THE EXPERIENCE OF CLINICAL NURSE SPECIALISTS IN ONCOLOGY WITH
REFERENCE TO PSYCHOLOGICAL SUPPORT: AN IPA STUDY

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others

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You know who you are and you know what you've done. Thank you.

ABSTRACT

Introduction: The presence of psychological distress following a diagnosis of cancer is well evidenced. To meet this need, the role of oncology clinical nurse specialists (CNSs) has expanded in line with national guidance to include the provision of psychological support to patients and their families. Skills training and supervision has been provided by clinical psychologists. However, there has been little research focusing on the role and experience of the CNS doing this work. This present study researched the experience of CNSs working with patients with cancer and their families in order to understand more fully their experiences.

Method: Eight CNSs from four NHS trusts were interviewed about their experience of their role, including the recent expectation of offering psychological support. These interviews were transcribed and individually analysed using Interpretative Phenomenological Analysis, before conducting a group analysis to identify overall themes.

Results: Four key themes and fourteen sub-themes emerged through this analysis. The first theme *'The everyday experience'* captured the experiences and demands of participants in their day-to-day work. *'The impact of working with patients'* captured a range of experiences of the emotional and existential impact that doing this work involves. *'Understanding and working out the role'* illustrated the way in which participants must work out their role and identity within their organisational context. Finally, participants experienced *'Needing recognition and support'* as they carry out this vital role. Two overarching phenomenological themes were also identified as '*ambivalence'* and '*uncertainty'* and these run throughout the experiences of all the participants.

Discussion: The findings were examined in relation to existing literature. The strengths and limitations of the study were presented and future research suggested. Finally, the clinical implications of this research were identified which included suggestions for training, the use of supervision and greater role clarity.

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ABBREVIATIONS

BACP: British Association of Counselling and Psychotherapy

BPS: British Psychological Society

CNS: Clinical Nurse Specialist

CST: Communication Skills Training

DSM: Diagnostic and Statistical Manual of Mental Disorders

IAPT: Improving Access to Psychological Therapies

ICD: International Classification of Diseases

IPA: Interpretative Phenomenological Analysis

MDT: Multidisciplinary Team

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

R&D: Research and Development

CHAPTER ONE

Introduction to the study

Until beginning this research I had little personal or professional experience in oncology. I had however been working with a range of health professionals including physiotherapists, nurses and occupational therapists, who were being required to offer psychological support to patients in a physical health setting. In talking with them about their experiences and the impact of working with patients in distress, I began to reflect on my own experience. I was working in a service as a low intensity therapist where I was required to provide psychological support to patients, having had little formal training and with limited supervision. After spending one and a half years in this role my most significant reflection was that I could no longer work in an environment in which there was little space for reflection about my work and its impact on me. I began to wonder about the experience of other professionals who were also offering psychological support to patients. I subsequently became aware of the role of clinical nurse specialists (CNS) in oncology and the increasing emphasis placed on their provision of psychological support to patients with cancer. I found out that some CNSs were completing psychological skills training and receiving supervision from clinical psychologists. At the same time I was working as a trainee clinical psychologist and was aware of the impact that working with patients in distress and offering psychological support had on me. I became really interested therefore in what the experience of offering psychological support was like for these CNSs. The genesis of this research came when I began to wonder about their role: what it entailed; what it was like for them to work with patients with cancer; and what it was like for them to offer psychological support.

Background to the Study

I will firstly outline the context in which this research is situated and secondly outline the need for and importance of this being undertaken. I will offer a critical engagement with the literature in the associated and overlapping areas of: CNSs in oncology; psychological support in nursing and oncology; and the clinician-patient relationship. I will also identify gaps in the existing literature related to the actual experience of CNSs, particularly when

offering psychological support to patients with cancer, having received training and supervision from clinical psychologists.

The context of psychological support in oncology services

Psychological responses to cancer:

Approximately 325,000 people were diagnosed with cancer in the UK in 2010 (Cancer Research, 2012) and worldwide, cancer is one of the leading causes of both morbidity and mortality (Siegel et al., 2011; Ferlay et al., 2010). There are continual advances in cancer treatment; despite this there continues to be an increase in cancer incidence rates (Mehnart et al., 2012). The presence of psychological distress following a cancer diagnosis is well evidenced (e.g. Zabora et al., 2001; Carlson & Bultz, 2003; Skilbeck & Payne, 2003). Cancer treatments can be associated with physical side-effects that may affect social, occupational and psychological functioning (Little et al., 2003). Other common psychological issues relating to physical functioning have been reported. These include functional impairment, chronic fatigue, existential issues around identity, the meaning of life, isolation, social, financial, and family (Holland et al., 2010).

Psychological responses to cancer are varied and in a meta-analysis of 94 interview based-studies, Mitchell et al. (2011) found the prevalence of depression to be 16.3%, adjustment disorder 19.4% and anxiety disorders 10.3%. The prevalence of any of these combined was up to 38.2% (according to DSM and ICD criteria). The studies included in the meta-analysis were restricted to those utilising psychiatric interviews. There will be many more individuals who experience psychological distress but who would not meet DSM or ICD criteria as diagnosed in a psychiatric interview. Other research estimates that 35-50% of cancer patients will experience clinically significant psychological distress (Zabora et al., 2001; Stark et al., 2002). Whilst many patients can manage their experiences without the need for input from health professionals, these figures suggest that there will be others who are likely to require specialist support. Patients frequently report unmet needs and a desire to access psychological support (Absolom et al., 2011). As such, the provision of psychological

support for patients with cancer (and their families) is significant and governmental policy reflects this; this is outlined in the following section.

Cancer Policy and Guidelines:

The rising public and professional anxiety regarding the increasing prevalence of cancer has placed it firmly on the political agenda (Willard & Luker, 2005). Both the Calman-Hine report (1995) and the National Health Service (NHS) Cancer Plan (DOH, 2000), set out strategies concerning the restructure and reorganisation of cancer services within the UK, aiming to reduce the variability and improve the quality of cancer care (Willard & Luker, 2005). Cancer networks were developed from 2000 as the organisational structure to implement the Cancer Plan (DOH, 2000). They aimed to improve the outcomes, experiences, quality and access of care, treatment and services for the population in specific geographical regions. Recent changes mean that, from the 1st April 2013, Cancer Networks have changed into Strategic Clinical Networks with new NHS structures coming into force. These are funded by the NHS Commissioning Board and cover conditions or patient groups where improvements can be made through an integrated, whole system approach of which cancer is one. They aim to help local commissioners reduce variation in services. The impact of these in practice is yet to be evaluated.

The Calman-Hine report (1995) emphasised the need for cancer patients to have access to someone with clinical expertise, specialist knowledge and good communication skills. Following this, the Cancer plan (DOH, 2000) highlighted the physical and emotional impact of cancer on patients and their families and emphasised the need for communication skills training. More recently, guidance from NICE (2004) on 'Improving supportive and palliative care for adults with cancer' provided evidence based advice on supporting cancer patients and their families. This guideline's fundamental premise is that distress in patients should be regularly assessed and addressed by staff with the required skills and knowledge. It suggests that patients' psychological symptoms are often not recognised, with the result that they are not offered access to relevant services. Additionally, it states that health and social care professionals often lack appropriate assessment skills and may underestimate the benefits of psychological support. NICE (2004) recommends that staff providing psychological care should be adequately trained and supervised and mechanisms to ensure

support should be available. It highlights the need for improvement in the assessment of individual needs for those with cancer across physical, spiritual, psychological and social dimensions. In addition, the psychological well-being of patients should be routinely assessed. NICE (2004) recommends four tiers of psychological support and expertise that should be available to patients (Figure 1).

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional experience	Screening of psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessment of psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Figure 1: The NICE (2004) four-tier model of psychological support in cancer care.

In practice it is commonly CNSs working at level 2 of this model who meet the expectations outlined by NICE (2004). It is recommended that CNSs should be trained in psychological skills to improve the assessment and intervention of psychological problems experienced by people with a cancer diagnosis (NICE, 2004). In addition to their existing roles and

responsibilities, CNSs are expected to demonstrate the provision of psychological support including a range of interventions. At least one individual is identified within each cancer site-specific team to provide this level 2 psychological care. As a result there is an increasing burden on the CNSs' time and resources as they fulfil a significant role in meeting physical, emotional and psychological needs.

Courses have been developed to address the training needs of nursing staff who are offering psychological support to patients with cancer. This level 2 training includes a teaching element and a period of supervised clinical practice in order to demonstrate competency in level 2 skills. This training is often delivered by clinical psychologists working at level 4 (NICE, 2004) and incorporates topics such as basic Cognitive Behavioural Therapy (CBT) for anxiety, depression and panic, assessment including specific measures, psycho-education, theories of coping, risk assessment, theories of loss and grief, problem solving and goal-setting. Participants attend supervision and complete a portfolio of supervised practice.

It is of interest that this stepped care approach, as demonstrated in the NICE (2004) four tier model, is also similarly replicated across other health conditions such as in renal (National Renal Workforce Planning Group, 2002) and stroke services (Intercollegiate Stroke Working Party, 2012). Within these settings CNSs are also one example of other health professionals who are receiving training and being tasked with psychological work.

The evolving role of the CNS:

In the UK, the role of the CNS was first developed in the NHS in the 1980's (Bousfield, 1997). The number of CNSs employed and the breadth of roles they perform has gradually increased (Raja-Jones, 2002). The reduction in working hours of medical staff, in addition to the increasing sub-specialisation of medical and surgical services has contributed to this increase and role expansion of the CNS (Cameron & Masterson, 2000). Few recommendations have been made, however, regarding the number of CNSs needed and their required caseload (Trevatt, Petit & Leary, 2008). Some argue that there is a lack of definition and ambiguity regarding the overall content, remit and nature of the role (Casteldine, 2002; Vaz & Small, 2007).

Within the area of oncology, the Calman-Hine report (1995) and the NHS Cancer Plan (DOH, 2000) outline the pivotal role of the CNS in multidisciplinary teams (MDTs) and the need for all patients to have access to their own CNS. As a result, the role of the CNS within oncology settings has expanded and many CNSs have been appointed as core members of MDTs (Willard & Luker, 2007). Governmental guidance also outlines the importance of meeting the emotional needs of patients with cancer. As such, one of the key components of the role of the CNS is the provision of psychological and emotional support to patients and families who may be experiencing difficulties due to physical illness (Clark et al., 2002, Seymour et al., 2002). Within MDTs, many CNSs have been allocated the responsibility of providing supportive care to patients with cancer (Willard & Luker, 2007). In a study of the roles and psychological health of members of MDTs across the UK, CNSs have been shown to provide the broadest coverage of information to patients (Catt et al., 2005). They have been described as 'the thread that runs throughout the patients' care in these cancer teams' (Catt et al., 2005, p.1095). Additionally, they were identified as being responsible for all aspects of the psychosocial well-being of patients and in many teams there was no alternative provision, should the CNS be unable to provide this support. It is clear that within cancer MDTs, CNSs are being tasked with the provision of supportive care to patients and their families (Hill, 2000).

Despite the key role of the CNS, studies have shown that the role of the CNS in MDTs is sometimes marginalised and this can impair the provision of supportive care (Willard & Luker, 2007). Willard and Luker (2007) utilised a grounded theory design in which twenty-nine cancer nurse specialists participated in observation and semi-structured interviews. They aimed to understand the strategies used by CNSs in order to implement their role. They found that one of the main problems for CNSs was being accepted and valued in MDTs and in particular by doctors. In order to overcome this difficulty with integration, CNSs employed strategies such as building good relationships particularly with senior doctors and trying to establish clear role boundaries in order to implement their role effectively.

Bousfield (1997) conducted a phenomenological investigation which aimed to understand how a group of CNSs think about and experience their role. Purposive sampling was utilised

to recruit seven clinical nurse specialists who worked across a variety of clinical directorates and specialties. Participants were also at various stages of their career and held different levels of responsibility in their area of work. Each CNS participated in an individual interview which was transcribed and analysed using the phenomenological method outlined by Giorgi et al (1975). The study found that CNSs had an enthusiasm for leadership and placed importance on maintaining specialist knowledge. It highlighted the diversity of the role and that lack of organisational, peer, management and medical support was common and demotivating. CNSs felt isolated in their roles and explained that there was a lack of structure and direction as to how to justify their role and manage time. Differing expectations were placed on CNSs by the medical teams, the organisation and themselves. They felt pressured to define and demonstrate the effectiveness of the role and felt that professional autonomy was important. The CNSs linked 'burnout' with a 'lack of support' and suggested that organisational expectation, stress, self-imposed demands, expectations of the role, pressures and limitations contributed to this. They highlighted that the role was in a transitional phase and suggested that there should be a supportive environment in which to establish a clear definition of the role of the CNS. This study was undertaken over 15 years ago and in this time there have been many changes. In order to further understand the role of the CNS within oncology and the psychological support they are being encouraged to provide, it is important to consider what is known about the provision of psychological support by nurses in health settings including oncology.

The evolution of psychological support in nursing and oncology

There has been an increasing emphasis placed on the provision of emotional support by nurses yet despite this, the understanding of what constitutes supportive care is variable (Skilbeck & Payne, 2003). This development has been influenced by the concept of 'new nursing' in which building holistic and close relationships with patients and knowing them well is advocated (Aldridge, 1994; Luker, 1997). The literature indicates that there are three levels of intervention addressed at meeting emotional and psychological need: good communication and usual care; emotional and psychological support; and psychological therapy. The distinction between these however is often unclear. There is a lack of clarity about the terms used to describe the process of emotional care and support. Skilbeck and

Payne (2003) suggested that terms such as 'psychological care and support', 'emotional care and support' and 'psychosocial care and support' are used interchangeably.

Nursing and psychological/emotional support

Within healthcare settings, good communication skills and psychological support can positively affect the experience of patients and may affect the psychological morbidity associated with their illness and treatment. It may also reduce the vulnerability of the patient to anxiety and depression (Maguire & Pitceathly, 2002). Furthermore, evidence suggests that effective communication can improve outcomes for patients who have cancer (Botti et al., 2006; Carlson & Bultz, 2003), and is an important factor in compliance with treatment, satisfaction and recovery (Chant et al., 2002). Following the recommendation that the ability to communicate effectively should be a condition of qualification for all healthcare professionals working with cancer patients in the United Kingdom (DOH, 2000), many communication skills training (CST) programmes have been implemented. Evidence as to their effectiveness is variable. A systematic review of the impact of CST programmes found that whilst experts rated them as improving practitioners' skills, there was limited evidence that they are effective in improving patient outcomes such as distress or satisfaction (Moore, Wilkinson & Mercado et al., 2004). In a later systematic review of CST programmes for health care professionals working with cancer patients (Moore, Wilkinson & Mercado, 2009) there was some evidence for the beneficial impact of CST on the behaviour of trained health professionals. Only three studies met the inclusion criteria, however, and the authors concluded that further research was needed.

Patient-centred supportive communication is seen as a fundamental part of nursing practice (McCabe, 2004), however, less is known about the psychological assessment and intervention offered. It is clear that governmental documents (NICE, 2004) advocate for skills in meeting the emotional needs of patients with cancer which go beyond good communication skills. Numerous studies and meta-analyses have shown the effectiveness of different psychosocial treatments in alleviating distress and improving quality of life in cancer patients (Meyer & Mark, 1995; Cunningham, 2000; Carlson & Bultz, 2003; Rehse & Pukrop, 2003). Despite this, there has been little research on the implementation of effective interventions (Redman, Turner & Davis et al., 2003; Jacobsen, 2009).

It is not only CNSs who are in a position in which many are providing psychological support. Mental health nurses are the largest professional group working in mental health in the UK (DOH, 2006). Documents such as 'Improving Access to Psychological Therapies (IAPT) Commissioning Toolkit' (DOH, 2008a) and 'Commissioning IAPT for the whole community: Improving Access to Psychological Therapies' (DOH, 2008b) highlight the importance of furthering nurses' abilities in both understanding and enabling them to deliver psychological therapies. In their systematic review, Curran and Brooker (2007) examined the contribution of mental health nurses in the implementation of evidence-based interventions finding that they are able to deliver these effectively. Despite the relationship between mental health nursing and talking therapies, the delivery of talking therapies has not been embedded into the mental health nurse's professional identity or training (Hurley, 2012). In the examination of the lived experience of mental health nurses Hurley (2012) interviewed twenty four mental health nurses to understand their experiences of their role in delivering talking based therapies that require extensive training. Three key characteristics of the environment in which the roles are enacted, that affect the implementation of talking therapies, were identified: obstacles to success; uncertainty; and low power and worth. The author highlighted that the issue of power and the power hierarchy within the NHS, serves as a barrier for mental health nurses delivering talking based therapies as it makes it difficult for them to embed this into their identity.

Crawford et al. (2008) found that community mental health nurses complete additional courses and training as part of identity work, in which they seek to define and develop their professional identity. Nurses are required to adapt to organisational change and respond to the demands of clients and other professional groups. Crawford et al. (2008) argued that it is this willingness of nurses to adapt and change in response to these demands that makes it difficult to change the dominant stereotypical conception of the nursing role. Similarly to other areas of nursing, the role of a psychiatric nurse was most easily understood when in traditional inpatient or secondary care setting. As the provision of health services has moved towards more community models, the professional identity of the mental health nurse is more diverse and their role has blurred with other professions, leading to stress (Farrell et al., 2011). Some literature has considered the relationship between mental and physical health nursing such as Cutcliffe et al. (2001) who highlighted the similarities between the roles of the mental health and palliative care nurse. They suggested that not all general

nurses possess the required skills to focus on psychological, social and spiritual needs of patients in order to work in palliative care. The role of the nurse in non-physical care and the development of the nurse-patient relationship were found to be key areas of commonality. Whilst there is a distinction between palliative care and oncology, the themes highlighted such as burnout, professional identity, organisational change and a multifaceted role are also be relevant for oncology nurses who are providing psychological support.

Psychological issues related to oncology:

In working within an oncology setting healthcare professionals encounter patients who bring with them emotional and psychological needs that extend beyond their physical care. In a qualitative study Absolom et al. (2011) interviewed twenty-three health professionals including surgeons, ward sisters, oncologists and CNSs. They described how these health professionals perceived their roles and responsibilities in relation to patient distress. They found that whilst all professionals described working within their area of medical expertise and offered a level of emotional support, there was limited access available to specialist psychological care services. The study highlighted the key role and responsibility placed on the CNSs in the provision of psychological support for patients. Whilst all health professionals acknowledged the importance of detecting emotional distress in patients, they relied on CNSs to undertake further assessment, provide emotional support and refer to specialist services. Team members reported depending on CNSs for the provision of psychological support. The CNSs in this study perceived psychological support to be a central part of their role, however, there was evidence that supporting patients in distress was a burden; at times they did not feel they had the necessary training or support. They were keen to access further training to help them deal with emotional distress and it was suggested that future support could involve obtaining regular feedback and supervision. As a qualitative-based study that only included a small proportion of CNSs this has important findings that could be investigated further by large scale quantitative research or by focusing solely on a sample of CNSs. It also utilised framework analysis to understand the data, a method which was designed for applied policy research. Further detailed understanding of the experience of the provision of psychological support specifically by CNSs, using a methodology suited to understanding individual experiences, would add to this literature.

Whilst the provision of psychological support is lauded in policy documents and understood as both important and effective, there are barriers faced in the implementation of this care. Schofield et al. (2006) described the precede-proceed model (Green and Kreuter, 1991) which was developed for use in public health as a way to explain health related behaviours and environments. It is also used to design, implement and evaluate public health interventions. Schofield et al. (2006) argued that it can be used to understand the barrier to evidence implementation and posits that three areas can affect behaviour: predisposing factors, enabling factors and reinforcing factors. Predisposing factors are for example, lack of knowledge of psychosocial care and personal beliefs and attitudes toward psychosocial care in cancer. Enabling factors are issues such as lack of time, lack of skills in the provision of psychosocial care, lack of private consultation spaces, lack of skills in the assessment and detection of psychosocial needs and lack of support. Lastly, reinforcing factors are for example feedback e.g. monitoring how well patients' psychosocial needs are being met and negative consequences for the evidence base not having being followed. This model is helpful in considering some of the areas that can impact on clinical practice. In the case of the provision of psychosocial support however, a more nuanced understanding which seeks to understand the relationship between health professionals and the patients to whom they offer psychosocial support would be useful. Having set the context of CNSs in nursing and oncology the available literature focuses down into more specific areas of this broadly defined role.

The clinician-patient relationship

Given that CNSs are taking on the provision of psychological support, it is also important to consider what is known about the relationship within which this might occur. Whilst the training in psychological skills is important, others have highlighted the importance of the therapeutic relationship. In research into what predicts outcome in psychotherapy, treatment factors such as the type of therapy provided, account for only a small percentage of the variance of therapeutic outcome (Johannson & Jansson, 2010; Lambert, 1992; Wampold et al., 1997). The single most important factor in therapeutic effectiveness is the quality of the therapeutic relationship (Cooper, 2008). The clinician-patient relationship is both rewarding and demanding. If the relationship is so central to successful outcome in therapy, this

increases the importance of the relational dimension and the impact of providing psychological support for CNSs in oncology.

Leiper (2001) suggests that the therapeutic relationship can be challenging and ruptures can occur as a result of the patient, therapist or a product of both. Safran, Muran, Samstag and Stevens (2001) argue that it is important to recognise and address any ruptures in alliance for successful therapy outcome. The emotional costs of providing therapeutic care and being in a therapeutic relationship can be seen in the extensive literature on burnout and compassion fatigue. Consequently there have been important developments in therapists seeing self-care as part of their ongoing professional development (Reeves 2013).

BACP's Ethical Framework states that 'Attending to the practitioner's wellbeing is essential to sustaining good practice' (2010, p. 10). Supervision has been seen as a vitally important support in this regard. Additionally, within the psychotherapy literature boundary issues are universally prevalent (Pope & Keith-Spiegel, 2008). There are many types of boundaries outlined relating to: role, time, money, language, self-disclosure and physical contact (Gutheil & Gabbard, 1993). There is also literature regarding both boundary crossing and violation and Gutheil and Gabbard (1998) adopt the term boundary transgression in order to capture both concepts. The concepts of rupture and boundaries in therapeutic relationships are not the focus of the present study however they are key issues which might also be present in the nurse-patient relationship. There is literature in the therapeutic domain regarding this therapeutic relationship. Given that CNSs are taking on psychological skills and work, with additional training and supervision from clinical psychologists, this nurse-patient relationship can be viewed as an example of this clinician-patient relationship; yet little is known about this experience.

Forsey et al. (2013) argue that if nurses place great value on their relationship with patients and their families this can lead them to be affected by the emotionally challenging aspects of their role and the experience of emotional distress. This supports the need for research into understanding the relational engagement and experiences of CNSs providing psychological support. It is clear that in the provision of psychological support, the nurse-patient relationship is vital (Burzotta & Noble, 2010). It offers both an essential tool for effective working but can also be problematic. When nurses provide more individualised care it can

cause them to feel increasingly responsible for patients' problems for which they have little control, placing more emotional and psychological pressure on them (Webb, 1981). Booth et al. (1996) proposed that this might explain why the expression of emotional difficulties by patients is sometimes found to be challenging by nurses and blocking is used. The term 'blocking' refers to the way by which health professionals might prevent patients from talking about their emotions as found by Maguire et al. (1996); Booth et al. (1996) suggested that this process might not be conscious. In considering the nurse-patient relationship, Dowling (2008) used an IPA design in order to explore nurse-patient intimacy within oncology settings and interviewed 23 oncology nurses and 30 patients. They drew upon a definition of intimacy that highlighted that it is a quality of relationship. This included emotional closeness, reciprocity of trust and openly communicating thoughts and feelings. The study found that nurse-patient intimacy is a process in which the nurse first identifies with the patient and develops empathy. Patient characteristics and the nurse's judgement of the patient affects identification with them and this in turn affects the development of intimacy. They understood intimacy to involve reciprocal self-disclosure from nurse and patient and use the term "professional friend". Whilst this process can be satisfying for the nurse, it also has emotional affects and peer support is often utilised. Whether the concept of intimacy is present or not, close relationships with patients seem to be central to the nurse's role. Others argue that in practice, understandings of intimacy actually represent over-involvement (Williams, 2001).

It is also important to consider the organisation within which the clinician-patient relationship resides. In their writing on crisis and impasse in therapeutic relationships, Leiper and Kent (2001) highlighted that therapeutic relationships reside within a wider context. More specifically it is important to acknowledge the organisational, professional and social contexts that the "therapeutic self" (Leiper & Kent, 2001 p.212) exists within. This environment can provide containment for the therapist and can enable difficult emotions to be both tolerated and processed. Organisational structures which are under stress might be less capable of containing those working within them. Issues such as under staffing, high workloads and frequent changes can affect this structure and contribute to the lack of security. When the therapist experiences particular challenges in their work, they might look for a form of safety and security and the organisational structure and the social system around the therapist might also do the same (Obholzer & Robert, 1994). With the

CNS-patient relationship in mind and the continual changes present within the NHS, if this organisational safety and security is not present, then this might provide a particular kind of challenge for the CNS. Having outlined some of the literature on the clinician-patient relationship I have also highlighted the impact that this can have on the health professional. It is therefore important to outline some of what is known about the impact of providing this support to patients.

The impact of providing emotional support:

In considering the relationships between health professionals and their patients, it is important to understand the impact of providing emotional support on the providers. Health professionals are often exposed to the pain and distress of patients and their families. Some have argued that this increases the likelihood of the professionals themselves experiencing difficult emotions (Towers, 2007). The concept of burnout was first developed by Freudenberger (1974) who described it as mental, emotional and physical tiredness caused by unfavourable work conditions. Others have understood the term as describing emotional exhaustion, low personal accomplishment and depersonalisation as a result of working in roles which require engagement with people; this can also lead to decreased effectiveness at work (e.g. Maslach, 1974; Maslach & Goldberg, 1998).

The very nature of working in oncology can lead health professionals to be frequently asked "Isn't it depressing? I don't know how you can do that work" and there seems to be a common understanding that working with seriously ill individuals must be depressing and therefore difficult to cope with (Wengstrom & Ekedahl, 2007). It should not be assumed that working in oncology is necessarily depressing, stressful and causes burnout. However, given the role of CNSs in patient care, it is important to consider this literature. There is a vast literature regarding burnout of staff working across all aspects of cancer care (Emold et al., 2011; Mukherjee et al., 2009) Studies comparing the levels of burnout across different professional groups in oncology teams have suggested that the level of burnout and work related stress amongst cancer nurses is comparable to that of doctors working in cancer (Bressi et al., 2008, Sharma et al., 2007). Bressi et al. (2008) found that in a sample of 387 healthcare professionals working in cancer, scores on the Maslach Burnout Inventory showed a high level of emotional exhaustion in 32.2% doctors and 31.9% nurses.

Additionally 29.8% doctors and 23.6% nurses showed high levels of depersonalisation. Sharma et al. (2007) however, showed that reported levels of job satisfaction by nurses were the highest amongst the multidisciplinary team.

The term burnout is now seen to be slightly outdated and the concept of compassion fatigue is now also used. Figley (1995) stated that compassion fatigue is the 'cost of caring' (p.1). This model of compassion fatigue is based on the idea that both emotional energy and empathy are essential when working with suffering, in order to build a good therapeutic alliance and to offer an empathic response (Figley, 2002). Yoder (2010) identified compassion fatigue in a group of nurses in a community hospital, who managed this with a variety of personal and work based coping strategies. Situations that evoked compassion fatigue included caring for young dying patients. This was difficult for the nurses as they were unable to 'rescue' the patient through making them better. Najjar et al. (2009) suggested that the definition is ambiguous and fails to adequately differentiate it from things like burnout. Despite this they argued that it can impact on providers of care in cancer but that further research is needed.

Contrary to the assumption that working in oncology is likely to lead to higher levels of stress, burnout, or compassion fatigue, Sherman et al. (2006) concluded that whilst there is a high level of burnout among oncology professionals, this is not necessarily higher than those in other occupational groups. Similarly, Kovacs, Kovacs and Hegedus (2010) found that there were no significant differences in the prevalence of burnout syndrome between oncology and non-oncology health care workers. While there is clear evidence of burnout in healthcare professionals, there does not appear to be greater demand or level of burnout in oncology. However, the role of CNSs in MDTs and in particular the expectation that they provide emotional support is largely under researched.

Other research highlights the satisfaction that CNSs have in their work. Taylor and Ramirez (2010) suggested that seeing the CNS as a key member of the MDT, and at the heart of the delivery of psychological care, contributes to job satisfaction as it increases the perceived value of their work. In a study of health professionals working in paediatric oncology, participants described personal rewards and professional satisfaction working within this setting (Hartlage, 2012). The sample however, was primarily psychologists, physicians and

social workers. We might hypothesise that the experience of the CNS, with their multifaceted role might differ from that of the professionals described. Similarly to research focused on nurses, a need for supervision, additional training, and better relationships between professional groups were identified by participants as important but lacking in its provision.

Coping and supportive strategies:

There is evidence that suggests that at times working with patients with cancer can be difficult for nurses including CNSs. Lazarus and Folkman (1984, p.141), defined coping as 'cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. They described both emotion-focused coping, which is coping that alleviates emotional distress, and problem-focused coping which attempts to manage the problem which is causing the distress. In order to understand the coping mechanisms of health professionals working with patients with cancer, Blomberg and Sahlberg-Blom (2007) conducted 16 focus groups. Participants were care team members who provided care for patients with advanced cancer and the data was analysed using a phenomenological method. They found that care team members used both closeness and distance to manage difficult situations (as described by care team members). In most situations the use of closeness and distance was understood by the authors as a spontaneous rather than a conscious choice.

In their study of 'blocking behaviour' Booth et al. (1996) provided training in key assessment skills to 41 hospice nurses and each nurse was asked to demonstrate an assessment of a patient's problem before and after the training. These interviews were recorded and assessed by trained raters in order to determine the frequency of responses that served as blocking the patient's disclosure of emotional distress. Findings showed that blocking behaviour is common in hospice nurses who were communicating with seriously ill individuals. They described that when patients disclosed their feelings it was often met with avoidance; the provision of a practically and personally supportive supervisor was felt to be important in encouraging their responsiveness and for working effectively. Blocking behaviour was shown to increase as patients disclosed their feelings more. In cancer care,

distancing has been shown to be a common strategy and is described as a way in which care staff can protect themselves from painful emotions (Wilkinson, 1991).

As well as coping strategies, there is a consistent message from the literature that nurses feel that they require more support in providing psychosocial care for patients with cancer (McCaughan & Parahoo, 2000; Botti et al., 2006). Clinical supervision for nurses providing emotional support is recognised (Jones, 2001), however, its provision is inconsistent (Clark et al., 2000). In a qualitative study of nurses caring for women with breast cancer, even experienced staff mentioned their need for support and to talk with peers (Odling, Norberg & Danielson, 2002). Nurses described there being no time to talk about their experiences other than coffee breaks and others unconsciously or consciously tried to distance themselves from work in order to be able to function at work and home. In their study of stress and coping in hospice nursing staff Hawkins, Howard and Oyebode (2007) found that the main sources of stress were high workload, issues of death and dying, and feeling inadequately trained to meet the emotional needs of the patient and family. They recommended the utilisation of further support and supervision. This literature focuses on general nurses and does not address the experience of the CNS specifically. Given the role of CNSs in the provision of psychological and emotional support, and as outlined, the importance and impact of the therapeutic relationship, there is need for understanding the experience of CNSs in doing this work including the utilisation of support and supervision.

Oncology nurses' perceptions of their work:

It is important to consider oncology nurses' perceptions of their work including the provision of psychological support. One study aimed to understand oncology nurses attitudes towards their provision of psychosocial care for families in which a member has advanced cancer, explore their opinions on the challenges in provision of this care and identify any associated learning needs (Turner et al., 2007). Focus groups and individual telephone interviews were conducted with oncology nurses. The provision of emotional support was described as a key aspect of their role however, three broad areas of difficulty were described; nurses' own challenges, system challenges and physical barriers. Nurses felt that they required more training in order to understand the emotional impact of cancer on both parents and their children. Some were concerned that by intervening they might make things worse and felt unconfident in their communication abilities, particularly remaining quiet and just 'being with' the patient (Turner et al., 2007, p.152). Lastly, they found a

predominant theme of 'burden of caring' which encompassed 'sadness and grief' and 'reflection on personal experience of loss'. Nurses acknowledged the emotional demands of working with families in an oncology setting but felt there was little recognition of the demands of this work and limited support structures in place. Some described their own experiences of loss and acknowledged the impact this might have on their work with parents. They identified systemic challenges such as 'culture of the workplace' and the 'traditional nursing practice' which is task focused and places emphasis on the importance of 'doing'. Time pressures and limited access to specialised psychosocial support such as clinical psychology or psychiatry were identified. The theme 'physician barriers to the provision of emotional support', highlighted that the unspoken attitude of medical staff towards psychosocial support influences the culture of the service and thus the responses given to patients. A lack of physician communication with patients and nurses around their condition or details of recent physician-patient consultations and prognosis were all seen to be barriers in the provision of emotional support. Nurses identified some educational needs including further knowledge particularly around parental needs, developmental stages and available resources to use with and suggest to families. Professional confidence was lacking particularly regarding the nurses' role and the value of providing psychosocial support. It was also identified that just 'being with' patients was not valued by nurses and they did not see its inherent value. Communication skills were highlighted as an educational need, particularly general skills and how to initiate discussions. The authors highlighted that underneath all of the focus groups and interviews, the theme 'the emotional burden of caring for others' was present. They described that the ability to 'be with' patients in distress is a core part of the caring role and is important for those experiencing distress. They proposed that this caring role can be a burden for nurses. They found that avoidance is often used; for example, at times the nurses physically and emotionally avoided parents. At other times nurses were aware of parent distress but felt reluctant to engage with this and commented that they felt unconfident in their professional role. Turner et al. (2007) suggested that perhaps the nurses were struggling to respond to distress because they felt distressed themselves. Furthermore, it seems that the nurses undervalued their roles in caring through listening, acknowledging distress and being emotionally present. One explanation is that devaluing results from a lack of understanding of the impact and benefits of emotional support and that this type of care contrasts from the traditional stereotyped task focused role of nurses. The authors suggested that given the 'burden of caring,' perhaps nurses

undervaluing their role in emotional care serves to legitimise their avoidance of becoming connected with the emotional experience of the patient. They proposed that further training should incorporate the evidence-base for the benefits of listening but also explore individuals' attitudes towards 'being with' patients. Nurses highlighted the lack of available support structures but also chose not to confide in colleagues and the authors argued that attention should also be paid to the wider context in which the nurses work and understand the attitudes toward psychosocial care within these. Considering the use of focus group methodology and the geographical location of the study, it would be useful to further develop this research with an individual interview methodology. This study raises many important themes regarding the provision of emotional support within an oncology setting however focused on the attitudes and opinions of nurses. It did not aim to understand the experience of nurses and furthermore its focus was on nurses not CNSs, who undertake a different role to that of a nurse.

Forsey et al. (2013) explored practitioners' understanding of their role in emotional support to parents of children with leukaemia. The study found that doctors and nurses differed in how they described the emotional care. Doctors relied on the potential for treatment to offer reassurance and did not feel the need to engage in conversations about parents' fears in order to meet their emotional needs. Nurses however, felt that providing emotional support was an essential part of their role, particularly openly discussing parents' concerns and anxieties. They described imagining themselves in the situation of the parents and felt responsible for the provision of emotional care, sometimes feeling overwhelmed by patients' distress. They often shared personal details about themselves as a way of building close relationships with families. Within the team however, their role was often invisible, as others in the team did not value this work and more specifically, hospital nurses described finding it difficult to manage both the physical and emotional needs. The authors also highlighted Menzies-Lyth's (1961/1988) work on the defensive coping strategies sometimes used to manage work stress, an example being distancing from patients (Menzies-Lyth, 1961/1988), and propose that caution should be taken in encouraging nurses to become more emotionally connected with their patients on order to prevent them from being overwhelmed by patients' distress. The differences in doctors' and nurses' perceptions of their provision of emotional support were thought to be related to their clinical roles. It would be useful to further this research, looking more specifically at CNSs in oncology. This could enable a deeper

understanding of their experiences of providing psychological support following the completion of a psychological skills training course and understand how they manage this experience and what support they use. Additionally, it would be useful to understand the experience of CNSs working across different tumour specific MDTs rather than just with parents of children with cancer given that this is the way cancer care across the country is provided.

CNSs, relationships and oncology

Given the extensive research of nursing, oncology and psychological support, there is limited research addressing the role of the CNS in oncology with relation to psychological support. This is significant in that it indicates that research in this area in under-represented. The relevant texts will now be discussed.

Skilbeck and Payne (2003) conducted a comprehensive literature review into emotional support and the role of the CNS in palliative care. They concluded that there was a lack of clarity around the use of the terms emotional care and support, yet there was an assumption within the literature of a shared understanding of these terms. Whilst they suggested that there is a developing understanding of the CNS role, they pointed out that there are few studies focusing specifically on the emotional care and support offered by CNSs to patients. Furthermore they suggested that this area of their role requires further definition. They highlighted that the process of developing emotionally supportive relationships is complex. The development of these relationships requires CNSs to have skills and knowledge to manage the process which includes both the encounters that they have with patients and families, as well as the organisational and social context within which this work takes place. They highlighted a need for research into emotional care in different care settings, into the strategies that are used in managing this emotional care, the sense that both nurses and patients make of their actions as well as how nurses manage the demands of this emotional work both formally and informally. This literature review focused on palliative care. It is clear that there may be similarities in the emotional work that CNSs in cancer generally, as opposed to CNS in palliative care, undertake. There may also however, be clear distinctions and there is a need for further research into the role of the CNS in oncology more generally.

Considering the recommendations around the improvements needed in the provision of emotional support for patients with cancer, Willard and Luker (2005) researched the ways in which oncology CNSs implemented their role amidst the formation of MDTs and through organisational change. Twenty-nine CNSs participated in individual interviews (in addition to observational methods) analysed using grounded theory. They found that one of the greatest challenges for the CNS was the 'treatment agenda' where the physical investigation, diagnosis and treatment are prioritised. Their experience was that supportive care is often subordinate to this. The organisation of palliative care and tumour specific services focuses on throughput of large volumes of patients. The dominance of doctors in the health care team meant that in many cases CNSs required approval from doctors in order to provide supportive care. Teams had differing understandings of what the CNS's role should be and this was felt to impact upon the ability of CNSs to provide supportive care. Supportive patient care was not always regarded as important and in some cases seen as an optional extra. CNSs were required to work hard in order to promote the importance of supportive care and even in teams that embraced this care, CNSs felt pressure to fill the gaps of medical shortages, limiting their ability to provide supportive care. The authors proposed that there needs to be a focus on (a) the interaction of patients and health care workers and (b) the organisation of the systems in which supportive care is supposed to be provided. They posited that CNSs' roles are multifaceted and they can experience a tension in managing both the emotional, physical and practical aspects to their role. This is also additionally shaped by the professional led services and the dominant opinion in the priority of care within a team.

Ablett and Jones (2007) argued that although working in oncology is deemed to be stressful, the literature shows that palliative care staff experience similar levels of psychological distress and lower levels of burnout to staff in other specialties. They utilised an IPA methodology to explore hospice nurses' experiences of work. They found 10 themes that hospice nurses used to conceptualise their work including: personal attitudes toward life and death; personal attitudes towards caregiving; personal/professional issues and boundaries; aspects of job satisfaction; aspects of job stress; ways of coping; personal attitudes towards work; awareness of own spirituality; past personal experience influences care-giving; and an active choice to work in palliative care. They argued that these themes are strongly related to commitment and purpose about work and they evaluated these themes against the available

literature in order to understand the interpersonal factors that promote resilience or that moderate the effect of workplace stress. They concluded that there are interpersonal factors that may enable hospice workers to remain resilient in their work. Whilst utilising a phenomenological approach aiming to understand the experience of nurses, this study focused on a sample of hospice nurses in oncology and not CNSs. While there is a relationship between nurses working in oncology and those working in palliative care in a hospice setting, there are also differences that will be experienced. Within a hospice setting, it is known that the patients will die, most likely from their cancer and therefore there is no drive for curative treatment; as such the conditions are different. There is a gap in the literature leaving room for a phenomenological focus on the experience of CNSs in oncology specifically.

There is one study that has utilised a phenomenological focus and explored the lived experience of the clinical nurse specialist in oncology (Loftus & McDowell, 2000). The authors sought to examine what the important and unique aspects of the oncology CNSs' experiences were. Sampling eight oncology CNSs, they undertook individual interviews that focused on asking participants to reflect on two critical incidents: one which they felt had not gone well and another that they felt had gone well. They analysed these interviews using thematic analysis and found four main themes: reflective practice; support; boundaries; and uncertain ground. They highlighted the lack of understanding about the supportive element of their role, thus making it difficult to understand the needs of the CNS in this area. They therefore recommended further research into this part of their role in order that appropriate support systems can be put in place. This research was undertaken over ten years ago, in which time many organisational changes have taken place. The changes to governmental policy relating to cancer, the provision of psychological support and the additional training in psychological skills that some CNSs are undertaking, suggest that there may have been development and maturation in the profession. This leaves clear scope for research, with a phenomenological focus, to understand the lived experiences of CNSs as they undertake their role. Furthermore, it is clear that many CNSs are now receiving training from clinical psychologists and are providing psychological support to patients with cancer. Despite this, we have little understanding of what this experience is like for CNSs, again warranting further research.

Summary

The psychological and emotional needs of patients and families with cancer have been well evidenced. Despite continual organisational changes within the NHS there is still a need to offer appropriate psychological assessment and intervention. The delivery of quality psychological care in cancer services requires both suitably trained staff and informed services in order to fulfil the wider vision outlined in government guidance and Department of Health documents.

CNSs provide psychological support to patients with cancer (and their families). In order to support CNSs in providing this care, clinical psychologists are often tasked with the provision of level 2 psychological skills training which many CNSs have completed. Clinical psychologists also provide support and supervision to CNSs working in cancer care. Clinical psychologists are therefore helping to train and support other professionals in working with the psychological and emotional needs of patients.

There is research from the wider therapy literature suggesting that the provision of psychological and emotional support to patients can be challenging. The literature suggests that in order for psychological support to be beneficial it requires the development of a therapeutic relationship with patients; this relationship can be challenging. As such, it may be that the development of psychological skills and the provision of psychological and emotional support by CNSs might also be challenging. There is a wealth of literature regarding specifically burnout and nursing as well as literature focused on palliative care. Despite this there is little research aiming to understand the experiences of CNSs offering psychological support alongside undertaking their wider role. In offering psychological support to patients CNSs might be being brought closer to the emotional experience of others and there is a need for understanding what this process is like for them.

Given that clinical psychologists are supporting and training CNSs in the psychological domain, there is a need to understand how CNSs are using the skills, training and support that they receive. Little is known about CNSs' experience of their day to day role, including the provision of psychological support. CNSs have a multifaceted role of which psychological support is one element; as such research which seeks to understand what it is

actually like for CNSs to be providing psychological support alongside their wider role is pertinent.

CNSs are undertaking limited training and receive limited supervision in the delivery of psychological interventions, yet are in positions in which they offer psychological support often to large numbers of individuals. There is therefore a clear need for this study that adopts a phenomenological focus in understanding the lived experiences of CNSs as they undertake their role including the provision of psychological support to patients with cancer and their families. Moreover, understanding this experience is also important as it might have implications for CNSs' training and support and thus lead to an improved patient experience. Given the existing literature and the gaps within this in relationship to the provision of psychological support by CNSs, and the provision of training and supervision by clinical psychologists this leads to the research questions which this research will now address:

Research Questions

- What is the experience of CNSs working in oncology?
- What is their experience of offering psychological support to patients with cancer (and their families)?

CHAPTER TWO

Methodological Approach

In order to explore the experiences of CNSs in oncology with reference to psychological support, a qualitative research design was most appropriate. Qualitative designs focus on people's subjective lived experiences, understanding the world they are situated within and the social process they engage in (Mason, 2002). Many qualitative methods attempt to obtain rich descriptive accounts and enable an understanding, description and explanation of social phenomena to be developed (Geertz, 1973). Writing with the discipline of psychology in mind, Willig (2008b) posits that qualitative designs enable the exploration of how individuals make sense of particular phenomenon or events, the meanings that these have and the ways in which individuals live through and manage these. They allow the discovery of new phenomena or areas where there is little current understanding (Robson, 2008) and highlight new avenues of scientific enquiry (Denzin & Lincoln, 2005). Findings are often developed through a bottom-up process and not driven by hypotheses or predictions drawn from pre-existing theory.

This research study utilised Interpretive Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) to explore the experiences of CNSs in oncology with reference to psychological support. This is because of the following reasons. IPA is an inductive qualitative approach to analysing data; it takes an epistemological position that psychological enquiry should seek to understand how people experience the world and considers the meanings that those experiences hold for individuals (Smith, Flowers & Larkin, 2009). Its origins lie in a publication by Smith (1996) who proposed the need for a qualitative methodology that enabled insight to be gained into how individuals experience and make sense of experiences and events in their lives. Whilst IPA was initially applied within health settings, it has since begun to be applied in the professional areas of clinical, counselling, social, and educational psychology as well as other disciplines such as business and general education.

Alternative methodological approaches

The following methodological approaches were considered before IPA was decided upon.

Grounded theory (Glaser & Strauss, 1967) was developed as a way of producing a theory from a data set. Data is analysed throughout the research process, with data collection continuing until saturation is reached. Traditionally, it has been used to address sociological research questions and focuses on theory construction to understand the phenomenon under investigation (Willig, 2001) although recent advances do allow for a more local narrative (Charmaz, 2006). The present study was not concerned with developing a psychological theory relating to particular experiences of CNSs and therefore grounded theory's focus on general theory construction was not deemed suitable. IPA's focus on the combination of hermeneutic and phenomenological approaches, as well as it's facilitation of a psychological rather than sociological foci, was considered more appropriate in addressing the research questions.

Discourse Analysis is concerned with how a phenomenon is constructed through language and how people use language to create and enact identities and activities (Starks & Brown Trinidad, 2007). It highlights the important role of language in both the construction of social reality (Willig, 2008a) and in describing an individual's experience. The focus of this study was on understanding the experiences of individuals and the meaning that individuals give to their experiences rather than an exploration of the language used by individuals. As such, discourse analysis was not deemed suitable in answering the research questions.

Rationale for IPA

IPA was considered to be the most appropriate methodology in the current research. IPA is a valuable tool in researching many areas relevant to both clinical and health psychology (Brocki & Wearden, 2006; Reid, Flowers & Larkin, 2005). IPA is also beneficial in health psychology, as it allows the opportunity to investigate phenomena in the individuals who are experiencing them, especially where there is limited research (Shaw, 2001). Whilst IPA aims to theorise out of a detailed examination of lived experience, it does not seek to construct theory in the way that a grounded theory methodology might advocate (Willig, 2001). The idiographic approach of IPA fits with this research which explores the experience of a small group of individuals rather than generalising ideas to large populations (Smith & Osbourne, 2007). This study sought to examine participants' experiences: IPA is

concerned with experience and the meanings attached to the experience and therefore deemed an appropriate methodology.

Theoretical Roots

IPA derives its theoretical roots from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). The philosophical approach of *phenomenology*, developed by philosophers such as Husserl and Heidegger, is concerned with experience and how this occurs in its own terms (Smith, Flowers & Larkin, 2009); as Husserl (1927, p.168, cited by Smith, Flowers & Larkin, 2009) phrases this, going 'back to the things themselves'. Within psychological research, pre-existing assumptions for a researcher may include prior knowledge of a phenomenon through the reading of relevant literature, personal experience and knowledge of theories relating to the research area. Husserl's (1927) approach to phenomenology poses that enquirers should bracket off their assumptions and pre-conceptions in order to explore the essence of phenomena through experience. Heidegger (1927/1962), however, developed this approach to phenomenology and suggested that an individual relates within a lived world and does not exist in isolation; it is this involvement in the lived world that influences their perspectives and understandings of their experiences. He uses the concept of inter-subjectivity which is used to describe the inability to move away from an experience as a result of the "shared, overlapping and relationship nature of our engagement in the world" (Smith, Flowers & Larkin, 2009, p. 17). Heidegger (1927/1962) argued that experience is embedded in context and is both shared and relational. It is difficult to be able to separate ourselves from the things we experience as we are too inextricably linked to them. Therefore, researchers must take into account their beliefs and assumptions and acknowledge it is not possible to fully bracket off these from our enquiry into the subjective experiences of others. As such, through the process of reflection, phenomenology aims to understand the unique experiences of individuals and how they make sense of their worlds.

Hermeneutics is a theory of interpretation; the process and how this process is shaped. Heidegger (1927/1962) suggested that as humans, we are constantly and actively attempting to make sense of our experiences. Our understandings of the world are constructed through a process of interpretation, and this is always shaped by our own positions within the world. The understanding that is gained of a person's experience is therefore dependent on what an

individual tells the researcher about their experience; it is the individual's account of the experience rather than the experience itself that is being understood (Smith, Flowers & Larkin, 2009). Hermeneutics suggests that our interpretations will be influenced for example by preconceptions and assumptions and therefore will not be truly objective; rather the analysis is another construction of the experience thus giving rise to the concept of the double hermeneutic in IPA. IPA is distinct from other hermeneutic approaches because of its focus on the individual and their 'sense making' (Finlay, 2011).

Idiography refers to the focus on the particular (Smith, Flowers & Larkin, 2009). Traditional nomothetic approaches in research focus on the generalisability of findings, attempting to produce an objective account (Giorgi & Giorgi, 2003; Reid, Flowers & Larkin, 2005). Idiography instead refers to the need to obtain an in-depth idiosyncratic account of the experience of an individual. It assumes that it is an individual's perception of the world that constitutes their personal reality and aims to develop a rich description of lived experience; how participants themselves make sense of their experiences (Finlay, 2011).

These philosophical roots are the foundation of IPA's epistemological position and help justify the appropriateness of IPA in the present study. IPA emphasises an in-depth exploration of the subjective accounts of phenomena, in an attempt to understand lived experiences (Eatough & Smith, 2006). Drawing on hermeneutics, IPA also utilises interpretation and acknowledges the impossibility of having direct access to participants' experience (Finlay, 2011). It therefore emphasises an interpretive, dynamic and reflective role of the researcher, in making sense of individuals' experiences through interpretation (Smith, Jarman & Osborn, 1999). There are two levels of interpretation, described by Smith (2008) as the 'double hermeneutic,' in which the analysis includes not only the participants' sense making , but the researcher's understanding of the participants' sense making. There is an interaction between individual and researcher and the individual's account is interpreted through the researcher's own world view. The focus of IPA is idiographic; it aims for an in-depth examination of an individual's experiences in their own context (Smith & Osborn, 2007). It is only after this detailed examination of each participant's account that IPA subsequently looks at convergence and divergence between participants (Smith, Flowers & Larkin, 2009). Given that my research questions focused on the particular experience of clinical nurse specialists there was a clear rationale for the selection of IPA as described.

Data Generation

Within qualitative approaches including IPA, a range of data generation methods such as interviews, action research, focus groups and diary methods are used. Within the approach of IPA, the aim however, is to gain a 'rich' detailed individual account of participant's experiences (Smith, Flowers & Larkin, 2009). Moreover, the chosen method of data collection should enable participants to freely and reflectively provide an account of their experiences of the phenomenon under investigation (Smith, Flowers & Larkin, 2009). Other methods of data collection were considered such as Participant Observation. This involves doing naturalistic research and going into the 'field' (Finlay, 2011). In the current study this would have involved me becoming part of the hospital settings in which the CNSs work, taking part in activities such as meetings and clinics, as well as interviewing participants. This would have enabled me to observe the relationship between participants and their patients and team members. In order to gain ethical approval however, this would have required gaining informed consent from all staff members and patients that I would have come in contact with. As such, this method of data collection was deemed unfeasible. The phenomenological focus of the research questions, aiming to gain an understanding of the CNSs' experiences, meant that semi-structured interviews were deemed best suited. They offered a flexible and exploratory approach, in order to gain rich, detailed accounts of these experiences.

Semi-structured interviews are a favoured method of data collection in IPA studies (Smith & Osbourne, 2008). They allow participants' in-depth accounts of experiences to be elicited and allow the researcher to ask questions which can facilitate a greater richness in the data (Smith, Flowers & Larkin, 2009). They facilitate the development of rapport and are suited to in-depth, detailed and personal discussions (Reid, Flowers & Larkin, 2005). They allow the voice of the individual to be heard, privilege a client narrative (Denzin & Lincoln, 2005) and allow a dialogue between researcher and participant in which questions can be modified upon consideration of participant's responses (Smith & Osborn, 2007). Overall, their aim is for the interviewer to enter the world of the participant (Smith, 2008).

Sampling

IPA is concerned with the detailed examination of people's lived experiences and purposive sampling methods are recommended (Smith, Flowers & Larkin, 2009). Purposive samples are generally relatively small and should be selected as they share similar experiences and/or perspectives relating to a particular phenomenon, rather than to represent a particular population. The research question should be significant for the group of participants and there should be a level of homogeneity, that is, there should be some alikeness about the sample (Smith & Osborn, 2003). Whilst there are no formal guidelines regarding sample size for IPA projects; between four and ten interviews is recommended for doctoral research projects (Smith, Flowers & Larkin, 2009). Given the use of an IPA methodology focusing on the experience of CNSs in oncology with reference to psychological support a small purposive sample was deemed appropriate.

Method

Design

A qualitative design was employed and IPA (Smith, Flowers & Larkin, 2009) was chosen as the methodological framework for the research. Purposive sampling was used and participants were recruited through five NHS Trusts. Data was collected through face to face semi-structured interviews which were audio-recorded and transcribed verbatim. Interviews were guided by an interview schedule which included a range of open questions, designed to elicit the experience of participants (Appendix VII). Transcripts were analysed individually to identify themes before each individual moving on to a whole group analysis across the sample. The number of interviews was within the suggested range for professional doctorate qualitative research using IPA (Smith, Flowers & Larkin, 2009).

Sample

The following inclusion criteria were used to maintain homogeneity, specifically in relation to participants having experience of the role of a CNS in oncology and of the provision of psychological support:

- Clinical nurse specialists currently working in oncology

- Completion of the level 2 psychological skills training provided by clinical psychologists throughout the Regional Cancer Network (now known as the Strategic Clinical Network).

- Completion of the portfolio of supervised clinical practice which includes attendance at clinical supervision.

Potential participants would have been excluded from recruitment for the following reasons:

- If they had not fully completed the level 2 psychological skills training

- If they were not fluent in English, however, it was assumed that the staff group would be fluent in English due to the position they already held in the NHS.

Recruitment Procedure

Recruitment took place within five large NHS Trusts. I contacted each Research & Development (R&D) department separately and as required, a local collaborator was identified within each trust. Local collaborators consisted of five clinical psychologists. Recruitment was planned to take place across six NHS trusts however contact was lost with one local collaborator. This meant that R&D approval was unable to be gained at the NHS Trust and no research activities took place there. Local collaborators across the five participating NHS trusts firstly identified all CNSs in their trust who met the inclusion criteria. Once these individuals were identified, local collaborators each collated a list of the potential participants and their contact details but did not share this with me. R&D approval was required from each individual NHS trust. Given the limited time scale of this study the dissemination of recruitment information was staggered across NHS trusts. As soon as R&D approval was gained from an NHS trust recruitment began. To begin recruitment, I contacted the local collaborator and provided them with a recruitment email template (Appendix I) with an attached recruitment poster (Appendix II). The local collaborator sent this email and attachment, to each identified potential participant. Respondents were requested to contact me themselves by email or telephone to express an interest in participating.

Information and Consent

Potential participants expressed an interest in the study by making contact, thus making an active choice to decide to find out more about the research and possibly participate. Following a participant expressing interest in the research, I spoke with them on the telephone to arrange a provisional interview date and then sent them a detailed information sheet (Appendix III). Interviews were scheduled to allow for at least fourteen days for them to read the information sheet and ask any necessary questions about the research. Prior to the interview commencing, participants were asked to confirm that they had read and understood the information provided. A consent form was produced (Appendix IV) which outlined the main principles of the research and participants completed this before participation.

Participant Information

The number of eligible potential participants was approximately 40 and the study received a good response rate. In total ten participants made contact and agreed to take part of whom nine were recruited; one participant cancelled the interview due to sickness and did not respond to further communication from me. An eleventh potential participant contacted the local collaborator and asked to take part in the study after recruitment had ended; this was explained to them and they were therefore not recruited to the study. Of the nine participants recruited only eight transcripts were analysed. This was because one participant was a palliative care CNS who worked into oncology as well as other specialities. Whilst they were interviewed in good faith, upon completion of the interview and transcription, it was recognised that the other eight participants were more closely homogenous.

Ethical Considerations

Ethical Approval was gained from the Leeds Institute of Health Sciences, Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine (LIHS/LIGHT/LIMM) joint ethics committee in JUNE 2013 Ref: HSLTLM/12/065 (Appendix V). Approval was gained from the R&D departments in the five participating NHS Trusts. Given the small sample that met the inclusion criteria the R&D approval letters

have not been included in the appendices to take a further step to ensure participant anonymity.

The main ethical issues in this study were the potential for participant distress, confidentiality and the disclosure of unethical practice. Participants' well-being was held in mind through an understanding of relational ethics (Danchev & Ross, 2014). The study had a small potential to cause distress due to participants talking about case examples of patients that they had worked with and how they found this work. Participants' well-being was prioritised and I informed them that they could take a break, terminate the interview or withdraw from the study at any time. Participants were informed of this in the information sheet and again prior to the start of the interview.

In order to ensure confidentiality the following steps were taken. Interviews were digitally recorded and participants were assigned a number and pseudonym. I transferred audio data to the transcriber using an encrypted memory stick and identified the interview recordings with the assigned number. Participants were asked not to provide names or identifiable data when referring to patients. No patient names were given but names of colleagues and places were replaced with '[names colleague]' and '[names place]'. At the end of the interview, participants were given the opportunity to identify any information that they felt made themselves or anyone else identifiable or that they were uncomfortable with. In this instance a discussion would have taken place about whether this was removed from the transcript and not analysed, or analysed but not used in the write up, however this did not happen. All data was kept in a combination of locked filing cabinet, secure university server and encrypted memory stick. All audio recordings and transcripts were dealt with in compliance with the Data Protection Act (1998) and the University of Leeds policy. Consent forms were kept separately to interview data. Participants were informed in the information sheet that if they described behaviour that suggested they had acted unprofessionally this would need to be reported to my supervisor and then possibly to the relevant authorities.

Procedure

Interviews

Participants were offered the opportunity to undertake the interview at their place of work or at the University of Leeds. All interviews took place at participants' places of work. Rooms were booked either by the participants themselves or by the local collaborator. Efforts were made to ensure the room was quiet and comfortable. The importance of establishing good rapport in one-to-one interviews has been highlighted (Smith and Osborne, 2003), therefore I took time at the beginning of the interview to reiterate the purpose of the study, the expected duration and the participant's right to withdraw. The interview schedule was used flexibly so that interviews were tailored to each participant. As such, the order of questions was adapted in each interview in a way that encouraged the conversation to flow and an attempt to mirror the language of each participant was made. Interviews were audio-recorded using a digital recording device. I also recorded my reflections about the interview and provided a summary of any notable non-verbal behaviour and my initial summary of the interview. I transcribed the first interview and this was a useful process in becoming immersed in and familiar with the data. Due to timing and practical constraints this was not possible for all interviews and the remaining were transcribed by an approved transcriber from the University of Leeds who had signed a confidentiality agreement. Recordings were transcribed verbatim and non-verbal communications were included (for example, laughter). I checked all transcriptions for quality and accuracy as well as to become more familiar with these interviews and their nuances, before analysis. The following table explains the transcription and reporting conventions used:

Table 1: Transcription Conventions

Convention	Meaning
I:	Interviewer
P:	Participant
[I:] [P:]	Where there is overlap in speech
..	Short pause
…	Longer pause
(pause)	Very long pause
Underlined text	Underlined fragments indicate speaker emphasis.
[...]	Represents text that has been deleted to make the extract clearer for the reader or to shorten a quote.
< >	Text which has been included to aid the reader's understanding.
<laughs>	Speaker laughs
[names person]	Replaces a name – removed to protect anonymity
[names place]	Replaces a place - removed to protect anonymity
[names hospital]	Replaces name of hospital - removed to protect anonymity

Interview Schedule

The principles of semi-structured interviewing outlined by Smith, Flowers and Larkin (2009) were used to guide my development of an interview schedule. Firstly, interview questions were designed to elicit different types of data in order to best answer the research questions, for example participant information, general opinions about their role and of the psychological support they offer as well as experiential data. The order of questions was considered; initial questions were deigned to elicit descriptive information from participants (e.g. work experiences, typical day to day role, how they came to be in their current role, other experience of nursing). It was hoped that this would facilitate rapport and engagement with participants before they were asked about specific case examples. The main section of the interview was focused on gaining in-depth experiential accounts of participants' experience of their role and their provision of psychological support. Smith, Flowers and Larkin (2009) recommend the use of open-ended questions which allow room for prompts and probing, and to use a 'funnelling technique' (Smith, Flowers & Larkin, 2009, p.61). For this reason broad questions were first asked which were then followed by more specific questions.

The interview schedule was initially devised then re-drafted and revised. This process was done in collaboration with both my research supervisors and in line with feedback from

members of the qualitative support group on the Leeds Doctorate in Clinical Psychology course. Refinements were made to the interview schedule so that it best facilitated experiential data to be gained and to ensure clear use of language. The wording of some questions was adapted and an unclear question was omitted (Appendix VI). I undertook pilot interviews at two points in the development of the schedule with another Psychologist in Clinical Training. Feedback was taken about how the interview felt for the pilot participant, and how well they felt the schedule guided their accounts of experience. One of these pilot interviews was recorded in order to become familiar with the recording equipment but also so that I could reflect on my interview technique. Listening to this recording made me think about slowing down my pace and making sure I asked only one question at a time. The pilot interview was also useful in order for me to become more familiar with the schedule and this method of data collection (Gillham, 2005) and to be able to use this interview schedule flexibly.

Whilst the schedule was purposefully structured, in practice I used this flexibly in order that the interview was guided by the participants' accounts. This meant that the order of questions was adapted, not all questions were asked and some questions were asked that were not in the interview schedule. This enabled the interview to flow comfortably, whilst also ensuring that each participant felt that their individual account was being heard. It also helped in the development of rapport between myself and the participant.

Data Analysis

Data analysis was influenced by the principles outlined by Smith, Flowers and Larkin (2009). Interviews were analysed individually in chronological order following these steps: 1) reading and re-reading; 2) initial noting; 3) developing emerging themes; 4) searching for connections across themes; 5) moving onto the next case; 6) looking for patterns across cases.

Stages 1-3

Firstly, each transcript was read while listening to the audio-recording as a way of engaging with the text and to bring back the felt sense of the interview. Annotations were made in the right-hand margin next to any sections of the text that seemed particularly interesting,

important or unclear. Additionally, I separately noted my responses to the interview and reactions to the text. The transcript was re-read numerous times and I began to make more notes, particularly thinking about three categories (descriptive, linguistic and conceptual). Key words, phrases and explanations were identified. For sections of the transcript in which I had questions about the context, or there appeared to be gaps in the account, the audio-recordings were revisited so that I could pay particular attention to the tone of voice and the ways in which participant seemed to be talking about their experiences. Any statements that seemed particularly relevant or interesting in relation to the research question were marked and notes such as comments, questions, summaries and associations were made. The transcript was also examined to identify sections which related to specific case examples that participants talked about. An example of this process can be seen in appendix VII. At this point I also wrote a summary document of my understanding of the participant and interview, highlighting anything that particularly stood out. Analysis continued as the explanatory notes were analysed and this was done by using large sheets of paper and mapping out any connections, patterns or questions. This process helped me to identify emerging themes, and I then moved back to the transcript and noted these emerging themes on the left-hand margin. I then produced chronological list in a word document of all the emerging themes.

Stage 4

Each individual theme was then laid out on individual cards on a large surface and those which seemed connected or related in some way were clustered together (Appendix VIII). An initial attempt was made to label these clusters in some way and some emerging themes were discarded, subsumed and merged with another emerging theme. On these occasions the original transcript was revisited to ensure consistency. The summary document was then revisited and I continued to write about my reactions to the participant, transcript and the overall sense of the interview as a whole. These notes assisted in the development of participants' pen portraits. Additionally, I created a table (for each participant) which enabled the themes to be viewed together, refined and merged were appropriate, or split into sub-themes. An extract from one table is shown below.

Table 2: Theme table

Participant	Line	Extract	Comment/Emerging Theme
Jackie	654	But yes, it is emotionally draining and the other thing, for me, being a CNS and being heavily involved in these patients is that, it has an impact on my day to day life. That .. I don't <long pause> I take each day and I use it for what I can. I'm very much for that, in my home life and you know with family and my children, I do as much as I can with them, when I can…	Impact on whole life outlook Existential impact

Stage 5

The process outlined in stages 1-4 were completed for each participant. Each transcript was analysed in turn, before moving on to the next transcript in order to limit the influence of the analysis of one transcript on another. A theme map was produced for each participant (Appendix IX).

Stage 6

Following the analysis of each case individually a group analysis was conducted in which patterns across participants were elicited (appendix VIII). This process was similar to the individual analysis, in that I wrote the subthemes for each participant on pieces of card. I then clustered and re-clustered these and continued to look at each cluster closely to ensure that extracts 'hung together' to constitute a theme. This was an iterative process and only once these clusters seemed to adequately reflect the group experiences, were key theme names then assigned.

Quality

In order to try and ensure the quality and validity of the findings I considered guidelines that can be used to promote high standards within qualitative research (Elliott, Fischer & Rennie, 1999). They outline seven quality criteria including: providing the contextual situation of participants, identification of the researcher's orientation and anticipations, the use of examples to ground the data, provision of credibility checks, coherence, accomplishment of

general and specific tasks, and resonance with the reader. I also considered principles for evaluating the validity of qualitative research outlined by Yardley (2000) including: sensitivity to context; commitment and rigour; coherence and transparency; impact and importance. These criteria and principles were use flexibly in order to improve quality rather than a rigid checklist (Yardley, 2011). The following procedures were therefore used to increase the quality and credibly of the study:

- Throughout the data analysis stage, my research supervisors read sections of numerous transcripts and comparisons were made between our notings and emerging themes. This was an important stage in order to maintain an open analytic attitude and to keep multiple interpretations at play in the early stages of analysis narratives. This enabled me to examine the patterns that were emerging and to also consider the patterns that were not emerging and consider this.

- A double coding exercise (Miles & Hubermann, 1994) was undertaken. My research supervisors read a large section of one transcript without having discussed this with me and made some notes relating to their observations and emerging themes. These notes were then compared with my own notes. This process was also undertaken with two additional transcripts with two peers from the Qualitative Research Support group.

- Extracts of transcripts with accompanying codes and themes were sent to my supervisors in order for them to see the process I was following and make comments if necessary.

- During the data analysis stage, I met frequently with my supervisors to talk about each transcript at various stages in its analysis.

- I kept a reflective research journal throughout this process. This enabled me to keep note of my own responses to the research, highlight significant experiences and increase my awareness of my own ideas and assumptions that might have emerged. This helped me to try and separate my own responses from those of the participants.

- I completed a reflexive interview with one research supervisor before beginning data collection.

- I have provided a statement of reflexivity to detail my own position in relation to the research topic which I will now outline.

Reflexivity

Reflexivity (Henwood & Pidgeon, 1992; Morrow, 2005) refers to the process by which the researcher engages with the data whilst being aware of their own attitudes, beliefs and assumptions. It is the active engagement of the researcher in all elements of the research process, including the initial development of the research, development of research questions, data collection and analysis. It has been described as the "continual evaluation of subjective responses, inter-subjective dynamics, and the research process itself" (Finlay, 2002, p. 532). In qualitative research, the researcher is the main research tool. They should be mindful of subjectivity but not view this as a limitation (Holloway & Wheeler, 1996). In the context of the methodological approach of IPA adopted in the current study, it is important for the researcher to situate themselves as part of the research process. Reflexivity represents the researchers engagement in the 'double hermeneutic' in which they are making sense of the participants sense making. There needs to be an awareness and appreciation of the ways in which the researcher's perspectives and own experiences will impact on their interpretation of participants' accounts. I have brought with me my own attitudes, assumptions, and both personal and professional experiences. In order to bring into awareness the consideration of myself as contributing to the construction of meaning in the research, I kept a research diary and provide the following reflexive statement.

Reflexive Statement

Following the onset of this research, I began a yearlong placement as a psychologist in clinical training in a clinical and health psychology department, specialising in oncology. I moved from having no experience of providing therapy to patients with cancer to this becoming my daily job. As part of my role I now work closely with CNSs. This ranges from informal contact, contact regarding patients and adhoc supervision. Additionally, I am now responsible for the psychological input into a newly formed MDT for Cancer of Unknown Primary; an area in which prognosis is often extremely poor. As part of my role I am developing a supervision group for three nurses (including one CNS) as well as developing and delivering training. My understanding of the roles of CNSs has therefore moved from the unknown, to an understanding gained from my interview experiences and now to a more personal and holistic understanding gained from developing working relationships with them. I have the experience of providing therapy for patients with cancer, four of whom

became acutely unwell and died whilst I was working with them. This has been a very challenging experience and I have found myself reflecting about the role of clinical psychology in this setting. These experiences of working with patients have made me reflect much more on the provision of psychological support to patients with cancer. I have found it particularly sad when thinking about those patients who leave behind partners and children. As I have gained more experience throughout the year, whilst at the same time as analysing my data, I have noticed myself resonating with some of the experiences that my participants shared with me. It was particularly noticeable following the completion of data analysis when I saw the similarities in my own experiences and those of the participants of the research interviews. I experienced similar emotional responses such as feeling sad when young people die, but also of having to negotiate differing agendas in my work such as those of the referrer, ward, patient, family, clinical psychology service, and my personal agenda. This has shaped my discussion in my research supervision and been noted in my research diary. Throughout the process I have continually reflected on my beliefs and assumptions, as well as recorded these after each interview. I have tried to stay close to my participants' experiences, the worlds in which they are immersed, and in their sharing with me.

CHAPTER THREE

Results

This chapter begins with an overview of the research participants followed by pen portraits that provide contextual information about each person. This leads into a summary of participants' accounts of what they do in practice in their day to day role, in order for the results to be set in context. A graphical representation of the overall group analysis is presented followed by a detailed description of the key themes and sub themes that emerged. Interview extracts will be used to illustrate these themes and the experiential accounts of the participants working as CNSs in oncology, providing psychological support to patients and families.

Participants

Eight CNSs were interviewed about their experiences of being a CNS in oncology and of providing psychological support to patients (and their families) with cancer. All participants had previously worked as nurses in many other specialties such a renal, gynaecology, oncology and surgery. They had worked in outpatient and inpatient settings and all had experience of overseeing ward-based or outpatient care. Their ages ranged between early forties to late fifties, with the most common being early fifties. Participants had been in their roles for between three and fourteen years, and for some this was their first CNS position. For others, they had worked as a CNS in a different speciality. All participants had received clinical supervision during their level 2 skills training; the majority of the participants still received clinical supervision from a clinical psychologist. Of those who did not, this was due to limited clinical psychology capacity. Participants were recruited from four NHS trusts. Each participant was given a pseudonym. To preserve anonymity, care has been taken in the details contained in the following pen portraits and a demographics table is not included.

Pen Portraits

Leanne

Leanne has worked as a nurse for over twenty five years across a number of specialities. She has been in her current role for less than five years. Leanne works with patients from when a cancer is suspected. She spoke of the importance of building trusting relationships with patients and does this through a variety of means such as text message, telephone, email and face to face. Leanne found it difficult to describe what the term psychological support meant to her. She explained that her work includes helping patients in extreme distress, supporting families, helping people understand what cancer means to them and dispelling myths about cancer. When talking about her role she described offering a range of support including problem solving, "talking and listening" reassurance giving, help with decision making, provision of information, understanding the impact of cancer, crisis management and "seeing through treatment". Leanne spoke of six case examples including her work with a patient in extreme distress for whom there were no more treatment options. She was persistent in trying to engage this patient and this involved "spending time with her". She was able to understand their distress and enabled the patient to begin to talk about these difficulties. Leanne feels that "sometimes you have to unpick things to understand" and highlighted the importance of seeing beneath overt behaviours. She talked of the sadness and difficulty in doing the role and provided a second case example of working with a young girl with a palliative diagnosis. The patient had a young daughter and her work included preparing for after the patient's death. She spoke of the balance between feelings of privilege and sadness, as well as the loss experienced when you know patients well. Leanne spoke of the need to have support from her team and from supervision but sometimes takes the emotional impact of work home. Leanne began and ended the interview with statements about the importance of psychological support for patients and the close relationship between physical and emotional well-being. She articulated that the provision of psychological support is an integral part of her role. She spoke of valuing supervision from a clinical psychologist when available and finds it challenging when this is not.

As this was my first interview, I felt relieved that Leanne had agreed to take part. I was keen to capture a comprehensive account of her experiences and was aware of my anxiety and my desire for it to go well. I have wondered whether this impacted on my ability to 'listen well'

to Leanne's accounts and affected the depth to which topics were discussed. I had to decide when to move on and when to stay with a certain topic. In later interviews I felt more able to prompt and encourage elaboration and gain a greater depth of understanding. In this first interview I moved on from topics more quickly than in the interviews that followed. The case examples are slightly less in-depth than other interviews, and this may have resulted from my interviewing style.

Jackie

Jackie has worked as a nurse for more than twenty five years and became a CNS over five years ago. The role of a CNS appealed to her because of the way she felt she could work more closely with patients and encourage service development. Jackie views the role of the CNS as a "centre point" within multidisciplinary teams. She enjoys developing long-term relationships with patients and their families and works with them right through from before diagnosis. Working within a supportive and "good" team is very important to her. The support she offers is varied and includes: decision making; problem solving; supporting her team; providing emotional support to patients; and information giving. She uses a variety of communication means but feels that working face to face is most effective. Jackie spoke of six case examples. Firstly, working with a young patient to make complex treatment decisions and who unfortunately died shortly after. She spoke of the sadness she experienced and of the support she sought from the clinical psychologist. She also spoke at length of her work with a patient requiring very invasive and life changing surgery that she supported emotionally through treatment. Jackie is extremely enthusiastic about her role and talked about the joy but also distress she experiences. She feels a pivotal point in the MDTs in which she works but struggles to define the role. Jackie wanted to participate in the study because of the insight it might give into the needs of both patients and staff. She was keen to talk, however we started late as she had urgent calls to make. I was aware that the interview could have gone on for much longer but due to commitments we finished at the planned time. I experienced Jackie as extremely enthusiastic and keen to protect and encourage the team in which she works.

Rachel

Rachel has always been interested in psychological care and has worked in a variety of roles within healthcare. She described her role as including counselling, listening, providing support, breaking bad news and developing longstanding relationships with patients. She was motivated to take part in the study because of her interest in psychology and feels committed to service development. One of the reasons she enjoys her role is because of the good outcomes her patients often have. She described having changed in both her personal and professional life as a result of her work. She has found it challenging to learn the limitations of her role and accept that she cannot support everyone. She spoke of the privilege she feels in building close relationships with some patients. She discussed five patients during the interview but focused on two at length. She described the sadness and distress she experienced when working with a patient and family who she developed a very close relationship with. She spoke of crying with the family as the patient's condition deteriorated but also how her emotional responses have changed as she has become more experienced. Secondly, she spoke of how rewarding the work is when outcomes are objective and tangible and described a patient with whom she built a good relationship. I experienced Rachel as very keen to focus on the psychological elements of her role and was eager to explain her skills to me.

Marilyn

Marilyn was intrigued by this study because of the continual debate about the role of the CNS in oncology. She was keen to participate in order for the results to be used as an added resource. She has worked as a CNS in oncology for more than five years and enjoys the variety of the role. She spoke of six case examples. She talked about the longstanding relationships she develops with patients and the way she follows patients throughout their experience of cancer. In particular, she spoke of a patient who she has known for years and who expressed their value of her support. She feels particularly sad when patients die yet feels privileged to have supported them; at these times she utilises support herself. She spoke of the need to hold all of her patients in mind and feels guilty when some patients impact her more than others. In managing this she remembers patients in her prayers and spoke of how crying can feel therapeutic. She discussed finding it challenging to support patients with a history of mental health difficulties. She feels strongly that more clinical

psychology provision is needed, in order for adequate supervision and for seeing complex patients. She spoke of the importance of 'being with' patients and feels that a large part of psychological support is providing time and space for patients. In contrast, she described feeling anxious when she sees no objective benefit of her work. Marilyn was very keen to talk about the emotional impact of her experiences and at times seemed to use the interview as active reflection on the work that she does. She feels the CNS is at the heart of patient care and that a core part of her role is to see patients as a whole, encompassing the emotional as well as physical. She struggles to define her role and feels that it is difficult to quantify. I experienced Marilyn as very reflective and keen to convey the impact of her experiences to me.

Claire

Claire feels like she has developed in her role over the last few years and particularly since doing the level 2 psychological skills course. She therefore wanted to take part in the study and was intrigued to know the results. She feels more equipped to support patients emotionally and psychologically. Claire feels she has learnt through her first experience of supervision from a clinical psychologist. She values being able to share the impact of her work with others and gaining reassurance. She finds it challenging when young patients die and values support in this. She talked about nine case examples which included supporting a patient who had an 'extreme' reaction to their diagnosis of cancer. She described the helplessness she felt in providing this support and the questions she still has about what happened to the patient after their care was transferred elsewhere. She described how patients can rely on her and ask her to be available to them throughout their care. One example is of a patient she had to unexpectedly give bad news to, and the guilt she felt after doing this. Claire was one of the few participants who talked in detail about her use of the skills offered in the level 2 course. She feels that it is important to provide holistic care that focuses on physical, emotional and psychological needs and feels that if as a CNS she does not do this, no-one else will fill this gap. She finds it hard to separate physical and emotional care, believing that the CNS is vital in their integration. Claire seemed really keen to portray the breadth of her role, as well as the way she had utilised the level 2 skills.

Sarah

Sarah was keen to participate as she felt it would be of value to the service. She has worked as a general nurse across numerous specialities and gradually developed an interest in oncology. She has always wanted to be involved in the holistic care of patient's not just physical treatment. She described finding the role stressful at times, particularly as she is the first point of call and feels responsible to provide for the patient when there is no-one else to undertake tasks. She talked about seven case examples. She spoke at length about a patient who found it difficult to acknowledge that they had cancer and the support she offered the patient and their partner. She found this difficult at times, as whilst she knew it was important to offer the patient time and space to explore their feelings, she felt drawn to offer practical support and referred to 'being a nurse'. She finds it challenging tolerating the uncertainty, when she builds longstanding relationships with patients and must support them when they relapse. Tolerating this uncertainty is something she finds distressing, and particularly the impact that this has on patients' families. She values the support from her CNS colleagues and feels this is essential in managing to continue in the role. Over time she feels that her role has become more diverse and there are increasing expectations on her which she feels take her away from the patient care that she is committed to. Sarah was really enthusiastic about her role but this interview felt more rushed than others, and she was made reference to the other jobs she had to complete after we had finished.

Judith

Judith is an experienced CNS and has worked across many clinical settings. She enjoys the service development side of her role but her main focus is on supporting patients' emotional wellbeing. She is keen to raise the priority of psychological support within her MDT but finds this challenging and experiences conflicting priorities. She feels experienced in sharing bad news with patients but finds this more difficult when they are younger. She feels that the impact of this role is distinctly different from previous nursing roles due to the way she sees patients as whole people rather than patients whom you know relatively little about. She found it hard to articulate what psychological support meant to her but tried to think about the support she needs in her own life, for example people to listen to her. She has learnt through experience and values the use of her intuition. She feels more comfortable in herself now which she feels impacts on the way she is in her work providing psychological support.

She found it difficult to bring specific case examples to mind and spoke of six with limited detail. These included: breaking bad news to a patient; working with a very anxious patient and offering strategies to manage this; giving a young boy a palliative diagnosis; finding it distressing supporting a young patient and children for whom there was limited service provision available; and dealing with impasse in her work. She spoke of being an advocate for patients within medical teams and ensuring their psychological support needs are met as fully as possible. She is passionate about helping patients and professionals see the relationship between emotional and physical needs. It seemed clear to me that she cares for consistently meeting the psychological needs of patients in a physical health setting.

Anne

Anne was motivated to participate in the research as she gets satisfaction out of providing psychological support and was keen to hear others' experiences of being a CNS in oncology. Anne is very experienced in the area of oncology and feels that much of her work involves "being with" patients rather than using specific interventions or tools. She values the longstanding relationships she builds with patients. She enjoys the autonomy she has and the way she can give uninterrupted time to her patients; she contrasted this with her experiences of ward work. She spoke of six case examples. These included supporting a patient who was dying and working with them and their partner in their final week of life. She found this work particularly distressing as she saw their "lives shattered" and explained that this was more difficult because she knew the family so well. Anne feels one of the things that helps her tolerate the emotional impact of the work is being able to make a difference in patients' lives. She also spoke of her support to a patient with a very complex illness and complications from their treatment. Whilst she felt pleased she could support this patient, at times she felt overwhelmed with sadness at the extent of the challenges they faced. She talked about the range of emotions she felt in doing this work and the support she drew upon from supervision and peers. She explained that she loves being the person who sees the patient throughout and who knows them well; she feels this is a unique aspect of her role and is what gives her most satisfaction. She most often draws on ad hoc support from her peers and uses this as a place to share her emotions so that they are less likely to impact her at home. She feels she benefits from supervision but places more value on this ad hoc peer support as it feels more available to her. I was struck by the way Anne seemed committed to her patients' well-being.

Summary

All participants came from a nursing background and had an average of six years' experience in the role. For all participants, psychological support was described as an essential part of their role yet it was difficult for them to identity and articulate what psychological support meant to them. At times it was also difficult to distinguish when participants were talking about psychological support specifically as many viewed this as an inseparable part of their role. They use multiple forms of communication (e.g. face to face, text, email and telephone) in their work with patients which differs from what the traditional therapeutic approaches might advocate. The helping techniques described by participants were varied and included: problem solving; anxiety management strategies; providing a place for patients to talk about their difficulties; offering practical support; liaison with other services; family support; CBT based strategies such as use of thought and behaviour diaries; relaxation; treatment coordination; and psychological support to patients during clinic attendance. Participants described being faced with the distress of patients every day and at times this impacts them both in and outside of work. Participants spoke about a variety of case examples and those not outlined in detail were concerned with the following areas: family support; supporting other staff; drawing on support from the clinical psychologist; helping patients with decision making; practical and social support; support after diagnosis; patients with whom it is challenging to build relationships with; the death of patients; using skills from the level 2 psychological skills course; anxiety management; managing patients when they are angry; working with patients post treatment; and managing patients who become 'dependent'.

Emergent Themes: Professional and Phenomenological

Having identified some unique details about each individual participant and described the specific characteristics of the sample, I will now provide a sense of participants' accounts of what their role entails in practice. This is important as there have been many changes to the general CNS role over the last ten years including the implementation of the level 2 psychological skills course in the last three years. As such, it is important to outline participants' constructions of what they do and with whom, in order to provide a context for the phenomenological results and how these might be understood.

Professional and Practice-based themes:

1. Patient contact

Participants described one of the main aspects of their role as being in contact with patients through ad hoc responses to telephone calls or emails. They spend much of their time in nurse or doctor led clinics to which patients attend. They also described arranging individual sessions with patients who require more support and this is often psychological support. Participants are also in contact on both a planned and ad hoc basis with patients' families. On occasion family members call in to see them, and at times they are in contact by telephone. This contact takes place either face to face or through use of telephone, text or email. This can be thought about in two ways.

1a. Content of Contact

When describing the content of their contact with patients, participants described listening, communicating empathy and building relationships with patients over time. Some participants described the use of psychological tools such as behavioural activation diaries and other CBT based strategies. Many participants talked about their contact with patients focusing on 'being with them' and providing a supportive space. They also spoke of helping patients with complex decision making and in managing their treatment, both physically and emotionally. What became clear from the interviews was that it was difficult for participants to distinguish psychological support as a separate and distinct part of their role. They also struggled to provide a definition of what psychological support meant to them. As such, these results draw upon both the general and psychological aspects of their work.

1b. Function of contact

Participants described the function of their contact as providing continuity and security for patients. They spoke of developing a good knowledge of patients and as a consequence patients feel that they are known within the health system. They are seen as people, not just a medical diagnosis. They also discussed their role in helping patients manage their emotions and cope with diagnosis and treatment. Another function of contact relates to the patients' families.

2. Joint Working and Administration

Participants work with other professionals including CNSs and doctors in order to identify the need for psychological support. They described either taking this on themselves or

supporting others in this role. They also spoke of advocating for the patient and communicating the patient's needs to other professionals. All research participants hand patients over to palliative care teams when they require end of life care, yet they still work with patients who have a palliative diagnosis, patients for whom there is no cure. So whilst there is some division in the provision of medical care, participants have roles in the supporting patients at the end of life. Participants also described the administrative elements to their role. This involves liaison with other health professionals including external professionals such as hospices and social care, helping patients navigate their physical treatment and making sure patients' treatment is well coordinated.

3. Receiving Support

Participants described receiving support from their peers on an ad hoc basis. At times this serves as a means to check in with others who understand the role and as a way of gaining reassurance about their actions. They also spoke of sharing the emotional impact of the work with their peers. Participants also described utilising the support of clinical psychologists through group supervision and on an ad hoc basis, gaining reassurance and advice.

4. Other

Participants spoke briefly about other areas of involvement that contributed to their role such as the value of mandatory training, continuing professional development (CPD) and being involved in peer review and service evaluation. However, this was not the main focus of the interviews.

Phenomenological Results:

Having summarised how participants described their day to day role, including the provision of psychological support, I will now outline the themes that emerged from a phenomenological analysis of the data. Four key themes that emerged were:

'The everyday experience'
'The impact of working with patients'
'Understanding and working out the role'
'*Needing recognition and support'*

In addition there were numerous sub-themes within these. What also emerged were two overarching themes *'ambivalence'* and *'uncertainty'* and these will be reflected on once the four key themes have been presented. The range of themes is graphically demonstrated in the figure below.
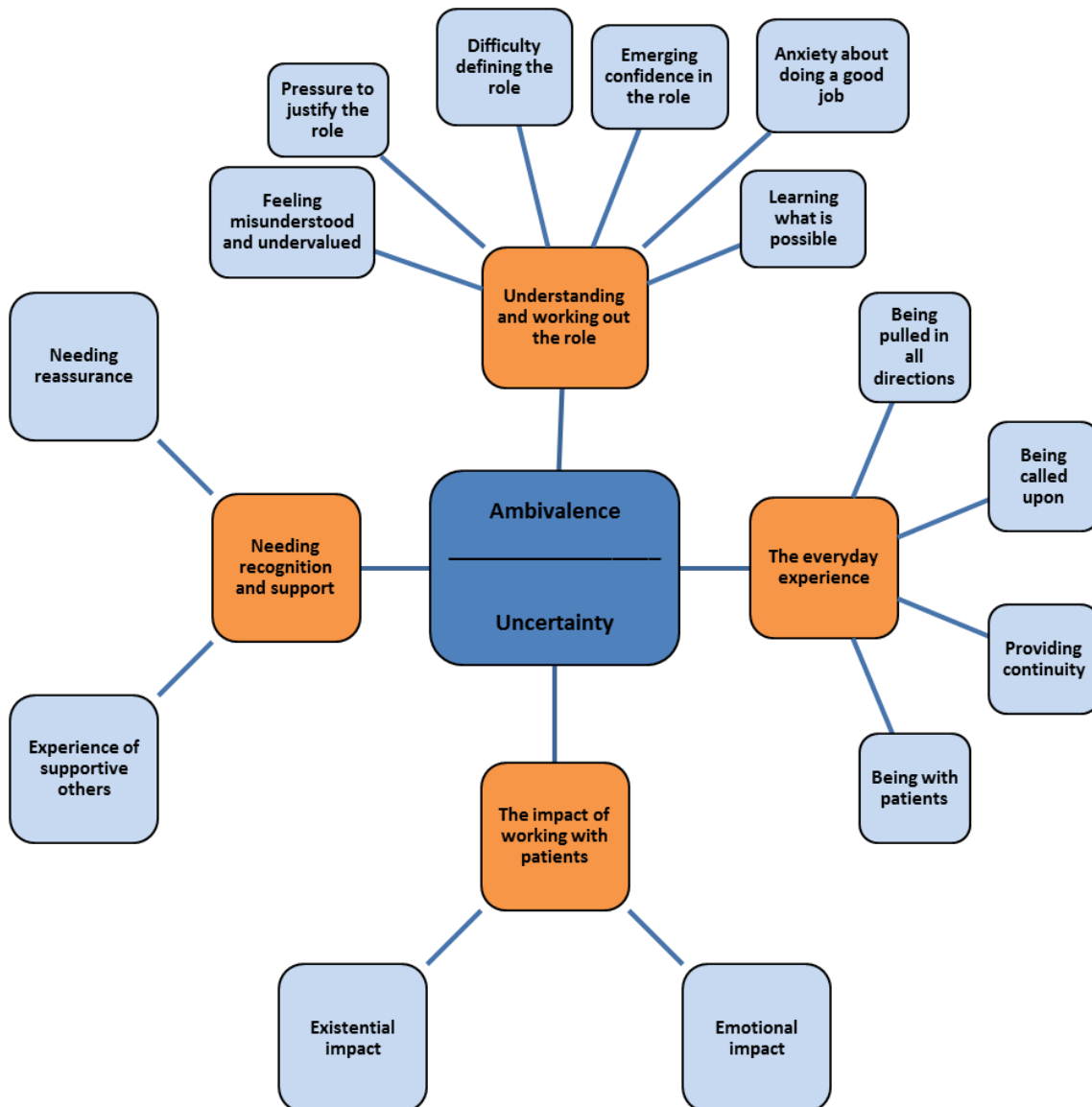

Figure 2: Graphical Representation of themes

I shall now explore these using the words of the research participants, and a critical discussion will be covered in the following chapter.

Key Theme 1: The everyday experience

This first key theme captured the experiences of participants in their day to day role including the demands that are placed upon them. It encapsulated participants' experiences of the external tasks and demands that they face in being a CNS in oncology and particularly offering psychological support to patients. It also described a sense of the impact that these have on participants' experiences.

Being pulled in all directions

Many of the research participants described themselves as being on the 'front line' in caring for patients with cancer. This is a rich metaphor that conveys emotional undertones of the stress and demand of offering patient care; which at times might feel like being in battle. Many of the participants described experiencing conflicting priorities. When there are many agendas at stake including the priorities of the participant, the wider MDT, the oncology service, the NHS trust as well as the patient and their family they can feel pulled in all directions. There was a sense that these priorities can conflict with keeping the patient at the heart of the caring process. This means however, that participants feel pulled in all directions and this can drive an external need to manage the multiple demands of the role including the provision of psychological support:

> *'the trust have got demands on what I do my manager's got demands on what I do but although they're important in <u>my</u> priority list they come a little bit further down. I do them, but as long as I know the patients are sorted out and that is the most important things to me if I know they're getting everything they need, that's my priory without a shadow of a doubt' (Leanne, line 365).*

Claire highlighted feeling pulled in all directions throughout the course of each day. She gave an example of wanting to provide emotional and psychological support to a distressed patient, yet being in a busy clinic, in which her colleague was trying to limit the time given to this patient. Here Claire identified her central role in the MDT in providing psychological support that goes beyond the registrar's experience or ability. She also highlighted the

tension of limited time and resources. She first referred to the patient as 'he' and then to the registrar:

> *'it's very difficult because I'm conscious on one hand that he's very upset and emotional but I'm also conscious that it's a very busy clinic and the registrar wanted me in with him because he was trying to ... keep the consultation to a minimum because he can't really deal with those issues.' (Claire, line 170)*

Others also described that being pulled in all directions can lead to feeling guilty. Sarah described feeling guilty when unexpectedly needing to break bad news to a patient but not being able to spend more time with her as she had to prioritise the clinic she was due to be in:

> *'So then she was even more upset and I had to go down to clinic [...] I felt I'd given her this news and then I'm going off to clinic' (Sarah, line 490).*

Being called upon

This theme captured the way in which participants are available and responsive to their patients' needs and as a result, are often unpredictably called upon and their day is affected accordingly. There was a sense that Leanne experienced this as intrusive:

> *'I have certain clinics I need to be in, I have certain [...] meetings I need to be in but yeah it can all turn upside down if get a call from someone who needs urgent something or other <laughs> they take priority' (Leanne, line 351).*

For some participants, being available and meeting the demands of their patients was experienced as an inevitable and important part of their role. At times however, this can be experienced as frustrating:

> *'Yes, I think [...] it's frustrating the fact that we are a point of contact for ... the patients they know that we are there for them, although it's frustrating at times, it's a really... important part of my job that they have access to me ... they know that if they've got any issues they can give me a ring. So that's a really important thing' (Sarah, line 118).*

Yet they were also keen to explain that a patient having ready access to them was of great importance, even when it generates a measure of frustration.

Providing continuity

This theme captured the way that participants experience providing continuity to patients. Many participants described this as vital as they help patients navigate the experience of cancer and the input from the various health professionals that this requires. This subtheme relates to another theme *'emerging confidence in role'* in which participants described themselves as the 'heartbeat', the 'lynch pin' and playing a 'pivotal role'. Such comments stress how vital this relationship is and how it is experienced by the CNSs. Jackie described the benefit of knowing patients well and providing continuous care so that she becomes identified as a safe-base for patients and adapts their care accordingly:

> *'you know them so well, you are able to ... tailor it really a little bit more to ... you're able to prioritise a little bit more because they've been there before, so there are some things you don't need to go over as much again, you can say to them, we've got you through the treatment so it's doable, we'll get you through it, you don't have to go into the finer details about the treatment.' (Jackie, line 431).*

Anne elaborated on this and described her experience of enabling patients to more easily navigate their healthcare and the benefit of being known to patients who feel that someone already has knowledge about their situation:

> *'So just to have somebody that they know, that they don't have to tell that whole saga to ... they'll ring and say I need my appointment bringing forward or I'm worried about something and we can make that happen very easily.' (Anne, line 1228).*

Marilyn talked of the benefit of being in longstanding relationships with patients who she knows so well, and the way in which this means that patients feel they can trust her with their difficulties. There was a sense that this is not only beneficial to the patient, but an aspect of the task demands that Marilyn benefits from and feels 'fortunate' to be part of herself:

> *'In my job I can, I'm very fortunate because I meet people for a long time ... […] I get to know everything about them and I feel they do open up to me. (Marilyn, line 414)*

These comments lead into another subtheme of *'being with patients.'*

Being with patients

This theme expressed the potentially therapeutic aspect of the CNS role in being with patients. Most of the participants described their enjoyment and fulfilment of coming alongside and being with patients. Some participants described the importance of being with patients which is often through 'listening' in depth to patients. Despite this, participants sometimes experienced a tension between the pressure to offer advice or problem solve alongside their sense that 'psychological' is something more and that offering advice is not always helpful:

> *'it's just having somebody there that can listen to you ... your concerns, your problems, if I can offer advice then I will but often psychologically you can't always offer advice' (Claire, line 403).*

Some participants talked explicitly of the importance of being with patients as opposed to identifying specific psychological skills, tools or techniques. There was a sense that some feel the pressure to identify the techniques they feel 'should' form part of their psychological support. Anne referred specifically to the use of 'being with' and 'intuition' in her work:

> *'I think a lot of it is being there with .. I would say that's the biggest thing, so it's not about using any kind of specific interventions or different theories or .. I mean I think it's .. for me and I guess I've been ... I've worked in Oncology for 13 years, so a lot of it is quite intuitive.' (Anne, line 66)*

Other participants also communicated this experience of being with patients, yet did not articulate this explicitly and undervalued the benefit to patients, of being with them in distress. Leanne questioned the relational impact of her work and the value of being with patients:

> *'I thought well she's given me permission I'll keep coming back and I just kind of spent time with her really we didn't necessarily talk about her cancer when I originally started going back, I'm not sure how much it did just being and not doing any sort of psychological tools' (Leanne, line 650)*

Overall, there was a sense that participants were often describing 'being with' patients, yet in the interviews found it difficult to articulate this, other than in the extracts mentioned above. It was as if this was an aspect they found it difficult to put into words.

Key Theme 2: The impact of working with patients

This cluster of themes captured that, central to participants' experiences of being CNSs in oncology, is the work that they do with patients. As a result of working closely with patients and their families including providing psychological support, they must face working with people who have a challenge to their health, who at times suffer, and who might die. It captured a range of emotional responses and includes the difficult experiences and feelings that are balanced by the sense that it is worthwhile. This theme also captured the experiences of the profound existential questions that doing this work involves.

Emotional impact

It clearly emerged that there is a huge emotional impact in being a CNS in oncology and providing psychological support to patients. This emotional impact is so significant that it resulted in five subthemes in order to capture the experience of the participants. There was a wide range of emotional phenomena that emerged and is captured through the themes of: *Sadness, Burden of Caring and Being with, Anger and Frustration, and Reward and Privilege.*

Sadness

This theme encapsulated the sadness that all participants experience at times, in the course of doing their work. This sadness is related to participants' experiences of working with patients who are facing difficult issues of life, death and health. Participants' experiences of sadness are influenced by aspects of the patient's own struggle and their relationship with the patients. They expressed these as *'Out of time'* and *'Knowing them well':*

    Out of time

Many participants reported experiencing sadness and distress when patients become ill or die at a young age. This is the experience of a form of objective sadness in which participants have a sense that there is a life course that people should live. When this does not happen it results in an increased emotional experience of that sadness. Dying at a young age is experienced as distressing because the participants feel that the patient has so much more to lose:

'My youngest patient was 29 when I met them. And that was quite distressing because it was so sudden .. so unexpected ...such a happy future to look forward to, a lot to live for. So that was quite distressing' (Rachel, line 828).

Related to this is the impact loss has on the patient's family, made even more difficult when they have young or teenage children. Interestingly both Rachel and Leanne used the qualifying term "quite" and there was a sense that this served to minimise the emotional impact and distress they experienced. This was significant in that both participants showed visible signs of sadness and distress as they talked suggesting that it was hard for them to express the distress they experienced:

'there are days when it is quite hard, I mean obviously the kind of patients we deal with, if you get three or four patients that are very distressed or upset or got lots of problems and… we've got quite a few young patients that are terminal at the moment, so dealing with them and their children and their partners and it's quite difficult' (Leanne, line 291).

Knowing them well

This theme captured the impact of the therapeutic relationship that participants described building with patients. There was a sense that knowing patients well causes participants to experience a greater level of sadness. Participants also expressed a depth of sadness that is experienced when these relationships come to an end. This theme captured the way that when participants come alongside patients and spend time 'being with' them, it opens them to the idea and experience of suffering. Participants enter into the suffering of their patients through the impact of loss of life and health. The patients they come to know so well, add to their emotional involvement and the experience that participants see an essential part of their role:

'it's heart-breaking really, those patients, when you see them because you get to know them so well, and their families and their circumstances and ... you know it's very .. it is, it's sad.' (Sarah, line 454).

In knowing patients well, participants come closer to the experiences of both patients and their families. Leanne expressed her ability to be real with one patient, and highlighted that some patients may so touch them, that they cry and reveal their emotion. In this case the patient found this helpful because it gave them a sense of another person sharing in their

sadness. This extract also suggested that Leanne feels that it is not usually acceptable to cry with patients but that the longstanding relationship was an extenuating circumstance. The use of laughter in the following quote engenders a shared experience:

> *'about three weeks before she died she came in to see me and said do you know what I've done? I've I've written down all of her favourite food and […] my gravy recipe because <laughs> coz she only likes my gravy… and that set me straight off I don't even know why that made me cry and I said <silly voice> will you stop it, and then I said look what you're doing and she started laughing and she said err she was like awww is that that's really, so we were sat holding hands and she had a cry and she said I I know I'm going to die and I need I need… somebody to know everything about her, so yeah, I did have a cry that day. But I'd known, I'd got to know her so well.' (Leanne, line 733).*

The burden of caring and being with

This theme identified the participants' experiences of finding it difficult to bear the emotional impact of their work at times. Whilst they view the patient work as a central part of their role, which can involve being with patients and coming alongside them as they experience difficult emotions, participants can also experience that it becomes a burden:

> **'***It was really hard, you know it's a sad .. sad.. story and it's hard sometimes. It's hard to know you're doing the right things it's hard to carry that weight.' (Jackie, line 1039).*

This felt experience of burden relates directly to the connection and relationship participants build with patients in the act of 'being with,' and coming alongside them through offering psychological support. Here Jackie repeated the word 'hard' four times in one short section. This next quote represents this burden and captures that at times the emotional impact can be overwhelming:

> *'I think that was a very traumatic time for her and I found it quite emotional but .. I do put my heart on my sleeves with patients and I empathise and I say, this must be so hard for you, what you're telling me .. and I try to do everything right and say the right things and […] come away but there's times when I've […]put my head in my hands and thought this is just so sad.' (Marilyn, line 236).*

For others, the cost of this work can deplete their own resources and become a burden. This varies from patient to patient:

> *'sometimes we have very difficult patients that are very emotionally challenging, very emotionally draining <long pause>' (Jackie, line 104).*

This sense of burden can extend beyond the work environment and is shown in participants' struggle to leave the impact of work, at work. Leanne has also learnt her own coping mechanisms and strategies:

> *'it's easy to take them, things home and worry about certain patients and certain people get to you more than others and, [...] the emotions of what's happened during the day sometimes, my partner knows that if I go home and say right I'm going for a shower... just leave me alone for half an hour and then I'm alright <laughs> so people gauge you don't they and they know how to deal with you' (Leanne, line 332).*

Similarly, personal circumstances can influence the experience of burden and Claire expressed that it can be influenced not only by being a CNS, but also by being human. This requires being able to navigate the complexities of life, yet at times a sense of work being a burden is inevitable:

> *'at the end of the day you're doing a job but you're human. I've got family, I've got kids .. I've got elderly parents, I've got this that and the other and .. sometimes things do get on top of you' (Marilyn, line 659).*

It highlighted the close relationship between the personal and the professional particularly in a role that involves caring for others.

Anger and Frustration

In some interviews I experienced a feeling of frustration and anger that came from the participants' phenomenological experience of anger. However when I examined the text they did not state this anywhere in a direct way. I felt that I was picking up the unspoken but very real lived phenomenological experience. This theme therefore captured this experience of anger and frustration that things can happen to people so young, and that these things can happen to anyone at all. This comes with a sense of unfairness, and of emotional distress, that life can be so difficult and seemingly unfair for some people. It is part of their emotional response to the existential challenge of death and suffering. Anger specifically, was less

obviously present in the textual accounts of participants than some of the other emotional responses, however, my sense and understanding of all participants, meant that it felt that the accounts of these two participants helps describe the essence of other participants experiences. In the following quote, Judith expressed her anger and frustration at the unfairness of the situation she was facing; that someone so young is able to die. It also described the anger and frustration she felt at the limited support available. She raised her voice in this extract and her intonation suggested the strength of her feeling. She went on to discuss how she was compelled to continue and try and find support for this patient suggesting that her anger and frustration motivated her to take action make some change in a difficult situation:

> '*Oh God, this is just rubbish! She's so young ... she's got a cancer that she knows she's going to die from and she wants some practical help. Her husband's having an operation [...] but it had been delayed before so he didn't want to delay it again. And all they said was ... "what about a family member, her family members are going to have to help." That was what I got from social work. It's frustrating.' (Judith, line 828).*

For both participants there was also a feeling such things should not happen to anyone, a sense of anger directed at fate. In the following extract Anne raised her voice and lifted her hands as she said "oh my God" which signalled the anger she felt:

> '*there's a lot of frustration within that because, some days you just think, oh my God, can nothing go right for this poor woman [...] and the guy that I spoke about earlier who has now got metastatic disease, I just think ... everything is going to go wrong with him.' (Anne, line 1130).*

Reward and Privilege

This theme located the way participants feel when they have done a good job and made a difference in someone's life. They experience this as rewarding. In contrast to when participants feel anxious when they are unsure of the impact of their work, the experience of 'knowing' they have done a good job is felt very positively. Marilyn repeated the word love four times in the following quote, demonstrating the extent of her emotion and as she spoke she was smiling and visibly expressing her emotion:

'I love the patient group, [...]I meet some fantastic people. Some families who are just amazing and... I love the feeling of doing some good and I think I do do good. And I just feel that .. when I can get my head set right and I do it I do it really 90% of the time probably, I can come away from work thinking you've done good today. I love it, I love my job.' (Marilyn, line 712).

At times this is when they have seen tangible change in the patient:

'I found it very very rewarding. Extremely rewarding because we have moved her forward and I'm doing my job. That's what I'm there to do, the really complex needs. And I suppose, selfishly, I thrive on that' (Jackie, line 876).

And at times this is when they receive feedback and know that they have made a difference however small:

'I sat with a lady the other day who's now going to die in the next number of weeks and she said how can I sit here, I feel like I'm waiting for God! And after about an hour's consultation she said to me, you know I feel so much better. That's what it's about. That's all that matters, at the end of it all.' (Jackie, line 1200).

Others experience this in the context of building relationships and really connecting with patients in a way that allows them to offer what they consider to be good support:

'you're building a relationship up so there's that mutual kind of .. getting to know each other and ... trust and they feel that they can open up and you're ... as you're getting to know the patient, you're able to pick up on cues and .. so you're working together and it feels very collaborative [...] Those are the patients that [...] feel .. that you've done a really good job with. That you have got them, got them through it and ... you've been able to support them in whichever way they've needed' (Sarah, line 682).

Many participants described the privileged of being able to draw alongside patients' journeys, and being allowed to share their intimate and personal experiences with them:

'I feel privileged, every day to do the job, I feel privileged to have that .. <u>involvement</u> with patients that are very personal .. intimate .. I mean it's physically intimate, obviously because of the nature of the disease but emotionally, intimate relationship with the patient.' (Rachel, line 182).

There seemed to be no difference in terms of age of the patient. The privilege described is about patients moving across the boundaries they have in place and sharing personal experiences with CNSs:

'I have to say I feel quite privileged really because they do share a lot of information with me that…they might not share with other people in the family and they don't share with friends and, very personal information because of the kind of, surgeries and treatments we do… some of the older patients, and and the younger ones don't necessarily talk about that with anyone so sometimes you know it's quite a privileged position to be in that they will actually share information with you […] … is probably the biggest thing, although at times it can be quite, stressful and difficult <laughs>' (Leanne, line 267).

Despite the difficult emotions participants experience, they also feel satisfaction, reward and privilege as they draw closer to patients and see the impact of their work.

Existential impact

Given the central focus on patients in the CNS role, this theme described their experience of facing existential questions and issues. These clearly emerge for the participants as they work with patients and enter into something of their emotional experience. The participants work with patients facing issues of life, death and suffering. This has an impact on their existential outlook and the way they re-evaluate their own self-experience and existential issues of living. This highlights the impact on participants, as people not just as CNSs in a professional role. Four specific subthemes emerged including: 'Facing an unknown prognosis', 'Facing the death of a patient', 'Gratitude' and 'Re-evaluating life.'

Facing an unknown prognosis

This subtheme captured participants' experiences of being a person with limited options to control uncertain outcomes, in this case the outcome of illness. It highlighted the difficult aspect of their experiences in working with people with whom they don't know what will happen:

'I've had one patient in particular who, she's relapsed several times and that is very .. very difficult because you feel that you're just getting her through it … and each time she's having treatment it's getting much more harder … for her to cope with the treatment and to cope with what's going on and then cope … and then that, finishing the treatment and then you can't say to her, this is it, you've finished, well done, get on with your normal life. We're having to monitor her and she knows that she's

relapsed before and it might well happen again. So yes, those ... that group of patients it is very .. it's challenging, can be quite distressing really to look after them because you get the phone calls from them, I found a lump or .. I've not been very well for a few weeks and you just have that niggly concern that right, here we go again kind of thing. And it's awful for them' (Sarah, line 409).

Facing the death of a patient

One of the most challenging aspects of the CNSs' work is when facing endings. Endings come in different forms when: the need for their input is no longer required; the patient receives alternative treatment elsewhere; they are moved to palliative care in another context; or that the patient dies. Many participants described finding endings difficult. Facing endings is experienced firstly when there is a break in an ongoing relationship because of the way patients' care is organised and the transition to palliative care. The loss they face is felt much more particularly when they have built longstanding relationships with patients. Rachel's real investment in her patient was shown in her repetition of "you want to be there". Participants experience a desire to continue supporting the patient, despite their potential deterioration and death and an all too human reluctance to let go, captured in the use of the word 'completely':

> *'one of the frustrating aspects of our role is when we hand over to palliative care, so I may have had a relationship for years with a patient but they once they need palliative care, we hand over completely. It's a complete break and that can be hard. That can be hard because you have built up a relationship with somebody and you want to be there until the end. You do, you want to be there, whatever that end might be, you want to be there with them, to that end. But you can't be.'* (Rachel, line 833).

Anne described that one of the challenges of endings is facing the unknown, no longer knowing about the patient's care and wellbeing, and having to tolerate this uncertainty particularly in the context of having a relationship with the patient. She also described having to depend on others for information about the patient's ongoing care. Interestingly she qualified this by saying "*if it's somebody that you've built up a relationship with*" implying this is not the case with all of her patients:

> *'It can be quite difficult, I think if it's somebody that you've built up a relationship with you're wondering how they're doing and are they alright and then ... you just*

find out from the GP or whoever when they've died. If they're not in touch, the
community Macmillan team will sometimes keep in touch with us and tell us if
there's any issues but, yes I think for some patients, who we've been in touch with
for a long time, that can be quite difficult.' (Anne, line 999).

All participants described managing endings in different ways and Marilyn described that endings are made more manageable by gaining information about the patient from other care providers. This means she no longer needs to tolerate the uncertainty of not knowing about the patient's care and death after her own input has finished. For Marilyn this is a way of coping with the loss she has experienced and facilitates her in emotionally letting go:

'sometimes it is quite nice because the Palliative Care team […] let us know how
things went […] I've found that a comfort, I like to know that because it puts a
closing chapter on the end of that person's life.' (Marilyn, line 364).

Endings are also experienced when facing the death of a patient. Participants sometimes feel helpless and Sarah articulated that there is only so much you can do when faced with patients going through such difficult experiences; that as a CNS but also as a human, you are limited. There was a sense that participants must realise that they cannot always control the outcome for patients, and it is not always possible or appropriate to intervene in their emotional response to this:

'there was nothing that I could have said to have .. to have changed how she was
feeling at that point. It's just ... it's <u>horrendous</u> what she was going through and just
acknowledging that fact with her, I guess, that life isn't fair and .. it's all you can do
at that time, isn't it?' (Claire, 764).

Participants confront their limitations and accept that in some situations nothing they can say or do will change what they experience as a sad outcome. Yet despite this, Claire described her experience of a sharing of physical proximity with the patient, an embodied way of being and communicating care when words do not feel enough. In the following extract the relationship between the experience of facing endings and the theme articulating participants' anxiety about doing a good enough job can be seen:

'she sort of pulled herself together […] saying, "it's not fair, I don't want to die"
but .. you couldn't talk to her. What can you say in that position really? Whatever I
had said wouldn't make it .. you can't change anything .. I think that's a time you
feel it's difficult to say to somebody who's only young that we can't cure you from
this and if we give you treatment then it may prolong your life but it won't ... it might

not be that long. Because how do you come to terms with something like that? […]
it's like you carry on with your life then you're in a nightmare you can't get out of.. I
had to sort of accept at this stage that, I was there for her and I was sat close to
her.' (Claire, line 690).

Facing endings in their relationships with patients, either through transition of care or because of death is challenging as it means participants are brought closer to the reality of both life and death.

Gratitude

Whilst there are challenges faced in coming close to existential issues, participants also talked of the benefit of this. This theme captured that in coming face to face with the difficult experiences of the patients they work with participants experience a sense of gratitude for aspects of their own lives. Whilst they expressed a general gratitude for many areas of their personal life, Rachel highlighted her appreciation of health and feels that this underpins the whole of her personal life. She articulated a valuing of and desire for good health. She has seen the pervasive impact of a threat to health and the way in which there is little you can do to control this. She also expressed a helpful balance in explaining that the role also makes her see what she does not have in life but views this positively:

'I think it makes me very grateful for what I have .. […] in my personal life. It does
highlight what I don't have as well …but that's a balance […]a good balance. And I
think each day puts into perspective what to be grateful for .. particularly good
health. […]. you can have everything else in your life, but actually if you don't have
good health, everything else is affected by that one thing. You can have money, it
doesn't buy you good health … will it buy better or quicker healthcare, arguably .. it
doesn't buy you good health. You can have a really good happy relationship but if
haven't got good health, you can't enjoy that fully' (Rachel, line 215).

This experience of gratitude also relates to the process of re-evaluation that some go through as they carry out their work.

Re-evaluating life

Some participants also described the existential impact of the role in terms of 're-evaluating life'. They feel that coming close to the experience of others who are facing issues of life,

death, health and illness, and overall a disruption of their expected life course, has an impact on their own outlook on life. They also experience putting themselves in the place of their patient, and having a developing understanding that there is a fine line between 'being' and 'not being' the patient and this further impacts their evaluation on how they life their life. The introduction of the idea of God and spiritual beliefs suggests that this is another framework through which some participants look at their existence, causing them to ask important questions:

> *'being a CNS and being heavily involved in these patients has an impact on my day to day life. I take each day and I use it for what I can. I'm very much for that, in my home life and you know with family and my children, I do as much as I can with them, when I can .. and if there's something out there that we want to do, if we can afford to do it, I will just* push the boat *out so we can go and do it. Because I look at my patients and I think, there go I for the grace of God. You know, if God, or whoever whatever your spiritual beliefs are .. so I think it does have a big impact.' (Jackie, line 616).*

Rachel expressed the crossover between personal and professional lives and the way that these interact. She also highlighted that this re-evaluation is seen favourably and is beneficial to her personal life. Again, drawing together the experience of the patient and herself, she made the connection that her work in coming alongside patients with cancer is life-changing for both parties:

> **'***Very fortunate .. it's not me sat there in their chair. So it can give you a sense of grounding .. Constantly re-evaluating your own life and that helps, I think real emotion, making decisions in your personal life, doing this sort of professional life .. [...] I think grounding is a good word [...] I'm sure for the patients that have a cancer diagnosis, we say to them, this will change your life. So it's a life changing event in your life .. but I believe being a CNS is as well. Very much so.' (Rachel, line 170).*

The re-evaluation that participants experience brings together their experiences of both the professional and personal and highlights the crossover and lack of distinction between these.

Key Theme 3: Understanding and working out the role

This third key theme captured the way in which participants are working out a role as a CNS in oncology, within the organisational context in which they are situated. This theme takes account of the organisational context of their role and focuses on this broader context. Each participant had to negotiate their specific role identity in an oncology setting. Some participants referred directly to the on-going challenges of being in the ever-changing NHS context. Overall, this theme encapsulated how they work out their role in relation to this context. There is a sense throughout all these themes that this is an anxiety provoking experience. Participants experience the need to tolerate the uncertainty that runs throughout their role encompassed by seven subthemes: 'Feeling misunderstood & undervalued', 'Feeling a pressure to justify the role', 'The difficulty defining the role', 'Emerging confidence in the role', 'Learning what is possible' and 'Anxiety about doing a good job'.

Feeling misunderstood & undervalued

This theme identified participants' feelings that others do not understand what their role encompasses. In particular the variety of tasks that they undertake leaves them feeling unappreciated and undervalued. They feel undervalued as nurses who engage in many different tasks including medical, psychological and those related to other professions such as social work. Jackie referred specifically to feeling misunderstood and there was a sense that she felt she should be valued because of the variety of work she undertakes:

> *'and I truly, if I'm absolutely honest, I don't think management really see all the different roles that we do and actually appreciate what it is the CNS teams do.' (Jackie, line 1173).*

In relation to the psychological support they offer, Claire described that this is not only misunderstood but seems to also be downplayed and undervalued. She feels that this is an important part of the role but that what it means to offer psychological support is not understood by others. When discussing the importance and value of offering psychological support to patients she said:

> *'people often say, I don't know what specialist nurses do and they think we're just there for a bit of tea and sympathy but it's not, it's far more than that.' (Claire, line 296).*

Related to this, other participants expressed the difficulties they face working in an organisation which is undergoing continual change and review at every level. Additionally, the provision of psychological support relates to mental health issues which are often seen as an undervalued element of illness. This is expressed in the following extract when Jackie said "oh, psychological support!" whilst rolling her eyes suggesting that this is undervalued by others. She also again reiterated the breadth of the role of the CNS:

> *'I think it's very challenging in the present NHS environment, I think when peoples' jobs are being questioned, bands are being looked at .. I think it's very hard for CNSs particularly because [...]people go, well <laughs> "CNS .. what do they do? Oh, psychological support!" I don't think people have any idea of what a CNS role really encompasses and the different hats you have to wear within that role.' (Jackie, line 1154).*

These extracts represent a complex picture of factors that can influence participants' experience of their identity as a CNS in oncology who offers psychological support to patients and is related to the following theme 'pressure to justify the role'.

Pressure to justify the role

Participants described feeling the pressure to justify their role. This is in part, due to a lack of knowledge about what they do in their role, but also related to the challenge of measuring the work that they do. They talked of feeling this pressure and whilst they do not identify its source specifically, they referred to the NHS as a whole. What is challenging for participants is the pressure they experience to measure and justify their work; to show demonstrable results. They described the need to justify their decision making, use of time and resources and experience this pressure in a very personal way:

> *'we're often asked as a CNS, "What do you do and what do you give?" [...] .. we've not given them any medicine, [...] .. but we've given them time .. allowed them to express and help deal with all ... come to terms with it. [...] .. in the NHS now they want results don't they, payment, results and I struggle with that sometimes you know to justify why I'm seeing somebody and why I'm ringing somebody.' (Judith, line 513).*

This extract also relates to the difficulty they experience in defining the role, particularly the psychological aspects.

The difficulty defining the role

As a result of 'pressure to justify the role', participants respond with their justifications but find this challenging. They described experiencing difficulty in trying to define the role that they do and what they offer to patients. They find it difficult to capture the work that they do for patients, particularly the psychological support that they offer. There is a sense that the work can be intangible. When talking about this Rachel said:

> *'it's a bit like your work, it's experiential it's qualitative, you can't measure it ...'*
> *(Rachel, line 762).*

Participants expressed a self-knowledge of the value of their role but this seemed tentative. One participant made reference to me and my work as a trainee clinical psychologist (i.e. not yet fully formed) as if I would be an ally and understand them more. It felt that they were seeking validation for their uncertainty about the role through me. In the context of feeling pressure to justify the role, participants experience a need to define what they do yet struggle to do this and to show others that they do a good job. There is also a sense in which participants feel defensive in the face of attack; that as a result of struggling to define, justify and tangibly measure what they do, they can feel attacked:

> *'but I think defining my role .. I know what I do ... and I know we do a good job .. but you'll never be able .. anybody to quantify it. Very hard. But that could be a lot of professions that have the same thing .. isn't it .. not ... but we just get picked on! We just get picked on a bit really! <laughs>' (Marilyn, line 1109).*

Emerging self-confidence in the role

Despite the challenges of working out and understanding their role, participants described an emerging self-identity, an increased confidence in their role, and a sense of the collective identity of the CNS in oncology. Whilst they experienced being misunderstood, undervalued and struggle to define their role, participants themselves still viewed themselves as playing a key role within the teams that they work, and as having an impact on the experience of patient even when others might not understand and value their role in the way they do themselves:

> *'the CNS is a really pivotal role and that's not just because it's me. I'm not just saying that because it's me and my team that do that. I think if you look at the patients and you talk to patients you can see it' (Jackie, line 1136).*

Despite the challenges they faced, participants hold strong beliefs about their value within MDTs through holding the patient at the forefront of their work. Research participants feel that they are at the centre of these teams, in which they coordinate and draw together all aspects of patient care. There is a sense that the functioning of the MDT would be compromised if they were not present and they feel pleased and proud of the job that they do. Rachel alluded to the uniqueness of the experiences of the CNS in oncology; that they maintain contact with and are a constant presence for patients throughout their treatment:

> *'I suppose we're a bit of a lynch pin really because we co-ordinate that patient's pathway and try and streamline it for them. So we're core members of the MDT, we attend the MDT meetings and as well as being the patient advocate, we have to be mindful of trust targets and all those budgetary considerations which are boring but necessary. But I think the CNS .. is <u>always acting</u> in the best interests of the patient. [...]the CNS is the one person that knows that patient throughout <u>the whole</u> of their pathway. Surgeons dip in and out, radiologists dip in and out .. the CNS is there right along, walking side by side in a sense.' (Rachel, line 795).*

The following quote highlights the tension and ambivalence that participants experience; whilst they have a degree of confidence in their role, this is tentative. There is a sense that in feeling defensive of their roles and worth, they still feel the need for approval from external others:

> *'I'm at the heart of that but I have got <u>so many</u> teams around me that I know that I'm not on my own and I'm at the heart of it but I spindle out' (Marilyn, line 1104).*

Overall, the research participants' confidence is still emerging and they seemed disappointed at not always being viewed by others as at the heart of teams in the way that they view themselves.

Learning what is possible

This theme captured the way that participants learn the extent of their role, and what is within their remit, particularly in relation to psychological support. Many participants specifically referred to their identity as a nurse and the role of a nurse in making things better. In order to work out and understand their role, participants have had to learn what is possible within their role as a CNS. This is also as a CNS who has done additional psychological skills training and who is incorporating this in their care with patients. Leanne commented that everyone involved in psychological care can face limitations; that however

qualified you are there are limits on your ability to 'make it better'. She also reflected on the idealised nature of being in healthcare: they feel the desire to heal. By being in an oncology setting and in offering psychological as well as physical care, this desire to heal is challenged. This theme captured the experience of participants recognising the limits, that everyone working with patients whether physically or psychologically must face at times:

> *'initially I used to think, I should be able to deal with everything "I should be able to make you better I'm a nurse" <laughing> whereas obviously, you can't <laughs> and even seeing a psychologist or a psychiatrist doesn't necessarily make it better <laughing> does it' (Leanne, line 630).*

When faced with providing psychological care, participants at times can feel helpless as the support they are offering is perhaps less tangible than the physical care they also offer. Sarah described feeling anxious about her ability to fix the patient and needing to tolerate the uncertainty that she may or may not be able to do this. Again she referred to her training and identity as a nurse and the way this impacts her focus, highlighting the way that at times she is drawn to the practical and tangible support, with measurable outcomes that she is used to offering:

> *'It's challenging, it's not easy .. from a nurse, you've very much into practical, well you're not sleeping, well let's look at things you can do to improve your sleep. So you're talking about the relaxation before you go to bed, the baths and this that and the other. Then you're talking about perhaps sleeping tablets, it's very practical things that you feel that you're offering. And then when they're talking about the crying all the time, you're starting to move into .. it's harder to do .. offer something <u>practical </u>to make that better really, so that's quite challenging. So again it's kind of looking at trying to look at things .. why are you feeling the way you're feeling and trying to explore that but you know .. it's .. it's draining and it's ... it's quite .. you worry for them really because you can't make it better immediately I think' (Sarah, line 257).*

Others described needing to tolerate and learn that they are limited in what they can offer and to whom it can be offered. Again, an experience of helplessness is evident when participants must tolerate 'not knowing' and realising that some things are out of their control. This also relates to the way participants begin to face the existential challenges challenge of working with people whose outcome and health are uncertain:

> *'as a nurse you feel as though you want to be able to do something to help everybody and to ... I don't know what I'm trying to say really ... it's .. if somebody's got a pain you can give them a tablet can't you, and you want to be able to do that. But psychologically and emotionally, you don't, don't always have the answers, to help somebody.' (Claire, line 773).*

It is interesting to note, that the desire to 'make it better' is very powerful and gets expressed by staff, patients and their families. This experience of patients and families is similar to participants' own experiences:

> *'the partners often wonder if they're on the right track, with what they're doing really and I think erm often because they want to do practical things to make things better' (Leanne, line 876).*

Anxiety about doing a good job

Related to '*learning what is possible*' are participants' experiences of *'anxiety about doing a good job'*. One of the strongest responses that emerged from the experience of all participants was that of anxiety. This theme captured the anxiety that they experience as a result of questioning their own abilities. This theme emerged repeatedly and was important for all participants. They expressed anxiety about their ability to carry out their role as they undertake tasks and as they reflect on them. It reflected their anxiety about competence and capability in doing the role. Participants' experience anxiety about not doing a good job, and furthermore their fear of not doing the right thing for patients. For some participants, there appears to be an implicit model of the right way and thus a standard they must work to, which potentially increases their anxiety and fear of getting it wrong:

> **'**So I said "now's a time where you've got to start being honest with them and honest with yourself". So ... it's difficult, I don't know if you do the right thing or not by saying that.' (Judith, line 905).*

Some participants retrospectively question their actions in relation to the support they offer patients. They question whether they have done the right thing and experience anxiety, particularly as they are dealing with complex medical situations which can be life limiting and changing. The following quote showed how Claire took on board the feelings of the patient and felt upset herself. It also demonstrated her need to tolerate the uncertainty of whether she had done the "right" thing:

'What do I do for the best here? Do I wait, make her wait another few hours .. do I explain what's happening ... so it was a difficult position to be in really. But in the end I said to her, "do you really want me to tell you?" I couldn't lie to her. So I had to explain it to her. So then she was even more upset and I had to go down to clinic. I felt I'd given her this bad news and then I'm going off to clinic .. I was upset and I was anxious and I kept thinking, have I done the right thing, to be honest.' (Claire, line 476).

Other participants demonstrated ambivalence; they experienced anxiety and the fear of getting it wrong but simultaneously questioned whether in reality, there is actually a model of the right way particularly in relation to psychological support. Judith talked about the need for clinical supervision and the impact it would have on her experience of working with difficult experiences that patients go though. She also asked a rhetorical question of me and this felt as if she was trying to include me, as a way of making sense of her anxiety:

'We're dealing with bad news everyday aren't we? .. it's not now and again it's every day. [...]. I think it would help and to know that you're doing the right .. I don't know if there is a wrong or a right thing, I think with psychological care ... [...] there's definitely things that you shouldn't do..' (Judith, line 961).

For many participants the experience of anxiety and questioning of their own actions drives a need for reassurance as seen in Judith's desire to ally with me expressing "we", rather than "I" or "you" in the above quote. When Judith said this she looked up at me and paused as if to be including me very much into what she was saying. I noted this in my reflections following the interview and it felt that this was a way of normalising her experience. As a result of gaining reassurance, this anxiety is often alleviated. Participants seek reassurance from their peers and in supervision and this will be described under the theme *'Needing recognition and support'.* When participants described feeling that they had got it wrong, this fear or anxiety extended to the potential impact this could have had on the patient, even making them worse, not clinically, but psychologically or emotionally. The following extract was said in the context of Leanne talking about a patient who she felt was making no progress and was questioning the impact of her sessions:

'I had to say to her "I don't really know what you get from seeing me but you obviously want to come", and she said "oh no no don't tell me that I can't come anymore" so then you get into that well am I kind of making this situation worse by saying we'll meet up every so often' (Leanne, line 1476).

Not only do participants experience anxiety about doing the right thing, they also experience anxiety specifically about whether they have done enough for their patients. This quote highlighted this experience and also demonstrated the relationship between participants' experience of anxiety and their *'need for reassurance'* in order to manage or dispel this. This can be seen in the tentative language used:

> *'because I do tend to question sometimes whether what I've done is right, and can I do anything else or ... and it's just having that reassurance really that .. I have done all I can for her and sometimes you've got to say enough is enough ..' (Claire, line 876).*

This fear of not doing enough is accentuated with patients that participants are more closely connected with, or that have a greater emotional impact on them. Marilyn articulated that this experience can be stressful and that at times, she can take personal responsibility for the way a situation has progressed, increasing the fear that she has not done enough. In this example Marilyn is talking about a patient who was particularly distressed after having a rapid deterioration in health and required palliative care. Marilyn expressed her knowledge that in some situations whatever she does she cannot affect the course of the illness and the deterioration of health. It suggests that momentarily participants can feel overly responsible because they want to cure:

> *'sometimes those ones that hit home .. and we may feel that it hasn't quite gone as well but in actual fact when we've talked about it there's nothing more we could have done. But sometimes we take those moments quite to heart, so sometimes I think it can be stressful' (Marilyn, line 191).*

This extract (*Marilyn, line 191*) begins to show participants' experiences of coming face to face with the challenges of health life and death, and this is most often out of their control. It also shows Marilyn's desire for things to go well for the patient and the stress, anxiety and sadness that she felt when this did not. In this moment she found herself questioning her role and whether she had done enough for the patient, despite the outcome being poor. It also alludes to the way in which she faced her limitations of what she could offer and the impact it could have.

Key Theme 4: Needing recognition and support

This final key theme captured participants' experiences of needing both recognition and support from those around them as they do their work. This was present in all accounts and related to participants' experiences of all aspects of their role and as such, is presented last. As participants go about their day to day tasks caring for patients, and experience the emotional and existential impact of doing this role they describe the value of being in relationship with others at work, including their CNS peers, other team members and clinical psychologists. This theme also relates to participants' experiences of the organisation; as participants work out and understand their role in this context, they articulate a desire to be supported throughout. Within this theme there is also the sense of anxiety that participants experienced and as such they expressed the need for both support from others and the need to share with others. They experience the positive impact of having a place of belonging in which they can return to for support and in which they have good relationships. This key theme encompassed two subthemes: '*Experience of supportive others*' and '*Needing Reassurance*'.

Experience of supportive others

This sub-theme captured the way that participants experienced the need to share the impact of their day to day work with supportive others, particularly when they faced challenging experiences. In sharing with others, participants valued the process of "offloading". Participants expressed that they do not always require anything back from their supportive others. Being held in mind and knowing they belong was often enough:

> '*So when I went back to the office yesterday, my colleague and one of the therapists were in the office and they were very much .. "are you alright, shall I get you a drink" and I was okay and then one of them texted me later that night and said are you alright after today. And it's that kind of being able to offload to somebody else that you work with ... and I've got that. I've got a good team who do that and we look out for each other. And that's a nice part of the role as well.'* (Anne, line 883).

Many expressed the tension of managing autonomy and lone working. Utilising support and needing to share with others in the context of lone working was important for many participants. The 'others', with whom participants share, varies for each participant but includes peers, other CNSs and clinical psychologists:

'if I'm on my own, […] I've got colleagues and friends that I know that I can ring and just say, Oh God I've had such a bad day, and […]I'll off load on them, and my colleagues' […]we'll share things and I've got a clinical supervisor who I share things with, so, I find that keeps me sane that keeps me feeling, OK well I'm alright to support other people because I've had a little bit of support myself... because I think that's when you run into problems when, you don't have that support around you' (Leanne, line 291).

This quote also highlighted the experience of participants needing to attend to self-care; that being supported themselves is essential in the context of being required to support others both emotionally and psychologically. Leanne referred knowingly to the consequences of not having this support. Other participants highlighted the isolation that can be experienced in not feeling able to share the emotional and existential impact on them outside the context of their workplace. This increases the importance of being aware of and acknowledging this within the work setting. Jackie highlighted the need for sharing this and provided what was for her a particularly distressing example:

'*I think it's really important that we <long pause> that we acknowledge that together and that acknowledge that it maybe that I'm really upset, that I'm finding it difficult with a particular patient […] because, once we go outside these walls, you can't share that distress with somebody else. You can't come home and tell your best friend, there's a 32 year old woman with a 3 year old that you've had to tell today that she's going die in the next few weeks. So .. it's vital that we're able to share that as a team and support each other' (Jackie, line 106).*

Participants also identified their lived experience; that the impact of this work, particularly the emotional impact, can become overwhelming. So when this does happen it is 'vital' (to use Jackie's word) that there is an active process which addresses this with supportive others. For Jackie this seems to be protective of her well-being and she feels that without this burnout is inevitable:

'You have to acknowledge, no man's an island, they say don't they? And also you can't .. you can't take <long pause> that impact on, that emotional impact on without addressing it. You can't keep taking it on and on and on because if you do, you will burn out.' (Judith, line 694).

Overall, there was an acceptance of the need to share with supportive others in the context of doing emotional work which has an emotional and existential impact. Marilyn said "It's

natural. It's nature". and this reflected participants' humanness, in coming close to the difficult emotional experience of another. At times there is a need for others to simply be with them in this experience just as they are with patients in their distress:

> *'And we've all had moments where we've broken down. It's natural. It's nature. [...] the Palliative nurse came to the funeral as well because he felt in a similar position to me really so .. we went together which was really nice. It was lovely…… So there's an opportunity, I think by sharing where I was going and they know what was happening .. that's sometimes all it needs' (Marilyn, line 258).*

Participants also expressed utilising supervision and being supported in order to help them manage their emotional response to death. This was even more the case for Claire when it was the death of a young patient:

> *'we had a young lad who was only 28 who died ... those are difficult times really but that's where the clinical supervision comes in because I was able to talk about that with them. So ... I think we have good support really.' (Claire, line 550).*

The demands of the role are such that participants feel it is important to share the impact of their work with others and receive support as they go about their day to day role.

Needing reassurance

Participants expressed the need for reassurance, especially when they felt anxious, from a place where they feel they belong and can access support. As described, at times participants feel anxious and unsure of themselves in their clinical work and have fears of not doing enough or of getting it wrong. As a result they seek reassurance which they described as alleviating some of these fears. There is variation across participants as to the form and place of this reassurance. This quote from Claire highlighted this need for reassurance in response to anxiety about a specific clinical situation in which she was asked by a patient about their prognosis. As a result of being honest with the patient she was aware that she had upset her and there is a sense that Claire wished she didn't have to do so:

> *'And I just went back said, do you know I don't whether I've done the right thing and she said she'd had a similar situation. And she said you did because you can't lie, if they're asking you outright can you, because they lose all trust. So .. I did feel OK once she'd said that to me really.' (Claire, line 524).*

Participants also feel the need for reassurance when they experience anxiety and fear about not doing enough for the patient. In particular, Leanne highlighted that this reassurance needs to come from someone who understands their experience and who they trust has enough knowledge to provide this. Many participants referred to this being specifically from a clinical psychologist. The clinical psychologist is seen as providing something that others cannot offer. This extract represents participants' experiences of wanting to be supported by a clinical psychologist who understands the psychological domain. This is important as participants have begun to draw from this domain in their psychosocial support to patients, particularly following the completion of the level 2 psychological skills course:

> *'I could have gone to the psychologist and said I had a really bad day this has happened that has happened, I did this this and this what do you think and she said "you know that's fine you couldn't have done anything else or actually what about this and what about that", that was really helpful erm and I think knowing you are on the right track is really helpful from someone who you know understands what they're talking about <laughs> and that can only be a psychologist really' (Leanne, line 1615).*

In contrast, others also gain reassurance from peers within the context of psychologist led group supervision, feeling comforted that they are in a similar position and alleviating the anxiety about whether they have done a good enough job:

> *'it was great to meet other CNSs and .. reassure yourself actually .. reassure myself that actually I have come across these patients, I come across these problems. Yes. So there's reassurance and an affirmation really that .. I'm doing an ok job actually.' (Rachel, line 928).*

Numerous participants referred to being reassured that at times, it can be appropriate to express their emotions with patients. Given that the expression of emotion with patients is often a contested area, particularly within the therapeutic domain, this extract demonstrates participants' anxiety of getting it wrong and the need for reassurance and 'permission' to be congruent with their emotions:

> *'it was almost as if talking to the other people on that course, the psych-oncologist .. giving me permissions actually, to let them see my tears and that I was sad and actually I was upset as well. You know it was ok to let them see that.' (Rachel, line 712).*

Overall being valued, recognised and supported by others who have a sense of who they are and what they do, is an important aspect of their role.

Summary

As this research has explored the lived experience of CNSs one pattern has become clear. There are different kinds and levels of experience that are being described. The first relates to participants' experiences of their role in the world, for example the organisational context; this includes the MDTs they are part of and what they actually offer patients. The other is a much more personal experience where they see the impact of the work in a more individual, existential, emotional and personal way. These have been woven together in the themes and sub-themes as this reflects the way these were discovered in the research. They do not come neatly separated out but are woven through their unique accounts of their experience.

In summary, these results identify the participants' understandings of what their role entails in practice. What is very clear is the breadth of their role that encompasses a wide variety of tasks, of which psychological support is only one, important as that is. What lies at the centre of their role is the work that they do with patients, or as one participant stated the 'heartbeat'. These results have shown something of participants' understandings of the psychological support that they offer. It is clear that whilst it is an important part of their role they do not always view this as a distinct element. Psychological support seems to pervade throughout their role as a CNS in oncology, and distinguishes them from other members of the teams within which they work. Yet despite this, they struggle to articulate what psychological support means to them.

The variety of themes and sub-themes has given voice to their understanding and experience of this 'vital' role that they do. Participants feel as essential their 'being with' patients and providing a continuity of care, through the building of relationships. This is a central and important part of their role, yet they also experience this as challenging as they are pulled between the differing priorities that are at play in their work with patients. There is an undertow of ambivalence that runs just below the surface throughout their experiences leading to mixed or confusing feelings about their work.

This research has also shown what it is like for participants to work with patients by 'being with' them. Such a way of working with patients can be 'difficult' as they experience the emotional impact of people who are suffering. It is unsettling and provokes a need to make sense of their own experiences. It leads to the emergence of existential questions and issues in which they are confronted with a re-evaluation of who they are and how they live life. Yet despite experiencing difficult emotions they simultaneously talk about the sense of reward and privilege they experience, and the positive way in which they re-evaluate their own lives. Again, they experience ambivalence, in that they experience a range of emotional and existential responses which are at times conflicting. They must also tolerate uncertainty as they face the impact of working with the unknown in the health outcomes of their patients.

These results also demonstrate the organisational element of their experiences. Participants encounter the systems around them, and this includes other professionals that make up those systems but do not always understand or value the work that they do, particularly the psychological support they offer. As such they feel pressure to define and justify the work that they do in a rather self-protective way. They experience the challenge of working out and understanding their role as a CNS in oncology who is also offering psychological support to patients. This experience is difficult for participants however, as they themselves face a level of uncertainty about the role that they do. In offering psychological support to patients they must work out what is possible. They talk of their identity as a nurse but describe this as being challenged as they work with the psychological which they experience as more intangible, difficult to define and in which they must tolerate uncertainty. At times they are drawn to practical tasks they have previously offered, yet simultaneously feel that in working with the psychological these are no longer most helpful. Again there is a sense of ambivalence in their conflicting feelings. They also experience anxiety as they learn what is possible in their role and learn what a 'good enough' job is within the psychological domain. Despite this, they have a limited but emerging confidence in their role and view themselves as an important and central part of the teams in which they work despite the uncertainty around their role and their ambivalence.

Lastly, these results have shown the importance of the support that participants draw upon as they carry out their role. As they experience the emotional and existential impact of their

work and as they continue to process and understand who they are and what they do within their organisational context they rely on the support of peers and clinical psychologist in helping navigate these complex experiences.

CHAPTER FOUR

Discussion

This study addressed two specific research questions: 'What is the experience of being a clinical nurse specialist (CNS) working in oncology?' and 'What is the experience of offering psychological support to patients with cancer (and their families)?'This chapter highlights the key research findings and relates these to the existing literature whilst offering a critical and reflective engagement. The strengths and limitations of the research are then outlined, followed by a discussion of the clinical implications and recommendations for further research.

Discussion of the research findings

The eight interviews undertaken with the CNSs to examine these research questions yielded four main themes which were:

- *'The everyday experience'*
- *'The impact of working with patients'*
- *'Understanding and working out the role'*
- *'Needing recognition and support'*

What runs within and between each of these key themes, which captures the essence of the experience of CNSs, are the phenomenologically based themes of *ambivalence* and *uncertainty*. The term ambivalence is defined as 'The state of having mixed feelings or contradictory ideas about something or someone' (Oxford Dictionary of English, 2010). In this study, ambivalence is a core theme that underpins the experience of participants. This is a continuous refrain in participants' accounts of their experience. This is echoed by their uncertainty at two levels; what they do and who they are. Whilst I have identified distinct key themes (along with sub-themes) there is a dynamic relationship between them. In the first part of this chapter the key findings are explored in relation to the wider literature. On the surface the role of the CNS in providing psychological support to patients might seem straightforward. Yet underneath this experience is complex as it touches upon their sense of identity, their relationships to the systems in which they work and their own emotional and existential experiences. This discussion tells the part of their story that has not been told

before and is focused around five areas: Professional Development, Identity and the CNS; Organisational Pressures; The emotional engagement of CNSs in their work; and Existential Impact.

Professional Development, Identity and the CNS

This study was developed out of a need to understand the experience of CNSs undertaking psychological skills training and offering psychological support to patients in response to governmental guidance. One of the first key findings from this study relates to participants' understanding of what psychological support means.

The understanding of psychological support

An important and novel finding is that participants found it difficult to distinguish the psychological support they offer patients from other aspects of their role. As illustrated through the pen portraits, all participants viewed psychological support as a central and important aspect of their role, underpinning all other elements of their care. It is also clear that participants do not generally offer formal psychological interventions to patients. Whilst at times they draw upon particular tools and strategies in their work, the provision of what CNSs might constitute as formal psychological interventions, is felt to be out of their remit and is deemed the responsibility of the associated clinical psychologists. Despite going through training designed to meet level 2 of the NICE (2004) guidance (in which skills and techniques are a core element of the training), CNSs do not always utilise these in practice. Participants spoke of drawing upon some cognitive behavioural based strategies taught in training but this was limited and not the main emphasis of their accounts. In addition, it was clear that participants do not offer this support in the traditional, one-to-one talking therapy tradition. The experience of participants offering psychological support was focused on the process of 'being with', 'journeying with' and 'offering continuity' to patients within a relational framework; they build relationships and place the patient at the heart of the care process. Whilst the support they offer differs from that which is taught, CNSs are still adopting elements of another group's professional activity in their provision of psychological support such as clinical psychologists, counsellors and psychotherapists.

Whilst focusing on participants' descriptions and narratives of their role rather than their experience, this finding is both important and interesting. CNSs undertake training to assist their work with the psychological and emotional needs of patients, yet minimise the use of specific techniques in their routine practice. They place great value on the provision of psychological support, yet find it hard to define or express what this means. Previous research has suggested there is ambiguity and uncertainty throughout the literature about the terms used to describe the process of emotional care and support. For example many terms are used interchangeably, such as psychological care, and support, emotional care and support, and psychosocial care and support (Skilbeck & Payne, 2003). For the participants in this study there was ambiguity and uncertainty in their use of these terms, and furthermore, the type of care that each entails. This study extends upon previous research by Loftus and McDowell (2000). They suggested that CNSs in oncology provide emotional support to patients but there is a lack of understanding about this aspect of their role; this makes it difficult to understand the needs of the CNS in offering emotional support. They highlighted that this aspect of the CNS role should be evaluated further in order to implement appropriate support systems. The present research provides a more detailed understanding about this complex role and the experience of CNSs. It shows that ten years later there is still uncertainty around the role of the CNS in providing psychological support to patients with cancer. Yet it also shows that there is a clear distinction between what CNSs are being expected to do as lauded in governmental documents and taught by the level 2 skills training, and what they do in practice. This can be difficult for CNSs, leaving them uncertain of who they are and what they should offer. Research by Evans (2014) on professional development may help in understanding this.

In researching professional development in education, Evans (2014) identified a gap between government policy and requirements and 'the micro-level cognitive processes of professional development' (2014, p. 179) that are required to make effective change happen. She argued that when policy requires a change in professional activity, policy makers tend to focus on certain aspects of professional development; that is the observable behaviours rather than the internal changes of both thinking and attitude. She developed a model which highlighted that professional development is not simply about behaviour change based on knowledge; what people do and how they do it. Instead there are also intellectual, mind-set and attitudinal components. She advocated for care to be taken to avoid a narrow conception

of professional development; it should not just been seen as taking place in particular planned times such as training courses. She argued that it takes place in any setting and should be seen as part of day-to-day working life. This allows professionals to extend their practice, enabling them to manage new experiences and to make links between knowledge and work experiences. Evans (2014) argued that there will always be a tension between prescribed policy change and the professional development seen in practice. Whilst writing for an educational context, these ideas are particularly relevant in explaining the novel finding of this research. CNSs are being trained to deliver psychological support through the acquisition of skills and techniques within a training course and period of supervision. Yet they learn through their practice and the psychological support that they offer often differs from the skills that have been taught. Moreover, their learning is not simply about what they offer, it is also in their understanding of what constitutes psychological support and what it means to offer this to patients. Evans' (2014) analysis, of the challenges of professional development in education and the tensions between government-driven policy requirements and how professionals actually develop, offers a parallel to this research with CNSs. She noted the importance of coaching and mentoring as aspects of professional development. While not advocating a new model, one solution would be for clinical psychologists to offer an equivalent professional development experience through the use of supervision. This difference between the policy demands and the enacted role of the CNS also has clear implications for participants' sense of identity.

Nurse vs CNS

In being a CNS, participants have made the transition from a traditional nursing role, which has an extensive history and sense of professional identity, to that of the CNS, a role which as described brings with it a degree of ambiguity. Participants experienced needing to learn what is possible within this role and this was clearly related to their sense of themselves as nurses. This study has found that many participants referred explicitly to the part of them that identifies *"as a nurse"*. When participants did this they were conveying that there is part of them that was, and still is, a nurse. Being a nurse leads them to act in certain ways, stemming from prior training and years of experience working within this paradigm. They related being a nurse to the way that at times they feel pulled to want to offer practical and achievable solutions in an attempt to make things better. Participants recalled that as a nurse

the role was objective, tangible and involved doing practical things to make a difference for patients. By contrast they constructed the delivery of offering psychological support in opposition to the nursing role. They experienced recognising that when working with the psychological they do not always make people better and face challenges as they "can't make it better immediately", "don't always have the answers" and feel that "I should be able to make you better". Whilst the same is true when working with the physical needs of patients for whom there is no cure, participants described sometimes struggling with not being able to offer something to patients in the way that they would have done, or would like to do "as a nurse".

Before the current extension of the role of the CNS in the provision of psychological care, there has been a gradual move from a view of nursing that involved an avoidance of engagement with patient emotions, toward a new appreciation, commitment and involvement with patients (Williams, 2001). This has further developed to the CNSs' role in the provision of psychological support and as they described in practice, the building of relationships. Previous research with general oncology nurses has highlighted that the traditional culture of nursing practice places an emphasis on activities and tasks, and was challenging for nurses' provision of psychosocial support; the importance was on 'doing', rather than 'being with'. Tension was experienced between the task driven goals of care and the reflective nature of psychological support (Turner et al., 2007). In the present study some participants experienced a tension; it was clear that participants valued 'being with' patients and providing a continuity of care yet at the same time some also viewed 'being with' as somehow different, or less 'psychological' than the psychological skills that they had been taught yet do not always implement. Others, while describing 'being with' phenomenologically, did not explicitly articulate this as 'being with' the patient. Participants demonstrated ambivalence, in that they both valued yet underplayed the importance of 'being with' patients; a finding supported by previous literature (Turner et al., 2007). The present study, however, has shown that CNSs are integrating psychological support into their role, but that there is tension and ambivalence in their self-identity. Whilst they are still nurses, they have developed professionally. Yet the way they have developed and the support they offer differs from the way in which policy has outlined; they experience both ambivalence and uncertainty as they negotiate this role.

Participants therefore experience a process of *'learning what is possible'* within the remit of their role. In offering psychological support, they must tolerate the uncertainty that they are limited and at times they cannot help patients in the way that they might like. They experience the psychological support they offer as less tangible than tasks that fall within the traditional nursing remit. They are now drawing upon a different framework of working with patients, a relational framework. This relates to the development of their identity as CNSs. Participants are drawing upon their identity as a nurse yet have outgrown its parameters; they have done limited psychological skills training and have taken on roles in supporting the psychological needs of patients, yet are not psychologists. They can draw upon their role as a traditional nurse, yet they now have new skills and ways of doing things, drawing from a psychological framework in their role as a CNS. It seems that their identity is in transition, that they are not one nor the other but are in the process of navigating between the two. Participants also described undertaking a multiplicity of roles under the umbrella of being a CNS (Farrell et al., 2011). They experienced being required to offer psychological support as well as physical care, thus drawing upon these different professional roles. There is a clear sense of uncertainty that runs throughout their professional identity as a CNS who offers psychological support. Participants experienced both an internally transitioning identity and externally doing a multifaceted role which includes the psychological. This brings with it uncertainty, ambivalence and anxiety.

What was clear from the findings was that participants experienced anxiety, particularly around their ability to do a good job, whether they had done enough for patients and whether they had done the right thing. This is principally in relationship to the psychological support that they offer. Glen and Waddington (1998) highlighted the relationship between stress and anxiety in the workplace and the issues of role conflict, complexity and ambiguity. The present study has found that role ambiguity is clearly experienced by the participants. Despite the role of the CNS having now been developed in the UK since the 1980's (Bousfield, 1997), the present study demonstrates that over twenty years later it is still shrouded in ambiguity. It is suggestive of a relationship between this phenomenologically-based ambiguity and their experience of anxiety. Not having a clearly defined role, undertaking tasks which differ to those which are taught and an unclear identity leads to anxiety and uncertainty about what they should be doing, and their competence and ability to do what they feel they should.

Overall, however, despite the outlined challenges CNSs also experienced the development of a limited but growing confidence in their role. There was a real sense of an emerging collective identity as CNSs. Participants described knowing, understanding and valuing the work that they do. It seems that to an extent, they know what they do, why they do it and the difference they make although at times, struggle to communicate this to others. Participants described themselves using terms such as the *"heart", "key"* and *"linchpin"* of the teams within which they work viewing themselves as a core part of their MDTs. Amidst the challenges they face, CNSs experienced knowing and feeling that they have an important and central part in the provision of care to patients. This finding is supported by Catt et al. (2005) who described CNSs as 'the thread that runs throughout the patients care in these cancer teams' (p.1095). This sense of participants coming together in unity could be explained by social identity theory (Tajfel, 1978; Tajfel & Turner, 1979) and self-categorisation theory (Turner et al, 1987). These posit that groups give us a sense of social identity and a sense of belonging to the social world. These theories suggest that individuals develop two primary identities: a personal self; and a collective self, which draws on the various groups they belong to. Social identity theory also suggests that there are three processes involved: categorisation in which we categorise objects and people in order to understand the social environment; social identification in which we adopt the identity of the group we have categorised ourselves as belonging to; and social comparison in which there is a tendency to compare the group we have identified with, with other groups. Self-esteem is maintained by viewing the belonging group as comparing favourably with other groups. Participants identify with being a CNS, and this idea is strengthened by the way participants at times used the term 'we' rather than 'I' when talking about their role as a CNS. It seems that one way participants manage the uncertainties and ambivalence they face in their role, is by identifying strongly as a CNS. Although this brings with it challenges as they develop from being a nurse to a CNS, who takes on psychological skills as just one element of their role, it seems that this helps them make sense of their social environment. It also provides a sense of belonging and therefore both an internal and external support.

Organisational Pressures

The research participants in this study experienced an underlying organisational pressure to defend and justify their role; a need to prove what they do, how they do it and identify the

contribution that they make. Participants felt a persistent need to justify and articulate what the role entails; a finding that is supported by previous research (Bousfield, 1997; Redekopp, 1997; Willard & Luker, 2007). The CNSs in the current study experienced feeling undervalued yet this did not impact on their integration and value in MDTs as found previously (Willard & Luker, 2007). They do, however, have to manage the differing expectations and priorities placed on them by the MDT. They are expected and depended on to provide psychological support by other members of their MDT, as found in previous research (Absolom et al., 2011) and must be responsive to the demands of the MDT, the organisation, the patient and themselves. As such they experience being pulled in all directions and negotiating many agendas and priorities (Glen & Waddington, 1998). This experience is stressful for participants and leads to feelings of guilt particularly when they cannot be there for the patient in the way they would like.

What was distinct about this research study is the specific focus on psychological support. As well as having differing understandings of what constitutes psychological support and finding it difficult to distinguish this part of their role, participants also experienced difficulties in articulating the psychological support that they provide to others. Additionally, they felt that their provision of psychological support is misunderstood and undervalued. Previous research has demonstrated the pressure CNSs feel in proving the effectiveness of their role (Bousfield, 1997). One reason for this is the nature of psychological support itself. As one participant described when referring to psychological support *"It's experiential, it's qualitative"* (Marilyn, line 762). Other research has suggested that the ill-defined job description of the CNS makes it difficult to qualify and quantify the impact of their role specifically in relation to the provision of informational and emotional support to patients with breast cancer (Droog, Armstrong, & Maccurtain, 2014). In the present study, participants' focus on the relational dimension of care, whilst drawing upon numerous paradigms in their work, means that demonstrating the effectiveness of their work to their medical colleagues can be challenging. The psychological support that CNSs offer is not routine nursing care, yet is not psychological therapy. There seems to be a need for this to be defined in its own right and seen as differentiable from the other elements of the role. Defining and measuring the impact of psychological therapy is an area that is becoming more pressing for other groups of professionals such as psychotherapists, counsellors and clinical psychologists yet this can be challenging (Kindermann & Tai, 2009). This suggests

that even those who are meant to be experts must address the challenge of defining and demonstrating the effectiveness of their work.

The Emotional Engagement of CNSs in their Work

The provision of psychological support conceptualised in policy is construed as something tangible. At 'level 2' (NICE, 2004) this support is defined as the screening of psychological distress and the application of psychological techniques, the example given is problem solving. Just as Evans (2014) articulated, the focus of policy makers here is on behavioural outcomes as a sign of professional development. Whilst the development of a nurse-patient relationship might be necessary in offering psychological support, this is not seen as the intention. What this study has shown clearly, however, is that CNSs offer support in the context of building a relationship. Despite the ambivalence demonstrated in participants' accounts of their psychological support, CNSs view relationships with patients as crucially important in their care. Knowing and being known to patients is experienced as a central and unique part of their role, yet it has many challenges.

One of the key and novel findings of this study therefore, is the emotional engagement of CNSs in their work. Working with patients with cancer, and providing psychological support has an emotional impact. Knowing patients well increases participants' experiences of sadness and distress when their patients go through difficult experiences. This study has shown that knowing patients well, becoming invited into part of their lives, and sharing in their experiences makes it more difficult for CNSs when patients' health deteriorates or when they die. This study has shown that getting to know patients well particularly influences their feelings of sadness in their work. A study by Forsey et al. (2013) supports this finding and suggested that if nurses place great value on their relationship with patients they can be affected by the emotionally challenging aspects of their role and may experience emotional distress. In the present study this is what CNSs do; they are on the frontline, available and responsive to patients' needs in the context of a valued relationship. The impact of this work is wide-ranging and involves mixed feelings in response to the demands of their role including sadness, burden, anger, frustration, guilt, doubt, reward and privilege; the phenomenon of ambivalence was also present throughout participants' experiences.

This research has also highlighted that CNSs are brought closer not only to the emotional experiences of the patient, but also wider family systems, including partners, carers and children. This can be difficult as participants become part of the rippling impact of illness, suffering and death. Some have argued that this increases the likelihood of the professionals themselves experiencing difficult emotions (Towers, 2007). Participants build longstanding relationships and get to know patients and their families well; journeying with them. For most participants this is really important; it gives them satisfaction but also accentuates their emotional responses to the distress of patient and their families. This finding highlights the importance of knowing the patient in the development of the nurse-patient relationship, viewed as a unique contribution of nursing (Radwin, 1996) and seen as a key area of nursing expertise (Manley et al., 2005). The present study shows that the provision of psychological support demands an increase in the relational engagement of CNSs with their patients, over and above the routine care that nurses provide.

One of the emotional responses that participants felt was both anger and frustration when faced with the suffering of patients. Anger can be an emotional response to situations in which an individual feels a threat, out of control or overwhelmed which Kubler–Ross (1969) identified as a normal part of the grieving process. This is demonstrated as frustration about not being able to do anything, or a feeling of helplessness at their limitations. There was a felt sense of anger throughout many of the interviews, picked up through their tone of voice and gestures, yet as described this was not clear in their transcribed accounts. There is a suggestion that for some participants there was an awareness of anger as frustration. Related to this, when describing their emotional responses, participants used qualifying terms such as "quite distressing". There is a sense that they feel they have to prove to somebody (internally and externally) that they can manage, be professional and not be overwhelmed by the burden of care. Further research into this area is warranted. This finding is supported by research into oncology nurses' perceptions of their supportive care to patients with cancer who found that a significant theme was the 'burden of caring' which encompassed sadness and grief (Turner et al., 2007). The authors suggested that in order to manage this burden nurses undervalue their role in emotional care, and this serves to legitimise their avoidance of becoming connected with the emotional experience of the patient. In contrast, the present study highlights that CNSs' experience of getting to know patients well and connecting with them on an emotional level is a fundamental and valued part of care. In the time since the

Turner et al (2007) study, it seems that the incorporation of psychological support as a key role has developed. It has been promoted through training and CNSs spoke clearly of its importance as part of caring for patients effectively.

The present study again demonstrates ambivalence. Whilst CNSs are tasked with the provision of skills based psychological support, in practice they become emotionally engaged with patients and experience the impact of this work. Phrases such as 'being with', 'being present', 'journeying with' and 'bearing witness' are used throughout phenomenological, existential and therapeutic literature (Worsley, 2009). Rogers (1957/1985) highlights the benefits of the therapist being fully in the moment and present with clients. In nursing the idea of being 'present' has been adopted highlighting its value in allowing the patient to connect with their suffering, whilst sharing with them and helping them to navigate their own path through their healthcare experience (Zyblock, 2010). Existential writers such as van Deurzen-Smith (1997) articulate that 'being with' brings its own demands as it draws on a person's capacity to be with themselves. For the CNS, their experience of their role is that that they respond to patients as people, to bear witness to their suffering and to be with them, not just view them as a cluster of medical symptoms.

Despite offering psychological support in the context of relationship and receiving limited psychological skills based training CNSs are not trained as therapists. Yet they do more than offer basic psychological skills and techniques and as a result become emotionally engaged with their patients. Most therapeutic trainings require the therapist to undergo personal therapy or involve a reflective component that focuses on personal and professional development (Payne, 1999; Hughes & Youngson, 2009). CNSs, however, are not required to have personal therapy. As CNSs engage in a process of 'being with' their patients this inevitably takes them into their own material; it has both an emotional and existential impact. Despite the ambiguity around the terms used for psychological support, and the differing expectations on each CNS, they are still drawing alongside patients as they experience a threat to their health that causes them emotional and physical suffering.

In her writing about nursing practice, Menzies-Lyth (1960/1988) suggested that nurses are exposed to the emotional experience of patients who are at their most vulnerable; it is therefore often nurses who experience the most emotional pressure within the healthcare

system. She noted that the nursing work itself, particularly physical contact and a close involvement with both illness and death, caused anxiety. She explained that hospitals can be seen as social systems that have traditionally created social defence systems such as depersonalisation of patients, task allocation and distancing, in order to help individuals 'avoid the conscious experiences of anxiety, guilt, doubt and uncertainty' (Menzies-Lyth, 1960/1988 p.452). In order to avoid these anxieties the organisation itself develops defences and she considered blocking (a term used to describe preventing patients' expression of emotion) about their as a defensive behaviour as a result of the anxiety produced by understanding patients' difficult, often uncontrollable experiences, both emotionally and practically. She also described another core defence mechanism within the nursing social system; the splitting up of the nurse-patient relationship. In practice this might be limiting the prolonged individual contact with any one patient.

In this study, the actual experience of CNSs in oncology however, contrasts with the nursing role described by Menzies-Lyth (1960/1988); they do develop relationships with the patient and they play a key role in many aspects of patient-care. The constitution of the psychological skills that are advocated by policy still sits clearly within the medical paradigm, and seems to be viewed in line with the way that, for example, medication and physiotherapy is offered; a relationship is necessary but not the intention of the work. Instead, however, the participants described developing long-standing relationships with patients and thus providing continuity as they navigate their health issues as part of a system. The adoption of a new way of nursing which values the nurse-patient relationship places great importance on the emotional dimension of care (Parse, 1992; McQueen, 2000). In their present role, the relationships that participants build with their patients contrasts with the social defences that Menzies-Lyth (1960/1988) proposes. Interestingly, on an individual level *Leanne* demonstrated one way of coping which is to depersonalise a person into a task, a role or a thing. While she recognised her emotions she slipped into the distancing coping mechanism by using the word 'thing' in the sentence: *"it's easy to take them, things home and worry about certain patients and certain people get to you more than others and, [...] the emotions of what's happened during the day sometimes" (Leanne, line 332).* Previous research supports this finding, showing that nurses can unconsciously or consciously try distance themselves from work in order to function well at both work and

home (Odling, 2002). What is also clear is the CNSs draw upon support in their role and as they experience its impact.

The need for support

As described, CNSs become emotionally engaged in with their patients. Not only must they develop professionally and navigate their identity, they face the emotional impact that building relationships with patients brings. This study has found that participants experience a need to access support in managing the emotions, anxieties, dilemmas and conflicts that emerge in their work. They also need to have places within which they feel they belong; where they are understood, listened to and can readily access support in helping them manage and share the impact of doing their role. Participants expressed the need to utilise both social support and clinical supervision in order to feel supported and equipped in their work. This is supported by the literature that supervised nurses continue to use both informal support networks as well as clinical supervision to discuss clinical issues (Teasdale, Brocklehurst & Thom, 2001). As part of needing to belong, participants experience the need for a place to share something of their emotional experiences with others as well as needing reassurance in response to the anxiety they feel about both their emotional responses to patients and with regard to their decision making.

Social support was found to be a really important resource for participants and they expressed the importance of sharing with others, gaining reassurance and knowing that they are not alone in their work. In particular they experienced the need to share the emotional impact of the work with others who they know will understand. This is supported by previous literature into the experiences of hospice nurses (Hawkins, Howard & Oyebode, 2007) and in the general nursing literature (Eastburg et al., 1994). Participants spoke of drawing upon this support on an adhoc basis, and described needing this when they encounter particularly difficult and emotive situations.

Jackie spoke of the burnout she felt was inevitable if the emotional impact of the work was not addressed, a finding supported by previous research undertaken with nurses working in oncology (Bousfield, 1997; Turner, 2007). There is an extensive literature on the concept of burnout in oncology professionals (Bressi et al., 2008; Emold et al., 2011; Mukherjee et al.,

2009; Sharma et al., 2007) and its more recent expression, compassion fatigue (Najjar et al., 2009). This was not a finding in my research.

A second type of support participants described was their use of both individual and group clinical supervision from a clinical psychologist. This has previously been recommended as a means of supporting CNSs in their work with patients with cancer (Absolom et al., 2011). Participants in this study turned to supervision to help them to manage the anxiety they experience through many aspects of their role. Participants described gaining reassurance specifically around whether they had done "the right thing" with patients and whether they had done enough for them. Clinical supervision helped them in managing the anxiety they experienced about doing a good-enough job for their patients. Similarly, in a study of nurses in cancer care, Palsson et al. (1994) described some of the narratives brought to supervision. They used the term 'overwhelming situations' to explain participants' sense of not knowing what to do. Others suggest that one of the key functions of supervision is to provide support and to reduce stress (Proctor, 1994; Wheeler & Richards, 2007).

With the level of autonomy that participants experience, some spoke of the need to share with others particularly when they have spent time working alone. Others described that sharing with others means they gain an understanding of how their peers might have responded; perhaps alleviating some doubt in their confidence in their abilities.

CNSs' work causes them to need to talk with someone who can help bring their experiences intro a form that is manageable. This role, with its element of offering continuity to and being with patients during difficult times, as well as the feelings and anxieties it raises, also means that CNSs experience a continuing need for a version of clinical supervision. Supervision offers a place of support where a person can express their anxieties, fears or even the impact that the client is having on the self. This is well attested to in the literature (Wheeler & Richards, 2007). Findings from this study clearly suggest the importance of clinical supervision as opposed to line management. Within healthcare structures supervision has often been viewed as line management, managing the patient's illness, rather than being a reflective space for the support or development of the practitioner, in this case the CNS.

Most of the supervision literature comes from within the counselling and psychotherapy field however this is also an emerging field in clinical psychology. Some literature argues that nursing is essentially about relationships with both patients and colleagues, therefore just as in the psychotherapy literature; there is a similar need for nurses to develop the interpersonal, emotional and self-reflexive skills in order to cope with their work which is often stressful (Bond & Holland, 2010). There are a range of models explaining the purpose of supervision (Wheeler & Richards, 2007; Proctor, 1991). These ideas have influenced clinical supervision in nursing practice and suggest that supervision can increase the competence of nurses, provide them with support and raise the quality of nursing care. The current study did not explore supervision in detail and this is an important future research area.

This study has also highlighted the way in which participants must tolerate an increasing level of uncertainty in their work with patients; that in offering psychological support participants need to tolerate their patients' health outcomes, and the 'not knowing' that the provision of psychological support entails. Casement (1985) highlights one of the roles of supervisory support as helping therapists work with the unknown and tolerate and stay with the state of not knowing. Whilst many of the CNSs in the current study are highly experienced and have done the role for many years, they still clearly articulate the need to be recognised and supported in their work. Irrelevant of experience level, previous studies support the current findings suggesting that even experienced staff express the need for support and being able to talk with their peers. There are however practical challenges such as limited time in order to access this support (Odling, 2002). Overall, participants in this research expressed the need to be supported and recognised both by their peers, in supervision and in the wider organisational context. These mechanisms of support and recognition of their work are important for all aspects of their work.

Existential Impact

Finally, this study has found that being a CNS in oncology and offering psychological support to patients not only has an emotional impact but also causes them to ask profound existential questions. The existential impact is wide-ranging. As discussed, participants build relationships with patients and their families. They have to face both certainty and

uncertainty in their work. CNSs are brought close to that which is certain; that not only those around them, but they themselves, will die. Yet they also have to face the uncertain with patients, when their prognosis is unclear. This existential impact, however, also includes participants' sense of gratitude and re-evaluation of aspects of their own lives.

Facing death and dying is challenging for CNSs in this study. When patients require end of life care they are transferred to palliative services. As a result, much of the literature into the impact of working with dying patients has focused on the hospice population (e.g. Hawkins, Howard & Oyebode, 2007). Yet this research has shown that participants still work with patients for whom there is no cure, and who will die as a result of their illness; the issue of death and dying is therefore pertinent. Previous literature suggests that nurses are often confronted with life-threatening, life-changing illness and death and as a result must confront their own anxieties about death, health, illness, loss, guilt and helplessness (Skogstad, 1997). Focusing specifically on CNSs, this study has found that whilst not always working directly with patients when it is clear that there are no more preventative treatment options, CNSs still encounter profound existential challenges. One of these is facing endings.

Participants in this study described facing endings with patients. They experienced an ongoing emotional and existential impact as they manage these endings, when their support is no longer required, or when patients die. Previous literature has suggested that when working with dying patients, nurses have to manage the expectation that the nurse-patient relationship they have built is to be severed (Peters et al., 2013) and they experience emotional distress, specifically feelings of loss when the nurse-patient relationship ends (Skilbeck & Payne, 2003). The present study takes these findings further and highlights some of the specific difficulties that CNSs encounter. Firstly, it is challenging for participants when their patients are transferred to palliative care. Having often built close relationships with patients, this is sometimes experienced as unsatisfactory. CNSs experience an early loss and one that is potentially unresolved because they are unable to see the patient through to the end. When discussing the transfer of a patient to palliative care Rachel articulated: *"That can be hard because you have built up a relationship with somebody and you want to be there until the end."* (Rachel, 835). This is also demonstrated in the value participants placed on gaining information about the patient from palliative care

once their own input has ended: *"I've found that a comfort, I like to know that because it puts a closing chapter on the end of that person's life."* (Marilyn, line 364).

In considering this, Freud's 1917 paper 'Mourning and Melancholia' is particularly relevant. He identified the importance of mourning as a normal and healthy response to grief and bereavement. Where he took our thinking forward was to suggest that the presence of 'melancholia' could be explained by the emotional loss that the person or object represented to the mourner. Such emotional investment in another is not always known by the person at the time, hence the experience of melancholy that goes beyond the normal experience of mourning. This experience of loss and mourning did not seem particularly problematic for CNSs. Worden (2003) focuses on grief tasks as opposed to grief or mourning processes. Rather than seeing bereavement as a linear process his research views it as the completion of specific tasks related to bereavement. These vary in time and intensity depending on each person. Part of the skill offered through psychological support is to establish what works for whom at what time. In an oncology setting aspects of these tasks can be worked through psychologically as each person prepares for the existential impact of cancer and the potential life-threatening aspects this introduces. It seems that this is what CNSs do. By offering psychological support, they enable patients to discover the nature of these emotional connections before any potential bereavement and identify specific tasks relevant for each patient. This was shown when Leanne spoke of patient writing down her daughters favourite gravy recipe: *"I know I'm going to die and I need I need… somebody to know everything about her"* (Leanne 735). This can also be applied to their own experiences of loss and bereavement when patients, with whom they may have close longstanding relationships, die. Participants experienced occasionally attending funerals and finding out about patients after the end of their care. This research has also identified the phenomenological impact of knowing the patients well; when such patients die (especially if they are young or younger than the CNS) it makes the sadness and loss experienced by some participants particularly difficult. Kubler-Ross (1969) surveyed over 5,000 health care workers including nurses, to discover their experiences with death of their patients. Approximately 98% of respondents struggled emotionally with some dying patients. A trend was noted in nurses, who identified that dealing with young patients and those of their own age was particularly difficult.

In discussing the existential impact of this work, these experiences can be discussed through the lens of existential theory (Cooper, 2003; van Deurzen-Smith, 1997; Yalom, 1980). Yalom's (1980) theory and approach are grounded in the understanding that all human beings face four existential concerns: death, freedom, isolation, and meaningless. Anxiety is generated from awareness of these and a vital task of human development is to confront the realities that each concern presents. This theory is applicable to this study in numerous ways. Firstly, Yalom (1989) posits that one of the prerequisites of offering psychological support to patients in distress is the need to tolerate uncertainty. When working with the emotional and psychological needs of patients, much of the work that goes on for patients is intrapsychic. Whilst patients might demonstrate observable changes that can be seen as a result of engaging in a therapeutic relationship, often these go unseen as the experience of the other is in many ways unknowable. Yalom (1989) wrote that in order to authentically engage with their patients, therapists often experience uncertainty. CNSs are working in the psychological domain which they themselves have identified as different to the physical in that there is a need to tolerate uncertainty: "*if somebody's got a pain you can give them a tablet can't you, and you want to be able to do that. But psychologically and emotionally, you don't, don't always have the answers, to help somebody*" (Claire, line 771). As such, in the provision of psychological support CNSs are not only being required to draw upon new ways of 'doing' with patients but new ways of 'being' with themselves.

Just as the patient comes close to confronting questions that are sometimes unanswerable, this process simultaneously exposes the CNS to these same questions. In becoming emotionally engaged with their work, and building relationships with patients, CNSs are exposed to the same existential issues as the patient and must confront and examine them in the same way. Clarkson (1995) wrote that this real relationship is 'the here-and-now existential encounter between two people … involves mutual participation in the process and the recognition that each is changed by the other' (p. 15). This study has clearly shown that CNSs are confronted with some of the existential questions that the patients themselves are faced with; the threat of illness and death. As a result some participants re-evaluate their own lives as they sense that the patient in front of them could also be themselves. Tillich (1952 p. 35) an existentialist philosopher and theologian wrote 'Anxiety is the state in which a being is aware of its possible non-being'. When a person realises their existence as they know it could be destroyed, anxiety is often experienced (May, 1967). Others have also

found that caring for dying patients is a particularly demanding role and causes nurses to face awareness of their own mortality and potentially anxiety (Peters et al., 2013). This study has shown that this can be difficult for CNSs. Participants expressed it being particularly difficult when patients deteriorate and there was a sense that in these cases the burden is heavier. These experiences portrayed the challenges that participants experienced in managing the underlying presence and threat of death. This is echoed in literature that highlights continual presence of existential threat, regardless of the phase of cancer (Lee et al., 2006).

Yalom's (1980) existential notion of freedom is also pertinent. It relates to an awareness of one's perceived responsibility to create one's world. He described this awareness as extremely frightening because it means an individual is responsible not only for their own successes but for their failures. It is important to hold this in mind when considering the anxiety participants experienced in relation to their ability to do a good-enough job for patients. Participants were confronted with the limitations of their personal and professional selves; that sometimes there is no more than can be done for patients. But in placing the patient at the heart of care, this can be difficult as participants described wanting to offer all that they can. There is a sense that they feel responsible for the outcome and seek reassurance from peers and supervision to help them manage their anxiety; that sometimes they feel they have done a good job, and at times they are concerned that they have not. Participants also experienced confronting their own limitations which at times can lead to a sense of helplessness and powerlessness in the face of illness of death. Participants must also come face to face with their own potential illness and death.

Other professionals, whose task is to offer psychological support and interventions such as psychotherapists and psychologists, are able to draw upon their theoretical basis or model to cope with the anxiety that working with patients can entail. For example, a psychodynamic psychotherapist might understand their own experience of anxiety in terms of projection, splitting or countertransference (Frosh, 2012). A person-centred therapist might understand this in terms of congruence or incongruence (Gillon, 2007). Both groups might use this theory as a way of making sense of and coping with the anxiety that can occur as a result of the therapeutic relationship that they build with patients. The challenge for the CNS is that whilst they have much experience of working with patients in distress, they have limited

training and therefore do not have the same theoretical depth to draw upon. In addition, it is clear that there is a distinction between the level 2 skills training and how this group of CNSs experience their role in practice. Whilst they clearly spoke of utilising the skills taught on the course, their accounts also focussed on the importance of the relational dimension of their work. They reported that this aspect of their role is supported through the use of clinical supervision. This group of CNSs did not view this distinction between training and role as problematic and most valued the training they received; however in practice, they are doing more than offering skills and techniques. They are building relationships with patients yet they are not trained as therapists. Within this they are exposed to some of the anxieties and existential questions that a therapist might face. As such they turn to their supportive others and seek reassurance that what they have done is satisfactory or that they have done enough for patients. As Malan (1995) discussed, what is fundamental to therapy is the fact that you cannot put right the bad things that have happened, but as a therapist you can help patients discover what they think and feel about it.

Lastly, Yalom's anxiety of meaninglessness relates to his understanding that the universe has no inherent meaning other than that which we bring to it. The meaning that we each create for example our understanding of ourselves and our world is captured in our individual identities. In order to cope with this existential concern an individual must develop a healthy identity. This is one way of explaining the uncertainty and ambivalence participants experienced in the development of their professional identity. In order to create meaning in their work with patients and in the provision of psychological support they must navigate this challenging process of developing their identity; a task that for the CNSs in this study is both complex and ongoing. They experienced facing the anxiety of being an autonomous adult who is free to make choices. In the role of psychological support they experienced fewer rules to fall back on than in the practice based nursing care that they have previously offered.

The narrative threads of ambivalence and uncertainty continue throughout the existential and emotional impact of working with patients. Participants experienced a wide range of emotional and existential responses in their work, some challenging and others more clearly having a positive impact. Cohen et al., (2011) found that oncology nurses view their roles as both stressful and rewarding providing support for the narrative of ambivalence that runs

through the results of this study. Alongside the challenges of this work, the present study has also found that participants experience a range of more positive emotional and existential impacts such as reward and privilege and a sense of gratitude for aspects of their own life, and particularly a renewed valuing of their own health. Others research has demonstrated that working with patients who are dying is a mutually beneficial process for both nurse and patient and enables nurses to consider their own mortality and begin to develop a level of comfort with death (Rittman et al., 1997). Yet this study has found that this is the case whether patients are dying or not. It is clear that for these CNSs this work brings with it personal rewards and professional satisfaction (Hartlage, 2012) as well as costs (Henderson, 2001).

Drawing these experiences together, some participants described that it is the satisfaction and the sense of making a difference that helps mediate both the emotional and existential impact and the challenges participants face as they learn what is possible in their control, and tolerate that which is not. Coming close to the difficult experiences of others as they build longstanding relationships in which the support they offer takes place, appears to be an essential part of their role. Despite the challenges they face at emotional and existential levels, if they feel that they make a difference, this helps them tolerate these challenges and making the impact worthwhile. Two quotes helpfully illustrate this:

> *'But I think we make a difference and that's kind of what keeps you going, but it is, there's not getting away from the fact that it is really sad.' (Anne, line 871)*

> *'for me knowing you are on the right track with people, and that you've built a relationship and that you've helped them, is kind of the emotional side of things you think, well at least it was worth it because, you know we've done all of that <laughs>' (Leanne, line 791).*

Overall, the impact of being a CNS in oncology and offering psychological support to patients is wide-ranging. CNSs highly value the relational dimension of their role but this is demanding, causing them to ask existential questions about life, suffering, death and leading to a re-evaluating of their own way of being. They see what they do as a privilege, but yet are fully aware of their limitations.

Summary

Taking this existential theory further in its application to this study, from a phenomenological-existential perspective the experience of CNSs in this study can be described as four key questions:

- *'Who am I?'*
- *'What do I do?'*
- *'What do I feel?'*
- *'Where do I belong?'*

The role of the CNS in oncology, and in offering psychological support to patients (and their families) with cancer is a varied, complex and dynamic experience for all participants. They experience little distinction between their role in general and the provision of psychological support; in many ways CNSs experience this as part of everything that they do and in who they are. CNSs face the challenge of developing their professional identity and this brings with it uncertainty and ambivalence. What is clear, however, is the tangible distinction between what is expected of and taught to CNSs, and what they do in practice. Rather than just the provision of psychological skills and techniques, in offering psychological support to patients, CNSs privilege the relational dimension of their work. As such they draw close to the experiences of others, building supportive relationships with those who have a threat to health. They therefore engage on an emotional level in their work. Ambivalence is clear; participants experience a wide range of profound feelings, attitudes and reactions. This work impacts CNSs on a fundamental level as they are faced with their own profound existential questions of 'who am I?', 'what do I do?', 'what do I feel?' and 'where do I belong?'. In considering these questions there is a pervasive thread of both uncertainty and ambivalence. While I have identified this ambivalence in the experience of CNSs in oncology offering psychological support to patients, I am not ambivalent or agnostic about my research or results. It is clear that CNSs play a crucial role in the care of patients with cancer, and in particular, offer well needed psychological support. For CNSs, whilst this role poses specific challenges, they experience great value, satisfaction and rewards in their work holding on to a sense that they make a difference. As such they are committed to improving the psychological physical and social wellbeing of the patient and should be supported in continuing this care.

Evaluation of Methodology: Strengths and Limitations

Design

Unfortunately only four of the six anticipated NHS trusts came on board with the study in time. In one trust the local collaborator dropped out of the study and therefore R&D approval could not be gained. In a second trust, gaining R&D approval was a lengthy process and at the point of approval the recruitment target had already been reached. Whilst this was not problematic due to the high and response rate from four of the six trusts, the potential recruitment pool was reduced by one third. I had aimed to recruit a range of participants from across the region; this meant that from one trust alone I recruited three participants. This sample might represent a self-selection bias, in that participants all reported being very interested in the provision of psychological support. There may be other CNSs who have done the level 2 psychological skills course who are less interested in this area of their work and have different experiences. Additionally, this was a female sample, however, there are males doing this role. A male sample might have produced a very different set of accounts. This might have the potential to reduce the general applicability of the findings to those who are interested the provision of psychological support within an oncology setting.

Data Collection

The use of semi-structured interviews enabled a flexible approach that could produce rich data. It was anticipated that this method would enable participants to talk about important experiences rather than being guided solely by the researcher agenda. One limitation of qualitative interviews is that they rely upon participants' recollection of events however this is valuable if a phenomenological approach to interpreting this data is used. Additionally, in this study participants work with very high case loads, and some found it difficult at times to recall examples of their work with particular patients. At times, participants expressed difficulty in recalling details of events and began to talk more generally about their work and share their opinions. As such they required further prompting to elicit particular experiential examples, which all participants did provide.

The accounts of experiences and events given by participants in this study are partial constructions just as memory of experiences is always partial and re-constructed. Data gained from interviews comes from the interaction between interviewee and interviewer

(Rapley, 2001). All interviews were undertaken at participants' place of work and a private space was requested. For one interview, the room was also a walkthrough to get to the kitchen and on one occasion someone walked through and back. On reflection, this disrupted the flow of the interview and potentially impacted on the depth of data gained.

As a result of this interaction between interviewer and interviewee, the questions and prompts that I used in the interview will have influenced the accounts of experience given by participants and may have meant that some experiences were not considered to be of interest or important by participants. Participants might have consciously or unconsciously made decisions to present themselves and their accounts of experiences in certain ways as a way of impression management. In this study it might have been that participants wanted to portray particular aspects of their psychological support to me, as a trainee clinical psychologist and not a nurse. Conversely, IPA researchers would argue that this may not need to be perceived as a limitation due to the fact that IPA is interested in experiences as the participant recalls it (Smith, Flowers & Larkin., 2009). Lastly, the fact that I am a psychologist in clinical training may have affected the accounts provided by participants. They were being asked about their provision of psychological support by someone whose main role in the provision of psychological support and therapy to patients. This may have affected and inhibited the way in which they talked about the training they received and their experiences of providing this support.

Quality Checks
Elliot, Fischer and Rennie (1999) suggest the following criteria for evaluating qualitative research: providing credibility checks; situating the sample; grounding in examples; owning one's perspective; coherence; accomplishing general vs. specific research tasks; and resonating with readers. Some of these criteria will now be applied to the present study.

Situating the Sample: This refers to the provision of a description of the sample, including key features and demographic details. Within the present study, detailed pen portraits and demographic information were provided. The pen portraits gave some information about participants' understanding of their role, highlights of the case examples they spoke about, their motivation for taking part in the study and some of the opinions they shared about their role in general.

Providing Credibility Checks: This is the process by which themes and interpretations are checked for their credibility. Within the present study, throughout the data analysis the individual participant themes were discussed with research supervisors. This involved going back to the data and assessing the credibility of my interpretations. Both supervisors also analysed a section of text from one interview and we compared the emerging themes in order to look at the credibility of my initial coding of the data. The master themes from the group analysis were also discussed at length with both research supervisors, again returning to the text. The qualitative research support group and discussion with a peer also doing an IPA study were utilised, to discuss reflections and thoughts about the analysis process. An additional method of credibility checking could have been to discuss the themes with participants themselves.

Grounding in examples: This is the process by which examples are provided to illustrate the way I have analysed and understood the data. An example of the data analysis process can be found in Appendix VII. The findings presented in the results section include participant extracts from the interviews in order to demonstrate some transparency in the analysis but also so that alternative perspectives and opinions can be considered by the reader.

Owning one's perspective: This refers to the awareness of one's own values and assumptions about the research, and demonstrating an understanding of how this might influence the interpretation of the data. I have provided examples of my own reflections about the topic area and the research process and how this might have impacted the research. This is in attempt to ensure the reader can make an informed decision about credibility of the findings.

Clinical Implications

The findings from this study suggest a number of clinical implications:

- CNSs described both benefiting from and valuing the level two training they had received and in particular the period of supervised practice after the course. Whilst CNSs experience their role as encompassing more than simply using the skills and tools taught on the course, they nevertheless reported finding this training useful. This finding is important, in light of current discussions around the future commissioning and provision of such training. It suggests that CNSs might benefit from the continuation of such training.

- In order to address the distinction found between the level two psychological skills training provided by clinical psychologists and the role that CNSs experience in practice, developments could be made to this training. This training could attend not only to psychological skills and techniques as highlighted in governmental documentation (NHS, 2004) but also to the process and impact of building relationships with patients as experienced by the CNSs in practice. Findings from this study suggest that it would be beneficial if training could include important areas such as self-care, 'being with' patients and tolerating uncertainty.

- CNSs experience the need for recognition and support and utilise support from both their peers and from clinical supervision. It is clear that clinical supervision is a vital resource and CNSs would benefit from receiving adequate supervision from appropriately trained professionals, who could be clinical psychologists. The distinction between line management and supervision needs to be maintained and therefore CNSs would benefit from receiving separate supervision and line management; an example of this recommendation is found in the British Psychological Societies' guidance (BPS, 2006). Developing relationships with patients has both an emotional and existential impact; CNSs are faced with issues of their own mortality. This further emphasises the need for adequate clinical supervision.

- This study has found that there is a significant emotional and existential impact on the CNS in doing this role in practice. This increases the value and place of personal development activities in this setting, including that provided by clinical

psychologists. This could provide support to CNSs as people not just focusing on the task components of the role but on the process issues that their work entails.

Future Research

The findings from this study lead to suggestions for future research:

- Tensions have been described in CNSs not developing their own paradigm and existing and drawing upon both the medical and psychological domains; this requires further research in order to further understand more about the professional identity of the CNS in oncology. The novel focus on psychological support in the present study has shown that clarity is needed around the expectations and role of the CNS in oncology offering psychological support to patients. Gaining this clarity might assist CNSs as they develop their own identity.

- It is clear that this group of CNSs utilise and value clinical supervision from clinical psychologists where available. Further exploratory research is warranted into the process and use of clinical supervision by CNSs who are providing psychological support to patients.

- This study has echoed previous literature and found that CNSs feel they play an important role in their MDTs and make a difference to the patient experience. It is important however, to understand this from the patient perspective and research is needed to explore the patient experience of receiving psychological support from a CNS.

- This research was only able to gain accounts of experience. An alternative methodology, such as one that enables the research to learn what CNSs actually do in practice would be useful, for example ethnography. Additionally, given the nature of the research it would be interesting to complete this research with an alternative interviewer such as someone unrelated to clinical psychology.

- Other groups of professionals and other clinical areas are utilising stepped care models in their provision of psychological support. This research could be replicated with these groups to gain an understanding of their roles and experience in the provision of psychological support in line with these models. It would be interesting to compare these findings with further research.

Conclusion

Clinical nurse specialists are an example of a group of professionals who are taking on psychological work with limited training and supervision. Whilst CNSs value and prioritise the psychological work that they do, this is a complex task. It requires them to identify and understand the nature of psychological support; a task which is challenging amidst their multifaceted role. Whilst psychological tools and skills can be taught and learnt, it is clear that for CNSs the provision of psychological support is much more complex. In working with patients with cancer (and their families) CNSs build relationships. Their role in offering psychological support is not just about the application of skills and techniques but involves drawing alongside patients whose threat to health can cause distress. There is a distinction between the role as identified by policy and in training and the practice and views of the CNSs themselves. Being a CNS in oncology and providing this psychological support has a profound emotional and existential impact. CNSs experience ambivalence in their wide-ranging responses to their work. Their role not only draws upon the professional but also the personal; the role of being human and available to others. CNSs are brought closer to the realities of both life and death. As they work with the holistic needs of patients including the provision of psychological support they draw upon both the psychological and medical domains and must answer the question 'Who am I?' At times they are drawn to offer tangible and practical support yet are learning that when working with the psychological this is not always possible. They experience the need to learn what is possible both as professionals but also as people who have a limited capability to fix and cure. They utilise and value support from their teams, peers and clinical psychologists through supervision. Overall, CNSs navigate the profound questions of: 'Who am I?', 'What do I do?', 'What do I feel?' and 'Where do I belong?' Through this, CNSs are concerned with and committed to the wellbeing of the patients and families with whom they work and for all participants in the present study these patients remain at the heart of their work.

Closing Reflections

I began this research by talking of my little personal or professional experience in oncology. As I have immersed myself in the experiences of a group of CNSs, I have learnt something of what it is like for other professionals to draw alongside people who are faced with a threat to health. As I have neared the end of this research I too, have been through numerous personal experiences that have caused me to reflect on the reality of both life and death. As such I have learnt through both my academic and personal journey. I began, unsure of the contribution of CNSs in the provision of psychological support. I now realise that for CNSs the provision of psychological support is far more complex than the application of particular psychological techniques. I appreciate the uncertainty and ambivalence in doing this role and in offering this psychological to support to patients with cancer.

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APPENDICES

Appendix I: Participant Email Invitation

Subject: Clinical Nurse Specialist Participants Needed

Dear CNS,

I am emailing you on behalf of Hannah Gormley who is a psychologist in clinical training on the course at the University of Leeds.

As part of her Doctorate in Clinical Psychology, she is conducting research into the experience of Clinical Nurse Specialists in Oncology. In particular, she is interested in finding out about your experiences of working with the emotional and psychological needs of patients.

You are eligible to participate in this research because you are a CNS working in oncology and have completed the level 2 psychological skills course.

I would be grateful if you could read the attached poster about the research study, to see whether you would be prepared to take part.

If you are interested, please get in contact with Hannah directly. If you do so, she will provide you with some more information about the research and arrange a mutually convenient time and location (your place of work or if you prefer, the University of Leeds) to meet with you.

Contact details:

Hannah Gormley (Psychologist in Clinical Training)
Telephone: 07970289884

Email: psc4hr@leeds.ac.uk
Postal Address:
DClin Programme
Leeds Institute of Health Sciences
University of Leeds
Charles Thackrah Building
Leeds
LS2 9LJ

Many thanks,

<LOCAL COLLAORATOR TO SIGN>

Appendix II: Recruitment Poster

UNIVERSITY OF LEEDS

Participant Information Sheet

Research Study: What is the experience of Clinical Nurse Specialists in oncology with reference to psychological support and the sense they make of these experiences?

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it would involve for you. Please read the following information carefully. If you would like more information please let us know.

What is the purpose of the study?
My name is Hannah Gormley and I am a psychologist in clinical training, based in the Leeds Institute of Health Sciences at the University of Leeds and employed by the Leeds Teaching Hospitals NHS Trust and I am carrying out this doctoral research study for educational purposes as part of my doctorate degree. I am conducting a study about the experience of offering psychological support to patients and am interested to find out more about the experiences of Clinical Nurse Specialists (CNS) working in oncology.

Why have I been invited?
I am asking you to take part in the study because you are a CNS working in oncology and have completed the level 2 psychological skills course.

Do I have to take part?
No, taking part in the research is entirely voluntary so it is up to you to decide. The aim of this information sheet is to give you enough information to make that choice. You are free to withdraw without giving a reason until 48 hours after the interview is complete at which point the transcription process will begin.

What will happen to me if I take part?
You will be asked to take part in an interview that will be conducted by me. The interview will take place at a location convenient for you, either the hospital you are based in or, if you prefer, the Charles Thackrah Building, University of Leeds. The interview would be arranged for a time convenient for you and would last about an hour. During the interview I would like to get an idea of your experiences of working with the emotional needs of patients and of providing psychological support. You would not have to give answers to any specific questions if you feel uncomfortable doing so. I will ask you not to provide any identifiable patient information. You will only have to take part in the interview once. However, if during the interview you feel that you would like to stop and continue with the interview at another time then this can be arranged. All

interviews will be audio-taped and typed up at a later date. All travel expenses incurred as a result of taking part in this study will be reimbursed.

What happens to the information collected in the interview?
All the information which is collected during the course of the research will be kept strictly confidential. The only exceptions for breaching confidentiality are if a) you give the researcher information that suggests you might be at serious risk or (b) you describe behaviour that suggests you have acted unprofessionally. In both cases the researcher will discuss this with their research supervisor, and inform you if she has to report this concern to the relevant authorities. Any information about you will be anonymised so that you cannot be recognised and no personal information will be included in the final report. All digital recorders and transcripts will be stored in a locked filing cabinet and will only be able to be accessed by the researcher and her supervisors. Recordings will be erased after the study is completed. Electronic files of the transcripts will be saved on the University secure drive for three years.

What are the possible benefits of taking part?
Participants in similar studies sometimes find that interviews allow them to reflect on their experiences.

What will happen to the results of the research study?
The results of the research will be written up by the researcher as part of her clinical psychology doctorate. A copy of the research will be kept in the University of Leeds library. The results will be published in academic journals and disseminated at research seminars and conferences. The research might also be submitted for publication in a peer-reviewed journal. You will not be identified in any way in the published reports; anonymised quotes will be used to illustrate the themes that emerge.

Who is organising and funding the research?
The principal investigator for this study is Mrs Hannah Gormley and the study is being run between: Leeds Institute of Health Sciences, University of Leeds, Leeds Teaching Hospitals NHS Trust, Bradford Teaching Hospitals NHS Trust, Airedale NHS Foundation Trust, The Mid Yorkshire Hospitals Trust, Harrogate and District NHS Foundation Trust, York Teaching Hospitals NHS Foundation Trust. The study is funded by the University of Leeds.

Who has reviewed the study?
This study has also been looked at by the University of Leeds Ethics Committee and has been found to be ethically sound. It has also been reviewed by each Trust's R&D committee and approved.

What if something goes wrong?
If at any time during or after the interview you feel distressed for any reason you will be offered the chance to talk to a Clinical Psychologist working with the Oncology Team. The researcher can provide you with these contact details. If you have a concern about any aspect of this study, you should ask to speak to the researchers (contact details at the end of the information sheet). However, if you are still unhappy and would like to

complain formally you can contact Clare Skinner, Faculty Head of Research Support, Faculty of Medicine and Health Research Office, Rm 10.110, Level 10, Worsley Building, University of Leeds, Clarendon Road, Leeds, LS2 9NL.

How do I join the study?
You have provisionally arranged a date and time in approximately two weeks to meet with the researcher. If you are still willing to take part in the research, having read this information sheet and having had any questions about the research answered satisfactorily, then the interview will be conducted at this time.

If you would like to ask any questions or require further information please contact the researcher using the details below and they will be happy to discuss these with you.

Mrs Hannah Gormley
Psychologist in Clinical Training

Email: **psc4hr@leeds.ac.uk**
Tel: **07970289884**
DClin Program, Leeds
Institute of Health Sciences
University of Leeds
Room G.04, Charles Thackrah Building
101 Clarendon Road
Leeds
LS2 9LJ

Thank you for considering taking part in this study.

Appendix IV: Participant Consent Form

UNIVERSITY OF LEEDS

DClin Program, Leeds Institute of
Health Sciences
University of Leeds
Room G.04, Charles Thackrah Building
101 Clarendon Road
Leeds LS2 9LJ

Consent Form

Tel: 07970289884

Participant Identification Number: _____

Research Study: What is the experience of Clinical Nurse Specialists in oncology with reference to psychological support and the sense they make of these experiences?

Name of Researcher: Hannah Gormley

Please initial box

1. I confirm that I have read and understand the information sheet dated _____ explaining the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

2. I understand that my participation is voluntary and that I am free to withdraw until 48 hours after the interview when the transcription process begins, without giving any reason and without there being any negative consequences. Should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I understand that relevant sections of my data collected during the study, may be looked at by individuals from the research team at the University of Leeds or from regulatory authorities, where it is relevant to my taking part in this research. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research ☐

4. I agree to quotes being used in the writing of a report on the understanding that my anonymity is maintained. ☐

5. I agree to the interview being audio-taped ☐

6. I would like a copy of the summary of results on completion of the study ☐

7. I agree to take part in the above study ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Researcher   Date   Signature

Appendix V: Approval Letter from Ethics Board

Faculty of Medicine and Health

Research Office

University of Leeds
Worsley Building
Clarendon Way
Leeds LS2 9NL
United Kingdom

✆ +44 (0) 113 343 4361

UNIVERSITY OF LEEDS

30 May 2013

Miss Hannah Gormley
Psychologist in Clinical Training
Programme in Clinical Psychology
Leeds Institute of Health Sciences
Charles Thackrah Building
University of Leeds, LS2 9LJ

Dear Hannah

Re ref no: **HSLTLM/12/065**

Title: **What is the experience of Clinical Nurse Specialists in oncology with reference to psychological support and the sense they make of these experiences?**

I am pleased to inform you that the above research application has been reviewed by the Leeds Institute of Health Sciences and Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine (LIHS/LIGHT/LIMM) joint ethics committee and I can confirm a favourable ethical opinion based on the documentation received at date of this letter and granted subject to the following condition:

- No research commences until Trust R&D approval has been obtained. (Please provide confirmation of NHS R&D approval to the committee when it has been received)

Document	Version	Date
University of Leeds Ethics Form 29.4.13	1	29.04.13
Email for advert 26.4.13	1	29.04.13
Study Poster V1 26.4.13	1	29.04.13
HGormley. Low Risk Fieldwork RA form 26.4.13	1	29.04.13
PIS V1 26.4.13	1	29.04.13
Consent Form V1 26.4.13	1	29.04.13
Interview schedule	1	29.04.13
HSLTLM12065 Reviewer 1 comments. HG response	1	23.05.13
Consent Form V2	2	23.05.13
PIS V2	2	23.05.13

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics Administrator for further information FMHUniEthics@leeds.ac.uk

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I wish you every success with the project.

Yours sincerely

Professor Darren Shickle
Acting Chair, LIHS/LIGHT/LIMM Joint REC, University of Leeds

Appendix VI: Interview Schedule

Semi-Structured Interview Schedule
Introduction and basic information

So, I'm Hannah Gormley and as you know I am really interested in your experiences of providing psychological support to patients with cancer. Thanks you for agreeing to meet today and offering to take part in the study. We've got about an hour today to talk about this. Do you have any questions?

<Consent Form>

<Remind participants not to provide any patient identifiable information>

1) Firstly, I was wondering what it was that made you interested enough in the study to come forward and be a participant?

2) Tell me about how you came to be a clinical nurse specialist in an oncology setting?

> {probes e.g. what was that like for you? Can you tell me a bit more? How did you feel about that? }

3) Would you tell me about what your day to day work involves?
> {probes: what's this like for you? What does your job involve you doing?}

> 3a) What aspects of this role you have described are most important to you and why?
> 3b) What training have you done in order to help you in that role? Can you tell me a bit more about this?

4a) You've mentioned psychological support as a (key) part of your role – what does the term mean to you?

OR:

4b) The literature on the role of the CNS suggests that one aspect of the role is providing psychological support. What does that term mean to you?

5) Thinking about the patients you have offered psychological support to (in the last 3 months), could you tell me about one case that would be broadly representative of the type of work you do?

- How would you describe what you did?
- Is that case representative of your work as whole?

- In the case you have just used what resources did you draw upon to provide the required psychological support?
- What was this like for you?
- How did you feel offering this support?
- So you've described feeling….. did you notice any other feelings?
- thoughts?
- So we've talked about the support you offered to other people – what kinds of support do you receive yourself?
- <if not mentioned the psyc course> I am aware that you have completed the level 2 psychological skills course – what role has this played (if any) in your provision of psyc support to this person?

6) Would you tell me about another case when you have found it <upsetting/more difficult/challenging> to provide psychological support?

   o What was this like for you?
   o How would you describe what you did?
   o Can you tell me a bit more about what it was that you think made it difficult/more easy?
   o How did you feel?
   o What was it like for you?
   o So you've described feeling… did you notice any other feelings?
   o Thoughts?
   o If and when do you feel anxious or concerned?
   o What do you do then?
   o What resources did you draw upon when you offered this support?
   o So we've talked about the support you offered to other people – what kinds of support do you receive yourself?

7) Would you tell me about a time where your work drew on the level 2 training course?

   <If this has been answered already ask: Would you tell me about a time where your work with a patient didn't draw on the training course but was more general?

   o What was this like for you?
   o How would you describe what you did?
   o Can you tell me a bit more about what it was that you think made it difficult/more easy?
   o How did you feel?
   o What was it like for you?
   o So you've described feeling… did you notice any other feelings?
   o Thoughts?
   o If and when do you feel anxious or concerned?

     o   What do you do then?
     o   What resources did you draw upon when you offered this support?
     o   So we've talked about the support you offered to other people – what kinds of support do you receive yourself?

Ending

So we're now close to finishing the interview. Overall, what do you make of the role you have in providing psychological support to patients? And psychological interventions?

<If not previously mentioned >
What was the training like for you? And how has it helped? What did it not help with?

Do you have anything else you feel you would like to say? Is there anything else that you think would be helpful for me to know?

<withdrawal of information>
Ask participant if they feel uncomfortable with anything they have said.
Discuss and agree with the participant on one of the following strategies:
a. if the participant is reassured at the end of the discussion, analyse and potentially draw on all data;
b. analyse all data but not draw on specific sections of the transcript for extracts;
c. withdraw an agreed segment of the data and analyse the remainder; withdraw the full interview.

Inform the participant that they can take 48 hours to consider this.

Thank you.
NOTE: Due the nature of semi-structured interviews the researcher will follow the participant in the interview and amend the interview schedule accordingly.

Appendix VII: Example of coding

anxious – always with patients like that? → like what?

Interview 1

Questioning capability

623	**P:** ermm I think yeah ermm initially I was like… I was a
624	bit worried like I always am with patients that are like
625	that, am I going to get into something that, is out of my
626	sort of remit but I've got more comfortable in saying
627	look I think, what we're dealing with here and what
628	we're talking about I can help you with to a certain
629	extent, but I think we need additional support, whereas
630	initially I used to think, I should be able to deal with
631	everything you know I should be able to make you
632	better I'm a nurse <laughing> whereas obviously, you
633	can't <laughs> and even seeing a psychologist or a
634	psychiatrist doesn't necessarily make it better
635	<laughing> does it ?
636	
637	**I:** <laughs> no
638	
639	**P:** it can just sort of like help guide them erm and err I
640	think, I've got more comfortable saying, I'm not
641	comfortable dealing with this because of whatever
642	reason, erm… because initially she when she was sort
643	of screaming and shouting at everyone, it is quite
644	difficult to get close to someone when that's what your
645	deal- sort of facing, erm but I'd I think was persistent
646	and I just kept saying, is it ok for me to come back?
647	And when she kept saying yes I kept thinking well
648	obviously she does want me to come back, if she'd of
649	said nooo, I think that would have been more difficult
650	[I:mmm] but because she said yes, I thought well
651	she's given me permission I'll keep coming back and I
652	just kind of spent time with her really we didn't
653	necessarily talk about her cancer when I originally
654	started going back… but then when she's told me
655	about her husband it was like <pause> yeah I can

Left margin annotations:
- Questioning capability
- developing confidence
- ideally as a nurse learning boundaries of role as CNS / & support
- *case example 1: How she feels offering support*
- developing confidence in role (& support)
- seeking reassurance from patient
- minimising role in being with – hard to articulate "being with"

Right margin annotations:
- Questioning capability
- Do I have the skills? get into something I can't cope with?
- Importance of time, things have changed as she spends more time in role.
- Importance of boundaries. more comfortable with limitations – pressure on self to fix. 'Social comparison'
- Prof identity as a nurse and what nurses should do? If they can't do it – is it ok I can't? – asking for reassurance from me? None of us can help so no one else is better than me.
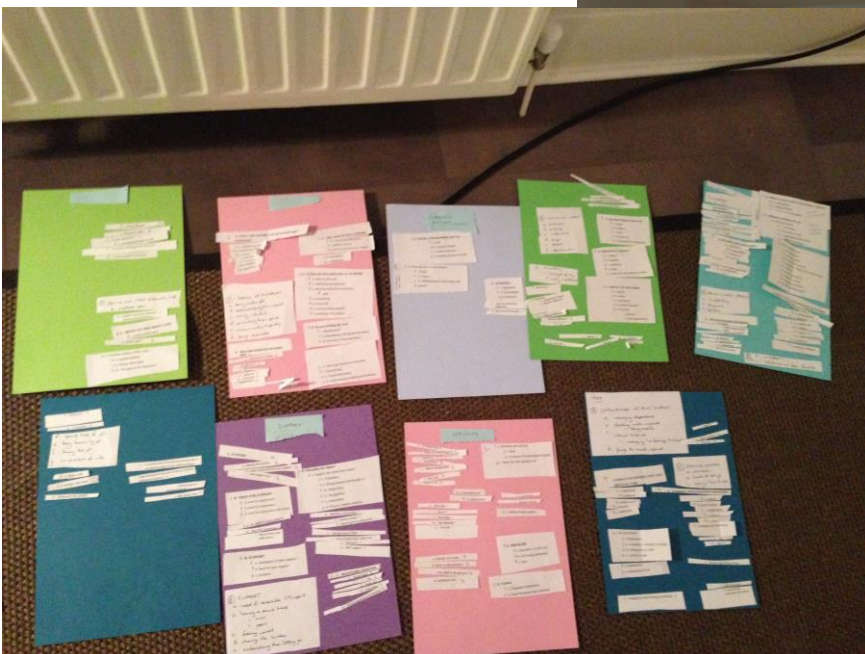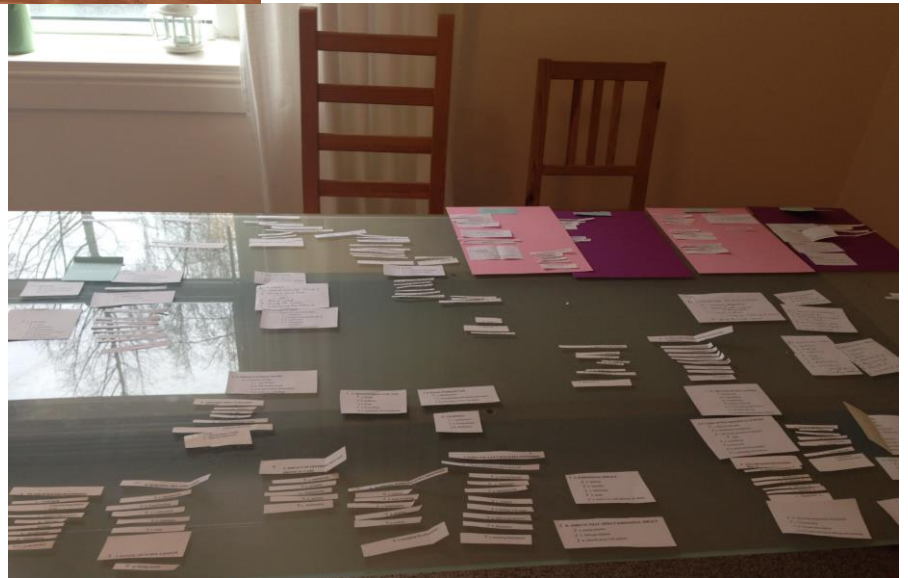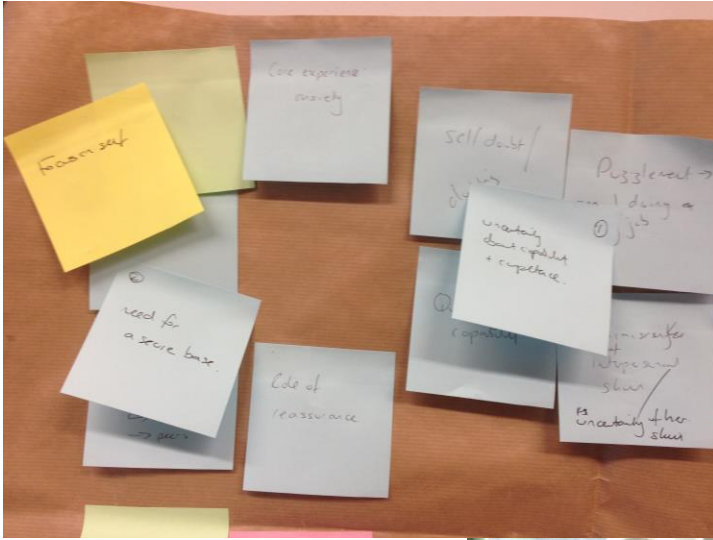- more comfortable with acknowledging limitations
- persistence / perseverance
- reassurance
- Hard if someone doesn't want help but seems to need it. – hard to not be wanted?
- playing down importance of spending time → does this feel less important?
- → feels like this feels to be the important stuff.

20

Appendix VIII: Photographs of individual and group analysis process

Appendix IX: Participant Theme Map

A. CONTEXT

    a. stress

    b. undervalued

    c. filling the gaps

    d. the need for psyc support

    e. misunderstood

    f. pulling things together

B. THE TASK OF PSYC SUPPORT

    a. being with

    b. normalising

    c. empathising

    d. being a safe base

    e. overcoming ambivalence

    f. problem solving

    g. hard to articulate psyc support

C. IMPACT OF THE WORK

    a. sadness

    b. burden

    c. satisfaction

    d. relating to patients

    e. frustration

    i. impasse

    ii. joint responsibility

D. NEED FOR SUPPORT

    a. need for supervision

    b. need for reassurance

    c. need for connection with others

E. ANXIETY

    a. questioning self

    b. doubting self

    c. model of a right way

    d. undervaluing her skills

    e. hard to tell you've done a good enough job

E. DILEMMAS

    a. PRIORITY

    i. guilt

    ii. commitment/self-sacrifice

    iii. managing conflict

b. HOW TO RESPOND

    i. the need to do

    ii. internal conflict

    iii. boundaries e.g. touch

    iv. acceptance – being with can be enough

    v. unfairness

    vi. containing emotion

    vii. difficult – no cure

    viii. transition of identity

    ix. painful learning process

c. OF STOPPING

    i. helplessness

    ii. acceptance – enough is enough

    iii. nothing else to offer

    iv. pulled to help

OVERVIEW OF THEMES

KEY THEMES	SUB THEMES			Leanne	Jackie	Rachel	Marilyn	Claire	Sarah	Judith	Anne
THE EVERYDAY EXPERIENCE	Being pulled in all directions			X	X			X	X		
	Being called upon			X					X		
	Providing continuity				X		X		X	X	X
	Being with patients			X		X		X		X	X
THE IMPACT OF WORKING WITH PATIENTS	Emotional impact	Sadness	Out of time	X		X		X		X	
			Knowing them well	X		X			X		X
		The burden of caring and being with		X	X		X	X		X	
		Anger & Frustration								X	X
		Reward & Privilege		X	X	X	X	X	X	X	X
	Existential impact	Facing an unknown prognosis							X		
		Facing Endings		X		X	X	X			X
		Gratitude				X		X	X		
		Re-evaluating life			X	X				X	
UNDERSTANDING AND WORKING OUT THE ROLE	Feeling misunderstood & undervalued			X	X			X			
	Pressure to justify the role						X			X	
	The difficulty defining the role					X	X	X			
	Emerging self-confidence in the role				X	X	X				
	Anxiety about doing a good job			X	X	X	X	X	X	X	X
	Learning what is possible			X					X	X	
NEEDING RECOGNITION & SUPPORT	Experience of sharing with others			X	X		X			X	X
	Needing reassurance			X	X	X		X	X	X	