, I have wondered that [inaudible 00:41:25] you know, being in the army, [inaudible] national service, that disciplined sort of view could be down, you know, to, down to being in the army. - Like, he's always been somebody I think whose glass is always half full, he's never a half empty glass, he's never been doom and gloom.
Adjusting to change	*Prioritising self-care*	- I've got good um good family, so my husband particularly, you know, I talk to him a lot. - I've got good friends, um who are very aware of what's going on with Dad, so they're very supportive. - About a year and a half ago I did *New To Golf* and started learning golf which I enjoy, so I play with...there's four of us ladies that play, so um that gets me out. - It's just great to be out in the fresh air, and it's exercise. - Normally I would go swimming, um but obviously with COVID I can't, so I find swimming quite good, good exercise and I relax when I swim so, yeah, so that's my coping.
	Strategies for adapting to reality	- The shock of the diagnosis in herself – took a while to sink in. - I'm feeling slightly a bit more emotional about it as I can see what the inevitable is going to be. - It's quite frightening. It's that thought of, that overwhelming feeling of, um of dread really.

		• [Dad] Lower in mood now. More…not anxious but just that low mood. Coming to terms. A bit shorter in temper. • You're beginning to realise that you're running out of time. • Dad is a little bit of bury your head in the sand. • I have chosen my moments and dropped the odd thing in and said, you know, "We need to start thinking about these things, Dad." Um but he he gets very um, "Oh, now you're anticipating trouble," you know, whereas my mum, you could've… easily had conversations with. • What I could see in him, really, I suppose is is, in a way it's that stages of bereavement, isn't it? You're beginning to realise that, yeah, this is your time, you're, you know, the grim reaper is knocking really. And I I could see that dawning on Dad, and sort of, areas where he was getting um… cross, I think, that...you know, "Well, *why* aren't I having any treatment? And *surely* there's something that can be done um, you know?" • People have been lovely on the phone, they've been very caring, but it's nothing like a face to face really, is it, it's not. • He [GP], sort of, explained to Dad that it [chemo] may not, it's not going to be the wonder treatment. It may prolong things but very slightly, but in the meantime, it could make him very ill, a lot more prone to infections, um so is it better to have that quality of life rather than go down that? So, I think that made sense to Dad more than anything and he's happy that he talked things over with the GP. • You suddenly start realising that this, you're not going to have him for that long now, you know. • Things are harder with Covid on top. • Effect on herself: Slightly anxious – how is it going to end? How will we manage? Will he stay in his own home? Will he come to us? Anxious re: if he is on his own in hospital because of Covid.
	Making practical adaptations	• COVID has annoyed me because of all the extra things we could be doing, you know, and taking Dad out for lunch and and things like that. • We were making more of an effort to go with him and things, you know, so my husband did more of the lifting for him, or my brother when he was home um would do all that sort of thing for him. • He is still doing tomato seeds and instead of being able to go down his garden which he's struggling coming up from the garden now, um we've bought, like, a little lean-to glasshouse that we've put close to his back door.

Appendix N: SDA sensitising issues with illustrative quotations

[This document was written to aid planning for the Stage Two interview study.]

The following sensitising issues have been identified from the in-depth IPA analysis of four carer transcripts and the surface reading of four joint interview transcripts. Of these seven carers, four were either veterans themselves, or had a military father. The sensitising issues were factors which could relate to the practicalities of conducting interviews, the relationship between researcher and participant, and the impact on participants.

Practicalities

British military service impacts individuals through the inculcation of the ‘military mindset’, training recruits in a unique cultural ethos and skill set (Wood, Cotterill and Cronin-Davis, 2017). The strict regime enforces orderliness, cleanliness and obedience, reinforcing a selfless team spirit, bound with loyalty. The expectation of strict punctuality is ingrained and becomes life-long (Perreira, 2020). The values of the Armed Forces are made explicit in their mission statements: “respect, integrity, service, excellence” (Royal Air Force, 2020); “courage, discipline, respect for others, integrity, loyalty, selfless commitment” (British Army, The, 2020).This culture and these values stay with veterans after they transition into civilian life. One participant made this explicit, when he described the NHS as being “not in my world” (F2MM p. 48). At a very practical level, the carers valued efficiency and the fact that professionals they met were well-equipped:

> F2MM p. 11 “Paramedics, they carry all this equipment, mobile job. [.] As far as they were concerned there was something serious.”
> F7MM p. 20 “She [ASG representative] brought all the forms and just got us to sign them and she filled them all in. [.] It was just everything was done.”

I therefore understand that I need to be well-prepared for my interviews, with all the videoconferencing in place and working, and a clearly explained plan, with attention paid to the time:

> F2MM p. 47 “I think we’re heading for lunch anyway aren’t we? Half past 12.” – responding to interviewer’s request for a few more questions.

Many of the interviews covered the complex issue of compensation, and I became painfully aware that, even after 18 months of immersion in the mesothelioma world, I was still confused about how this worked for veterans. The compensation process is something I will need to understand properly before my empirical study starts, so that my participants don't start to doubt my credibility.

The participant-researcher relationship

The issue of power in the participant-researcher relationship seems very important. Hierarchies of power came up often in the interviews. The chain of command in the military was very present as an organising principle, leading participants to have strong expectations about how the world does and should operate.

> F2MM p. 24 "You have what they call a chain of command, but you don't step outside your role. So you are responsible for whatever is in the square. [.] You pass it on to somebody else [.] and up the ladder it goes."
>
> F2MM p. 48 "Everything is defined for you, and it's defined by what's in the rules. The rule book."
>
> F7MM p. 5 "It certainly wouldn't have been a local initiative, because people [in the AF] don't do that kind of thing. It must've been a directive from higher up that people who'd been exposed had their records filed."

These expectations were reflected particularly in how they talked about their interactions with the NHS, and with MPs/the government. It was also an element in how they described interactions with the legal system. Powerful figures featured throughout the transcripts, often being described in terms of 'bigness', with the participants being reciprocally 'small':

> F7MM p. 10 "I'm too low down on the food chain [.] but somebody needs to raise a question. [.] He [MP] is Edward Agar, Secretary of State of Justice, so he's quite a big chap."
>
> F2MM p. 50 "If the coroner couldn't get the information, how was a little person like me going to get the information?"

Sometimes these powerful people wielded their power in beneficial ways, e.g. the coroner who took on the NHS; the palliative care consultant who fast-tracked a patient into a hospice; the surgeon who gave hope:

> F2MM p.33 "It [obtaining the lost records] was only because the coroner threatened the NHS with a subpoena."
>
> P12MM p. 13 "Somebody [surgeon] that says, 'Well, I can do this, I can do that, give

> you an extra two to three and a half years.'"

They had high expectations about responsibility; people high up in the chain of command should care about those lower down; they should be trustworthy; they should face up to things when mistakes happen:

> F2MM p. 22 "When you're in a responsible position, [.] you either face up to it and you accept your responsibilities and you know that may affect other people if you make the wrong decision, but you get on and do it, and you take the plaudits [.] but you also take the brick bats."
> F3FC p. 9 "Duty of care is when somebody looks after you, they take the responsibility for having caused whatever it was."

Carers and patients described instances of being let down by the powerful. This could be an NHS consultant misdiagnosing mesothelioma; a consultant suddenly reminding them about mesothelioma's poor prognosis; the MOD hiding information about asbestos exposure; being personally blamed for poor NHS systems; lawyers wanting money:

> F2MM: p.49 "The situation after [wife] had died with regard to the NHS and the loss of the documents [.] was probably the worst time of my life."
> F3FC p. 9 "They [MOD] are not taking responsibility for looking after his treatment for something that they put him in a situation that caused it."
> F7MM p. 26 "The only thing that probably really let us down, I think, were the surgeons."
> P11MA p. 23 "She [consultant] felt the need to rub it in a bit and say, 'But it could blow up at any time, you know.'"
> P11MA p. 19 "It was like it was my fault because I didn't have a blood test, but I didn't know I needed to have one."
> F6FC p. 36 "It's all money, money, really, so they [lawyers] want their money, but then they're telling me, well, you might have to give some of yours back."

I also became aware through doing the SDA of the potential overlap between the participants' experiences of *medical* research and my own research. Because the illness is currently incurable, there is a great deal of focus within the mesothelioma community on medical trials. The participants often referred to their experience of the *idea* of research and their participation in it. There was sometimes an aura of magic around the process and the researchers, e.g.

> F9FC p. 10 “Someday, someone’s going to find something that will sort this out.”

I also noticed that participants had a tendency to describe research in terms of sport or games, or show researchers having childlike excitement:

> F7MM p. 30 “It’s early doors in that sort of therapy [immunotherapy]” – an idiom from football.
> P8MA p. “His oncologist, he was so excited. [.] He said, ‘It’s a beautiful response’. He said, ‘It’s like throwing a stake with a dice’, he said, ‘like throwing a six.’”

This chimed with my personal experience of meeting a mesothelioma patient in hospital, who described her surgeon as “like a little boy at Christmas” when he was talking about her unusual presentation.

There was a sense that the researchers were high status and rather detached from the patients, not bothering to communicate with them about the work:

> F7MM p. 27 “The professor [.] said her case was so unusual he was thinking about writing a paper on it – whether he actually did or not, I don’t know because he’s the world’s busiest man.”

At times, it seemed as if the participants’ understanding of the research process was rather hazy. This included a lack of awareness of how exactly their experience might be of interest and use to researchers:

> P13MN p. 1 “There was a sort of guy researching.”
> F7MM p. 37 “I don’t know quite really what you’re interested in.”
> F7MM p. 33 “Just chatting to someone is the least I can do.”

One participant, F6FC, seemed apologetic about not being to be able to answer some questions straightaway, using the response “Good question” several times to cover her embarrassment.

Participants often expressed their willingness to help with research, framing it as ‘being good to help others’ e.g. F9FC p.10. However, there were hints that they found, or expected, the interview to be difficult. P12MN finished the interview by saying, “Thank you very much for making it not too painful" (p. 22). I noticed that more than one anecdote about breaking confidentiality or guidelines appeared in the data (F6FC p. 30, F2MM p.21), so I wonder if the confidentiality of this research process may have been a source of underlying anxiety.

The message I take for myself is that I may be positioned as powerful, as an 'expert researcher', with the accompanying expectations of care and potential for letting down my participants. I hope to listen to my participants in the way that P12MM experienced as being respectful and curious, rather than coming from a directive, arrogant, powerful position:

> P12MM p. 21 "He (GP) would listen to you and spoke to you as if he was sort of feeding off of you. Whereas the other lady that I saw there, she was dictating to you and really she didn't have a clue what she was talking about."

I need to be clear about the purpose of my study, and to be respectful and explicit about the valuable contribution the participants will be making.

The impact on participants

We have already seen how veterans and their families have been inducted inside a military culture which has very strong values. This sense of there being the insiders, the military community, and then the outsiders, the civilians, is an important aspect of my research setting. There is a general feeling that civilians can't understand people from the AF community, which F4FC spelled out:

> F4FC p. 19 "I have been labelled an honourary squaddie, which to me is a huge compliment. Because apparently I do get it and a lot of civvies don't."

I was aware of this issue before I undertook the SDA (from studying PTSD in military personnel), and I was pleasantly surprised at how willing the participants were to be patient with the civilian interviewers and not use much military jargon. F2MM was happy to spontaneously translate into "civilian terms" (p. 5) for the interviewer. This makes me feel less anxious about the way language is likely to be used in my interviews.

However, F4FC's comment above comes from a very significant part of the interview, where she spells out the effect on the patient of being questioned by a civilian as part of the compensation process. As I will be talking to carers about potentially very distressing topics, I found her explanation of how things can go very wrong in such conversations to be extremely useful. She is talking about veterans being asked to revisit active service, but I suspect that this also applies to exploring difficult illness experiences. She says:

> p. 20 “It can sometimes hit a really raw nerve because of what they’ve seen and what they’ve done, and what they’ve experienced. And that needs to be dealt with in an empathic way, it doesn’t need to be dealt with in a brusque…squaddies don’t like ‘there-there darling, you’ll be alright,’ but they also don’t like people to just trample all over it. [.] No squaddie wants to be patronised. [.] I remember thinking it’s good he’s got me here to mop up afterwards. [.] Anybody who’d had that experience on their own and was left on their own to sort of reel a little bit from what little bit of the box had been opened, would probably be struggling a little bit.”

She also praises the interviewer for showing the right reaction:

> p. 21 “You don’t have to say ‘Oh my God, that must have been awful,’ because a squaddie would hate that. Just the fact that you said ‘wow’ means that you’ve understood how tough that must have been.”

She later warns that:

> p. 22 “If you’re going to force something out, it’s going to hurt more and you’re going to re-traumatise that person.”

I learned from this woman that as a civilian I will need to tread carefully, and perhaps rein in my usual counsellor-style amounts of empathy, whilst trying to show warmth and understanding in a less obvious way.

Throughout the SDA process, I was aware of a discomfort amongst the participants around negative emotions. There did, though, seem to be some emotions that were ‘allowed’, i.e. fear, anxiety and anger:

> F6FC p. 14 “I was very cross”.
> P13MN p. 1. “You obviously look online and scare yourself shitless.”
> F10FC p. 3 “Perhaps if we went more we’d feel a bit more comfortable, we wouldn’t be quite as anxious socially.”
> P8MA p. 9 “That [money] is my biggest worry at the moment.”
> F7MM: p. 26 “I think at first she was afraid of dying.”

Also mentionable were positive feelings:

> F9FC p. 9 (about another couple’s good mesothelioma news) “I’m glad it has been for him.”
> F7MM p. 20 “It’s a really happy [meso support] group and very friendly.”

However, there seemed to be a taboo about other negative feelings, particularly around loss, grief, sadness and feeling ‘low’. F9FC was very clear that “when you just constantly talk about the same thing all the time it’s just bringing you down.” The analysis of this participant’s transcript suggested a huge amount of control was going in to minimising negative emotions. For example, she said (p. 7): “You just have to suck it up because whatever time there is I don’t want to be miserable.” She was also very clear that she didn’t like sympathy (p. 7). F7MM described his wife as not “a great one for communicating her feelings” (p.21), and he described how his inability to talk about his work because of military secrets had over time eroded intimacy between them. F6FC explained that she did not like support groups where people sat and cried (p.26). Throughout her transcript, there were examples of her suppressing expression of any grief or feelings of loss, yet she seemed to *have* them. For example, she described her toddler grandson:

> p. 22 “He keeps saying “’Where’s Grandpa, where is he? I miss him!’ You’re like, ‘Oh God’”.

For this widow of a senior naval officer, crying or getting upset were things that small children did, and were not acceptable for adults:

> p. 25 “We wouldn’t have been lying here in a puddle. [.] We didn’t all sit hugging each other in a corner.”

F2MM also did not express feelings of loss for his wife in a personal way. Instead, he gave a lot of detail about how respected his wife had been in the military community across the world. Interestingly, the only *direct* expression of grief for her was spoken through the words of a young woman who had met her as a child:

> p. 43 “The email said ’I’m very sorry to hear that [wife] has died. She said ‘My family and I are very sad, and my dolls are sad too.”

F10 FC explained the effect of the diagnosis:

> p. 2 “I think one of [P13]’s low points, [.] it was, who’s going to take the [family] pictures, which seemed a bit silly.”

The phrase ‘poor me’ cropped up on several occasions, and was associated with feeling sorry for yourself and being rather pathetic. F6FC used this phrase more than once, in the context of not wanting to/thinking of asking for support, but actually needing it (p. 24): “Not that I’m saying ‘Oh, poor me’, but…” This phrase was also used by P11MA:

> P11MA p. 18 “If I am going through a little period of, I suppose in one way, poor me, [.] then I’ll contact them [Meso UK nurses].”

In fact, there seemed to be a feeling among some participants that allowing emotional upset into awareness could be absolutely catastrophic:

> F10FC p. 5 “We try not to think about it. [.] It’s in the back of your mind and just carry on because otherwise you’d just go completely mad.”
> F4FC p. 16 “I kind of just keep it in the back of my mind, otherwise I’d go mad.”
> F3FC p. 14 “I wouldn’t want him to end up in a situation where he suddenly might start thinking negatively about it.”
> F4FC p. 17 “I don’t like it when he makes more of a fuss of it than necessary. Whereas I’m like, no, you’re not as ill as that, you’re fine, it’s alright, carry on. Because I want him to carry on forever.
> F4FC p. 23 “That really upset him and when we came home, he was really, really, you know, almost hanging himself depressed.”

F6FC expressed the idea that, during his service career, her husband had been protecting her by not talking about any worrying aspects of his work. This was partly because of military secrets, but he also said “I don’t want to worry you, or well, you know, it’s not going to make any difference” (p. 27). This was a man who forbade his coffin to be taken into the church as it would be too “upsetting” for his family (p. 21), and who didn’t tell them he was close to death, though he knew.

In terms of my interviews, these reactions to having and/or displaying emotions make me wonder what might happen in my interviews if my questions do lead to participants feeling ‘upset’, as feeling vulnerable seems to be avoided at all costs. I hope to avoid participants feeling shamed. It will certainly be essential for them to have support easily available after the interview. It is probably important that *I* don't appear to be upset by anything that I hear.

The SDA process has led me to question how emotionally aware this group of participants actually are. There seemed to be some difficulty in naming feelings or putting them into words. For example, F6FC described the huge turnout for her husband's funeral as "quite nice" (p. 20). Other expressions included:

> P13MN p. 4 "There's obviously ups and downs."
> F10FC p. 4 "Sort of lost it" – describing herself overcome and crying.
> F10FC p. 5 "OK most of the time. [.] It can be different things that sort of ebbs and flows, if you like, very often at night."
> F3FC p. 6 "I felt gutted."
> P8MA p.14 "As much as I don't like my situation, I don't let it bug me on a day-to-day basis."
> P12MN p. 20 "She [GP] went all sort of out of her pram."

Participants did, though, sometimes vocalise the emotional impact of events using sounds or metaphors (often physical/military), which were very expressive:

> P12MN p. 7 "It was a bit of a bombshell."
> P11MA p. 15 "It just come as a bit of a blow [.] like going into a surreal world. [.] You just feel like screaming at people. [.] Now it's like walking around with an unexploded bomb in your chest."
> P11MA p. 18 "A bit of a slap in the face"
> F2MM p. 14 "That was another kickback."
> F7MM p. 12 "Oof!" and "Wallop!"

I was struck in some places in the interviews where participants were talking about potentially highly emotive things, and they just didn't 'go there', i.e. they didn't mention having any feelings about these issues. So, one might mention an anecdote about another military wife who had got mesothelioma from washing clothes, but not apply that to herself/his wife in terms of Damocles syndrome anxiety (F6FC p. 41; P8MA/F3FC p. 14). Another example is where F3FC explains that her husband is at the last resort treatment, which only works on 20 per cent of people (p. 8), but there is no related emotion from her or her husband. F7MM seemed to have no interest in/awareness of his own feelings or 'carer perspective', except for feelings of outrage towards the MOD and one district nurse. P8MA seemed to have no conception of the idea of ‘emotional support’, e.g. p. 10 when talking about the possibility of contacting the Meso UK nurses, he says “A nurse you think is somebody to give you medical help”, and his response to being asked about ‘support’ is to talk about financial benefits. All this leaves me with some anxiety that my study participants may not be able to articulate or be aware of the psychological effects I am wanting them to discuss.

There also seemed to be some issues around couples’ mutual lack of understanding/intimate communication:

> P8MA p. 6 “I don’t know how [F3FC] felt, I’m sure she was worried.”
> F6FC p. 28 “Towards the end, he hardly spoke. [.] I’d be rabbiting on about anything. [.] I suppose he definitely went into himself.”
> F7MM p. 35 “She maybe confided in one or two of them [friends].”

This makes me worry that my participants may not be able to talk to me easily about the effects on their deceased patients. Another related issue is the use of “we”. By this, I mean that in some couples, there didn’t seem to be any differentiation between the two people: the experience was presented as joint and identical for both:

> F9FC p. 3 “We don’t want to keep talking about it”.
> P8MA p. 7 “We want to be told what’s going on precisely.”

Another aspect of the interviews relating to the carer’s talk about the patient is the tendency to eulogise. This happened whether patients were deceased, or were present in the joint interview. F2MM was very concerned to honour his wife, explaining in detail how she had had an RAF flypast, which even Margaret Thatcher didn’t get at her funeral (p. 46), and to present her as unflinching (p. 19). F3FC was a keen ‘gate-keeper’ of her husband’s mental state, determined for him to stay positive. She said:

> p. 7 “[P8MA] is very together with all of this and his attitude to life hasn’t…you know, he’s been great.”

F7MM’s wife was presented as a wonderful person, constantly volunteering and helping other mesothelioma patients. Whilst this eulogising is natural, I wonder if it might prevent participants giving a more nuanced picture of the journey they have been through with the patient. It will take very sensitive interviewing to navigate this issue.

Out of all the participants, one couple, F4FC/P11MA did in fact seem to have better emotional awareness and ability to think psychologically, and to discuss differences as a couple. F4FC was the woman who warned about potential re-traumatisation. Interestingly, she was the youngest participant, inher mid-40s, so this may have been a generational effect.

A final sensitising issue that may affect how my participants communicate their experience to me is the use of humour. A sense of humour is valued in the British AF as a way of allowing individuals to face danger and of enhancing social bonding in the group (King, 2004). P11MA articulates this idea exactly:

> P11MA p. 21 “The Parachute Regiment, [.] we’ve got a different outlook on life. [.] We’re not the type of people who will give up, if that makes sense. Very black-humoured, you know. We’re the type of people who said, ‘I’ve lost my leg!’ ‘You’ve got a spare one, carry on.’ [.] We take the mickey out of each other but our hearts are together.”

There were many examples of participants using humour as a coping mechanism. It often popped up when the interview edged towards moments of pathos, when sad or fearful feelings might have been around, or where there was a sense of powerlessness or betrayal. Sometimes this humour was voiced as understatement or irony. Here are some examples:

> F2MM p. 19 “”You probably know what an Abraham’s needle is, and it’s not a nice thing.”
> F7MM p. 13 “He said, ‘I’d have surgery, I’d recommend surgery.’ But he was a surgeon (laughing)”. [sarcasm about moment of being let down]
> F6FC p. 12 “If you get lots of infections [.] your resistance will be pretty low, so that’s nice, isn’t it?” [sarcasm about moment of bad news]
> F6FC p. 16 “Afterwards they thought he had sepsis, and it was all good fun.”
> F4FC p. 24 “I turn into a little five year old child when I’m in front of a doctor. And my doctor knows that and so she takes the mick out of me, you know, and she knows how to treat me.”
> P12MN p. 11 “My wife doesn’t drive, so it would be a bit of a nightmare with her at the wheel!”
> F2MM p. 15 “She said to the consultant, ‘Well, if I can’t go abroad, I’m going to do a world tour of the British Isles!’”

> F2MM p. 39 “They gave us a suite. It was the bridal suite. [.] [Wife] saw the funny side of that.”

In the following dialogue, we can hear humour in the ‘mickey-taking’ tone both participants use (F10FC/P113MN p. 5):

> Interviewer: What do you do when you’re having a ‘down’? What helps?
> F10FC: Blub (laughs).
> I: Sorry?
> F10FC: Blub, cry (laughs).
> P13MN: Open the wine (wife laughs).
> F10FC: Yeah. Oh, you try…you…you know, the best thing is try to do is to stay as long as we can, but then, you know, as you say, there are times that if something happens and you can’t.
> I: Yeah, of course, yeah.
> F10FC: So, silly things really, you know? The thing with…a lot of people say it’s something silly but just tips you over the edge.
> P13MN: Usually something I’ve done (all laugh).

In this sequence, we can see the disparaging term ‘blub’ used about crying, then the disjointed section as the carer struggles to articulate the reality of the difficult feelings, then she heads back into the idea of ‘silly’, followed by the husband undercutting with a joke.

My thoughts about the use of humour in terms of planning for my interviews are that I need to be ready for this strategy to be used, and to be sensitive about probing at that point. Also, I suspect it will be helpful if I am not too serious and po-faced from the very start of my contacts with participants, whilst at the same time being respectful towards them.

Appendix O: Participant information sheet and consent form

PARTICIPANT INFORMATION SHEET: Individual Interview

Title of Project: The psychological effects of mesothelioma: carers' experiences in the UK military context

(part of the MiMES Military Mesothelioma Experience Study)

Name of Researcher: **Virginia Sherborne**
Principal Investigator: **Professor Angela Tod**

I would like to invite you to take part in an interview as part of a research study about living with mesothelioma. Before you decide whether or not to participate, I would like you to understand why the research is being done and what it would involve for you. Please take time to consider the following information carefully and discuss it with others if you wish. If you have any questions about this study, please feel free to contact a member of the research team using the contact details at the end of this information sheet. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

There is little research to help us understand the experiences of Armed Forces personnel/ veterans with mesothelioma. We need to know more about the health and support needs of them and their families so that we can improve current services and care.

The aim of this stage of the research is to understand the experience and support needs of British Armed Forces personnel/ veterans with mesothelioma (with and without exposure through the Armed Forces) and their carers[1], from the perspective of the carers.

This research is being conducted between March 2020 and November 2021.

Why have I been invited?

You have been invited to take part because you have responded to an invitation through an organisation like Mesothelioma UK or an Asbestos Support Group. You will be someone who:

- Is a carer/main informal supporter of someone who has served in the British Armed Forces and has received a diagnosis of mesothelioma OR
- Was a carer/main informal supporter of someone who served in the British Armed Forces and received a diagnosis of mesothelioma and who died (from any cause) in the last **24** months.

We will be inviting a range of carers to participate, including people of different ages and genders. We would like to identify up to 10 carers of people with mesothelioma who served in the British Armed Forces who are willing to take part in an interview.

Do I have to take part?

It is up to you to decide whether or not to take part. Your participation is entirely voluntary. If you agree to take part, you be will be required to sign a consent form. You are free to withdraw without negative consequences and without giving a reason.

Please be aware that once data has been anonymised and included in project reports this data cannot be withdrawn from this study. This data can however be withdrawn from future studies.

What will happen to me if I take part? What do I have to do?

You will be contacted by me, Virginia, who will discuss the study with you and check that you are happy to take part. Following this, I will set up a date for the interview. I will conduct the interview online, using Google Meet videoconferencing. I expect the interview to last up to 60 minutes.

If you agree to take part, I will ask you to sign a consent form. I will ask your consent to digitally record the audio of the interview. The recording will be typed out and all names and identifying data will be removed.

The interview will explore your views and experiences of the **psychological impact** of mesothelioma for Armed Forces personnel/veterans and their carers, from the carers' perspective. Topics that will be discussed in the interview will include: the impact of diagnosis; emotional responses; coping strategies; mental health; negative and positive changes; relationships; information and support needs.

What are the possible disadvantages, risks or benefits of taking part?

There are no anticipated advantages, disadvantages or risks of taking part in this study. Whilst there is no immediate benefit for those people participating in this project, many people enjoy being involved in discussions of this nature and it is hoped that the research findings will help to improve the experiences of other patients and family carers in the future.

Thinking and talking about their family member or friend's illness may upset some participants. If this happens, we will pause the discussion if you wish. We can signpost towards help and support should this be required.

---

[1] We have defined a carer as the **main informal supporter (family or friend)** of British Armed Forces personnel/ veterans with mesothelioma.

There is a very small chance that, during an interview, someone will reveal something that causes concern about their health or safety. If this occurs, with your agreement I will feed this information back to the Mesothelioma UK Helpline for advice. I will only do this with the participant's permission.

Will my taking part in this study be kept confidential?

If you take part in an interview then all identifying information will be removed when the interview recording is typed out. Some quotes may be used when the research findings are written up, but no names will be used and all data will be anonymous. You will not be identifiable in any reports or publications.

Data collected in the study may also be looked at by authorised people to check that the study is being carried out correctly. I have a duty of confidentiality to you as a research participant. All the information that is collected about you during the course of the research will be kept strictly confidential.

If you agree to me sharing the information you provide with other researchers in future projects then your personal details will not be included.

What is the legal basis for processing my personal data?

According to data protection legislation, I am required to inform you that the legal basis I am applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1) e). Further information can be found in the University Privacy Notice www.sheffield.ac.uk/govern/data-protection/privacy/general.

As I will be collecting some data that is defined in the legislation as more sensitive (information about health and wellbeing), I also need to let you know that I am applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

What will happen to the data and the results of the research project?

Data processors, for example, transcription services will have access to your identifiable data. Once the data has been transcribed all identifiable information will be removed and pseudonym words will be used to replace relevant names and places.

Only members of the research team will be able to access your data during the study. Following transcription, only the anonymised data will be used.

How long will anonymised data be stored for?

Identifiable personal data will be destroyed as soon as possible once it is clear that this will not affect the purpose of the research. This identifiable data will therefore be destroyed once the project has been completed.

The results of the study may be published in scientific journals and/or presented at conferences. Study findings will be discussed by stakeholder organisations to identify service developments and improvements.

You will not be identified in any report/publication as a result of this study. A copy of the study findings will be made available to all participants if desired.

Your data will be stored on the University of Sheffield secure server, only accessible to those who are authorised to access it. Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering future research questions. I will ask your explicit consent for your data to be stored and shared. Transcripts of the discussion will be kept for at least 10 years.

Who is the Data Controller?

Virginia Sherborne at the University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who is organising and funding the research?

The study is being funded through a research grant from Mesothelioma UK and conducted by Virginia Sherborne. I am a postgraduate researcher at the Division of Nursing and Midwifery in the University of Sheffield, and I am conducting this research study for my PhD project.

Who has reviewed the study?

This study has undergone ethical review by the Division of Nursing and Midwifery at the University of Sheffield and has been approved.

What if there is a problem?

It is extremely unlikely that anything will go wrong as a result of taking part in this study. However, if you have any concerns about this study, or if you have any queries or questions please contact a member of the research team, Virginia or Angela. You can find our contact details at the bottom of this page.

If your complaint has not been handled to your satisfaction then you can also contact the Director of Research at the Division of Nursing and Midwifery, Dr Tony Ryan. If your complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: www.sheffield.ac.uk/govern/data-protection/privacy/general.

Further information and contact details

For further details, please contact:

Virginia Sherborne: Postgraduate Research Student
Division of Nursing and Midwifery

The University of Sheffield
Barber House Annex
3a Clarkehouse Road
Sheffield S10 2LA
hvsherborne1@sheffield.ac.uk

OR

Prof. Angela Tod: Principal Investigator
Division of Nursing and Midwifery
The University of Sheffield
Barber House Annex
3a Clarkehouse
Sheffield S10
2LA Tel: 0114
2222057
a.tod@sheffield.ac.uk

To contact a person outside the project:
Director of Research: Dr. Tony Ryan
Division of Nursing and Midwifery
The University of Sheffield
Barber House Annexe
3a Clarkehouse Road
Sheffield S10 2LA
t.ryan@sheffield.ac.uk

If you decide to take part, this information sheet is yours to keep and, if desired, you will be given a copy of your signed consent form.

Consent Form

MiMES: Military Mesothelioma Experience Study

Please tick the appropriate boxes	**Yes**	**No**
Taking Part in the Project		
I have read and understood the project information sheet dated Nov 2020 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will involve taking part in an individual interview and that this will be audio recorded and transcribed. Any identifiable information will be removed.		
I understand that my taking part is voluntary and that I can withdraw from the study before [date]; I do not have to give any reasons for why I no longer want		

to take part and there will be no adverse consequences if I choose to withdraw.		
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.		
I understand and agree that my words (my data) may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.		
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.		
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I give permission for the data that I provide to be deposited in the University's ORDA data repository so it can be used for future research and learning.		
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

Name of participant [printed] Signature Date

Name of Researcher [printed] Signature Date

Project contact details for further information:

Research Associate: Virginia Sherborne
Division of Nursing and Midwifery
University of Sheffield
Barber House
3a Clarkehouse Road
Sheffield S10 2LA
hvsherborne1@sheffield.ac.uk

Principal Investigator: Prof. Angela Tod
Division of Nursing and Midwifery
University of Sheffield
Barber House
3a Clarkehouse Road
Sheffield S10 2LA
Tel: 0114 222 2057
a.tod@sheffield.ac.uk

To contact a person outside the project:
Director of Research: Dr Tony Ryan
Division of Nursing and Midwifery
University of Sheffield
Barber House
3a Clarkehouse Road
Sheffield S10 2LA
t.ryan@sheffield.ac.uk

Appendix P: Participant characteristics forms

Form for those not yet bereaved:

Participant Characteristics

Code name:

Please fill in the table below. Use any descriptive terms that feel right for you. Feel free to leave any boxes blank if you wish.

	Carer's details	**Patient's details**
Age		
Gender		
Ethnicity		
Education level attained		
Armed Forces branch		
Dates of AF service		
AF rank		
Occupation(s)		
Date of mesothelioma diagnosis		
Type of mesothelioma		

Form for those bereaved:

Participant Characteristics

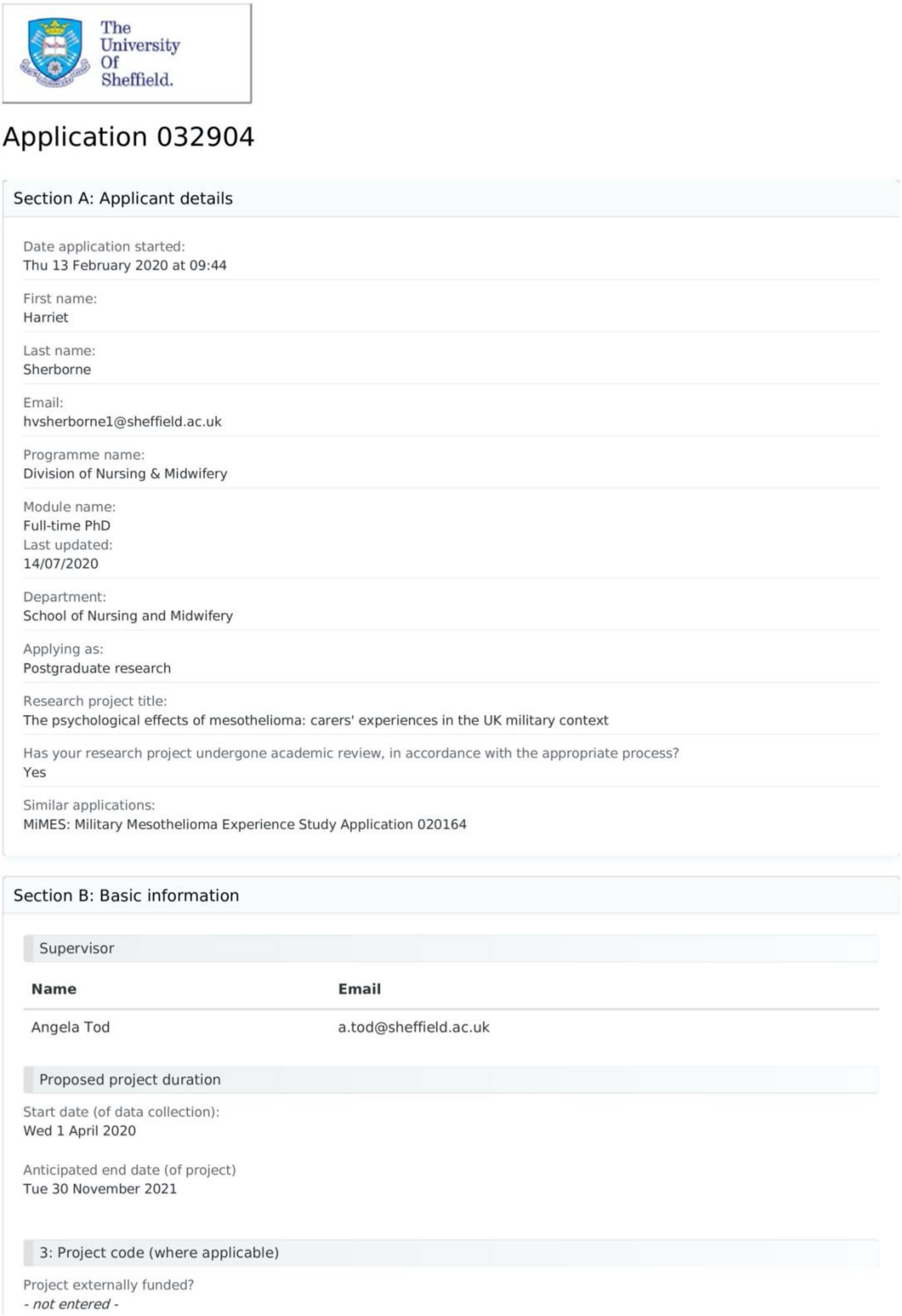
Code name:

Please fill in the table below. Use any descriptive terms that feel right for you. Feel free to leave any boxes blank if you wish.

	Carer's details	**Patient's details**
Age		
Gender		
Ethnicity		

Education level attained		
Armed Forces branch		
Dates of AF service		
AF rank		
Occupation(s)		
Date of mesothelioma diagnosis		
Type of mesothelioma		
Date of death		

Appendix Q: University of Sheffield ethics application form



The University Of Sheffield.

Application 032904

Section A: Applicant details

Date application started:
Thu 13 February 2020 at 09:44

First name:
Harriet

Last name:
Sherborne

Email:
hvsherborne1@sheffield.ac.uk

Programme name:
Division of Nursing & Midwifery

Module name:
Full-time PhD
Last updated:
14/07/2020

Department:
School of Nursing and Midwifery

Applying as:
Postgraduate research

Research project title:
The psychological effects of mesothelioma: carers' experiences in the UK military context

Has your research project undergone academic review, in accordance with the appropriate process?
Yes

Similar applications:
MiMES: Military Mesothelioma Experience Study Application 020164

Section B: Basic information

Supervisor

Name	**Email**
Angela Tod	a.tod@sheffield.ac.uk

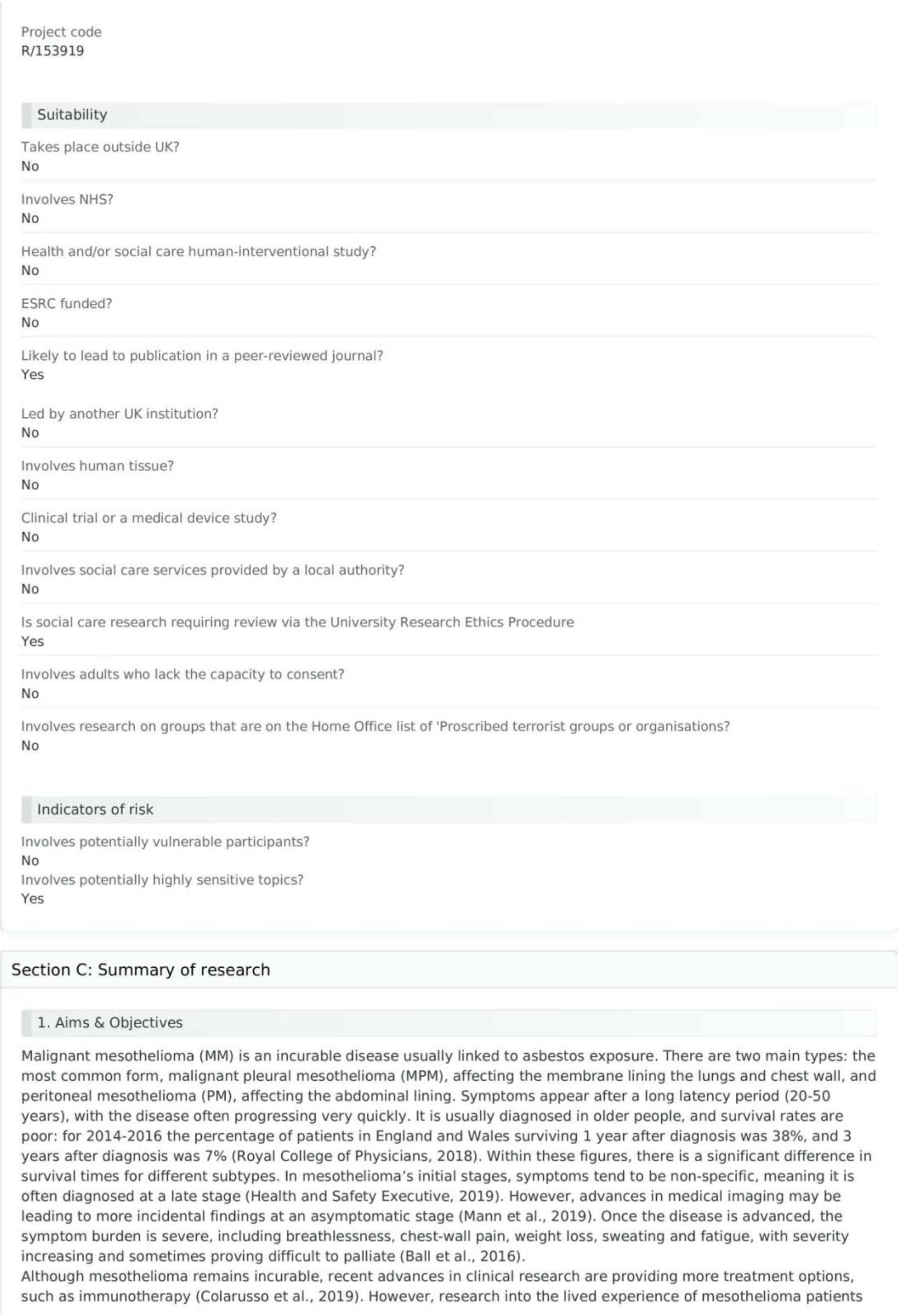
Proposed project duration

Start date (of data collection):
Wed 1 April 2020

Anticipated end date (of project)
Tue 30 November 2021

3: Project code (where applicable)

Project externally funded?
- not entered -



Project code
R/153919

Suitability

Takes place outside UK?
No

Involves NHS?
No

Health and/or social care human-interventional study?
No

ESRC funded?
No

Likely to lead to publication in a peer-reviewed journal?
Yes

Led by another UK institution?
No

Involves human tissue?
No

Clinical trial or a medical device study?
No

Involves social care services provided by a local authority?
No

Is social care research requiring review via the University Research Ethics Procedure
Yes

Involves adults who lack the capacity to consent?
No

Involves research on groups that are on the Home Office list of 'Proscribed terrorist groups or organisations?
No

Indicators of risk

Involves potentially vulnerable participants?
No
Involves potentially highly sensitive topics?
Yes

Section C: Summary of research

1. Aims & Objectives

Malignant mesothelioma (MM) is an incurable disease usually linked to asbestos exposure. There are two main types: the most common form, malignant pleural mesothelioma (MPM), affecting the membrane lining the lungs and chest wall, and peritoneal mesothelioma (PM), affecting the abdominal lining. Symptoms appear after a long latency period (20-50 years), with the disease often progressing very quickly. It is usually diagnosed in older people, and survival rates are poor: for 2014-2016 the percentage of patients in England and Wales surviving 1 year after diagnosis was 38%, and 3 years after diagnosis was 7% (Royal College of Physicians, 2018). Within these figures, there is a significant difference in survival times for different subtypes. In mesothelioma's initial stages, symptoms tend to be non-specific, meaning it is often diagnosed at a late stage (Health and Safety Executive, 2019). However, advances in medical imaging may be leading to more incidental findings at an asymptomatic stage (Mann et al., 2019). Once the disease is advanced, the symptom burden is severe, including breathlessness, chest-wall pain, weight loss, sweating and fatigue, with severity increasing and sometimes proving difficult to palliate (Ball et al., 2016).
Although mesothelioma remains incurable, recent advances in clinical research are providing more treatment options, such as immunotherapy (Colarusso et al., 2019). However, research into the lived experience of mesothelioma patients

has remained sparse, with a resulting lack of awareness of this disease's unique psychosocial impact (Bonafede et al., 2018a). Further research into the psychological aspects of mesothelioma is required to map any changes that may be occurring alongside the changes in medical treatment and prognosis. This applies to carers as well as patients, as their wellbeing is an important part of the picture (Lee and Lyons, 2019, Colarusso et al., 2019), yet it has not been a particular focus of mesothelioma research to date (Guglielmucci et al., 2018B).

Whilst there are no figures for the incidence of mesothelioma in UK veterans, in the USA it is estimated veterans make up a third of all mesothelioma patients (Mesothelioma Applied Research Foundation, 2015). Health professionals and other support groups have suggested that British veterans may have specific difficulties throughout their mesothelioma journey, for example in getting a diagnosis, and accessing support and care. The University of Sheffield's Military Mesothelioma Experience Study (MiMES) began in July 2018, aiming to find out more about how structural factors, attitudes and barriers might be interacting to influence their diagnosis and care needs.

The qualitative patient experience study within MiMES has two aims:

to understand the experience and health/support needs of British Armed Forces personnel/veterans with mesothelioma (with and without exposure through the Armed Forces)

to identify how best health professionals and support agencies within the Armed Forces and NHS can best meet the care and support needs of British Armed Forces personnel/veterans with mesothelioma (including lung cancer/mesothelioma nurse specialists, veterans associations, and asbestos support groups).

This project, part of MiMES' qualitative study, will explore the psychological effects of mesothelioma from the carers' perspective in the UK military context, with the aim of enhancing diagnosis and care provision throughout the illness journey.

BALL, H., MOORE, S. & LEARY, A. 2016. A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer. European Journal of Oncology Nursing, 25, 62-67.

BONAFEDE, M., GHELLI, M., CORFIATI, M., ROSA, V., GUGLIELMUCCI, F., GRANIERI, A., BRANCHI, C., IAVICOLI, S. & MARINACCIO, A. 2018a. The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: A systematic review of published studies. Am. J. Ind. Med.

COLARUSSO, G., TERZIC, J., ACHARD, V. & FRIEDLAENDER, A. 2019. The role of immunotherapy in mesothelioma. Precision Cancer Medicine, 2.

GUGLIELMUCCI, F., FRANZOI, I., BONAFEDE, M., BORGOGNO, F., GROSSO, F. & GRANIERI, A. 2018B. "The Less I Think About It, the Better I Feel": A Thematic Analysis of the Subjective Experience of Malignant Mesothelioma Patients and Their Caregivers. Front. Psychol., 9.

HEALTH AND SAFETY EXECUTIVE. 2019. Mesothelioma in Great Britain. Available: http://www.hse.gov.uk/statistics/causdis/mesothelioma/mesothelioma.pdf [Accessed 24th September 2019].

LEE, C. S. & LYONS, K. S. 2019. Patterns, relevance, and predictors of dyadic mental health over time in lung cancer. Psycho-Oncology, 28, 1721-1727.

MANN, S., KHAWAR, S., MORAN, C. & KALHOR, N. 2019. Revisiting localized malignant mesothelioma. Annals of Diagnostic Pathology, 39, 74-77.

MESOTHELIOMA APPLIED RESEARCH FOUNDATION. 2015. Asbestos Exposure in the Military [Online]. Available: https://www.curemeso.org/2015/11/10/asbestos-exposure-military/ [Accessed 05/11/2019].

ROYAL COLLEGE OF PHYSICIANS 2018. National Mesothelioma Audit report 2018 (for the audit period 2014–16), London, Royal College of Physicians.

2. Methodology

This is a qualitative, two-stage study using individual interviews:

Stage one: secondary data analysis

The first stage will serve to identify sensitising issues and allow fine-tuning of the research questions and interview schedule. The dataset will be interview transcripts collected in 2019 for another study within MiMES. Consent was given by the participants for such use of their data. Transcripts will be analysed using Interpretative Phenomenological Analysis (IPA) methodology (Smith, 2009), with the aid of qualitative data analysis software such as QUIRKOS or NVivo.

Stage two: individual interviews

The second stage will explore the psychological effects of mesothelioma from the carers' perspective, collecting and analysing data from semi-structured face-to-face (or if necessary phone) interviews with carers of UK military veterans with mesothelioma. Topic guides will be created using findings from the literature and from the stage one secondary data analysis. Interviews will be digitally recorded and transcribed in full. Ethical principles and conduct will be followed regarding informed consent, anonymity and confidentiality. Each interview will start with verification of consent, including consent to record digitally. Transcripts will be analysed using IPA methodology, with the aid of qualitative data analysis software such as QUIRKOS or NVivo. After transcription, if clarification is required of any points, the transcript may be returned to the participant for checking.

SMITH, J. A. 2009. Interpretative phenomenological analysis : theory, method and research, Los Angeles, Los Angeles : SAGE, 2009.

3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

Yes

Raises personal safety issues?

Yes

Interviews will take place in participants' homes or a community venue (or over the phone/Google Meet if this is not possible). Interviews may take place outside Sheffield. Most interviews will take place during office hours. Before going to an interview at a participant's home or community venue, the researcher will leave details with a colleague e.g. time of interview and researcher's mobile phone contact number plus a sealed envelope with the address of the interview location. The envelope will be destroyed afterwards to maintain anonymity of the participant. After the interview has finished, the researcher will contact the colleague by phone to let them know they are safe. The researcher will ensure their own mobile phone is fully charged, and will have an emergency number on speed dial, as well as 999.

If the researcher does not make contact at the expected time, then the colleague will take action. They will first call the researcher's mobile. If no response, the colleague will open the envelope and contact the police. The colleague will be a researcher in the Division of Nursing and Midwifery at the University of Sheffield, someone who can be trusted to understand and maintain the confidentiality of the research process.

If the researcher encounters a threatening situation, e.g. an aggressive participant, family member or pet, they will explain to the participant that they feel uncomfortable and ask to change the venue or reconvene at another time.

Section D: About the participants

1. Potential Participants

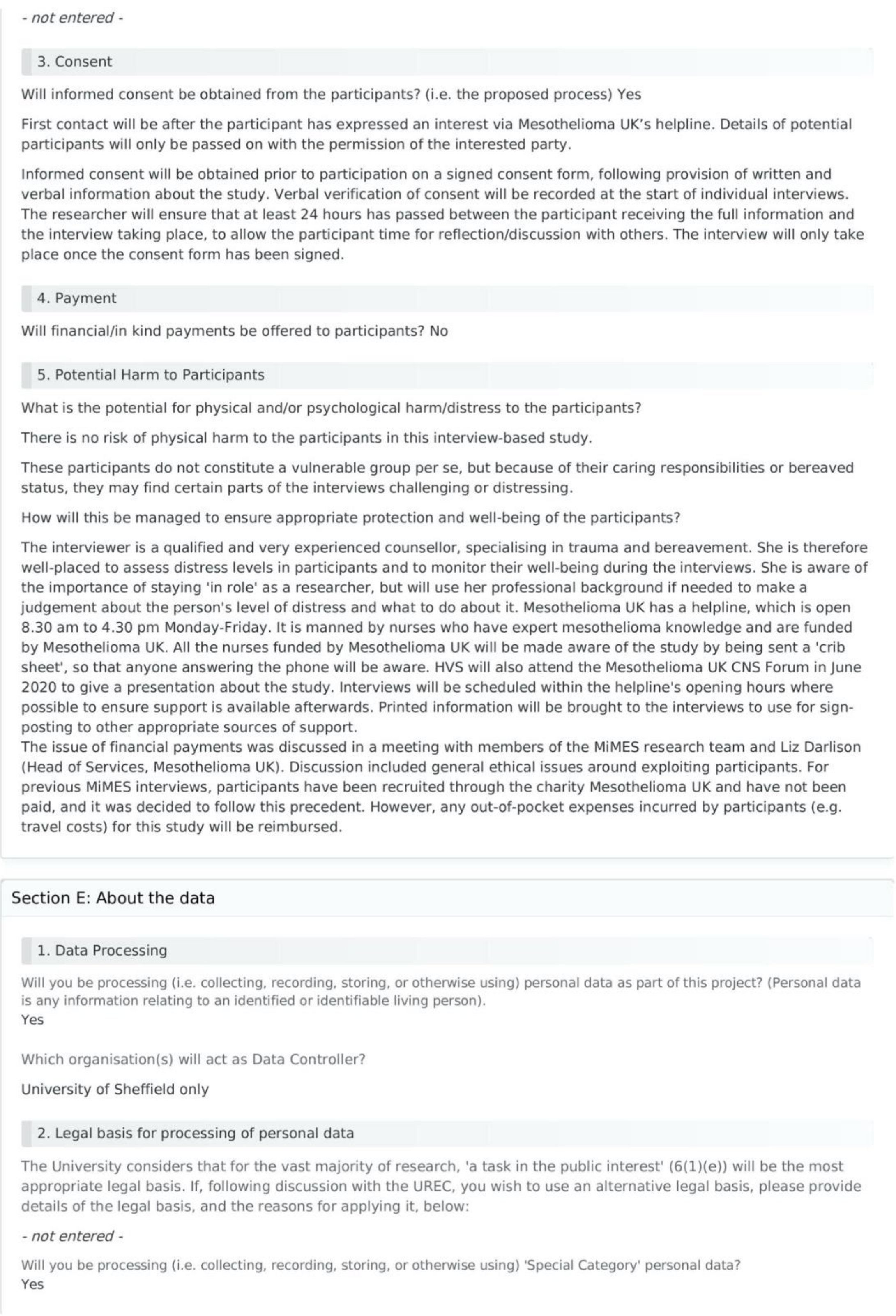
As the focus of this study is to increase understanding of the experience of mesothelioma, the sample will include carers/main informal supporters of British Armed Forces veterans with mesothelioma. The sample may include those who are up to one year bereaved, as well as current carers. Using purposive sampling, I will seek a range of carers in terms of age, gender, time since diagnosis and treatment centre. This study uses Interpretative Phenomenological Analysis (IPA) methodology, which takes a flexible approach to sample size: it depends on the richness of the data, the commitment to in-depth engagement with it, and practical constraints (Smith and Osborn, 2015), recognising that the next interview could always bring unique data (Cronin and Lowes, 2016). I shall therefore aim for 8-10 participants, using my previous experience with IPA and also examples in the literature as a guide, e.g. Smith judges 14 a "relatively large" sample for IPA (Smith, 2011a) (p.24).
Inclusion criteria:
Aged 18+
The main informal carer (whoever is the main source of informal support, including partner, relative or friend) for a UK military veteran with a diagnosis of mesothelioma, either living or up to 12 months deceased
Capable of giving informed consent to participate.

2. Recruiting Potential Participants

All participants will be recruited through stakeholder groups and organisations: Mesothelioma UK, military support organisations and local Asbestos Support Groups. Information about the study in advertisement format will be circulated via Mesothelioma UK's website and magazine, and verbally by their specialist nurses. Information in advertisement format will also be circulated via the support organisations and groups. Interested potential participants will be directed to express an interest via Mesothelioma UK's helpline, who will ask their permission to share their contact details with the researcher using an 'Expression of Interest Form' provided by the researcher. With that permission, the researcher will make initial contact through the person's preferred route (email or phone). She will then talk the potential participant through involvement, either by phone or through exchange of emails. She will then send a full information sheet and consent form. The researcher will ensure that at least 24 hours has passed between the participant receiving the full information and the interview taking place, to allow the participant time for reflection/discussion with others. The interview will only take place once the consent form has been signed. After consent has been given, a 'Participant Characteristics Form' will be sent to the participant in order to collect demographic data.

2.1. Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by CiCS? No



- not entered -

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

First contact will be after the participant has expressed an interest via Mesothelioma UK's helpline. Details of potential participants will only be passed on with the permission of the interested party.

Informed consent will be obtained prior to participation on a signed consent form, following provision of written and verbal information about the study. Verbal verification of consent will be recorded at the start of individual interviews. The researcher will ensure that at least 24 hours has passed between the participant receiving the full information and the interview taking place, to allow the participant time for reflection/discussion with others. The interview will only take place once the consent form has been signed.

4. Payment

Will financial/in kind payments be offered to participants? No

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

There is no risk of physical harm to the participants in this interview-based study.

These participants do not constitute a vulnerable group per se, but because of their caring responsibilities or bereaved status, they may find certain parts of the interviews challenging or distressing.

How will this be managed to ensure appropriate protection and well-being of the participants?

The interviewer is a qualified and very experienced counsellor, specialising in trauma and bereavement. She is therefore well-placed to assess distress levels in participants and to monitor their well-being during the interviews. She is aware of the importance of staying 'in role' as a researcher, but will use her professional background if needed to make a judgement about the person's level of distress and what to do about it. Mesothelioma UK has a helpline, which is open 8.30 am to 4.30 pm Monday-Friday. It is manned by nurses who have expert mesothelioma knowledge and are funded by Mesothelioma UK. All the nurses funded by Mesothelioma UK will be made aware of the study by being sent a 'crib sheet', so that anyone answering the phone will be aware. HVS will also attend the Mesothelioma UK CNS Forum in June 2020 to give a presentation about the study. Interviews will be scheduled within the helpline's opening hours where possible to ensure support is available afterwards. Printed information will be brought to the interviews to use for sign-posting to other appropriate sources of support.
The issue of financial payments was discussed in a meeting with members of the MiMES research team and Liz Darlison (Head of Services, Mesothelioma UK). Discussion included general ethical issues around exploiting participants. For previous MiMES interviews, participants have been recruited through the charity Mesothelioma UK and have not been paid, and it was decided to follow this precedent. However, any out-of-pocket expenses incurred by participants (e.g. travel costs) for this study will be reimbursed.

Section E: About the data

1. Data Processing

Will you be processing (i.e. collecting, recording, storing, or otherwise using) personal data as part of this project? (Personal data is any information relating to an identified or identifiable living person).
Yes

Which organisation(s) will act as Data Controller?

University of Sheffield only

2. Legal basis for processing of personal data

The University considers that for the vast majority of research, 'a task in the public interest' (6(1)(e)) will be the most appropriate legal basis. If, following discussion with the UREC, you wish to use an alternative legal basis, please provide details of the legal basis, and the reasons for applying it, below:

- not entered -

Will you be processing (i.e. collecting, recording, storing, or otherwise using) 'Special Category' personal data?
Yes

The University considers the most appropriate condition to be that 'processing is necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)) . If, following discussion with the UREC, you wish to use an alternative condition, please provide details of the condition, and the reasons for applying it, below:

- not entered -

3. Data Confidentiality

What measures will be put in place to ensure confidentiality of personal data, where appropriate?

Privacy and confidentiality will be respected throughout this research study. Interviews will be conducted in a room where others cannot overhear.

Data processors, e.g. transcription services, will have access to identifiable data. To ensure trustworthiness of the transcription service, either the service used for transcribing previous MiMES interviews will be used, or one recommended for health-related IPA transcription by an experienced professional researcher ("Transcription UK").

Once the data has been transcribed, all identifying information will be removed and pseudonyms allocated to participants. Identifiable information refers to names, addresses, and the regions where the research is conducted. The names of organisations mentioned by participants will not be mentioned in reports of findings.

Following transcription, only the anonymised data will be used. Members of the research team will have access to anonymised data.

Identifying number codes will be placed on each recorded file and in the headers of transcripts. All transcripts and audio files will be labelled with this number code. A key matching each code to each participant and their identifiable information such as name, age and contact details will be stored securely.

The results of the study may be published in scientific journals and/or presented at conferences. Study findings will also be discussed by stakeholder organisations to identify service developments and improvements.

Participants will not be identifiable in any report/publication as a result of this study. It is possible that some occasions may occur where it is difficult to present the findings without some indication of who the participant is. For example, if the participant works for a service which is unique within the country or is an active volunteer within the charity and is known to people. If this occurs, any data or description will only be included with the express permission of the participant, or minor omissions will be made in the reports/publications.

Due to the nature of the research, it is very likely that other researchers may find the data collection to be useful in answering future research questions. Participants will be asked to provide their explicit consent for their data to be shared in this way. If participants consent to use sharing their information they provide with other researchers in future projects, then personal details will not be included. Only anonymised data will be shared with other researchers.

4. Data Storage and Security

In general terms, who will have access to the data generated at each stage of the research, and in what form

The MiMES project will be subject to review and audit within the University including review of the site file. This will be kept on a university server and only accessible to the research team using password protection. The University of Sheffield researchers (Angela Tod – PI and Harriet Virginia Sherborne) will have control of and be custodians of the data generated by the project. Transcripts will be saved to the project site file alongside a pseudonymisation log containing identifiable data.

Interviews will be digitally recorded, transcribed, pseudonymised and stored on a password protected computer in line with University regulations. Transcripts will be pseudonymised as soon as possible and only pseudonymised transcripts will be printed in hard copy. Hard coies, if printed, will be stored in locked cabinets.

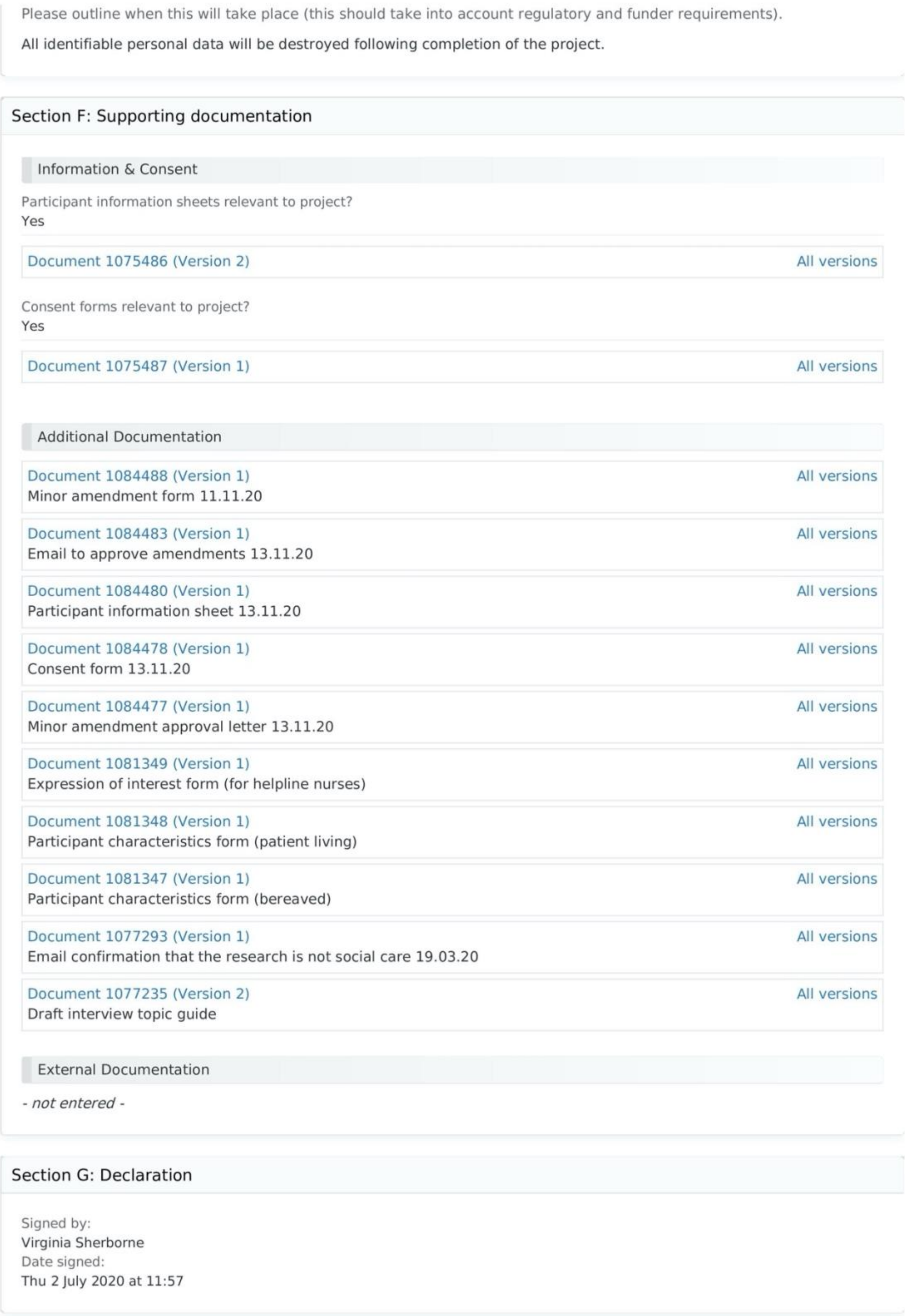
All recordings will be transferred from devices as soon as possible and deleted from the voice recorder. All consent forms will be scanned. The original hard copy will be stored in a locked cabinet and the scanned copy will be stored on the project site file. Research team members will have access to this project network storage. External access will not be required for members of the research team during this project.

Recordings will be deleted at the end of the study but transcripts and pseudonymisation logs will be saved for 10 years in line with University of Sheffield and RCUK recommendations. Relevant primary data needs to be accessible to others for a suitable period of time. 10 years is the suggested amount of time (UoS, 2018).

What steps will be taken to ensure the security of data processed during the project, including any identifiable personal data, other than those already described earlier in this form?

None

Will all identifiable personal data be destroyed once the project has ended?
Yes



Please outline when this will take place (this should take into account regulatory and funder requirements).

All identifiable personal data will be destroyed following completion of the project.

Section F: Supporting documentation

Information & Consent

Participant information sheets relevant to project?
Yes

Document 1075486 (Version 2)	All versions

Consent forms relevant to project?
Yes

Document 1075487 (Version 1)	All versions

Additional Documentation

Document 1084488 (Version 1) Minor amendment form 11.11.20	All versions
Document 1084483 (Version 1) Email to approve amendments 13.11.20	All versions
Document 1084480 (Version 1) Participant information sheet 13.11.20	All versions
Document 1084478 (Version 1) Consent form 13.11.20	All versions
Document 1084477 (Version 1) Minor amendment approval letter 13.11.20	All versions
Document 1081349 (Version 1) Expression of interest form (for helpline nurses)	All versions
Document 1081348 (Version 1) Participant characteristics form (patient living)	All versions
Document 1081347 (Version 1) Participant characteristics form (bereaved)	All versions
Document 1077293 (Version 1) Email confirmation that the research is not social care 19.03.20	All versions
Document 1077235 (Version 2) Draft interview topic guide	All versions

External Documentation

- not entered -

Section G: Declaration

Signed by:
Virginia Sherborne
Date signed:
Thu 2 July 2020 at 11:57

Appendix R: Interview topic guide

Smith et al.’s (2009) suggestions have been consulted for constructing a topic guide for IPA semi-structured interviews:

- Use open rather than closed questions, and ones which don’t make assumptions about the participant’s experiences.
- Between 6 and 10 prompts are suitable for about an hour’s interview.
- A flexible approach to the order of questions within the interview is helpful, though it can be useful to ‘funnel’ towards more sensitive issues in the later part of the interview.
- Use probes, such as ‘What do you mean by ‘unfair’?
- Use prompts, e.g. ‘Can you tell me a bit more about that’?

Interview Topic Guide:

- Request to continue recording right until the end of the video call.
- Review confidentiality and renew consent.
- When I’ve read about people in your situation, I’ve noticed people use different terms, e.g., carer. What terms do you use?
- Please could you tell me about your experience of being a carer for your partner* with mesothelioma?
- How have you experienced any changes in yourself as a person – either positive or negative? And in your partner?
- What were your coping strategies? And your partner’s?
- Are there any ways your partner’s military background affected the illness’ impact on you or on them?
- Can you describe any effects of the illness on your mental health? Or your partner’s?
- Have you experienced any changes to your relationship with your partner? Or with anyone else?
- Are there any ways that you and your partner’s help and support needs could be better addressed?
- If you had to summarise the most important points from what we’ve just talked about, what would you say?
- Is there anything else about this experience that you feel we haven’t adequately covered yet?

- If there is anything I’m not sure about after the interview has been transcribed, would you be happy for me to contact you for clarification?

Prompts and probes will be used throughout as needed, e.g.

- What was that like for you?
- What did that mean to you?
- Tell me more about that.
- You mentioned X, can you clarify what that means?

* Wording will be changed depending on participant’s relationship to the patient.

Appendix S: Participants’ comments about being interviewed

[Note: each bullet point denotes a separate comment by the participant from a different part of the interview.]

F15MM

- F15MM: [Big sigh]……You don’t mind me getting upset, do you?
  VS: I don’t at all, but if at any point you want to have a pause, just let me know.
  F15MM: No, I’m fine…[gulps] I’ve cried in front of so many strangers [laughs], it’s mad.

- F15MM: I’m glad you recorded it [laughs], it’s a load of waffle but it’s helped me as well, so thank you. In the last three months, well the last three months I’ve not reflected on the last few years really, just reflected on the last months. I think it’s healthy to reflect and talk about things, so I’m quite happy doing it.

F16FC

- F16FC: And I really thought I’d forgotten half of this but talking to you it’s all come back, and it’s all you know been squashed up. So…
  VS: Well, what’s it like for you that it’s all coming back, and washing around?
  F16FC: Well, I just feel like sitting down and having a good howl. After I’ve spoke [sic] to you, I should go upstairs and have a big hug. Yeah.
  VS: Well, I’m sorry that it’s brought up…
  F16FC: No, no, no.
  VS: …that feeling again. I guess that’s one of the things that can happen when we have this kind of interview. And it’s…
  F16FC: Well.
  VS: …it’s why I sent – you know when I sent the link – I sent a document of phone contacts and things. It sounds like you have [specialist nurse] and other support around you?
  F16FC: Yes, we are very, very lucky.

- F16FC: Well, I hope it’s been helpful for you. I feel as if I’ve been a bit, I dunno, here, there and everywhere. If you can understand what I’ve said half the time.

F17FC

- F17FC: It’s actually been really therapeutic, and I apologise that I got a bit emotional a few times but it…

  VS: That’s absolutely natural and fine, and thank you so much for being so open about everything and…

  F17FC: It’s important, isn’t it? There’s no point in doing it if I’m not going to be open and honest and, you know, give you an answer that comes from the heart, so…and it all has done, um…yeah. I, I do feel it’s been quite therapeutic to talk about it. The questions are really clever as well, by the way.

  VS: Oh, really?

  F17FC: I don’t mean clever. I mean, in terms of it’s very easy to word a question wrong and then you, kind of, don’t necessarily get what you were looking for, but I think those questions were, really, they were very, very apt.

F18FC

- F18FC: Well, thank you, it’s been quite exciting, in a way, to be part of the research project really. Thank you for your time.

F19FC

- F19FC: I’ve enjoyed it in a weird sort of way [laugh].

  VS: Thank you. I mean, is there anything that…you know, I’ll get the transcript and if there’s anything I don’t understand, is it okay for me to contact you and sort of check?

  F19FC: Yeah, of course it is. Yeah. And if you want to do it again, I’m more than happy, if I can help, yeah.

F20FC

This interview was hampered by having to switch to telephone and no comments about the interview process appear in the transcript/handwritten notes.

Appendix T: Signposting document

Signposting list for post-interview sources of support

Sometimes after a research interview where difficult experiences have been discussed, people like to talk things through with a supportive listener.

Here are contact details if you would like to access some support:

- *Mesothelioma UK Information Line* – all the nurses who take turns to answer this information line are aware of my research project. The line is open from Monday to Friday 8:30 am until 4:30 pm.

  Tel: 0800 169 2409

- *Cruse Bereavement Care* – their helpline is open at these times:

  Monday: 9.30am-5pm
  Tuesday: 9.30am-8pm
  Wednesday: 9.30am-8pm
  Thursday: 9.30am-8pm
  Friday: 9.30am-5pm
  Saturday and Sunday: 10am -2pm

  Tel: 0808 808 1677

  Email: helpline@cruse.org.uk

- *Macmillan Support Line* – support and information for patients and carers/families/friends. "Our cancer information and support specialists offer a listening ear. We can talk about whatever matters to you. We can also offer guidance and help you find the right information and support in your area. If you need to talk, we'll listen."

  Support Line is open 7 days a week, 8am to 8pm

  Tel: 0808 808 00 00

- *SSAFA, the Armed Forces Charity* – "If you lose someone who has previously served in our Armed Forces, or you are ex-Forces and you lose someone, then SSAFA is committed to supporting you during your bereavement. Everyone needs different support when they are grieving. If you need emotional support, our volunteers can be there to listen as you come to terms with your loss."

  Helpline is open 09:00 to 17:30 Monday to Friday:

  Tel: 0800 731 4880

- *Combat Stress mental health helpline* – If you're currently serving or have serve in the UK Armed Forces, you can call Combat Stress' 24-hour mental health helpline. If you're a family member or carer worried about the mental health of a loved one, or need to talk to someone yourself, you can call the helpline too.

  Open 24 hours, day and night

  Tel: 0800 138 1619
  Text : 07537 404719
  Email: helpline@combatstress.org.uk

- *Samaritans* - 'If you need someone to talk to, we listen. We won't judge or tell you what to do.'

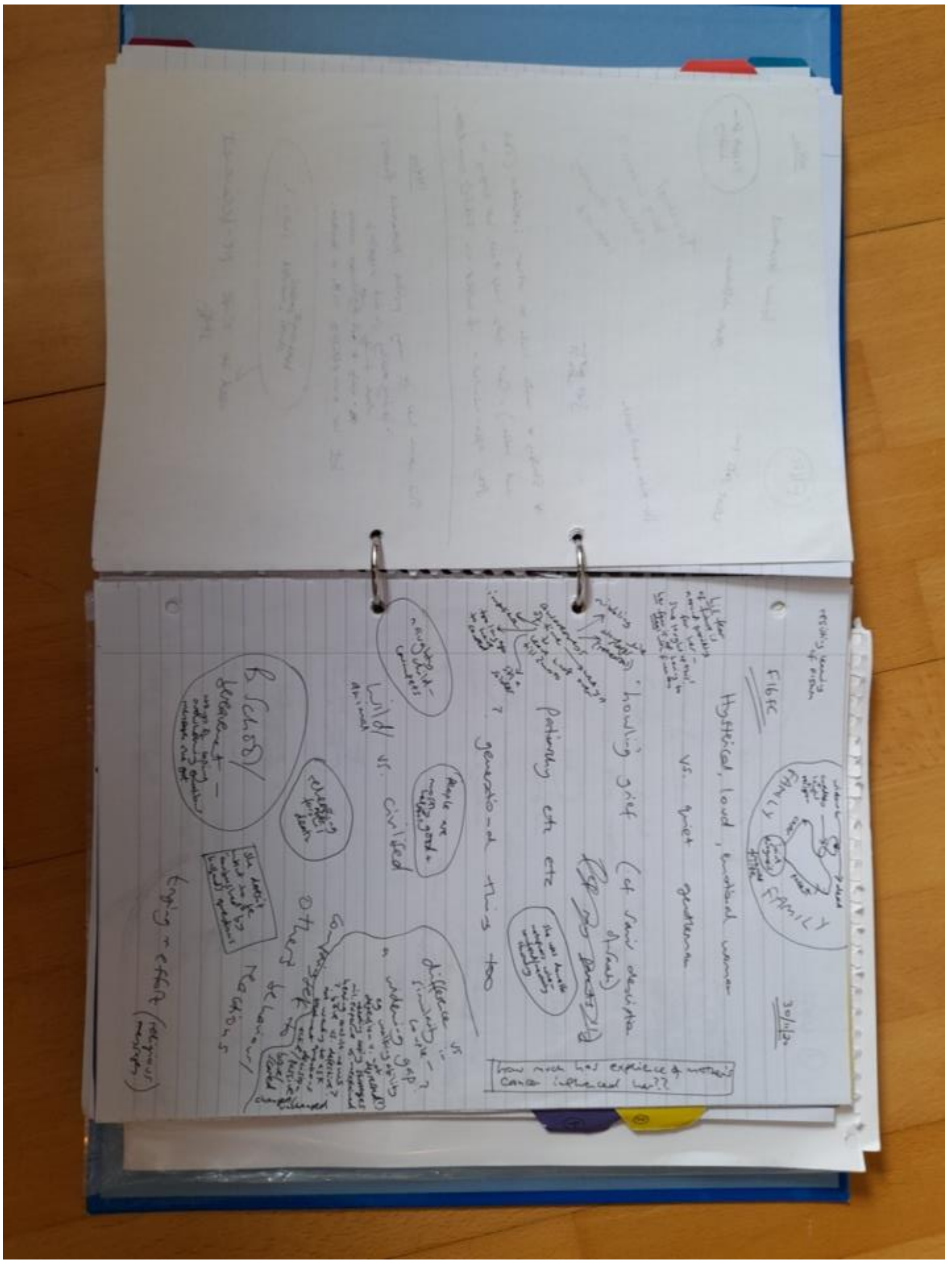
  Open 24 hours, day and night

  Tel : 116 123 from any phone.

Appendix U: Examples of audit trail records

Throughout the interviewing and analysis process, I kept hand-written notes which were always dated. These were filed systematically as I went along, thus providing a clear audit trail as the study progressed.

Example 1: notes made whilst I developed F16FC's themes



F16FC

FAMILY

Hysterical, loud, emotional women

vs. quiet gentlemen

'howling grief'

patiently etc etc

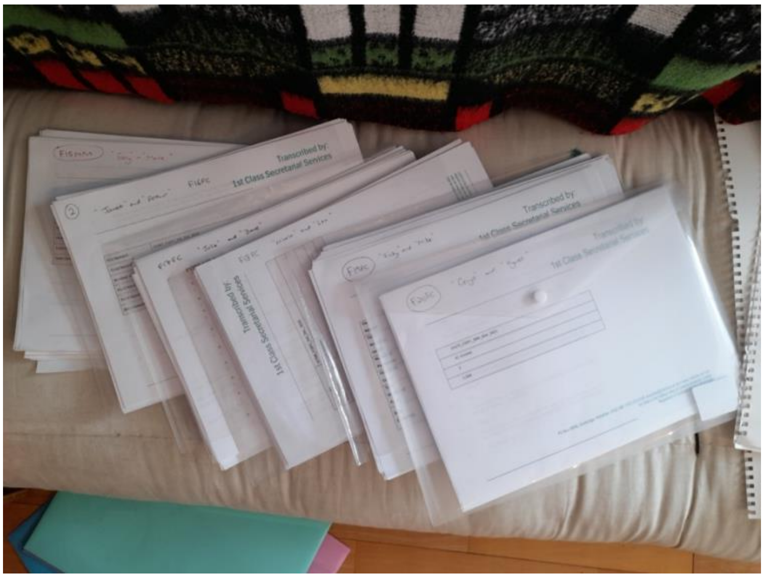
wild vs. civilised

Others

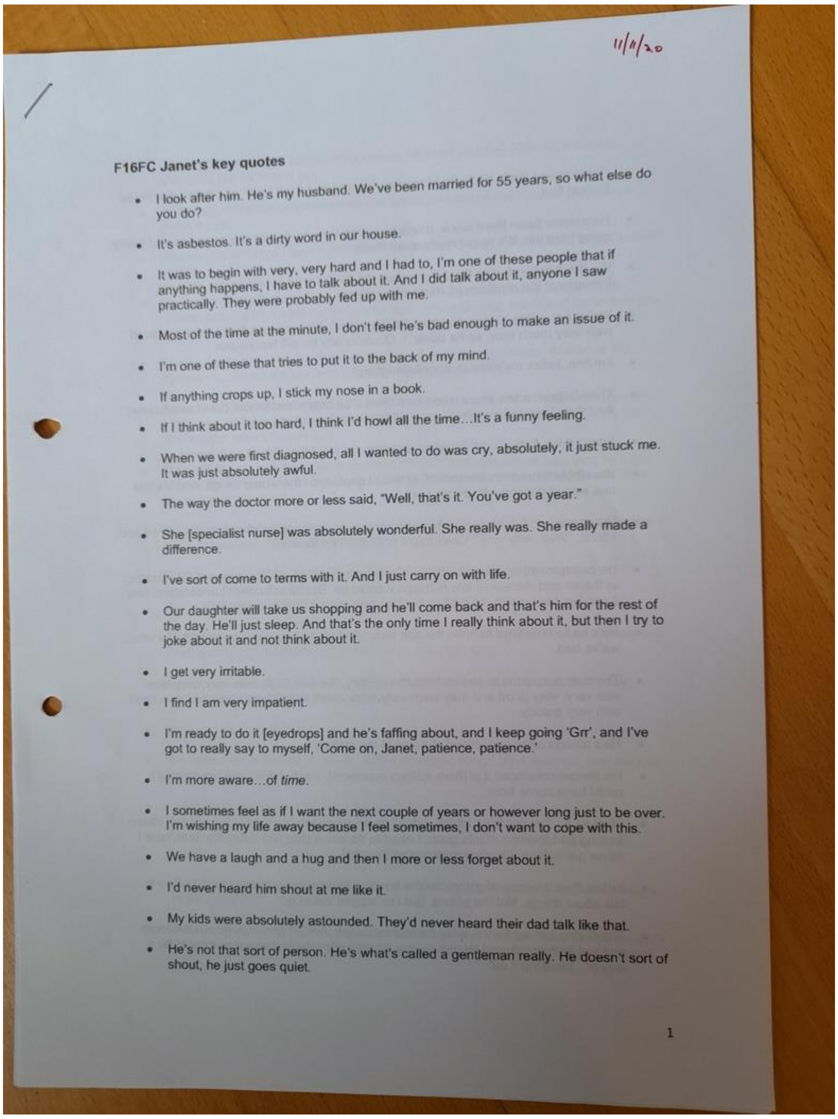
difference vs similarity

How much has experience of mother's cancer influenced her??

Example 2: annotated transcripts filed systematically



Example 3: List of F16FC's important quotations sent to supervisors



11/11/20

F16FC Janet's key quotes

- I look after him. He's my husband. We've been married for 55 years, so what else do you do?
- It's asbestos. It's a dirty word in our house.
- It was to begin with very, very hard and I had to, I'm one of these people that if anything happens, I have to talk about it. And I did talk about it, anyone I saw practically. They were probably fed up with me.
- Most of the time at the minute, I don't feel he's bad enough to make an issue of it.
- I'm one of these that tries to put it to the back of my mind.
- If anything crops up, I stick my nose in a book.
- If I think about it too hard, I think I'd howl all the time…It's a funny feeling.
- When we were first diagnosed, all I wanted to do was cry, absolutely, it just stuck me. It was just absolutely awful.
- The way the doctor more or less said, "Well, that's it. You've got a year."
- She [specialist nurse] was absolutely wonderful. She really was. She really made a difference.
- I've sort of come to terms with it. And I just carry on with life.
- Our daughter will take us shopping and he'll come back and that's him for the rest of the day. He'll just sleep. And that's the only time I really think about it, but then I try to joke about it and not think about it.
- I get very irritable.
- I find I am very impatient.
- I'm ready to do it [eyedrops] and he's faffing about, and I keep going 'Grr', and I've got to really say to myself, 'Come on, Janet, patience, patience.'
- I'm more aware…of *time*.
- I sometimes feel as if I want the next couple of years or however long just to be over. I'm wishing my life away because I feel sometimes, I don't want to cope with this.
- We have a laugh and a hug and then I more or less forget about it.
- I'd never heard him shout at me like it.
- My kids were absolutely astounded. They'd never heard their dad talk like that.
- He's not that sort of person. He's what's called a gentleman really. He doesn't sort of shout, he just goes quiet.

1

Appendix V: Feedback email from a bereaved carer

Below is an extract from an email received 27/4/21 about my scoping review from a UK medical professional whose relative had recently died from mesothelioma.

Hello,
I have just read your paper on the effects of mesothelioma on patients and carers. [.] Your themes identified certainly rang true with me, even with my enhanced knowledge of cancer treatments and services available, trying to get any information on what was happening was very challenging!

Appendix W: Evidence submitted to Defence Select Committee

Experiences of female Armed Forces veterans who died from mesothelioma – evidence submitted to UK Parliamentary Defence Select Committee Inquiry "Women in the Armed Forces: from recruitment to civilian life"

Virginia Sherborne on behalf of the Mesothelioma UK Research Centre – Sheffield

Introduction

In July 2020 the Mesothelioma UK Research Centre was established at The University of Sheffield, funded by the charity Mesothelioma UK. The Research Centre is based in the Division of Nursing and Midwifery at the Health Sciences School.

The aim of the Mesothelioma UK Research Centre – Sheffield is to conduct a portfolio of robust and rigorous research with a reputation for excellence. The goal is for the research to benefit the care of people diagnosed with mesothelioma and their families. The Research Centre is funded by Mesothelioma UK, a charity and national specialist resource centre, specifically for the asbestos-related cancer, mesothelioma. Mesothelioma UK are dedicated to providing specialist mesothelioma information, support and education, and to improving care and treatment for all UK mesothelioma patients and their carers.

The Research Centre has recently conducted a mixed methods study exploring the UK veteran experience of living with mesothelioma (MiMES). This was funded as part of Mesothelioma UK's 'Supporting Our Armed Forces' initiative (SOAF), and included funding for a PhD student, Virginia Sherborne. In October 2020 Virginia completed a secondary data analysis of transcripts from MiMES interviews with veteran mesothelioma patients and/or their informal carers. She then began conducting interviews with carers of British veterans with mesothelioma, focussing on the psychological impact of the disease. Two examples of female veterans' experiences stood out from the interview data as relevant to the Select Committee's remit, in particular its interest in whether the needs of female veterans are currently met by the available services. These examples are presented below, in anonymised form. Both interviews were carried out with the carer after the veteran had died.

Janet's[31] story

Janet served in the RAF, and later worked as a contractor for the MOD until her retirement. She died from malignant pleural mesothelioma in her 60s. Her Armed Forces service was the most probable source of her exposure to asbestos. When Janet collapsed with symptoms of mesothelioma, she was wrongly diagnosed with and treated for chronic obstructive pulmonary disease (COPD). Her condition deteriorated and she was diagnosed with mesothelioma only three months before her death. She received compensation from the MOD for her industrial injury.

Janet's husband Malcolm (also a veteran) described the impact of the misdiagnosis:

> "I'd lost my wife. She'd survived six months. I was capable of being on my own because I'd been on my own as a result of my job. I'd been on my own many times before, and so had she been on her own, so being on our own didn't cause a problem to either of us. But it was the nature in which Janet had died so suddenly, with a disease, an industrial disease that only a few months before we didn't know that she had got."

Marie's story

Marie also served in the RAF, and later worked as a contractor for the MOD. She died in her 40s from peritoneal mesothelioma. Marie's illness too was misdiagnosed. This led to her cancer being untreated for a whole year. It had spread widely by the time she was correctly diagnosed. Initially, the investigating consultant told Marie she could not possibly have mesothelioma. Her husband, Gary, explained that she was told, "You're too young, you've not worked in an industrial background, you haven't got it."

Great distress was also caused to Marie and Gary (both veterans) by the fact that the MOD refused to accept her cancer had been caused by asbestos exposure. Officials argued that peritoneal mesothelioma was not caused by asbestos, despite Marie's consultant oncologist writing to confirm that this was the case. Marie had to engage lawyers to sue the MOD to obtain compensation, even though she remembered being exposed during her service years. Gary explained, "We met in basic training in the RAF, we had to scrub the

---

[31] The pseudonym 'Janet' for this veteran was changed to 'Patricia' during the writing of the thesis to avoid confusion.

walls, the pipes, everything, the pipes were laden with asbestos, she breathed it in, they killed her, that's it."

Gary also described the impact of Marie's difficulties with the NHS and the MOD:

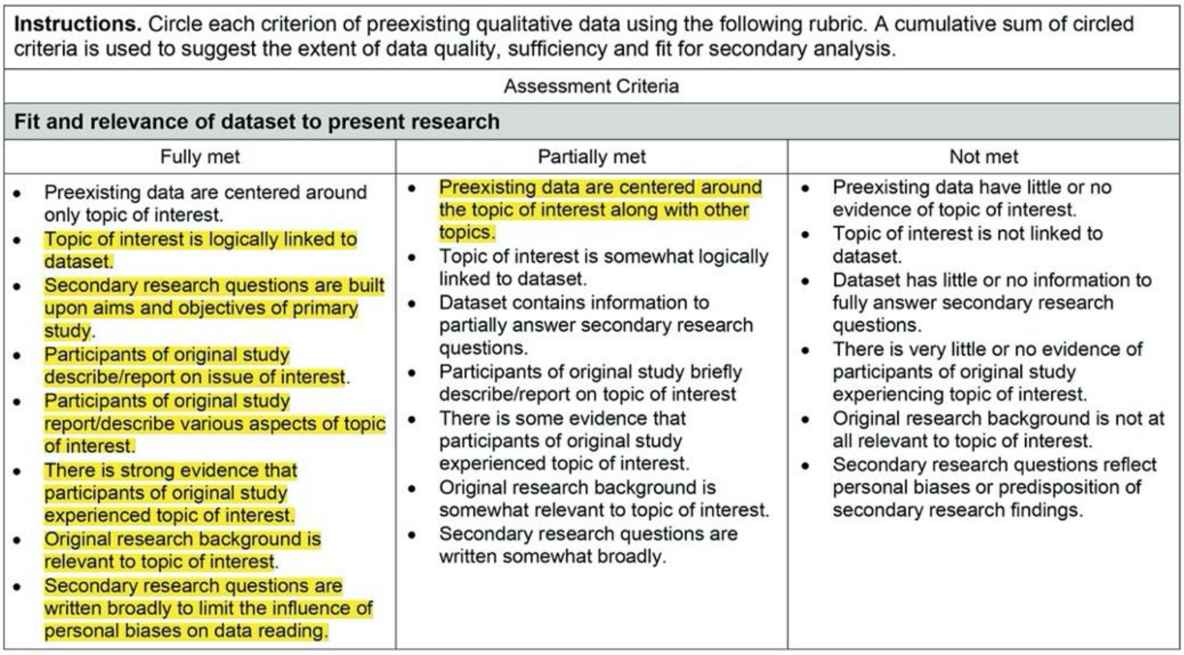
> "So, I had [NHS Trust] had a failing of trying to get my wife proper treatment and the MOD not backing up, and I've just left, really, two years earlier the RAF, after a full career in the RAF and the army, and we've lived our lives travelling around with the MOD and I was like, "What is the, what is the problem?"

Conclusion

The experiences of Marie and Janet illustrate how the needs of female veterans may not be being met by the available services. The delay in getting a correct diagnosis matches the findings of a recent UK research study (Senek *et al.*, 2021), which looked at gender differences in mesothelioma. Women with pleural mesothelioma are often diagnosed later than men, possibly because healthcare professionals have a greater awareness of mesothelioma risk in traditionally male occupations. For women with peritoneal mesothelioma, other gynaecological diseases are often considered as likely diagnoses first. In their report of the MiMES study, Ejegi-Memeh et al. (2020) showed that the pattern of exposure to asbestos was different for veterans compared to civilians. As well as occupational exposure from working directly with asbestos (e.g., maintenance of Sea King helicopter wiring), military personnel could have indirect exposure. This could arise from living accommodation (e.g., on board ships), combat experiences (such as searching bombed out buildings) and extensive travel. Domestic exposure for military veterans is therefore distinct from domestic exposure for civilians.

In summary, it is important that services provided both within the MOD and in the civilian health environment are aware that female veterans may have an increased risk of exposure to asbestos as a result of their military service compared to non-veteran women. This would help suspicions of asbestos-related diseases such as mesothelioma to be raised at an earlier stage, increasing access to effective treatment and improved quality of life. It would also allow female veterans to receive the compensation they deserve in a timely manner.

Appendix X: Sherif's (2018) diagnostic guide

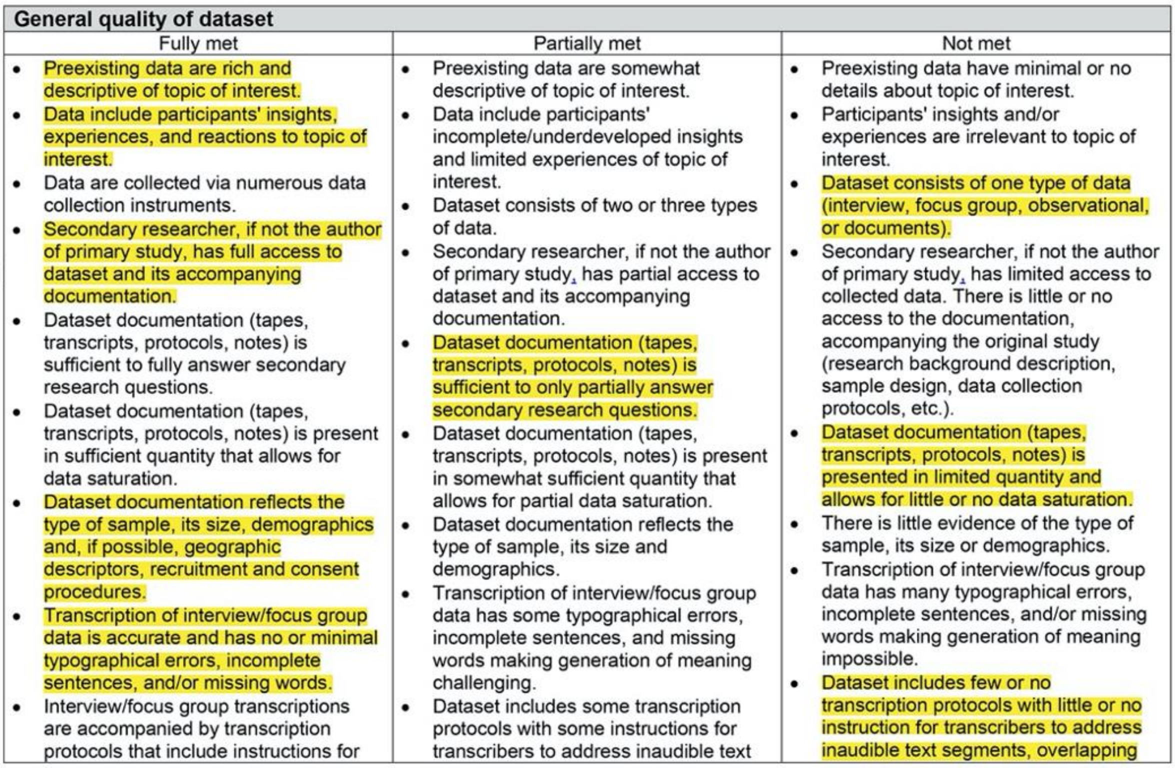


Instructions. Circle each criterion of preexisting qualitative data using the following rubric. A cumulative sum of circled criteria is used to suggest the extent of data quality, sufficiency and fit for secondary analysis.

Assessment Criteria

Fit and relevance of dataset to present research

Fully met	Partially met	Not met
• Preexisting data are centered around only topic of interest. • Topic of interest is logically linked to dataset. • Secondary research questions are built upon aims and objectives of primary study. • Participants of original study describe/report on issue of interest. • Participants of original study report/describe various aspects of topic of interest. • There is strong evidence that participants of original study experienced topic of interest. • Original research background is relevant to topic of interest. • Secondary research questions are written broadly to limit the influence of personal biases on data reading.	• Preexisting data are centered around the topic of interest along with other topics. • Topic of interest is somewhat logically linked to dataset. • Dataset contains information to partially answer secondary research questions. • Participants of original study briefly describe/report on topic of interest • There is some evidence that participants of original study experienced topic of interest. • Original research background is somewhat relevant to topic of interest. • Secondary research questions are written somewhat broadly.	• Preexisting data have little or no evidence of topic of interest. • Topic of interest is not linked to dataset. • Dataset has little or no information to fully answer secondary research questions. • There is very little or no evidence of participants of original study experiencing topic of interest. • Original research background is not at all relevant to topic of interest. • Secondary research questions reflect personal biases or predisposition of secondary research findings.



General quality of dataset

Fully met	Partially met	Not met
• Preexisting data are rich and descriptive of topic of interest. • Data include participants' insights, experiences, and reactions to topic of interest. • Data are collected via numerous data collection instruments. • Secondary researcher, if not the author of primary study, has full access to dataset and its accompanying documentation. • Dataset documentation (tapes, transcripts, protocols, notes) is sufficient to fully answer secondary research questions. • Dataset documentation (tapes, transcripts, protocols, notes) is present in sufficient quantity that allows for data saturation. • Dataset documentation reflects the type of sample, its size, demographics and, if possible, geographic descriptors, recruitment and consent procedures. • Transcription of interview/focus group data is accurate and has no or minimal typographical errors, incomplete sentences, and/or missing words. • Interview/focus group transcriptions are accompanied by transcription protocols that include instructions for	• Preexisting data are somewhat descriptive of topic of interest. • Data include participants' incomplete/underdeveloped insights and limited experiences of topic of interest. • Dataset consists of two or three types of data. • Secondary researcher, if not the author of primary study, has partial access to dataset and its accompanying documentation. • Dataset documentation (tapes, transcripts, protocols, notes) is sufficient to only partially answer secondary research questions. • Dataset documentation (tapes, transcripts, protocols, notes) is present in somewhat sufficient quantity that allows for partial data saturation. • Dataset documentation reflects the type of sample, its size and demographics. • Transcription of interview/focus group data has some typographical errors, incomplete sentences, and missing words making generation of meaning challenging. • Dataset includes some transcription protocols with some instructions for transcribers to address inaudible text	• Preexisting data have minimal or no details about topic of interest. • Participants' insights and/or experiences are irrelevant to topic of interest. • Dataset consists of one type of data (interview, focus group, observational, or documents). • Secondary researcher, if not the author of primary study, has limited access to collected data. There is little or no access to the documentation, accompanying the original study (research background description, sample design, data collection protocols, etc.). • Dataset documentation (tapes, transcripts, protocols, notes) is presented in limited quantity and allows for little or no data saturation. • There is little evidence of the type of sample, its size or demographics. • Transcription of interview/focus group data has many typographical errors, incomplete sentences, and/or missing words making generation of meaning impossible. • Dataset includes few or no transcription protocols with little or no instruction for transcribers to address inaudible text segments, overlapping

transcribers and decisions addressing inaudible text segments, overlapping speech, unfamiliar terminology, and language-specific nuances. • Dataset includes many instances of information restating, summarizing, and/or paraphrasing of participants' insights to assure collected data are correctly recorded and understood. • Access to participant contact details is available to only the author of primary research. • When secondary analysis research is conducted by the author of primary study, consent form allows for reconnecting with study participants to clarify characteristics of original research and/or complete missing information.	segments, overlapping speech, unfamiliar terminology, and language-specific nuances. • Dataset includes some instances of information restating, summarizing, and/or paraphrasing of participants' insights to assure collected data are correctly recorded and understood.	speech, unfamiliar terminology, and language-specific nuances. • Dataset has a couple or no instances of information restating, summarizing, and/or paraphrasing of participants' insights to assure collected data are correctly recorded and understood.
Trustworthiness of dataset		
Fully met	Partially met	Not met
• Dataset includes detailed description of primary research questions, study aims and objectives. • Dataset includes detailed description of primary research timeframe, its settings, and data collection settings. • Dataset includes credentials and institutional affiliations of team members who conducted primary research.	• Dataset includes some description of primary research questions, study aims or objectives. • Dataset includes some description of primary research timeframe, its settings, or data collection settings. • Dataset includes incomplete credentials or institutional affiliations of team members who conducted primary research.	• Dataset includes little or no description of primary research questions, study aims or objectives. • Dataset includes little or no description of primary research timeframe, its settings, or data collection settings. • There is no information about credentials or institutional affiliations of team members who conducted primary research.

Timelines of dataset		
Fully met	Partially met	Not met
• Secondary researcher, if not the author of primary study, has full access to timeline of research initiation, data collection, and analysis. • Data points and protocols of data collection are time-stamped. • Data are current and/or relevant to present day topic of interest.	• Secondary researcher, if not the author of primary study, has some access to timeline of research initiation, data collection, or data analysis. • Either data points or protocols of data collection are time-stamped. • Data are somewhat current and/or relevant to present day topic of interest.	• Secondary researcher, if not the author of primary study, has limited or no access to timeline of research initiation, data collection, or analysis. • Data points and protocols of data collection are missing time stamps. • Data are outdated comparing to present day topic of interest.

Appendix Y: Master table of super-ordinate themes for the whole dataset

Super-ordinate theme 1: Going the extra mile

Just keeping on going

This sub-theme related to the veteran patients' and carers' reactions to the diagnosis of this incurable, rare disease, with its typically poor prognosis. It also concerned their ways of dealing with the symptoms, including breathlessness, pleural effusion, pain, cough, weight loss, lack of appetite, and fatigue. The impact of the disease's unpredictable progression, often with sudden deterioration, was relevant, as was the effect of carers needing to take on more and more practical tasks to support the patient, both with symptom management and practical daily living.

F15MM Gary: I was fighting all these [NHS incompetence issues], I use the word fighting, I was fighting really, making myself ill because [.] I was still having to work all the time with this, and I was crying in the car on the way to work, just not sleeping.

F16FC Janet: I said to my son, "I just want it all to be over. I can't cope with this." Then, after time, it all changed and I realised, well, he wasn't really disappearing just yet. And then that was it. And you just got on with it.

F17FC Julie: When you've got to deal with all their personal hygiene needs and shopping and cooking and cleaning *and* holding down a full-time job, that's a real challenge.

F18FC Nicola: He never really left the military. [.] He was always sort of, "Stand by your beds!" I wouldn't say strict, but just very, very disciplined. [.] Quite stoic, and I guess probably some of that did have an impact on how he dealt with processing the prognosis. [.] "Bloody nuisance, this," and "Crack on".

F19FC Vicky: We thought we could manage it ourselves without having extra carers in. And I think again we made a mistake. I should have asked for help sooner. I didn't ask for help in the home until five days before he died.

F20FC Cerys: He said, "The thing is, [.] we're not the type, Cerys," he said, "to just sit in a chair and curl up and die."

Expecting and receiving committed back up

This sub-theme covers how carers and patients experienced needing and receiving support. The carers talked about how the level of effort made to support them impacted them psychologically. The sources of support mentioned included health care professionals, care agencies, Ministry of Defence representatives, lawyers, coroners, counsellors, Asbestos Support Groups (ASGs), specialist charities, the Christian church, work colleagues, neighbours, relatives and friends. The carers' interactions with these sources of support impacted them both positively and negatively. Expectations of the level of supporters' effort tended to be high, and when carers and/or patients felt let down, this could be very difficult.

F15MM Gary: I was, like I said, fighting to…well, dealing with the incompetence of [local NHS] Trust, the incompetence of Veterans UK, and the incompetence of sometimes the health professionals.

F16FC Janet: I said [to 13-year-old granddaughter], “What on earth am I going to do without Granddad?” She says, “Don’t you worry, Grandma, you’ve got us.”

F17FC Julie: I then had to go and watch him fighting for breath and…have him asking me for his BiPAP machine back; that’s the last words he said to me, BiPAP. He was so desperate to still be able to breathe; he was so desperate to still be able to fight it. I had to stand and watch while they decided not to give it back to him because it was doing him…more harm than good.

F18FC Nicola: It pushes out the negative stuff really because you just think there are some very kind-hearted people out there.

F19FC Vicky: He wasn’t allowed to see the doctor [GP] because of COVID. [.] I don’t blame the doctors, they were following what the government had told them to do, but finally they said he could go for an x-ray.

F20FC Cerys: Previously, [feeling] a little abandoned, no, that’s too strong a word, but no faces to names. “Oh well, he’s 87”, a feeling of he’s not being dealt with as robustly.

Super-ordinate theme 2: Staying the same person

The recognisable patient

This sub-theme related to issues concerning identity. Participants described and made sense of ways in which the veteran patient appeared to have changed as a person or related how they seemed to have stayed the same.

F15MM Gary: I just dumped them [neglectful friends] and Marie still kept in touch, but she just did it, she’s like a puppy sometimes, she was just doing it to help them.

F16FC Janet: Sometimes I think, ‘Ooh, do I know you as well as I think I do?’ and then other times it’s just fine.

F17FC Julie: Even on the worst days when we’d been shared the worst news, he would tell the consultant or the nurses a joke.

F18FC Nicola: Dad still wanted to be known as that he was a dad, that he was a husband, he was a neighbour, he was a best mate, he was a friend. And yes, you’ve got this awful diagnosis and prognosis, but he [.] is still Len.

F19FC Vicky: I didn’t notice any changes [as a person] in Michael at all. He was always caring, kind, deeply religious.

F20FC Cerys: To look at him then [at diagnosis] I would’ve thought we’d have a good few years left with him, but it’s actually quite rapid how things have been changing. Because he’s been quite young for an 87-year-old, you know, he hasn’t been a frail gentleman.

The recognisable carer

This sub-theme related to issues concerning identity. Participants described and made sense of ways in which they themselves appeared to have changed as a person or related how they seemed to have stayed the same.

F15MM Gary: That’s not me at all, but I don’t care anymore. [.] I’ve changed as a person.

F16FC Janet: I feel as if…I've got lazy, I think. I don't do so much around the house as I did. I keep looking and thinking, "Ooh, gosh, I need to do some cleaning today and that," and I never get it done. It's always tomorrow [laughs].

F17FC: I've lost the person who was my reference point for everything, so I feel as though I'm losing some confidence in myself.

F18FC Nicola: I'm very much like my dad. I try not to take life too seriously. I only try and be grown-up on a number of occasions.

F19FC Vicky: Sometimes I read things into situations that maybe aren't there, find I'm a bit sensitive over…if people criticise, not criticise in a nasty way but just say something, I think it's personal to me. [.] I think I'm wanting people to value me, yeah. That's odd…I feel like…I know Michael's made his mark…[tearful]…and I don't want my life to be…wasted.

F20FC Cerys: You hold it together for everybody else, don't you, as the woman in the family, the mother, the daughter, the sister, everybody comes to me, and so you hold it together for them. But in between I've had my odd little moments where I think, "Oh," [sharp intake of breath] you know, "this is my dad."

Super-ordinate theme 3: Needing to know

Choosing what to share

This sub-theme explores how the veteran patients and carers experienced having to make choices about what others needed to know. They talked about choosing what to share between patient and carer, and what to share with others, such as relatives, colleagues and friends. Factors affecting these choices included whether they wanted to protect others; whether talking was a coping strategy; and whether they desired to keep things private.

F15MM Gary: We've always said from that day forward, that we will not…try and…candy-coat the truth.

F16FC Janet: Sometimes you feel like, you know, asking how it's developing or how long he's got or how the...I don't feel I like to ask in front of him. But he says, "Oh, just ask." He doesn't seem to mind.

F17FC Julie: From the minute that the consultant came into our cubicle and drew the curtain around and told us, I felt him withdraw from me. And I think that was because he was afraid but also, he didn't want to scare me.

F18FC Nicola: Outwardly, he didn't [change as a person], he just wanted to crack on, he wanted a normal routine. Underneath, though, as he said it a number of times to me, he was utterly devastated.

F19FC Vicky: Michael initially didn't want people outside of really just me and Katy knowing that he'd got cancer because he didn't want them to look at him as 'Michael with cancer'. And that was tough because I wanted to go out and say to everybody, he's got cancer. So, I found that really hard.

F20FC Cerys: I find it difficult to talk to him about it [dying] because I know it's not a subject he's comfortable about talking about. But I have chosen my moments and dropped the odd thing in and said, you know, "We need to start thinking about these things, Dad." But he gets very um, "Oh, now you're anticipating trouble."

Information exchange and professionals

This sub-theme related to participants' experiences concerning what they and the patients needed to know from professionals, such as HCPs, Veterans UK, and charities. Sometimes this included information they felt they did not need to know and wished to avoid receiving. Also covered are issues of carers and patients sharing information with professionals, and issues of professionals sharing information with each other.

F15MM Gary: It was that perception by the consultant, no, no, you're too young, no, you're not in heavy industry.

F16FC Janet: It was that doctor that was quite abrupt with it. And I think that's at the back of my mind, that's what upset me more than anything. [.] Perhaps it was meant to come out like that. I don't know. But I mean, what suits one person doesn't suit another.

F17FC Julie: It was very difficult for me to be able to speak to anybody that had any understanding, detailed understanding and expertise, around this illness.

F18FC Nicola: When we were talking about as and when the time comes for him to head off and stuff, he chose from the start that he was going to be going to the caravan site in the sky. [.] I can only describe it as super-cool that everybody in our care team that was involved got on board with that as well. That was really lovely, because then he could open up a bit more.

F19FC Vicky: It was just there were so many people involved. If we'd have just had one central person, which [laughs] it's impossible, isn't it, but that would have been lovely. If we'd have just had one person that we phoned to say now, you know, this is happening this week, next week.

F20FC Cerys: He kept saying to me, "Well, nobody's really talked to us about it and what about treatment? Aren't I getting any treatment?" And yeah, so I think that probably hasn't helped the situation.

Raising awareness

This sub-theme related to carers' wishes to raise awareness about various topics:

- *HCPs and the public needing to know more about mesothelioma and asbestos risk*
- *HCPs learning better ways of communicating with patients and carers*
- *lack of knowledge about where veterans were in the UK*
- *the MOD's attitude to asbestos risk and exposure*
- *public knowledge about hospice provision and grief*

F15MM Gary: The disappointment with the [local NHS] Trust is just awful, and I'm, I try to, I'm in the [safety critical] industry, we always get told if you make a mistake, put your hands up, it's a no blame environment.

F16FC Janet: N/A

F17FC Julie: There's something huge there around the whole raising awareness about the fact that it's not just people that are in their eighties now that may have worked on the railways. There are other groups of the population that are likely to have been exposed. And that for me I think is a biggie, because if were looking for it we might have even asked the question.

F18FC Nicola: There are people that are being diagnosed with this much younger. I think that's what's also kind of got to me, we're in 2020 and it's like, 'How is this still happening to people?'

F19FC Vicky: I’ve written a little book to help youngsters who might be experiencing somebody dying around them, it might be their grandad or whoever, who’s got mesothelioma.

F20FC Cerys: N/A

Appendix Z: ‘Cancer Revolution’ exhibition piece

“Wife and welder” sculpture by Sam Sherborne (2019)

My husband Sam, an artist blacksmith, made this steel sculpture in the Spring of 2019. This was while I was recuperating from surgery for Stage 2 lung cancer. I had got my unexpected diagnosis in November 2018, literally weeks after starting a PhD at the University of Sheffield, researching the patient and carer experience of mesothelioma, a type of lung cancer! At the time of its making, the sculpture meant a lot to me. It seemed to sum up for me the support I had got from Sam while I was ill. There was also something strong and forward-looking about it, which helped me feel positive.

Then in January 2020, Sam was diagnosed with prostate cancer. We had to go through the whole experience again, only this time our roles were reversed. Since then, the sculpture has had this extra dimension, a sort of equality, where each of the two figures is supporting the other one. I can still see the strength in the figures, but sometimes when I look at it now, I see their staring eyes and recognise the terror we went through together.

For me, this very personal sculpture really embodies the complex experience of being a patient and a carer for someone you love with cancer.

[The sculpture is roughly 35 x 28 cm.]