

**The patient experience of stem cell transplant and
how survivor testimonies influence this: an interview
study**

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Submitted in accordance with the requirements for the degree of
Doctor of Clinical Psychology

The University of Leeds

School of Medicine

Academic Unit of Psychiatry and Behavioural Sciences

July 2017

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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ACKNOWLEDGEMENTS

I would firstly like to thank my supervisor Dr Siobhan Hugh - Jones, who supported and encouraged me to look deeper and write better, and always sent me back out of her office with renewed enthusiasm and confidence. I would also like to thank my field supervisor Dr Merry Hill, without whom this project would not have been created, and for her vital emotional support when it was difficult for me to hear and make sense of the stories I heard.

There are many people who helped along the way with recruitment, funding, transcribing and proof reading, without which the study would have ground to halt rapidly, thank you for often going above and beyond to support the work and myself. Thank you to Suzanne, Karen and Dr Gileece, without whom I wouldn't have any participants. Thank you to the Max Hamilton Fund for the research grant which enabled the transcription of the interviews to take place, this funding was essential to the research. Thank you to the Anthony Nolan charity, who funded the making and the editing of the filmed testimonies, particular thanks to Chiara and Billie. Thank you to Jade who put in many hours of painstaking work to transcribe the filmed testimonies. Thank you to Julie, for all her offers of help, especially in the final furlong for the time she spent proofreading the report.

Thank you to my family and friends who supported me through this process, my mum, dad, sister and Emily, who provided welcome distractions and encouraging nudges when I needed them. Thank you to my partner, Nathaniel, whose support has been unconditional, particularly over the last three years.

Finally I would like to thank the people who took part in the research, who gave up their time to help me and others and shared hopes and fears that were sometimes deeply personal and private. I was bowled over by the generosity of people who when they were facing the unthinkable, thought about helping others and I felt privileged to have walked alongside them for a little while in their journey. I hope I have represented their thoughts and feelings well and that this research will inform others about their experiences in the hope that they will be better able to support future patients.

ABSTRACT

Haematopoietic stem cell transplant (HSCT) is a treatment for some malignant conditions and is considered to be a demanding experience both physically and psychologically. This study aimed to explore (a) the experience of participants preparing for and undergoing a HSCT and (b) how they experienced viewing a film of survivor testimonies as part of this process. The survivor testimonies were designed to be used as a clinical intervention for people preparing for a HSCT. Seven participants were recruited and a multiple interview design was employed to explore their experience at three different stages of treatment. The interview data was analysed using Interpretative Phenomenological Analysis (IPA). The data cohered around a central theme of vulnerability, which changed over time, from being overwhelming, to being resisted, to being recalibrated. It emerged that the effect of the testimonies was overwhelmingly positive. Participants found the resource a hopeful and optimistic counterbalance to the fear and uncertainty they experienced being diagnosed with a life threatening condition and undergoing a potentially curative but also life threatening treatment procedure. The knowledge acquired from using a film as a stimulus in research interviews is discussed, along with the contribution to the existing literature on the experience of HSCT patients, the clinical implications of how the care of transplant patients can be improved and how the resource of survivor testimonies can be used to support patients going forward.

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KEY TO ABBREVIATIONS

HSCT	Hematopoietic Stem Cell Transplant
GvHD	Graft versus host disease
NHS	National Health Service
REC	Research Ethics Committee
IPA	Interpretative Phenomenological Analysis
PPE	Personal Protective Equipment
T1	Time point 1
T2	Time point 2
T3	Time point 3
MF	Myelofibrosis
HL	Hodgkin Lymphoma
T-PPL	T-Cell Prolymphocytic Leukaemia
CMML-1	Chronic Myelomonocytic Leukemia type 1
AML	Acute Myeloid Leukaemia
HIV	Human Immunodeficiency Virus

CHAPTER ONE: INTRODUCTION

This study explored the patient experience of receiving an allogeneic hematopoietic stem cell transplant (HSCT) as treatment for a haematological disease. The study involved interviews about experience, as well as patients' view of a short film purposefully designed as a resource to support those undergoing a transplant. This introduction sets out context for the study, including the assumptions of myself as the principal investigator and my relationship to the topic as well as the aims of the study and the approach. Chapter two reviews literature pertinent to the study.

The thesis takes the position that being diagnosed with a haematological disease is a cataclysmic event in a person's life. Unlike other types of cancer, the refractory nature of haematological diseases mean that there are generally fewer treatment options available and, compared to other cancer treatments, the physical and psychological demands of a HSCT are extensive (Biagioli, Piredda, Alvaro, & Marinis, 2016; Cooke, Gemmill, Kravits, & Grant, 2009). There are treatment related side effects from the pre-transplant conditioning treatment (usually chemotherapy and radiation therapy) and patients are in isolation for long periods of time, which takes a heavy toll on a patient, physically and psychologically (Perry, 2000; Rueda-Lara & Lopez-Patton, 2014). The outcome of treatment is uncertain and the patient may have to live with severe life-long side effects which can impact upon quality of life (Pidala, Anasetti, & Jim, 2009). The recovery process is estimated to be around one to two years, which can impact upon people's roles as caregivers and their ability to be financially independent (Baker, Curbow, & Wingard, 1991; Stepanikova, Powroznik, Cook, Tierney, & Laport, 2016).

The present study aims to bridge the gap in areas that have been under researched, such as how patients experience HSCT treatment at different stages, how their experience and needs change over time along with how patients can be supported using psycho-social interventions. This understanding can be used to inform the clinical practice of medical, nursing, social care and psychology staff working with these patients.

A hermeneutic phenomenological methodology was used to explore the experience of seven participants undergoing a HSCT over the course of three

interviews across the treatment and their experience of viewing a film of survivor testimonies prior to their own transplant.

My relationship to the topic was that I was training to be a clinical psychologist whilst completing the research as part of the Doctorate in Clinical Psychology training programme. Having worked in a Health Psychology department I was interested in how research can be used to understand psychological distress around illness and treatment, and whether psycho-social interventions can be used to support patients and relieve distress. I had several conversations with the field supervisor about her experience working as a clinical psychologist with haematology patients in a Psycho-oncology Service for 10 years. In her work, the field supervisor noticed that patients often reported they had felt unprepared psychologically when entering into the HSCT procedure. Whilst they were aware of what would happen during the course of their treatment through conversations with health professionals and written educational information, they were unprepared for, and had not spoken about how they might feel during the procedure and what they may experience emotionally. This gave rise to the idea of developing a resource where people who have already been through a HSCT could pass on their knowledge and wisdom about how they experienced the procedure and how they coped. The film of survivor testimonies developed during the present study was designed to be a source of hope as it showcases those who have already been through the experience, and survived the challenges.

The thesis begins with a literature review and a justification of the study. The literature review briefly outlines the tasks involved in a HSCT, what we already know from qualitative studies on the lived experience of patients and a summary of perspectives on using psycho-social interventions with HSCT patients. It is purposely not an exhaustive account of the literature available on HSCT but will focus on the areas relevant to the present study.

CHAPTER TWO: LITERATURE REVIEW

This chapter will begin by outlining some key experiences of patients undergoing a HSCT. It will then explore the most recent qualitative studies on the lived experience of patients, and studies investigating how a person uses information seeking and narrative resources in preparation for a HSCT.

2.1 Haematopoietic stem cell transplant as treatment

There were a total of 3,840 stem cell transplants in the United Kingdom in 2013 (British Society of Blood and Marrow Transplantation, 2013). Conditions using HSCT as a treatment include, but are not limited to, severe aplastic anaemia (bone marrow failure), blood cancers such as leukaemia (cancer of the white blood cells), non-Hodgkin lymphoma (cancer of the lymphatic system) and certain blood and immune system disorders such as sickle cell anaemia or thalassemia (National Health Service, 2015). Haematological malignancies are often candidates for a more aggressive cancer treatment such as HSCT because of their refractory nature and the lack of other treatment options for cure or maintenance (Rizzo et al., 2006).

Hematopoietic stem cells are blood-forming cells which either divide to form more blood forming cells or mature into different types of blood cell. A hematopoietic stem cell transplant (also known as a bone marrow transplant or a peripheral blood stem cell transplant) is a procedure which replaces the stem cells that have been destroyed by high doses of chemotherapy/radiation therapy during a pre-transplant conditioning phase. There are three types of HSCT; allogeneic (stem cells collected from a donor), autologous (recipient's own cells used) and syngeneic (donor is an identical twin). If a donor is being used, the stem cells are collected either by extraction via an operation from the bone marrow or through peripheral blood donation. The stems are transplanted to the recipient intravenously.

2.1.1 Risks and side effects

A HSCT is often a last option for a cure given the significant associated risks. Treatment-related mortality is high and survival has been quoted in the literature as

35- 40% in those under 40 years old with acute lymphoblastic leukaemia (Goldstone & Rowe, 2009). Even if the treatment is effective against the disease, a HSCT has a significant side effect profile from both chemotherapy and radiotherapy given in the pre-treatment stage. These side effects commonly include but are not limited to; nausea, loss of appetite, fatigue, hair loss, mouth ulcers and infertility. In 35 – 50% of cases following an allogenic HSCT, patients will develop graft vs. host disease (GvHD) (Jacobsohn & Vogelsang, 2007). This is when a donor's immune cells attack the recipient's organs. Symptoms are dependent on the specific organ targeted by the disease, often the skin, liver and gastrointestinal tract. As well as the underlying disease, GvHD is a threat to whether the HSCT is successful. Severe GvHD has poor survival outcomes with 25% of patients with grade III surviving longer than five years, which reduces to 5% for patients with the most severe GvHD (Ferrara, Levine, Reddy, & Holler, 2009). Following a HSCT, patients have been shown to have reduced life expectancy compared to the general population. Mortality rates are twice as high as the general population for HSCT survivors who are disease free at 2 years post HSCT and this remains significantly elevated 15 years post-transplant (Syrjala, Langer, Abrams, Storer, & Martin, 2005).

2.2 Psychological factors and whether they are related to survival

As well as being physically demanding, a HSCT is also psychologically demanding (Farsi, Nayeri, & Negarandeh, 2012; Perry, 2000), with estimates indicating that 50% of HSCT experienced distress before the treatment compared to 30% of other cancer patients (Cooke et al., 2009). HSCT patients used a variety of coping strategies to deal with the physical and psychological demands of the transplant and some have been shown to be more effective in reducing distress than others (Farsi et al., 2012; Fife et al., 2000; Mytko et al., 1996). The most common coping strategies used by HSCT patients and found in studies are; acceptance of the situation, seeking information, comparing one's situation to something worse, optimism and positive thinking, and religiousness (Farsi et al., 2012). Avoidant coping strategies have been associated with the highest levels of distress during transplant (Mytko et al., 1996). A further discussion of coping strategies employed by HSCT patients can be found in '2.4.5. Coping strategies'.

Several studies have found that psychological factors such as anxiety, depression, adjustment and coping styles can impact upon a patient's survival chances (Hoodin, Kalbfleisch, Thornton, & Ratanatharathorn, 2004; Molassiotis, Van Den Akker, Milligan, & Goldman, 1997; Pillay, Lee, Katona, Burney, & Avery, 2014); however, this is a contested area of the literature, with some studies disputing the relationship. A study that examined 31 patients, using psychological assessments prior to HSCT with a follow up 1-2 years post-transplant, Molassiotis et al. (1997) found that shorter survival was associated with disease specific factors (mismatched marrow grafts and disease progression) along with psychosocial factors such as higher symptom distress, less hopefulness and more acceptance of the situation. They proposed that "psychological/psychosomatic and personality characteristics may act directly by interacting with immune function or indirectly by leading to other behaviours known to affect survival in cancer patients" (Molassiotis et al., 1997, p. p271). Other studies have come to alternative conclusions that psychological factors do not directly influence survival, but they are related to the severity of the illness which is a predictor of mortality (Pillay et al., 2014) or sometimes they have found no direct relationship between psychosocial factors and survival (Broers et al., 1997).

In summary, psychological factors such as anxiety, depression, adjustment and coping styles may impact upon a patient's survival chances (Hoodin et al., 2004; Molassiotis et al., 1997; Pillay et al., 2014). There is also evidence that the ways in which patients cope with a HSCT may account for their psychological adjustment and quality of life following the transplant (Mytko et al., 1996). Whilst optimal ways of coping have been identified, a significant absence in our understanding is what effective interventions can be offered to support patients to either reduce distress or increase the use of effective coping strategies.

2.3 The lived experience of having a transplant

Qualitative studies have deepened our understanding of how people experience undergoing a HSCT. Exploring and understanding the experience of HSCT patients is important in order to develop effective interventions to support patients with the physical, psychological and social challenges of the treatment and to challenge ineffective clinical practice. A useful literature review on the experiences of HSCT patients (Adelstein, Anderson, & Taylor, 2014) was identified and will form a base to

explore current literature in this report. A further two studies exploring the qualitative experience of patients undergoing a HSCT were identified as being published after the literature review between 2013 and 2017 and were also considered.

2.3.1 The contribution of the Adelstein et al. literature review (2014)

Adelstein et al. (2014) published a literature review of studies on the lived experience of HSCT patients which included 24 studies published between 1989 and 2012. Of these, eight studies explored the lived experience of patients, five focussed on coping, four looked at psychological morbidity and three centred on post-traumatic growth. They concluded that the studies revealed physical, psychosocial and spiritual challenges that occurred during treatment and recovery from a HSCT. Coping style appeared to be a mediator in the level of adjustment to the challenges patients faced and importantly meaning-making or making sense of what had happened to them was an important part of effective coping. Those patients who found meaning in their experience were better able to manage their physical symptoms, and were less likely to report psychological morbidity after transplantation than those who struggled to find meaning in their experience. Therefore, Adelstein et al. (2014) recommended that interventions designed to promote meaning-making would be beneficial to patients undergoing a HSCT.

This next section will focus on what can be learned from the eight studies of lived experience identified by Adelstein et al. (2014) and a table (Table 1) illustrating the studies identified in Adelstein et al. (2014) is presented at the end of the section.

2.3.2 Physical symptoms and side effects

In the eight studies identified by Adelstein et al. (2014), physical side effects (fever, fatigue, pain, alopecia, cognitive issues, medication side effects, and changes in sexuality (Adelstein et al., 2014)) were a central concern of patients and brought about distress. Even though physical side effects caused distress and were a central concern, the majority of these eight studies reported physical symptoms as secondary to the psychosocial and spiritual challenges faced by patients (Adelstein et al., 2014; Persson, Hallberg, & Ohlsson, 1995; Thain & Gibbon, 1996).

We know little about the symptom experience of patients undergoing allogeneic HSCT, but remarkably a study by Bevans, Mitchell, and Marden (2008) found that

levels of emotional distress were higher before the patient underwent the treatment, even though they were not experiencing physical symptoms at this stage (Bevans et al., 2008).

2.3.3 Psychosocial concerns: Uncertainty, loss of control and facing mortality

Amongst the psychosocial concerns reported in the eight lived experience studies identified by Adelstein et al. (2014), they found that feelings of loss of control, facing mortality and uncertainty were common (de Carvalho, Gonçalves, Bontempo, & Soler, 2000; Gaskill, Henderson, & Fraser, 1997; Persson et al., 1995; Sherman, Cooke, & Grant, 2005; Thain & Gibbon, 1996; Xuereb & Dunlop, 2003). Patients experienced a loss of control because they were dependent on others, particularly nurses, for help. They experienced loss of control of bodily functions with vomiting and diarrhoea which caused them to feel humiliated (Persson et al., 1995).

Patients also experienced their lives being threatened both by the disease at diagnosis which would be fatal if left untreated and by the treatment which could either cure the disease or end their life. This experience was associated with shock and fear (Xuereb & Dunlop, 2003). The threat to life provoked both feelings of hopefulness and hopelessness about their expectations of the disease and treatment prognosis: “They seemed to concentrate on the threat to their lives; hovering between giving up and struggling for survival, trying to gain control” (Persson et al., 1995, p. 139). Thain and Gibbon (1996) noted that some participants in their study recast the odds of survival in their favour and others tried to distract themselves from thoughts of dying. Whilst they accepted thoughts that they may die, they wanted to concentrate on having a positive outlook, therefore managing their day-to-day mood (Thain & Gibbon, 1996). As well as the threat to life, Xuereb and Dunlop (2003) found that participants talked about the threat to life in terms of ‘valued aspects’, either relationships or activities; the meaning the illness and treatment had to each individual depended on the values that were most important to them in their life at the time of diagnosis and whether it threatened these.

Uncertainty was a major theme that emerged from several studies. Participants described uncertainty about whether they would survive and therefore could not make plans for the future other than putting their affairs in order in case they should not survive (Persson et al., 1995; Thain & Gibbon, 1996). Following a transplant, feelings of uncertainty are still present, but are focussed on the potential for relapse. Sherman

et al. (2005) found that uncertainty around relapse was most intense for those who were closest to transplant compared to those who had their transplant years ago. Participants were also uncertain about finances, work and relationships and whether they would ever return physically to their pre-transplant self (Sherman et al., 2005).

2.3.4 Relationships and role changes

In a number of studies, patients also described feeling isolated from family, friends and the outside world (de Carvalho et al., 2000; Gaskill et al., 1997; Sherman et al., 2005; Thain & Gibbon, 1996), although they seemed to understand the rationale for being in isolation whilst in hospital (Persson et al., 1995; Thain & Gibbon, 1996). For some, this seemed a temporary inconvenience, whilst for others it was frightening and represented abandonment (Thain & Gibbon, 1996). Whilst hospital rooms were set up with means to access the outside world, i.e. television, telephones and computers, the experience of isolation was most difficult for those who did not have daily contact with family and friends (Persson et al., 1995). Isolation became frustrating, particularly as patients approached discharge, and potentially this represented a desire to regain control of their lives (Thain & Gibbon, 1996). Support from family and nursing staff was important and strengthening of relationships was described.

Adelstein et al. (2014) also described other social concerns of patients identified by the eight lived experience studies. These social concerns were regarding the loss of relationships, role changes and changes in school or work goals (Gaskill et al., 1997; Sherman et al., 2005). Parents found that they were no longer able to be the primary care provider and that their role within the family dyad had changed. With friends they found they were frustrated by other's concerns, which seemed trivial to them now, and they also found that some friends were uncomfortable with their traumatic experience and distanced themselves (Sherman et al., 2005).

2.3.5 Coping strategies

In dealing with the illness, medical treatment and resulting psycho-social issues, patients were observed to adopt different strategies. Persson et al. (1995) observed coping strategies patients described included; gaining control of one's situation, developing knowledge and relying on family support.

Differences in coping may account for individual's adjustment to cancer and treatment (Cohen & Lazarus, 1979). Some active coping strategies (such as planning

and acceptance) are associated with reduced distress, whilst avoidant or passive coping strategies appear less effective at reducing distress in cancer and HSCT patients (Carver et al., 1993; Manne et al., 1994; Mytko et al., 1996; Stanton & Snider, 1993; Widows, Jacobsen, & Fields, 2000). Mytko et al. (1996) found that avoidant coping was related to more psychological distress, in particular, passive avoidance strategies (such as fantasising that a miracle would happen or that the stressor would disappear) rather than active avoidance (such as eating, drinking or smoking to feel better).

There are limitations when attempting to measure ways in which people cope with complicated life events such as cancer or HSCT. Studies commonly used measures of coping such as the 'Ways of Coping Scale' (Folkman & Lazarus, 1988), which takes a snapshot in time and it is therefore difficult to know the particular stressor the individual had in mind when completing the measure in the context of a HSCT because there are many stressors that could be affecting the patient. The measure also does not illuminate whether different coping strategies are adopted for different stressors, so evidence on the best coping strategy is likely to be limited. Research suggests cancer patients use a variety of coping strategies over time (Jarrett, Ramirez, Richards, & Weinman, 1992) and that this flexibility is beneficial (Carver et al., 1993).

2.3.6 Theories of coping with life threatening illness

There are a number of theories of coping with life threatening illness in the literature, which will be briefly considered here and two will be further examined in relation to the findings in the discussion chapter. Taylor (1983) proposed a 'theory of cognitive adaptation' to threatening events such as being diagnosed with a life threatening illness or receiving a risky medical procedure. In this theory, it is proposed that successful adjustment to the threat depends on to what extent the person buffers against the threat using 'illusions'. When referring to 'illusions', Taylor was describing how a person may look at the known facts with a positive slant. She argued that the adjustment process centres around three themes; making meaning, regaining mastery and restoring self-esteem (Taylor, 1983). Whilst some elements of this theory have been investigated further in relation to life threatening illness, particularly the role of meaning making for cancer patients, it is an older theory that seems not to have gained traction in the literature. It does appear to make intuitive sense that patients

would strive to make sense of what is happening to them, cope by gaining mastery over the task they face and also put a positive slant on their prognosis or situation. Therefore, it is possible that this theory has become common sense knowledge about how people cope with such adverse events.

A more popular theory is Kubler-Ross' model of the five stages of grief, which has also been applied to how people cope with life threatening illness (Doka, 1996). This model postulates that a person will move through five stages of emotional experience following a loss. There have been criticisms of the use of this model to understanding coping with life threatening illness, for example, it does not take into consideration the individual nature of responses (Doka, 1996). It was suggested by Doka (1996) that a more beneficial model would be task oriented, therefore taking into account the differing tasks faced by patients at each illness phase, and also it would consider the wide range of coping strategies employed to manage these.

There are theories of how people cope with traumatic events such as Janoff-Bulman's 'theory of shattered assumptions' (Janoff-Bulman, 1992) and 'terror management theory' (Greenberg, Pyszczynski, & Solomon, 1986) which can be applied to how a person may experience and adjust to being diagnosed with a life threatening illness and undergoing a HSCT. These will be examined further in the discussion chapter. The most recent theory identified for this literature review was Johnson's 'self-regulation theory of coping with physical illness' (Johnson, 1999) which is based on Leventhal's original 'theory of self-regulation' (Leventhal & Johnson, 1983). Johnson's theory uses cognitive psychology research into how people process information from their internal and external environment, incorporate this information with memories of past events and use this to make decisions on how to respond. It proposes that each individual will respond differently because they are guided by the meaning they ascribe to the event, their individual goals and how they appraise their responses (as moving them closer or further from their desired goal). Each time a person responds, they appraise their response and act according to that appraisal, and in this way, are self-regulating. A recent study by Baliouis, Rennoldson, Dawson, Mills, and Das Nair (2017) attempted to test whether the self-regulatory model could be used to explain the pattern of distress in patients undergoing a HSCT. Using questionnaires that measured anxiety, depression, stress, coping and illness perceptions, they found that greater distress was associated with

negative perceptions of the illness, HSCT and coping which provides some support for the self-regulatory model.

Some theories of how people cope with life threatening illness have been briefly presented, however there is an absence of a unified psychological theory of distress and coping in HSCT patients, which would bring together the knowledge gained from research into the many factors associated with distress and also the ways in which patients have been shown to cope. This lack of a unified theory may have hindered development of interventions aimed at supporting patients undergoing a HSCT (Baliouis et al., 2017).

Table 1 Table of lit review papers from Adelstein et al. (2014)

Year	Authors	Title	Method/Analysis
1988	Collins, Upright, and Aleksich (1988)	Reverse isolation: What patients perceive	Interview/Thematic Analysis
2014 Brazil	de Carvalho, E. C., Gonçalves, P. G., Bontempo, A. P. M., & Soler, V. M.	Interpersonal needs expressed by patients during stem cell transplantation.	Interview/Critical Incident technique
1997 Australia	Gaskill, D., Henderson, A., & Fraser, M.	Exploring the everyday world of the patient in isolation	Interview/Thematic Analysis
2004 Sweden	Persson, L., & Hallberg, I. R.(2004)	Lived experience of survivors of leukemia or malignant lymphoma.	Interview/Phenomenological-hermeneutic
1995 Sweden	Persson et al. (1995)	Acute leukaemia and malignant lymphoma patients' experiences of disease, treatment and nursing care during the active treatment phase: an explorative study.	Interview/Phenomenological-hermeneutic
2005 California, USA	Sherman, R. S., Cooke, E., & Grant, M.	Dialogue among survivors of hematopoietic cell transplantation: support-group themes.	Support Group/Thematic Analysis
1996 United Kingdom	Thain, C. W., & Gibbon, B.	An exploratory study of recipients' perceptions of stem cell transplantation	Interview/Latent Content Analysis
2003 Australia	Xuereb, M. C., & Dunlop, R.	The experience of leukaemia and stem cell transplant: searching for meaning and agency	Interview/Phenomenological-hermeneutic

2.3.7 Studies since the Adelstein et al. review (2014)

Two further studies which were published after the Adelstein et al. (2014) review were identified as important in understanding the lived experience of the HSCT patient and these will be discussed below.

The majority of studies investigating the lived experience of having a HSCT are qualitative interview studies, although there are a few studies using different methods including Mische Lawson, Chau, and Schoel (2015) which explored themes that emerged from patient's art-making in order to investigate the experience of undergoing a HSCT. Participants were asked to paint tiles to be displayed in the treatment centre's 'tiles of hope' project. The most dominant themes that emerged were around faith, hope, positive attitude, nature and social support. Less dominant themes were creative expression, fighting, appreciation, and negative expression. It was surprising that 'faith' had emerged as the most dominant theme in this study, as this did not emerge as dominant in the studies reviewed by Adelstein et al. (2014). The study was conducted in Kansas, United States of America and it is difficult to conclude whether this theme would be as dominant if the study was repeated in the United Kingdom. Statistics from the 2011 UK census indicated that 67.7% of people across England and Wales were affiliated with a religion (Office of National Statistics, 2013), compared to 80% of people in Kansas (Pew Research Center, 2014). The study stated that the tiles were used in a public art project within the hospital, and potentially this could have served as a social pressure to present positive or socially acceptable messages on the tiles, as these were to be viewed by members of the public and other patients. Participants may therefore have held back from presenting the 'darker' or less acceptable side of HSCT which others may have found uncomfortable.

Brassil et al. (2015) explored the experiences of 14 young adults between the ages of 18 and 24 using interviews. They identified the developmental priorities for young adults at this stage to be establishing identity; developing a positive body image; risk taking; exploring and confirming one's sexual identity; establishing autonomy from parents; increasing involvement with peers and dating; and beginning to make decisions about employment, higher education, and family commitments. A particular strength of the study is that it focusses on the experience of people who are in the same age group and therefore life stage. It is likely that the priorities of young adults at this developmental stage will be distinctly different than that of older adults and therefore

should be considered separately. Most other studies included participants with a broad age range and therefore may miss any differences across age groups.

In summary, qualitative studies that have investigated the lived experience of patients undergoing a HSCT have provided us with rich data to help us to understand what it is like to go through this intense and risky treatment regime. We know that there are many side effects of treatment and symptom distress can be high as the treatment progresses. Whilst treatment side effects can be painful and distressing, patients described the psychosocial impact of the HSCT as the most troubling aspect of the experience. Diagnosis is seen as a cataclysmic event, where a person goes from being healthy and in control of their lives to not being able to plan or predict their future and having to put their lives in the hands of others. Patients experienced loss of control, fear of death and uncertainty. This information is helpful for health and social care staff who are supporting patients during this experience. Enabling them to better recognise psychosocial problems that may occur and to support patients to understand what to expect (Persson et al., 1995), to plan and be involved in their treatment and to make sense of their experience and provide ideas of ways of coping (Persson et al., 1995). In coping with the challenges of a HSCT we see patients attempt to move from a position of powerlessness to a position where some control can be achieved and this is most effective when done in accordance with a person's values and needs (Xuereb & Dunlop, 2003). The studies reviewed so far that explored the lived experience of HSCT patients were useful in the present study to have an idea of what might emerge and compare to what actually emerged in participant narratives during the interviews.

2.4 Preparation for HSCT: Information seeking, testimonies and hope

The present study is concerned with the experience of the HSCT patient as they prepared for and underwent the transplant. 'Information seeking' was identified in previous studies as a coping strategy that patients used during the initial preparation stage for treatment and over the course of their transplant to shift them from a position of uncertainty to a position of more certainty (Persson et al., 1995; Xuereb & Dunlop, 2003). The intervention in the present study is a film of survivor testimonies designed to be shown to patients as they prepared for their transplant. The film was designed to provide information to the participants about how others experienced the transplant, ways in which they coped and also to instil hope. Therefore the following section will

focus on literature available on how HSCT patients prepare for their treatment, how patients gain knowledge and information about their treatment, how survivor narratives have been used in cancer research and the role of hope in HSCT.

2.4.1 Preparation

Preparedness is defined as a state of readiness for uncertain outcomes; it can help us to take advantage of opportunities and also to manage setbacks (Sweeny, Carroll, & Shepperd, 2006). The more prepared a cancer patient is for what will happen to them during treatment, the more their expectations and actual experience will align, the less shock they will feel and the easier it will be for them to integrate what has happened to them with their existing knowledge and assumptions (Brennan & Moynihan, 2004).

Preparation for HSCT at the specialist centre where this study was based involves a combination of written information given to the patients and verbal information in the form of meetings with a specialist nurse and the haematology consultant. A patient will meet at least twice with the consultant to discuss the HSCT as a treatment option, the likelihood of extended life or cure and the risks involved so they can decide whether to consent. Patients also have the option to meet with a specialist nurse who can answer any questions a patient may have and speak to the practical aspects of the transplant to support the patient in preparing for this. It is recognised that patients may find it difficult to effectively process information given to them in initial meetings with their consultant or specialist nurse due to high levels of emotion; therefore this is supplemented with a guide to transplant. This guide includes information on a whole range of topics from practical information such as, what happens at each stage of the transplant, and what foods you should avoid to information on how to cope with side effects and also information on the psychological impact of having a transplant. The aim of the written information is that patients have easy access to information that they are seeking, at a time they are able to process it.

Jacoby et al. (1999) argue that because there usually is no other viable treatment option for patients offered a HSCT, and without the HSCT their life will be significantly shortened, informed consent has little significance for the patient. The most important finding from this study was that an important factor for the patient in these meetings was whether they could trust their consultant, rather than whether they understood the information. According to the authors, the participants in the Jacoby et al. (1999) study

were not making a decision per se, as there was no alternative treatment and the meetings served to meet the emotional needs of the patients as well as the cognitive. The meetings were important for the patients in terms of building trust in their medical care team and therefore instilling hope and optimism for a positive outcome.

There is a lack of research into how patients can be supported in preparing for a difficult medical treatment. One study was identified that investigated an intervention aimed at encouraging patients to prepare for a transplant (Perry, 2000). It yielded promising results in terms of supporting the psychological adjustment of patients. Perry (2000) investigated the efficacy of using a checklist to prompt patients to explore key areas of preparation for their transplant, in the hope of increasing patient empowerment and reducing dependency. Perry found that participants who took part in the intervention were better prepared, less anxious and had fewer problems than a comparison group. Unexpectedly, it also found that the participants in the intervention group showed higher scores for hopelessness, helplessness and fatalism. Interviews were used to explore some of the results and it emerged that patients often requested information which was not supported by the hospital. Perry concluded that the study showed tentative indications that an intervention designed to increase patient empowerment resulted in better post-transplant adjustment. However, a larger cultural shift would be needed in the transplant centre in order to make use of the benefits of this intervention.

2.4.2 Information seeking

Information seeking is a common coping strategy employed by cancer and HSCT patients, particularly during preparation for a HSCT, and it appears to be part of the patient's attempt to cope with the disruption of cancer (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Increasing their knowledge, particularly through written material, was thought to also increase feelings of security (Persson et al., 1995) by reducing uncertainty and increasing control (Haberman, 1995). A qualitative study by Haberman (1995) using semi-structured interviews with 23 adults of mixed gender (male 61%), and predominately under 40 (78%), found that individuals diagnosed with leukaemia undergoing a HSCT often stated that they did not know what to expect from the procedure. In an attempt to make an unknown and uncertain future more predictable, participants recalled their own stories of previous cancer therapy which allowed a more vivid image to appear of what to expect. Averill (1973) suggested that people feel a

sense of control when they can generate a cognitive image of a future event using information they have been given. In support of this, preparatory information prior to a stressful medical procedure has been found to reduce psychological distress, anxiety and feelings of helplessness (Johnson, Fuller, Endress, & Rice, 1978), increase treatment compliance (Rainey, 1985) and resulted in faster recovery time (Wallace, 1986). Xuereb and Dunlop (2003) noted that when information was sought by HSCT patients in the hospital setting, they were often seeking a certain sort of information and their needs were not always met which caused considerable stress “Patients were especially interested in the concrete way that cancer would affect their everyday life, rather than its factual or statistical component” (Xuereb & Dunlop, 2003, p. 402). The film of testimonies used in the present study have been designed with this in mind, that often patients are seeking information that tells them what it is like to undergo the HSCT, which is a different quality of information than medical facts and statistics.

A major theme that emerged from a qualitative analysis of HSCT survivor discussions in focus groups conducted by Jim et al. (2014) was that patients desired to have “detailed” and “genuine” information from survivors. It appears that it is helpful to patients to unveil the mystery of what is ahead, in order to make their uncertain future more certain and to feel prepared or to avoid feeling unprepared as the unexpected becomes the expected. The study also found that participants typically adopted two different approaches to managing their anxiety through information; ‘monitors’ sought out lots of information from a variety of sources and ‘blunters’ avoided sources of information and found lots of information stressful.

Avoiding sources of information, as seen with patients categorised as ‘blunters’ may be linked to the coping strategy of denial: “You know it’s happening, you know it’s real, but you don’t think about it too deeply because you couldn’t cope with it if you did” (Brennan & Moynihan, 2004, p. 20). People sometimes use the defence mechanism of denial or avoidance to slow down the rate at which they process the new information and its implications (Brennan & Moynihan, 2004). In summary, the findings described above suggest the importance of allowing patients to choose the amount and type of information with which they wish to engage. It is therefore important to be guided by the needs, preferred coping style and resources of the patient. In the present study it is expected that those patients who adopt a ‘blunter’ style in relation to information

seeking would not be likely to participate, because they would not choose to participate in a study where they are asked to watch a film which provides more information.

2.4.3 Narrative communication as an information seeking strategy and as social comparison

Storytelling has been used as an intervention with cancer patients to encourage people to make sense of their experience, to problem solve, to instil hope (Chelf, Deshler, Hillman, & Durazo-Arvizu, 2000), to develop a coherent self and reformulate their identity (Hsieh, 2004) and reduce isolation when stories are told in groups, including internet support groups (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005).

Stories are used as tools to process their experience by those who construct them and they are also of value to those who hear them, to model how people cope with illness, and to provide encouragement to others (Hoybye et al., 2005). Survivors of cancer are experts by experience in managing the illness which make them an attractive resource of information to others undergoing similar experiences (Kreuter et al., 2008). Survivor stories have a greater impact on others when the listener values knowledge passed on through experience and sees it as a legitimate and useful source of information. When the listener identifies with the storyteller, views them as a similar other and likes them, the story is experienced as more powerful by the listener (Kreuter et al., 2008). It was hoped that the testimonies used in the present study would speak to the participant in this way, as the participant identifies with the survivor as a similar other and also an 'expert' in this experience.

As well as using the stories of other patients to gain information, research suggests that cancer patients also use them to gain a better understanding of threat by making comparisons between themselves and the person telling the story (Rini et al., 2006). Social comparison theory (Festinger, 1954) postulates that, in order to have a stable and accurate appraisal of ourselves, we compare ourselves with similar others in terms of the object of comparison. If the motivation behind the comparison is to better ourselves, we may make upward comparisons to those who we see as performing better than ourselves and we push ourselves to be better and more capable than them. In some instances, we may want to improve our self-esteem and make downward comparisons to those we see as less fortunate than ourselves (Taylor & Lobel, 1989). Using social comparison theory and the findings of the study by Taylor and Lobel (1989), I might

expect that the patients in the present study would make both upward and downward social comparisons depending on the motivation for making the comparison.

2.4.4 Hope

Snyder (2002) defines hope as a cognitive process, a way of thinking rather than an emotion alone. Hope is defined as “the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways” (Snyder, 2002, p. 249). As well as thoughts about goals, hope includes a process of appraising one’s abilities and motivations to pursue or achieve these goals. Snyder (2002) argues that the hope theory consists of:

1. Goals (setting goals, both short-term and long-term)
2. Pathways (finding different ways to achieve your goals)
3. Agency (believing that you have the motivation and resources to achieve your goals)

Individuals who become physically ill and who have high levels of hope have the benefit of being more focussed and motivated to do what they need to do in order to recuperate (Snyder & Lopez, 2002). Hopefulness has been associated with better adjustment in many physical illnesses and injuries such as burn injuries (Barnum, Snyder, Rapoff, Mani, & Thompson, 1998), spinal cord injuries (Elliott, Witty, Herrick, & Hoffman, 1991) and blindness (Jackson, Taylor, Palmatier, Elliott, & Elliott, 1998) by helping people to cope with pain, disability and other stressors of the physical illness.

In cancer research, hope is viewed as a way of coping with fear, so hope of survival would be a way to manage or cope with a fear of death (Cohen & Ley, 2000). Cancer patients have also been found to gain a sense of hope after hearing the stories of cancer survivors (Rini et al., 2006) and it is therefore expected that the film of survivor testimonies will also foster hope in participants.

2.5 Study Rationale

There is a high rate of unmet needs in HSCT patients identified as physical, psychological, financial and informational (Barata, Wood, Choi, & Jim, 2016). It is

estimated that 51% of haematological cancer patients have at least one unmet psychological need, and 25% have seven or more (Barata et al., 2016). This is based on findings of a review which was completed in Spain, relying heavily on a study conducted in Australia but also based on many studies from around the world. The findings may differ across countries, depending on the quality of health and social care available for patients; however, it is likely that unmet need in HSCT patients in the UK is also high. Whilst there was a high level of psychological and informational need identified, the literature review set out in this chapter has also identified that there is a paucity of research that investigates interventions that address these concerns of patients, and supports them. Barata et al. (2016) call for research into psychosocial interventions aimed at reducing distress and this is echoed in research by Adelstein et al. (2014) and (Perry, 2000) which indicated that research such as the present study is urgently needed. The film of survivor testimonies has been designed as an intervention to support patients and an exploration of how patients experience this will help to bridge this gap in the research. The film of testimonies is designed to be a source of information that can be re-watched. It was designed this way because patients find it difficult, in the preparation for a HSCT, to absorb information. The film was also designed to speak to the emotional aspects of the transplant as well as the cognitive and instil hope that they will be able to manage the demands of the transplant, because patients place importance on building hope and optimism about the treatment.

Previous studies have tended to focus on the patient's experience either following diagnosis or after the transplant, therefore we do not know whether the needs of the patient change over the course of the treatment. There is a need for studies that explore the patient's experience of the transplant procedure itself to better inform healthcare professionals of that experience and assist them in supporting patients and meeting their needs. A gap has been identified in the literature on how patients experience different aspects of the treatment and whether their experience changes over the course of the treatment. There is therefore a need for studies to interview multiple times over a HSCT procedure because it is lengthy and previous studies relied on the patient's recall of the experience. Patients' recall of the experience may have altered with hindsight and patients may have different needs at different stages of the transplant, which is unknown. The present study will attempt to bridge this gap by exploring the patient's experience at different stages of treatment.

2.6 Research aims and objectives

Aim 1: The aim was to explore the experiences of undergoing what are termed last option medical procedures that have high morbidity and low survival. Objective 1.1: this was achieved through a longitudinal, hermeneutic and idiographic interview study of people with haematological disorders as they prepared for (interview 1), undertook (interview 2) and recovered from (interview 3) a HSCT.

Aim 2: A secondary aim was to explore the potential of patient testimonies in enhancing the life of those undergoing such procedures. This was achieved first by constructing an intervention based on and using patient testimonies of a HSCT (Objective 2.1) and second, this was achieved through a hermeneutic and idiographic interview (interview 2) nested into the longitudinal study prior to transplant (Objective 2.2).

CHAPTER THREE: METHODOLOGICAL FRAMEWORK, DESIGN AND METHOD FOR AIM ONE (LONGITUDINAL COMPONENT)

This chapter describes the methodological framework, design and method of data generation and analysis for the longitudinal component of the study, which addresses aim one. In order to study the patient's experience of undergoing a HSCT and of viewing survivor testimonies, a longitudinal, interview design was used. A qualitative approach was adopted given its capacity to describe, understand and explain subjective, intra- and interpersonal experiences, through gathering rich and detailed accounts (Geertz, 1973).

3.1 Methodological approach

As the aim of this research was to explore the experiences of patients, a qualitative approach was an appropriate one. Qualitative methods in psychology involve the gathering and analysis of text-based data (Smith, 2008). These methods are generally adopted when the researcher is concerned with exploring, describing and interpreting the experiences, both personal and social, of those under investigation (Smith, 2008). A phenomenological, hermeneutic, and idiographic approach was used and an Interpretative Phenomenological Analysis (IPA) framework was adopted and described below.

3.1.1 An interpretative phenomenological approach

Commonly used approaches to data analysis in qualitative research include, for example, grounded theory, interpretative phenomenological analysis, narrative analysis and discourse analysis (Frost, 2011). An Interpretative Phenomenological Analysis (IPA) approach was decided as the most appropriate approach to analyse the interview data given the research aims.

3.1.2 Alternative methodological approaches

Grounded Theory (Corbin & Strauss, 2014; Glaser & Strauss, 1967) can be considered similar to IPA, considering its emphasis on interpretation and meaning. A grounded theory approach to exploring experience of HSCT and filmed survivor testimonies

would have used participant interview data to inductively derive a model or theory of the factors that influence preparing for, and undergoing a HSCT. The focus of the present study was to examine what it is like to have HSCT rather than develop an explanatory level account of the factors and influences therefore, a Grounded Theory approach was not considered suitable.

An alternative approach of Thematic Analysis (TA) (Braun & Clarke, 2006) was considered but not deemed the most appropriate as IPA has a robust theoretical background, which TA does not. The benefit of IPA is that it focuses on the particular both by examining the data in painstaking detail (which enables a depth of analysis) and also by focusing on particular people's understanding in a particular context of a particular phenomena (an event, process or relationship) (Smith, Larkin, & Flowers, 2009). IPA has a theoretical underpinning around phenomenology and pays much closer attention to the individual and their context first, before group level analysis. This is important because each participant, whilst receiving the same treatment may have had a different experience getting to this point from diagnosis. For some participants it has been a relatively short journey, three months from noticing symptoms, having a diagnosis to HSCT. For others they have lived with the illness for many years, undergoing many different treatment regimes before getting to this point. The experience of each participant of this procedure will also be based upon all of their life experiences up until this point.

3.1.3 Ontological and epistemological framework of IPA

IPA was first used as a distinct research method in the mid 1990's by Jonathan Smith and is a relatively new approach to qualitative research (Frost, 2011). IPA focuses on the person's lived experience. It attempts to understand a person's point of view, and examine how they are making sense of their world (Frost, 2011), although, it emphasises that there is an active role for the researcher in that process (Smith & Osborn, 2008). The researcher cannot gain direct access to a person's experience; it must be interpreted by the researcher and therefore is subject to the researcher's interpretative activity (Smith & Osborn, 2008). IPA involves a double hermeneutic, as 'the participant is trying to make sense of the world, the researcher is trying to make sense of the participants making sense of their world' (Smith & Osborn, 2008, p. 51).

An IPA approach to research is often conducted when the topic has a considerable existential significance, such as health and illness, or with issues of identity, such as sexuality or life transitions (Smith et al., 2009). IPA is particularly relevant to health psychology research and the vast majority of IPA studies published are in this area (Brocki & Wearden, 2006). In the past health research has focused on the biomedical model of illness, where a person's symptom experience maps simply onto a disease or illness profile; it is now recognised that a person's construction of the illness has a role to play in their experience which has increased interest in how a patient experiences, interprets and makes sense of their physical experiences (Brocki & Wearden, 2006; Smith, 1996). IPA draws on theoretical ideas from phenomenology, hermeneutics and ideology which are briefly outlined below.

3.1.4 Phenomenology

Phenomenology, founded by Edmund Husserl in the early 20th century is a philosophical method of inquiry into what it is *like* to be human (Smith et al., 2009). Several key thinkers as well as Husserl have influenced the development of phenomenology, namely Heidegger, Merleau-Ponty and Satre. Smith et al. (2009) point out that the value of phenomenology philosophy for psychology research is that it helps us to think about how we might examine and scrutinise lived experience. Husserl maintained that all of our knowledge comes through our consciousness, since nothing could ever be spoken about or witnessed otherwise (Giorgi & Giorgi, 2008). Husserl was particularly concerned with how people might come to know their own experience of a phenomenon (Smith et al., 2009). He was interested in how he might go about creating the right circumstances so that a person may be able to identify the essential qualities of an experience and communicate them, stripping back the tendency for humans to order things and fit them into pre-existing categories. This human processing of experiences gets in the way of knowing the essential qualities of the experience for the person. This is the phenomenological process of reflexivity, whereby humans attempt to disengage from the taken for granted nature of our everyday experiences and attend to the those experiences (Smith et al., 2009). Phenomenological research aims to illuminate and capture as closely as possible the way a phenomenon is experienced (Giorgi & Giorgi, 2008).

3.1.5 Hermeneutics

IPA involves interpretation which is guided by hermeneutics theory, itself influenced by philosophers such as Schleiermacher, Heidegger and Gadamer (Smith et al., 2009). It was largely concerned with providing a robust foundation for the interpretation of written texts including biblical, historical and literary works. Schleiermacher argued that the interpretative process involves understanding the writer as well as the text, and if the researcher engages in an analysis that is detailed, comprehensive and holistic then they may offer an interpretation that has meaningful insights which includes, but also may exceed, the explicit claims of participants (Smith et al., 2009). The interpretative analyst is able to do this because of their unique perspective which emerges from a detailed analysis of the data, an awareness of the context in which the data was produced, as well as access to the larger data set and to psychological theory (Smith et al., 2009).

Phenomenology and hermeneutics were linked by Heidegger who wrote about human discourse as having different levels of meaning, an easily accessible surface meaning and also a concealed meaning (Moran, 2002). Heidegger observed that phenomenology is made up of two parts derived from the Greek *phenomenon* translated as 'show' or 'appear' and *logos* which can be approximately translated to mean 'discourse' or 'judgement'. Therefore, phenomenology is concerned with examining the thing which may be disguised or latent as it appears (Smith et al., 2009). Rather than suggesting that the meaning of the participant's discourse is concealed from them and needs to be interpreted by the analyst, Heidegger saw phenomenology as understanding the thing as it shows itself, how it appears on the surface, as this will be connected with the deeper latent form (Smith et al., 2009).

Gadamer emphasised the relationship of the interpreter to the data; that there is a dialogue between the analyst's pre-conceptions and the data (Smith et al., 2009). Interpretation can be hindered by the pre-conceptions of the analyst, which is why it is important for the analyst to be aware of these (as far as this is possible) through a process of reflexivity; at times the analyst is aware of his or her own pre-conceptions, whilst some are revealed as they engage with the data. Many remain out of conscious awareness. See 'Reflexive Box 2 and 3' in the results chapter for a discussion of my experience with becoming aware of potential influences and biases. The analyst approaches the data through the veil of his or her own biases and also cannot have direct

access to the participant's experience, but in reality produces "an account of how the analyst thinks the participant is thinking" (Smith et al., 2009, p. 80) which is termed a 'double hermeneutic' in IPA.

3.1.6 Idiography

The third major influence on IPA is idiography, which is a focus on the particular. This is in contrast to the 'nomothetic' approach which seeks generalised claims about the laws of human behaviour (Smith et al., 2009). IPA focuses on the particular both by examining the data in detail and also by focusing on particular people's understanding in a particular context of a particular phenomena (an event, process or relationship) (Smith et al., 2009). In order to do this, IPA studies use small and selected samples and often utilise single case studies. However, IPA deploys analytic processes to move from a single cases to group levels claims (Smith et al., 2009).

3.1.7 Reflexivity in qualitative research

To be reflexive means to 'bend back upon oneself' (Finlay & Gough, 2008) and in research refers to a researcher being critically self-aware of how their background, experiences and pre-existing theoretical knowledge may shape their research findings (Finlay & Gough, 2008). Researchers engage in a process of reflexivity in order to demonstrate that their findings are trustworthy (Finlay & Gough, 2008).

A challenge in the present research was that I may already "know too much" (Snelgrove, 2014). As a clinical psychologist in training who has had much experience of studying psychological theories, there was a risk that I would not approach the data with an open mind from the start and would apply psychological theory too soon. I also had to guard as far as possible against using common sense assumptions about what it is like for the participants to undergo a HSCT. It is impossible for a researcher to put aside or 'bracket' all of their prior knowledge and assumptions (Snelgrove, 2014). However, they can put in place processes to try to identify when they are using these assumptions or prior knowledge and acknowledge the impact on analysis (Snelgrove, 2014). I kept a research diary of thoughts, feelings and knowledge on the topic in the research design stage and added to this diary before and after research interviews and when thoughts and feelings seemed to emerge in daily life. This was my attempt to monitor the impact of any pre-existing theoretical knowledge, assumptions, beliefs or experiences that may

be impacting on the analysis. I also used research supervision to try to identify potential bias, to act as a check for and improve the transparency of the analysis. During this process the supervisor questioned some interpretations of the data, prompting me to reveal the process of coming to particular conclusions which often made explicit some knowledge I had of the participant which had not previously been made explicit. This added a level of transparency to the analysis, improving the quality. Examples of the process of reflexivity throughout the research are given in the reflexive boxes distributed throughout the report.

3.2 Design

A longitudinal, hermeneutic and idiographic interview design was deemed the most appropriate method to generate data to meet the research aim. Several data generation methods were considered, including a mixed methods approach using surveys to investigate participants' experience of the testimonies alongside outcome measures of coping, anxiety and depression. However, this approach was deemed problematic, as it would involve predicting a priori the experience of a HSCT and ways in which the testimonies might impact upon participants (i.e. that the experience of a HSCT would be shaped by coping and that the testimonies might impact on fear and anxiety). It would also be difficult to demonstrate that any change in the outcome measures was because of the testimonies. Given that we know little about how people engage with testimonies, and that undergoing a HSCT is complex and subjective experience, it was thus considered more appropriate to utilise an exploratory methodology rather than a hypothesis driven approach.

An exploratory method can be operationalised in many ways. Focus groups were considered, but rejected, given that: (i) it is not possible for participants to gather in a focus group until after they have received the HSCT and are recovered enough to be discharged from hospital; and (ii) participants would only be well enough to gather in a group once they have recovered - therefore, they would have to recollect their experience of the HSCT and testimonies many months after the event.

3.2.1 Qualitative interviews

Face-to-face semi-structured interviews were chosen as the most appropriate method to gather descriptions of the interviewee's life world (Brinkmann, 2013). 'Life world' is a term used by the phenomenologist Edmund Husserl in 1954 to describe the world in which individuals experience phenomena and inter-subjectively share it. Phenomena are first experienced, which can be described as the essence of experience, before it is understood on any other level, i.e. by categorising it. Therefore interview questions posed were ones which aimed to elicit descriptions of the interviewee's experience first, before any understanding of why they might be experiencing this is explored (Kvale, 1983).

Utilising a set of pre-determined but broad topic areas to cover during the interview, ensures that interviews focused on the area of interest so that the research questions could be answered whilst also allowing for flexibility by following up on participant's statements and or permitting the interviewer to partly shape the direction of the interview (Kvale, 1996). It is important to remember that interviews are suited to exploring participant's subjective experience if the researcher holds in mind that the data is also co-constructed with the interviewer. The way the study is framed for the participant, the pre-determined topic areas and the interviewer's reactions and emerging questions in the interview all impact upon the data that is generated as interviewees orient their narrative to what appears to be of interest (Kvale, 1996).

Often used in health research (Smith, 1995; Smith, 1996; Smith, Flowers, & Osborn, 1997), semi-structured interviews have been used to good effect by others investigating the experience of people undergoing a HSCT (Coolbrandt & Grypdonck, 2010; Haberman, 1995; Xuereb & Dunlop, 2003). Semi-structured interviewing also drew upon my skills as a Psychologist in Clinical Training, including rapport building, active listening, and communicating empathy in order to support participants to tell their story.

3.2.2 Multiple interviews with participants

In the present study, it was expected that some participants may have been diagnosed many years ago with the illness that has led them to eventually require a HSCT. "Illnesses occur over time and it is over time that the processes in which IPA is

interested unfold” (Brocki & Wearden, 2006, p. 9). Incorporating multiple interviews with the same participant was chosen because of the potential benefits of having a temporal context to the research (Flowers, 2008). Having multiple interviews allows participants more space and time to talk freely about their illness history, which provides context to their experience of the HSCT and testimonies. The experience of participants may change over the duration of the HSCT, particularly as this process has distinct phases and can take a few months to complete. Interviewing participants once after the transplant may elucidate how the participant experienced the transplant in hindsight, which may be different to how they made sense of their experience when they were actually undergoing the treatment.

According to Grinyer and Thomas (2012), there are several benefits of multiple interviewing including assisting the development of rapport, which may mean the participant feels more comfortable to disclose personal and emotional information. See ‘Reflexive Box 1’ for an exploration of rapport building in the research interviews. Having multiple interviews rather than one longer interview is less tiring for participants who are unwell, as in the present study. There is also the benefit of having the opportunity to end a conversation, particularly if the participant becomes distressed, knowing that it can be picked up at a later interview. The gap between the interviews can allow both the participant and researcher to reflect and possibly to clarify ideas in subsequent meetings and each interview can focus on a different aspect of the participant’s experience.

Whilst repeat interview designs are less common than a single interview approach, it has been suggested that using multiple interviews with the same participant can uncover greater detail, depth and complexity of meaning of a person’s experience (Hollway & Jefferson, 2000) as well as promoting knowledge of patient’s evolving experiences and needs over time (Murray et al., 2009; Snelgrove, 2014) . There are examples of this approach being used to good effect in health research, for example when studying how women experience their body post breast cancer surgery (Slatman, Halsema, & Meershoek, 2016), care experiences of patients with life limiting conditions in minority ethnic groups (Worth et al., 2009) and newly diagnosed type 2 diabetes patients’ adjustment over time (Peel, Parry, Douglas, & Lawton, 2005).

Conducting multiple research interviews with the same participant poses challenges of (i) sample attrition, a particular problem in health research where participants may become too ill to take part in further interviews and may also die during the study timeframe (Grinyer & Thomas, 2012) and (ii) demands on time. Meeting with participants several times encouraged the development of increased empathy and closeness which was beneficial for building trust and encouraging openness during interviews, and for stepping into the participants lifeworld during the analysis. It was also challenging and this is discussed further in ‘Reflexive Box 1’ below.

Reflexive Box 1 – The role of empathy in research interviews

When Rosie (a study participant) said to me “there are few who care and the rest are just curious”, I was a little taken aback. I did not know at the time what troubled me so much about it. In hindsight I realised I was upset to think that my presence may be taken for being just curious, and not caring. It seemed to me as though she was describing others’ curiosity as having a negative impact upon her, that it was a sort of nosiness, to satisfy their own needs rather than be supportive. It highlighted to me a potential selfishness in what I was doing in the research and of reservations I’d had at the start of the project, of taking people’s time when so much was going on for them.

It is potentially more difficult to show you care in a research interview than in a therapeutic encounter. You are not intending any therapeutic benefit, rather you are gathering information and I could see how this could be perceived as being curious rather than caring. I did want to show participants that I cared, because I did, and their stories really affected me. I wondered whether my attempt to remain professional or objective, was experienced as distant or lacking in empathy by participants. I came to realise that expressing emotion or empathy did not necessarily mean giving up objectivity or compromising the quality or rigour of the interview.

Snelgrove (2014) points out that whilst there has been much written about the impact of certain characteristics of the researcher on the research for example, age and gender, there is very little written about the impact of research empathy on the research process. It has been claimed that being empathic in interviews, rather than making the research 'less scientific' may assist the interviewer in bracketing their own experience, as being empathic requires the interviewer to put aside their own thoughts and ideas whilst they are opening themselves up to the lifeworld of the participant (Ashworth & Lucas, 2000). Kvale (1994) also writes about the interviewer as the research tool and using the humanness of the interviewer to facilitate different nuances and depths within an interview, rather than requiring the interviewer to be detached and non-intervening. Throughout the interviews I aimed to be supportive and empathic without being directive or therapeutic and I used my emotional sensitivity to do this.

This also impacted the way I analysed the data, I used empathy when reading the transcripts to immerse myself in the participant's world. I lingered with the narrative and tried to feel what they were feeling and notice whether this was different to how I may have been thinking or feeling in a similar situation. I believe this use of empathy helped me to stay close to the participant's experience.

3.2.3 Interviewing with a stimulus

The use of the film of survivor testimonies prior to an interview was considered to be the best way to meet the research aims of the study. Thus, the study involved three semi-structured interviews, with the viewing of testimonies incorporated into the second interview. Interviewing methods have become both creative and diverse, moving beyond using words alone. There are examples of health research studies incorporating visual methods, using timeline interviews (Berends, 2011; Leung, 2010), and photo-elicitation interviews (Drew, Duncan, & Sawyer, 2010; Oliffe & Bottorff, 2007) to enhance inquiry and support participants to articulate their story (Harper, 2002). Harper (2002) argues from his experience of using photo elicitation techniques in research, that using images or film within an interview elicits a different type of information from the interview, because the presentation of a visual method bridges the gap between experience and recall. The film of testimonies used in the interview in the present study,

was being explored as an intervention to support patients as they underwent a HSCT rather than as a means to support participants to articulate their story as in photo-elicitation studies. The film was therefore not generated by participants or about their personal lives; however they may have felt close to the content of the film as the survivors talk of their experience undergoing the same treatment the participants are embarking on.

3.3 Method for data generation and analysis

The procedure for data generation and analysis for the longitudinal component of the study will be described in the following section, including ethical considerations, recruitment, data generation and analysis procedures.

3.3.1 Ethics

It is the researcher's ethical obligation to weigh up any potential risks to participants (Orb, Eisenhauer, & Wynaden, 2001) and limit these risks as much as possible. There were significant ethical considerations, discussed below, including using quotations from the interviews which may identify the participant and interviewing people during a time when they may be physically unwell or distressed.

3.3.1.1 Ethical approval

A substantial amendment was submitted to the National Health Service (NHS) Research Ethics Committee (REC) to use the data gathered from the filmed testimonies to conduct a thematic analysis as this data was found to be incredibly rich, and also to use the filmed testimonies as a resource for clinical staff working with HSCT patients. These work streams were undertaken by members of the research team and was not the focus on the present study. Approval was granted on 9th October 2015 (Reference Number 14/YH/0155).

A further substantial amendment was submitted to change the design from mixed methods to a qualitative study as a result of the literature review and consultation with supervisors. Approval was granted on 29th June 2016 (Appendix 11 Reference Number 14/YH/0155).

3.3.1.2 Consent

Participants were taken through the consent procedure at the beginning of the first interview. Each item on the consent form (see Appendix 12 for consent form) was discussed with the participant as they initialled these and the opportunity was given for them to ask questions. Participants were made aware that they had the right to withdraw at any time during the interview process or subsequently, with limits on when their data can be retrieved fully following data collection and analysis. The issue of consent was revisited at the beginning of each interview. Decisions around whether a patient had capacity to consent were made by myself and a consultant haematologist.

3.3.1.3 Anonymity and confidentiality

During the consenting process it was explained to participants that a pseudonym would be used in dissemination to maintain as far as possible their anonymity. However, it was explained that interview quotations and some contextual information (i.e. diagnosis, age, gender, area of work) would be used in the report and therefore it was not possible to guarantee full anonymity. Presentation of participant data in qualitative studies makes it difficult to maintain anonymity if the participant's story is known to others reading the report. Discussing this openly during the consent process ensured the participant was fully informed and had the opportunity to decide what information they gave during the interviews.

3.3.1.4 Data storage and protection

Consideration was given to the storage of data to avoid situations where the data was accessed by others outside of the research team. An audio recording device was used during interviews which was kept on my person during transportation from the place of interview to my home or office. The interview was then immediately transferred and stored on the password protected University of Leeds N-drive. The signed consent forms were stored in a locked filing cabinet in the research supervisor's office. Recordings were sent to the transcribing company via secure data upload and transcribed files were stored on the password protected University of Leeds N-drive. A non-disclosure agreement was sought and received from the transcription company. Only myself, the field supervisor and research supervisor were able to access the original recordings, personal details and transcribed interviews. The recordings and

consent forms will be destroyed by September 2019 which is in accordance with the University of Leeds data protection policy.

3.3.1.5 Ethics and interviewing participants who are unwell or distressed

Interviewing participants who may be unwell or distressed posed some ethical dilemmas, and little could be found in the research literature about this (Mathieson, 1999). An ethical dilemma when a participant becomes upset was whether to continue with the interview in order to gain more insight into their experience or stop the interview, offer support, find alternative immediate support or refer to an appropriate service (Orb et al., 2001). It is difficult to anticipate all situations that may arise in qualitative research, and some on the spot decision making was always required. However, I decided to work collaboratively with the participants if they became upset during interviews to enquire whether they wanted to stop or continue and also checking in with them at the end of the interview, giving the opportunity to discuss whether they would want further support to be arranged or to be signposted to supportive organisations such as Macmillan nurses or the Anthony Nolan charity. It was also possible that the participants may have experienced some benefits of telling their story to the researcher such as catharsis, healing, a sense of purpose or altruism and empowerment (Orb et al., 2001; Peel, Parry, Douglas, & Lawton, 2006).

When organising a time to interview participants, I paid considerable attention to the wellness of the participant and myself as the interviewer. If I had knowingly been in close contact with someone who was unwell or was feeling unwell, the interview was postponed to a time when I had been physically well for 48 hours. I contacted the participants on the day of the arranged interview to ensure that the participant was feeling well enough to participate. It was also reiterated to the participant at the beginning of each interview that they were free to pause or end the interview at any point they wanted to. I adhered to the haematology ward's infection control policy which sometimes required wearing personal protective equipment (PPE), such as gloves and apron to protect both parties from infection.

3.3.2 Recruitment

3.3.2.1 *Recruitment process*

Recruitment was conducted with the assistance of the transplant co-ordinator who identified patients who were being assessed for a HSCT. A copy of the information sheet (see Appendix 13) was sent to the patient's home address or given to them in clinic by the transplant co-ordinator, the specialist nurse or the consultant. The patient was only contacted about the research after giving consent to undergo the HSCT procedure. The patient was contacted by the transplant co-ordinator and if interested in either participating in the study or receiving more information they were asked if they would consent to being contacted by telephone or meeting at a pre-transplant appointment. At this point I contacted the patient by telephone or met with them to answer any questions and organise consent taking and the first interview.

3.3.2.2 *Inclusion and exclusion criteria*

Probability sampling which is often used in quantitative studies was not used due to the small sample size in this study and it was not deemed useful in answering the research questions. The inclusion/exclusion criteria were developed using a judgement sampling approach and using an element of convenience sampling within this (Marshall, 1996).

The research recruited NHS patients who were:

- adults undergoing a HSCT at a specific transplant centre in Leeds, West Yorkshire. Not all recipients of this procedure are diagnosed with cancer and patients with a non-malignant haematological disorder such as thalassemia were also eligible. Patients receiving HSCT without the presence of a haematological malignancy were not excluded, as evidence suggests that their experience of the HSCT process does not differ to that of people with haematological cancer (Trigg et al., 1999).
- receiving an allogeneic transplant. There are two types of HSCTs. Allogeneic transplantation involves taking healthy stem cells from the bone marrow of another person, who is a related or unrelated donor, and transferring them to the bone marrow of the recipient. Autologous transplantation uses the bone marrow cells taken from a patient's own body and cleared of any diseased or damaged cells before being transplanted back into the patient's body. The risks of post-

transplant complications such as GvHD are generally considered to be less with autologous transplantation and this was therefore not considered a completely comparable experience (Bjorkstrand et al., 1996).

The research excluded NHS patients who:

- were undergoing autologous transplant. The filmed testimonies were from people who had undergone an allogeneic transplant (see inclusion criteria for reasons).
- did not fluently speak English, were deaf or hard of hearing, due to the survivor testimonies being filmed in English. Unfortunately, at the time of the research being conducted there were no resources available to translate the filmed testimonies into other languages or provide support for people who are deaf or hard of hearing.
- were under 18 years of age or judged to be lacking in capacity to consent.

Outside of these criteria a convenience sampling approach was used; each patient who met these criteria was approached regardless of age, life experience or gender. During recruitment it was observed that, by chance, more male than female patients had been approached to take part in the research. This was attributable to more males being assessed for HSCT at this time. It was decided at this point to stop recruiting male patients and to try to recruit female patients.

3.3.2.3 Sample

The sample size of the present study was decided based on current literature on qualitative studies, in particular those using IPA, and also the context of the current study. Smith et al. (2009) emphasise that, in studies using an IPA, 'less is more' in order to gain a rich understanding of the lives of participants (Hefferon & Gil-Rodriguez, 2010; Reid, Flowers, & Larkin, 2005). There are differing suggestions of appropriate sample sizes for IPA studies ranging from as few as three participants (Smith et al., 2009) to fifteen (Reid et al., 2005) with six being suggested as optimal (Reid et al., 2005). Smith et al. (2009) suggest an estimate of between three and six participants for an undergraduate or Masters level IPA study and between four and ten data sets for a professional doctorate. With this in mind the I aimed to recruit seven participants which would translate to 21 interviews. It was anticipated that the rate of attrition could be up

to 40% based on statistics of HSCT patient survival rates. Therefore more participants were recruited to compensate for this and ensure an appropriately large sample size if the attrition rate reached 40%. Seven participants were recruited and completed an interview at time point one (T1), six of these seven participants went on to be interviewed at time point two (T2), and five of the seven participants went on to be interviewed at time point three (T3). The attrition rate was not as high as anticipated and a total of 18 interviews from seven participants were generated for analysis. Despite the lower than estimated attrition, this number of participants and data points is still within the recommended guidelines of appropriate sample sizes for an IPA study (Smith et al., 2009).

3.3.3 Data generation

Participants were given the choice of when the first interview would be held. Figure 1 below indicates approximate timings of HSCT related events alongside the timings for recruitment and interviews. These are approximate as there were delays in treatment events for a number of reasons including infection or not being able to locate a suitable donor.

It was hoped that for each participant the design indicated in figure 1 would be followed; however, not all T1 interviews occurred prior to the participant being admitted to hospital. This was due to the unpredictable nature of having a HSCT. Often the patient would know an approximate date that they would be admitted, but would only know the actual time at very short notice. Participants tended to be busy in the weeks prior to coming in to hospital, making practical arrangements for being away from home for a period of time and seeing friends and family who they predicted they may not have as much contact with in the coming weeks or months. Some participants were reluctant to have the first interview held in their home and preferred it to happen in the first few days of their admission. In these cases, the first and the second interview were sometimes held close together, within a few days of each other. Table 5 in the 'Chapter Five: Results' presents the timings of interviews for each participant in relation to their treatment. T2 interviews were planned to happen in the few days prior to participants receiving the stem cells, also known as day 0. On the whole, this was facilitated; however, on a couple of occasions this did not happen as participants were unwell on the day of interview. T3 interviews were planned to be conducted in the few

days prior to discharge. This was difficult to facilitate as participants often found out that they were being discharged at the last minute and an interview could not be arranged. Participants were asked to make contact when they were aware that they were close to discharge, and on a couple of occasions the participant did not make contact for some time following discharge, or contact was prompted.

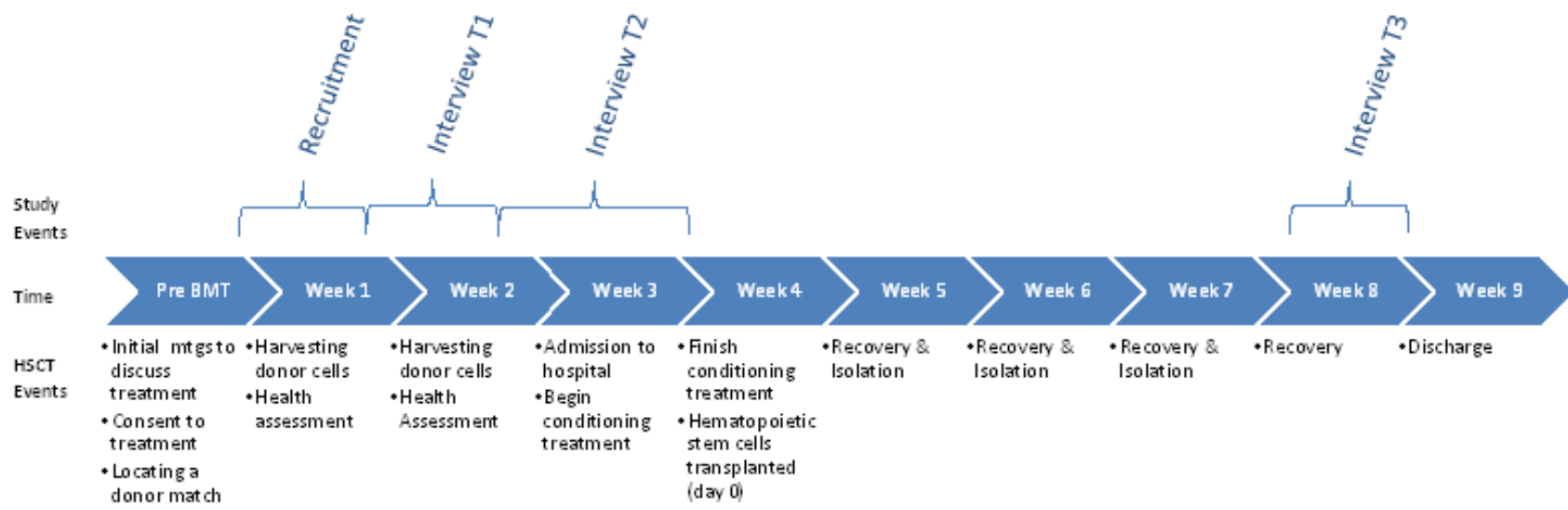


Figure 1 Timeline of treatment events (bottom) and research events (top).

3.3.3.1 Interview Schedule

I facilitated all interviews which were recorded on an audio recording device (Patton, 1990). An interview schedule was used flexibly (Table 3 below) for each time point. The schedules consisted of open ended questions and follow ups which were optional and as much as possible, I was guided by what was salient to the participant, which enabled conversations to unfold naturally and allowed for exploration of unanticipated areas. T1 and T3 interviews lasted up to an hour. T2 was different and the filmed testimonies would be watched and then an interview facilitated for up to an hour.

Table 2 Interview schedule for T1, T2 and T3.

Question	Follow up questions
<p>T1 1) Tell me a bit about how you first found out you needed a transplant?</p> <p>2) What does having a transplant mean to you?</p> <p>3) What has life been like in the run up to the transplant?</p> <p>4) Does this experience remind you of any experiences you had in the past</p> <p>5) Is there anything important that you think we've not talked about?</p>	<p>What was it like finding this out? What did you think/feel? Who did you tell? What was the first thing you did after you found out? What was most important to you at this time?</p> <p>What are your hopes and fears for the transplant?</p> <p>Have you felt like you are preparing? How important is this? Where do you think your ideas about preparing for something come from?</p> <p>In what way is this similar or different? Are there any strategies you've used?</p>
<p>T2 1) What was it like for you watching those testimonies?</p> <p>2) Tell me a bit about how have you been since the last interview?</p> <p>3) Is there anything important that you think we've not talked about?</p>	<p>Is there anything that sticks out in your mind?</p> <p>What was it like coming into hospital/being in hospital? How have others found it? Are there any ways of coping that you have been using? Anyone/anything been useful or a hindrance?</p>

T3	<p>1) Tell me a bit about how things have been since the last interview?</p> <p>2) How do you feel now you've had the transplant?</p> <p>3) What has helped/hindered you?</p> <p>4) Looking back, how well prepared do you think you were for the treatment and the time after ?</p> <p>5) Was there anything you wish you had done/known?</p> <p>6) Looking back, how much impact do you think the testimonies had on you?</p> <p>7) Is there anything important that you think we've not talked about?</p>	<p>What was it like having the stem cells? , What was it like being in hospital after?</p> <p>Would you recommend the procedure to others in your situation?</p> <p>Did any bits of stories stay with you? did you use any of the advice? Was there anything missing from the testimonies that would have been worth knowing?</p>
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At T2 the participant and I viewed the filmed testimonies on a laptop, followed by an interview for up to an hour about their experience of watching the testimonies and also about their experience since the T1 interview. After the interviews, I noticed that when I asked about their experience of watching the testimonies, participants tended to talk in general terms about how patients would find them useful, encouraging or hopeful rather than about their own experience or the impact on them. This was discussed in supervision with the research supervisor and field supervisor and it was hypothesised that participants needed some support to introspect on their own experience as the task of communicating to others how something is experienced in the moment is novel, and also the emotional task of engaging with the testimonies at this point when they are receiving their treatment in hospital may be challenging.

In order to support participants, I forewarned them that I would be asking what it was like for them to watch the testimonies and emphasised that I was interested in *their* experience. This allowed the participant to think about their experience as they watched it,

knowing this would be the task required of them. After watching the film, I repeated the question and also raised the issue that because they are undergoing a HSCT, the content of the film may be so immediate for them, that they may or may not find it challenging to watch. By raising this, I hoped to open channels of communication about their experience, making it acceptable to talk about the difficulties as well as positive aspects of viewing the film. It was hoped that this would encourage participants to engage with their own experience rather than imagining others watching the film, and I noticed a definite shift towards this in subsequent T3 interviews.

3.3.4 Data analysis procedure

This section describes the process of analysis using IPA from transcribing the interviews and organising the data to preliminary coding and theme generating. Whilst there is a degree of flexibility, according to the analytic task presented, IPA has clear theoretical principles and also a set of common processes. An account of the processes typically used by IPA researchers set out by Smith et al. (2009) was utilised in the data analysis. The process I engaged in can be thought of in five stages as follows;

Stage 1. Transcription and data preparation

Stage 2. Familiarity with the text

Stage 3. Description

Stage 3. Exploratory notes and developing codes

Stage 4. Theme generation

Stage 5. Developing cross-cutting themes

A challenge in writing about the procedure of analysis is that it can appear a more linear process than it was in reality. IPA is a dynamic, iterative process, with the analyst going back and forward between different analytic processes (Smith et al., 2009). Each stage will be described in detail below, and in general it followed this linear procedure, but with some flexibility and moving back and forth between the stages.

I aimed to move from the part to the whole (Smith et al., 2009). For example, a line of text is understood by looking at the context of the whole interview, and the whole interview can only be understood by looking at each utterance and therefore analysis is circular in nature (referred to as the hermeneutic circle) (Smith et al., 2009). This was a challenging process and the occurrence of multiple interviews at different time points for each participant created an extra layer.

Each interview was sent for transcription after the interview was conducted and analysis was not started until all interviews were complete. Transcripts were analysed by participant, so all interviews for each participant were analysed before moving onto the next participant. The decision was made to analyse the transcripts by participant rather than by time point initially, so that the whole narrative of each participant was not lost within the time points and individual differences could be identified. Once themes were generated for each interview, they were grouped by time point in order to discover what themes were emerging at each time point. These decisions were made in an attempt to pay attention to both individual participants and also what is emerging in different time points. Each stage of analysis will now be described in detail.

3.4.4.1 Stage 1. Transcription and data preparation

I was not able to transcribe the interviews due to time restrictions, so for pragmatic reasons a professional transcription company was used. Verbatim transcription was requested which presents the interview in the form of a play-script between the interviewer and the participant and every verbal utterance is transcribed, including filler words such as ‘um’. The transcripts were checked against the recording for accuracy, during which missing words were inserted. During this process I also paid attention to the emotions present during the conversation and added notes about what was happening in the room, mainly from memory, e.g. laughter, pauses, crying.

3.4.4.2 Stage 2. Familiarity with the text

Following each interview I made notes on thoughts and impressions of the whole interview. This was used in subsequent interviews as reminders of areas to explore and also read before starting the analysis as a reminder of initial observations. Each transcript was read

and re-read to encourage familiarity with the text, which is endorsed by Smith et al. (2009). During this process I made notes of any ideas in the margin so that this could be put aside for later evaluation (Smith et al., 2009).

3.4.4.3 Stage 3. Exploratory notes and developing codes

Once the transcript had been listened to, read through twice, and notes made, each line of the transcript was systematically reviewed and anything of interest was recorded. This is referred to as referred to as ‘exploratory notes’. As described in Smith et al. (2009), I focussed on descriptive (what was being said), linguistic (the language used) and conceptual (a move away from what is explicitly said and becomes more abstract or interpretive) observations. I focussed on descriptive and linguistic comments at first, (recorded on the right hand side of the transcript) and became gradually more involved in teasing out more abstract and conceptual ideas which were written as codes (recorded on the left hand side of the transcript). These codes represented my interpretation of likely meaning or experience of the participant implied by the text. Figure 2 shows a page of transcript from Vincent’s interview at T1, showing descriptive, linguistic and conceptual annotations (exploratory notes) on the right and emerging codes on the left.

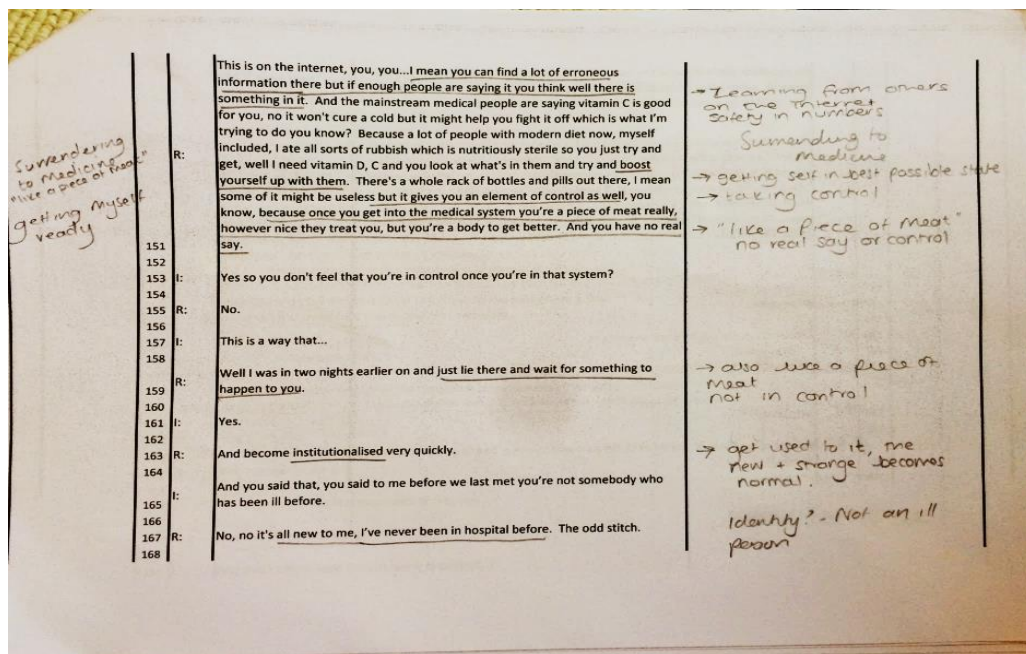


Figure 2 An example of a typical page of transcript with analysis annotations at stage three.

In line with typical IPA practice, each interview transcript was analysed wholly before moving onto the next transcript. In order to get an overview of the codes present in each transcript, a map of codes was created for each transcript. This map included where possible, in vivo codes, in order to stay close to the data. Each code also included line numbers pointing to the original extracts so that it would be easier to cross reference to the original extract corresponding to each code in later stages. Figure 3 shows an example map of codes for one transcript (Vincent T1), with arrows representing interconnections and patterns present in the data .

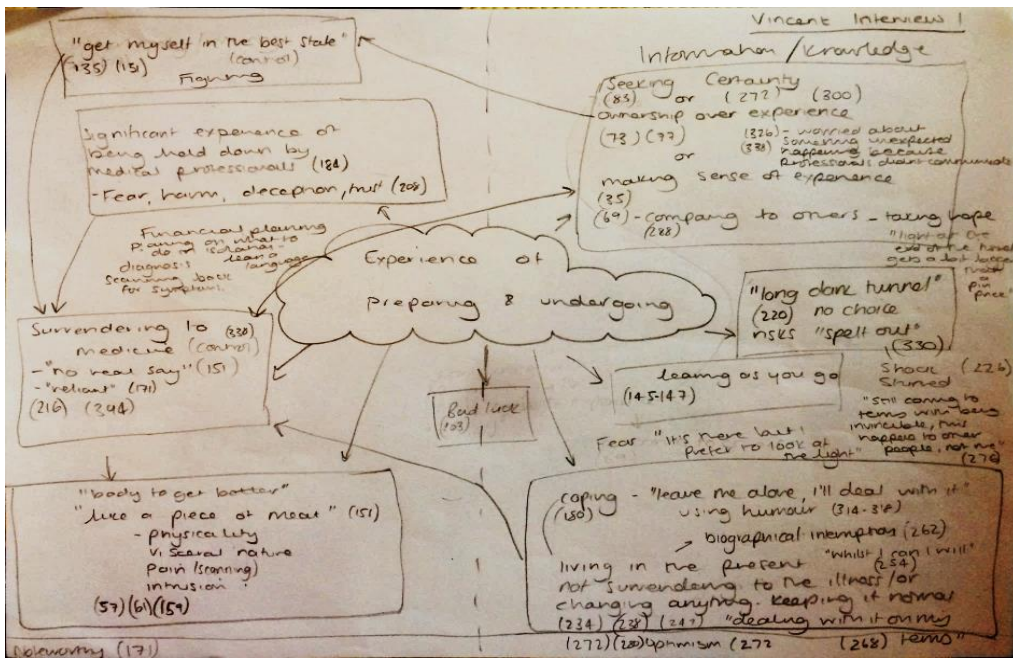


Figure 3 A picture of a map of codes for one transcript (Vincent T1).

Data related to the participant’s experience of viewing the testimonies and therefore relevant in fulfilling the second research aim was included in the map of codes and clearly marked so it was alongside the rest of the data but could be treated separately.

Every interview transcript was analysed this way, in participant order (Vincent T1, T2, T3 then China T1, T2, T3 etc.). When it was agreed with the research supervisor that the data had been thoroughly explored and a sufficient number of codes had been developed, I moved on to stage four.

3.4.4.4 Stage 4. Theme generation

At this stage there were many codes and the task was to organise and refine these into emerging themes. The aim was to engage with the data of each interview as independent of each other as much as possible, to ensure the themes were genuinely present in the data, however, total exclusion of knowledge of other transcripts is impossible. At this stage supervision was used to explore the data and analysis and to check agreement of interpretations (Elliott, Fischer, & Rennie, 1999).

Refining the many codes into a smaller number of themes involved merging some similar codes together and abandoning some codes that did not have much support as well as mapping the interconnections. This involved a move away from working with transcript, however maintaining the in vivo codes and line number references helped in staying close to the data in this stage of the analysis (Smith et al., 2009). Refining the codes into themes helped me to be able to say something about the experience of participants from the data in the transcripts in a concise way. A map of themes for each interview transcript was produced and an example (Vincent T1) is presented below in Figure 4.

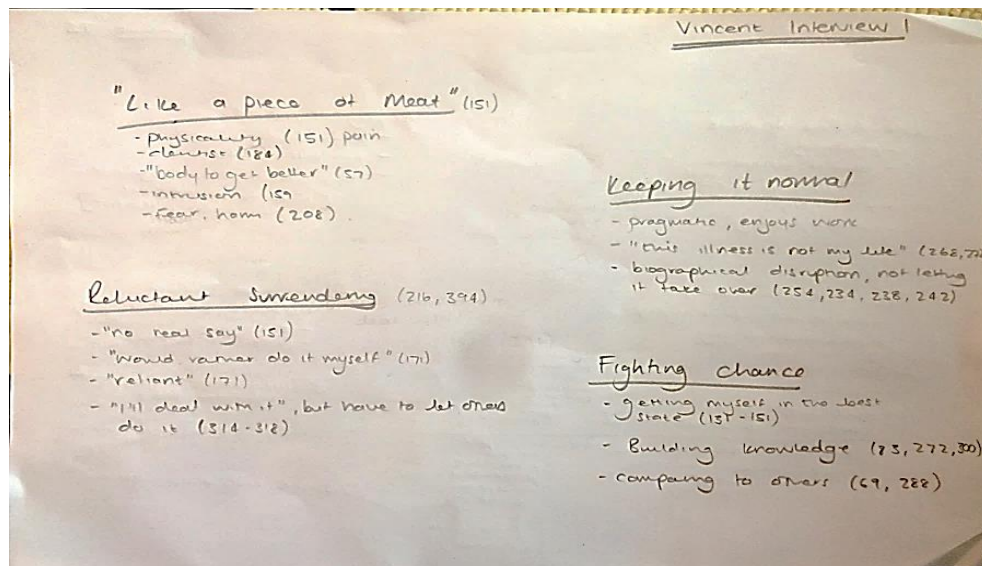


Figure 4 A picture of a map of themes for one interview (Vincent T1).

3.4.4.5 Stage 4. Developing cross-cutting themes

Stage four moved the analysis from the individual to the group in order to develop cross-cutting themes. Themes for each participant were tabulated and grouped into time points so they could be viewed alongside each other. This facilitated the generation of themes across participants at each time point and helped to further refine the themes. A picture of this process for T1 is provided in Figure 5 below.

Themes for each participant are tabulated in a vertical direction and participants are placed next to each other, so that similarities in themes for each participant can be easily seen. Similar themes are highlighted in the same colour. Strong and frequent themes can then be easily identified next to infrequent themes which may only be present for one individual.

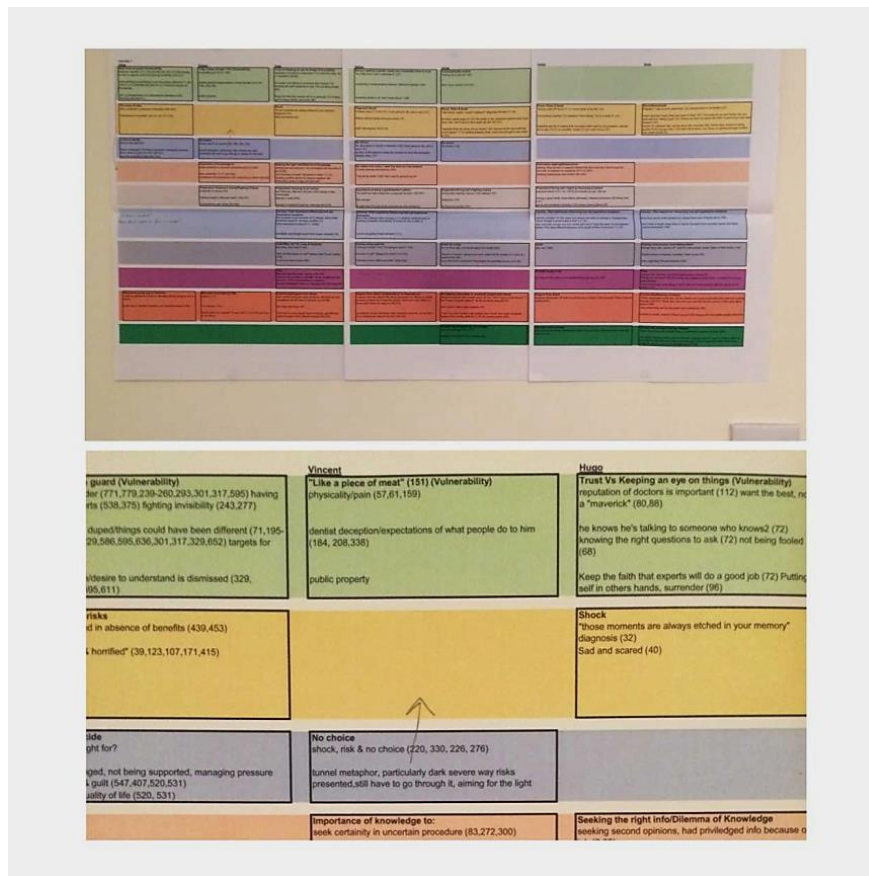


Figure 5 A picture of the tabulated and colour coded themes for T1 printed on three sheets of A3 paper (top) and a close up showing two participants (bottom).

Themes that were judged to be similar were refined into superordinate themes and the interconnections with each other were identified. This enabled the final superordinate themes and sub-themes to be identified. The process of refining the tabulated themes into superordinate themes and sub-themes for each time point is demonstrated in the picture in Figure 6 below.

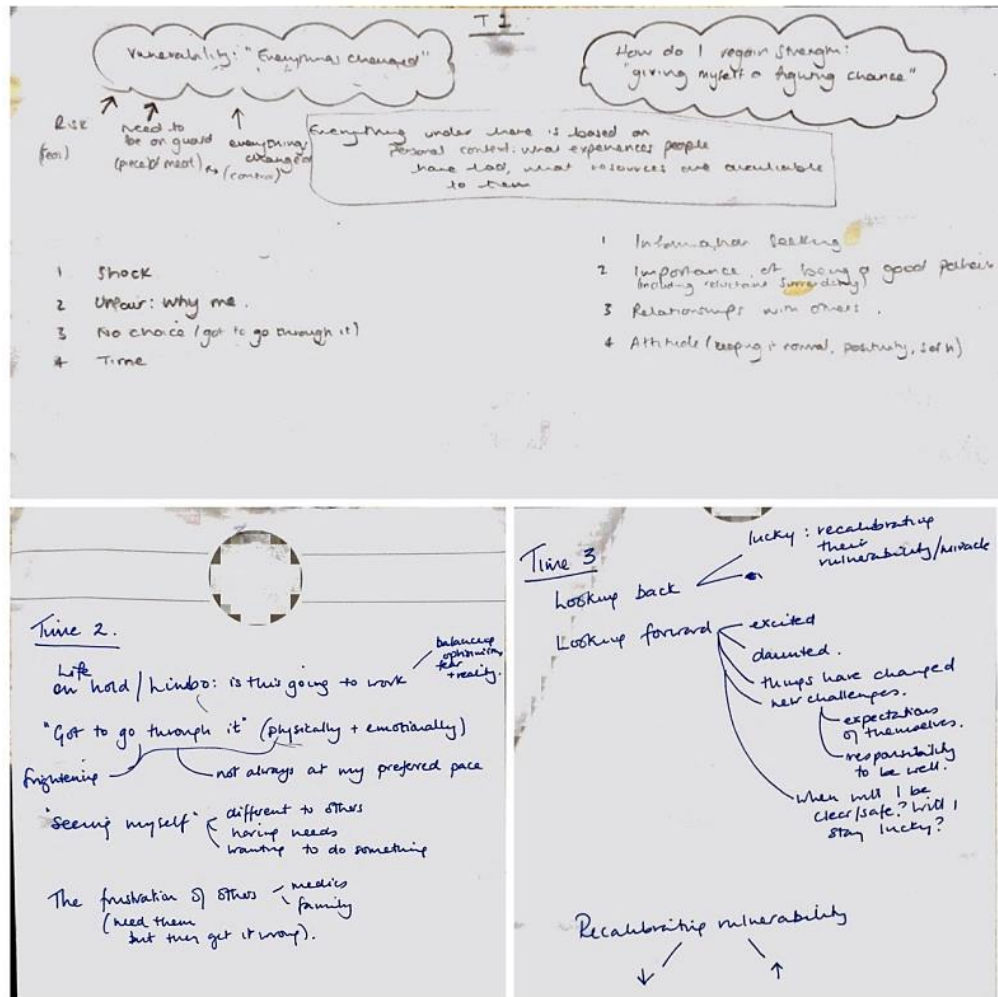


Figure 6 A picture of three pieces of paper used in the analysis process to visually map the superordinate themes and sub-themes for each time point.

3.3.5 Quality control: reliability and credibility

Whilst qualitative researchers place importance on reliability and validity in qualitative research, there is considerable discussion amongst researchers as to how the quality of qualitative research should be assessed. Many do not deem it satisfactory to assess qualitative studies using the same criteria that are applied to quantitative studies (Smith et al., 2009). Reliability tends to refer to how reliable the data collection and analysis is at producing consistent results, which assumes that qualitative processes can be standardised. Validity refers to the degree a concept, conclusion or measurement can be said to correspond accurately to the real world. Reliability and validity concepts come from a positivist approach, and it is argued that they should be redefined for use with a naturalist approach (Golafshani, 2003). Glaser & Strauss (1967) encouraged qualitative researchers to consider ‘credibility’, ‘usefulness’ and ‘trustworthiness’ when assessing the quality of qualitative research.

Many guidelines have been produced for assessing quality in qualitative research. However, Smith et al. (2009) caution against using guidelines which resemble easy to use checklists as it is argued that these may encourage the quality control process to become “simplistic and prescriptive and the more subtle features of qualitative work get missed out” (Smith et al., 2009, p. 179). Smith et al. (2009) recommend using approaches which present general rather than prescriptive guidelines for assessing quality and recommend Lucy Yardley’s (2008) approach. Yardley’s approach presents four broad principles for assessing quality which are: sensitivity to context, commitment and rigour, transparency and coherence, and impact importance. A discussion of the processes by which the present study demonstrated quality is presented in chapter six ‘6.4.1 Quality’.

CHAPTER FOUR: METHODOLOGICAL FRAMEWORK, DESIGN AND METHOD FOR AIM TWO (TESTIMONIES COMPONENT)

This chapter will outline how aim two (to explore the potential of patient testimonies in enhancing the life of those undergoing such procedures) was achieved by first constructing an intervention based on and using patient testimonies of HSCT and secondly through a hermeneutic and idiographic interview nested into the longitudinal study prior to transplant (interview 2).

The design was informed by a review of the literature and a stakeholder consultation, described below. The development and testing the appropriateness of the film of testimonies will then be described followed by a description of the use of the testimonies in interview 2.

4.1 Stakeholder consultation

As well as justification from the current literature that this study is needed, a clinical need and a desire for a resource such as the testimonies was identified from stakeholder consultation work completed by the field supervisor at St James's University Hospital, Leeds. This work is covered briefly here, as it was conducted prior to the start of this project, but was a main driver for the research in terms of identifying a need for a resource like the film of testimonies, and it shaped subsequent choices in the research design.

The aim of the stakeholder consultation was to assess whether there was a clinical need or a desire for a resource of survivor testimonies and to understand how patients would like this intervention delivered. Participants who took part in the consultation were patients who had either received, were waiting for a transplant or were family members of someone who had. They were invited to take part either in an online survey or a focus group. In total, 12 participants responded to the survey and 13 participants attended a focus group. Some example questions from the survey were;

1. How well prepared for the transplant did you feel?

2. What are your views on sharing the stories of patients who have already had a transplant with patients who are due to have a transplant?
3. At what point during the transplant procedure do you think it would be helpful for patients to receive a collection of other patient's stories?

Overall, the findings (which remain unpublished) from both the survey and the focus group supported the need for a resource that shares patient testimonies and participants stated that it is something they would like to access themselves. There was a general feeling of being unprepared for transplant from the pre-transplant respondents. More of the post-transplant patients said that they had felt well prepared; however, some participants described feeling prepared for the medical procedure but not for the emotional aspects of having a transplant. In response to this, the film developed was designed to meet this need. The participants were also asked how they would like the testimonies presented which will be discussed in '4.2 Developing the film'. The findings from this consultation were that there is a need for a resource such as this and further research is required to measure its effectiveness as an intervention when used to help patients cope with the emotional demands of HSCT.

4.2 Developing the film

I joined the present study at the point when five of the ten testimonies had been filmed and was involved in the filming of the further five testimonies. The field supervisor and I secured participant consent, and conducted interviews and the debriefings. The testimonies were filmed by the Leeds Teaching Hospital Trust Medical Illustration team. Approximately 10 hours of footage was captured which I edited to 30 minutes of footage with the field supervisor (this process of editing is described below). The technical task of piecing the edited sections of footage together was also conducted by the Medical Illustration team and funded by the Anthony Nolan charity.

It emerged that participants would like a variety of different formats for accessing the resource including a booklet, website and audio file. This was not possible for the current study, although, in the future additional formats could be introduced. There were

mixed results in terms of the content of testimonies. Some participants felt the resource should only contain testimonies of hope such as positive success testimonies, whereas others favoured a more balanced approach with both positive and negative experiences being conveyed. There are ethical issues around promoting false hope and presenting an image of the procedure that does not reflect reality. Therefore, in response to these findings the film of testimonies developed was edited to include, as much as possible, both themes of hope and encouragement and also a balanced view of the complications and difficulties individuals faced. There were several suggestions on how to group the testimonies. At this point it was decided that it was appropriate to group by specific issue rather than by patient, due to time constraints of editing the film to 30 minutes.

4.2.1 Ethical Approval

Developing and using the film of patient testimonies in a study was subject to review by the local Research Ethics Committee (REC) governed by the NHS Health Research Authority (HRA). Ethical approval was granted by the Yorkshire & Humber – Bradford Leeds Research Ethics Committee on 9th October 2014 (Appendix 1 Reference No. 14/YH/0155).

4.2.2 Recruitment

Potential participants were identified through attendance at a HSCT follow-up outpatient clinics and psychology outpatient clinics. Patients were invited to participate by a member of the clinical team. Interested patients were invited to leave their contact details at their next outpatient appointment and were contacted to explore their interest, to answer any questions and to then arrange a suitable interview date.

4.2.3 Inclusion criteria

The study aimed to be as inclusive as possible. All patients who had received an allograft HSCT in the last five years were eligible for participation if they had capacity to consent and could speak English fluently. Ten participants, seven males and three females with an average age of 49 years were recruited to attend St James's Teaching Hospital to give an account on film of their experience of having a HSCT. A consent form was signed by each participant.

4.2.4 Interviewing

Each interview lasted for around an hour, and followed an interview schedule (Appendix 2) with follow up questions. The questions encouraged participants to tell their story, for example, was their experience what they expected, what helped them get through it and what would they tell others about it.

4.2.5 Editing

Approximately 10 hours of footage was generated which needed to be edited to a total of 30 minutes. Each interview was watched and each section was labelled with a description of what was being said (see Appendix 3 for an example of this). I completed this separately from the field supervisor and then we came together to compare. Each interviewer then decided separately which segments should be included and excluded from the film, based on the inclusion and exclusion criteria (set out below) and we then compared ratings. This editing criteria was informed by ethics, the pre-study focus groups, experience based on clinical practice and the pragmatics of editing the footage to 30 minutes.

Inclusion criteria were:

- Material that was relevant to helping a patient prepare for the procedure, emotionally and practically
- Material that could foster hope and optimism
- Material that was balanced and honest, to avoid the “prison of positivity” and supported the normalisation of a range of feelings
- Material that offered ways of coping
- Material that had the potential to prepare patients for experiences they may not be expecting
- Material that included personal testimonies that could evoke an emotional connection to the content

Exclusion criteria were:

- If the material was not factually correct regarding procedure/outcomes
- If the material could be seen as offensive to one person or group
- If the material was not broadly relevant, i.e. only pertained to one hospital or patient
- If the material was beyond the scope of the HSCT procedure i.e. pertained to disease history, prior treatments, making the decision to have HSCT, or post HSCT information.

Inter-rater agreement on inclusion and exclusion was high. The highest rate of agreement for a single testimony interview was 89.5% and the lowest rate of agreement was 69.7%. Following this initial edit, the length of the film exceeded 30 minutes and was therefore edited further. The field supervisor and I rated separately each section of footage from 1 to 3 (1= best fit) according to how well it fit the editing criteria (see Appendix 4 for an example). Whether the theme of the footage was repeated was also taken into account, any repeated themes were rated as 2. The field supervisor and I, then came together to compare. At this stage all sections that had been rated 1 were included in the final edit and any sections that were rated either a 2 or a 3 were discussed and decided upon.

At this point the interviews were transcribed by an intern working with the field supervisor and the transcriptions of all the sections of footage that had made the final edit were then used to make the decision on the order of the edited footage. Each section of footage was grouped by theme. These were: account of experience, support, giving up/keeping on, psychological strategies for coping, side effects, speeding up/slowing down of time, isolation, loss and survivor guilt, positivity and hope. They were then ordered to offer a coherent story (see Appendix 5 for images of this process). In order to better illustrate to the viewer the themes that were being presented (a limitation which was identified when the appropriateness of the film was tested), the themes were illustrated by titles which appeared on screen. The titles that appeared in the film in order of appearance are illustrated in Table 2. below. An edit decision list was sent to the Medical Illustration department at this stage indicating which segments of footage were to be edited together for the final 30 minute film.

The final edit of the film used in the study was approximately 30 minutes and a copy has been provided on a CD with this thesis.

Table 3 Titles appearing in the final film by order of appearance.

Order of title appearance	Title (appearing as text on screen)
1	“Ten people were asked to share their experience of having a transplant”
2	“Was the transplant what you expected?”
3	“What helped you during the transplant?”
4	“Reminders of what is important”
5	“Looking forward and keeping motivated”
6	“Noticing the positives”
7	“Reminding yourself that this will pass”
8	“Gaining control”
9	“Coping with isolation”
10	“What do you wish you had known before you had the transplant?”
11	“How do you feel about the transplant now?”

4.3 Testing the film

The appropriateness of the edited film of testimonies was tested prior to this being used with participants in the study. This was accomplished by gaining feedback from people who had previously undergone a HSCT and families of transplant patients and medical professionals working with people undergoing a HSCT.

4.3.1 Ethical considerations

As the research was being conducted outside NHS premises and seeking members of the public rather than patients as participants, the research was subject to university rather than NHS ethical procedures. Ethical approval was granted by the University of Leeds School of Psychology Research Ethics Committee on 18th April 2016 (reference number: 16-0121).

There were two further amended ethics applications submitted due to difficulties recruiting for the research (reference numbers: 16-0190; 16-0223). Ethical approval was therefore applied for and granted by the same committee on: 11th July 2016, 8th September 2016 (Appendix 6).

4.3.2 Recruitment

The original intention was to gain feedback from a focus group of people who have previously undergone a HSCT. However, recruiting people who had previously undergone a HSCT and were willing to travel proved difficult. It was decided that it may be more convenient (and encourage participation) if participants could view the film of testimonies online and complete feedback via an online survey. Participants were recruited via an email sent from Anthony Nolan and also social media platforms (Facebook and Twitter). The inclusion criteria were: English speakers who had previously undergone a HSCT, had been a carer or family member of a HSCT recipient, or were a medical professional working with patients undergoing HSCT.

4.3.3 Materials

The survey was designed using Bristol Online Survey software (for questions see Appendix 7) and was accessed via an online link emailed to interested participants. A link to the edited film of online testimonies was also emailed to the participant. This film was hosted by You Tube, and was only accessible via the link. The film could not be accessed by members of the public searching You Tube.

4.3.4 Process

An invitation email (see Appendix 8) and an information sheet were sent from the Anthony Nolan charity to a list of contacts who previously consented to be contacted by Anthony Nolan for research purposes. The email invited those interested in taking part to contact me by email. I then sent an email response containing links to the film and the survey (see Appendix 9 for email). An invitation email was also sent to clinicians working in the Haematology department at St James's University Hospital asking them to watch the film and complete the survey. A request for participants was also posted on a Facebook page for

HSCT patients and survivors ‘Bone Marrow and Stem Cell Transplant Survivors’ Club’ (see Appendix 10 for post).

4.3.5 Data analysis

The data from the survey questions which required a free text answer was analysed using content analysis. Further discussion of the content analysis method is presented in ‘4.4 Using the patient testimonies film in interview two and data generation’ when the method is used again to analyse the data from the interviews pertaining to the participants’ experience of the testimonies.

4.3.6 Findings and implications

There were 10 respondents to the survey, five males and five females, ranging in age from 34 to 63. Seven respondents had previously received a HSCT from donor stem cells, one was a relative/carer and two were medical professionals working with patients undergoing HSCT. Eight participants were from the UK and two were from Italy.

When asked to describe the tone of the film, the majority (n=5) described the film as ‘positive’ or ‘hopeful’, two respondents described the film as either ‘neutral’ or ‘real’, (e.g. “I like that it sounds neutral and not trying to sugar-coat it”). One described the film as overly positive which did not reflect their own experience (e.g. “none of the people interviewed seemed to have any of the problems I experienced”). Seven felt that the film made people aware of the most important aspects of having a HSCT, but three did not agree. Two respondents stated that the film focussed on the transplant itself rather than later side effects (i.e. GvHD, depression and anxiety) which was the intention for this study. One respondent suggested that due to the film’s positive presentation, it should be presented alongside information about risks of the procedure. All ten respondents felt that the film was appropriate to show patients undergoing a HSCT (i.e. not distressing or worrying). Of those respondents who had previously received a HSCT, none had seen a resource like this. Six commented that they would have liked to have had access to a similar resource. One respondent felt that it did not cover aspects of the transplant process that were important to them and two respondents reported that they could not comment due to having not had a HSCT. The film was therefore deemed suitable for use with participants.

4.4 Using the patient testimonies film in interview two and data generation

The film was used during interview two of the longitudinal study and the process of data generation is described in chapter three '3.3.3 Data generation'. The data generated was analysed using a content analysis approach. The findings are described in '5.4 Results of the content analysis of the data on the patient testimonies'.

Content analysis is one of numerous qualitative methods used to analyse text, that has been widely used in health studies (Hsieh & Shannon, 2005). The purpose of content analysis is to classify large amounts of text into an efficient number of categories with similar meaning, and is therefore a subjective interpretation of the content of the text (Hsieh & Shannon, 2005). In this analysis the categories or themes represented explicit or inferred communication by the participants. A conventional approach to the content analysis was used as there was no existing theory on the phenomenon being studied (the experience of the testimonies) and codes and themes were allowed to flow from the data.

Data analysis started with the researcher reading and becoming immersed in the transcripts, followed by highlighting parts of the text that seemed to capture key thoughts or concepts which were labelled codes. Themes were then generated by clustering codes together into meaningful units. Example quotes from each theme were picked to represent and communicate the essence of the theme to the reader.

CHAPTER FIVE: RESULTS

This chapter begins with participant pen portraits before detailing the stages of data collection for each participant. Analytic outcomes are then reported from the longitudinal component of the study, beginning with an overview of important analytic decisions, then a diagram of the main themes, before detailed descriptions of the main themes and sub-themes and the time point to which they relate. Illustrative extracts are presented from a range of participants; at times, depth and attention to individuals has been traded because of the breadth of the entire project and the amount of data collected across time points and in relation to the testimonies. The results of the content analysis of the data pertaining to the patient testimony component of the study are then presented.

5.1 Participants

Seven participants were recruited, four males and three females. There was a range of ages from 29 to 61 years. Participants were diagnosed with a range of haematological conditions with the majority (four of seven) undergoing the transplant within 8 months of diagnosis. Three participants had been diagnosed some time before the transplant (from 1 year 9 months to 20 years before) and had undergone treatments aimed at managing the condition before being told that a HSCT was the only option for a cure. All participants except one were born in the UK and all participants lived in the UK at the time of transplant. Five of seven participants were white. At some time during the first interview, each participant was asked to choose a pseudonym; this is used throughout this report to ensure anonymity. Table 4 below outlines key demographic and medical information for each participant.

Table 4 Participants' demographic and medical information.

	Gender	Age	Identified Race	Diagnosis	Time (diagnosis to HSCT)	No. of days an inpatient
Vincent	<i>Male</i>	<i>55</i>	<i>White British</i>	Myelofibrosis	<i>8 months</i>	<i>34</i>
China	<i>Female</i>	<i>44</i>	<i>British Mixed-Race</i>	Acute Myeloid Leukaemia	<i>1 year 9 months</i>	<i>32</i>
Hugo	<i>Male</i>	<i>46</i>	<i>White British</i>	Hodgkin Lymphoma	<i>8 years</i>	<i>24</i>
James	<i>Male</i>	<i>52</i>	<i>White British</i>	T-Cell Prolymphocytic Leukaemia	<i>6 months</i>	<i>unknown</i>
Nathan	<i>Male</i>	<i>60</i>	<i>White British</i>	Chronic Myelomonocytic Leukemia type 1	<i>8 months</i>	<i>29</i>
Hayley	<i>Female</i>	<i>61</i>	<i>White British</i>	Myelofibrosis	<i>20 years</i>	<i>25</i>
Rosie	<i>Female</i>	<i>29</i>	<i>Australian Mixed-Race</i>	Acute Myeloid Leukaemia	<i>5 months</i>	<i>55</i>

5.2 Pen Portraits

The pen portraits are designed to contextualise the interview data and are based on responses to questions asked at the end of the first interview (see Appendix 14 for questions) and interview content. The pen portraits highlight the different journeys for participants and are an attempt to help the reader stay connected to their personhood. They

also attempt to capture the ‘whole’ person rather than the fractured impression given by individual interview quotes. (Hollway & Jefferson, 2013).

5.2.1 Vincent

Vincent was 55 years old when he participated. He was diagnosed approximately one year before with Myelofibrosis (MF) which is a rare blood disorder which causes scarring of the bone marrow. Vincent was diagnosed after visiting the doctor with a cough that he had experienced on and off for a couple of months, which was the first time he had visited his GP in over 10 years. Vincent reported he and his wife did not have children, and enjoyed spending time with family and friends. Following his diagnosis, Vincent was offered a HSCT as the first line of treatment and he was told that if he decided not to have a HSCT, the prognosis was that his lifespan would be up to four years. Vincent decided to go ahead with the HSCT and a non-related donor was located after not too much trouble. The only information he had about his donor was that he was male and Australian. Vincent worked in a scientific industry up until being admitted to hospital, as he was determined that the disease and treatment would not take over his life. Vincent had three interviews, the first being at his home prior to him being admitted to hospital, and then a second time two days prior to him receiving the stem cells, also known as ‘Day 0’. The third interview was three days prior to his discharge. At this point Vincent was looking forward to getting back to work at some point in the future once he had recovered his strength. He seemed to speak freely and openly about his experience during the interviews with particular focus on the physical experience of the procedure. Hearing him describe the physical aspects of the treatment, particularly the intrusive nature of some procedures and the pain was uncomfortable to listen to. I would describe Vincent as a practical ‘matter of fact’ man, and this is how he seemed to be in his approach to the transplant. He came across as extremely knowledgeable about the medical aspects of the transplant; however, he was also interested in exploring how his past experiences impacted upon his emotional experience.

5.2.2 China

China was 44 at the time of participating in the research and was diagnosed with Acute Myeloid Leukaemia (AML) almost two years prior to receiving the HSCT. It is a rare type

of cancer which is more common in people over 60. She underwent several different types of treatment without success prior to being offered a HSCT and described feeling let down by this because she was not always aware of her options when she was offered treatment and only became aware of possible alternatives later. At the time of diagnosis, China was building her own business which she was unable to continue after becoming unwell. She was a single parent and close with her parents who lived nearby. We spent a lot of time talking about natural healing and the mind-body connection which was an important part of China's life. The interview at T1 was conducted in China's home, during which she had her own blend of aromatherapy oils burning contributing to her home being a very calm, relaxing space. The HSCT was delayed as China developed an infection and I interviewed China again two days before her 'Day 0' and again two days before she was discharged. At this point China was looking forward to getting back to her own more comfortable environment and considering how she may develop her interest in natural healing into a career in the future. China spoke at length about her experiences, on a wide range of topics, with a particular focus on her emotional experience rather than the practical or physical aspects of the treatment. These were some of the longest and fullest interviews facilitated.

5.2.3 Hugo

Hugo was 46 years old at the time of participating. He was diagnosed with Hodgkin Lymphoma (HL) in 2009 and has previously received a HSCT using his own cells (autologous). Hodgkin Lymphoma is cancer of the lymphatic system, which is part of the body's immune system. He was hopeful that the first HSCT would keep him in remission for many years to come, however he was always aware that he could potentially need a transplant using donor cells. Unfortunately Hugo's disease relapsed meaning he was then offered a HSCT using donor cells, with his younger brother being his matched donor. He described living with his wife and three children who were between the ages of 15 and 26. Whilst he underwent the HSCT he took a break from his work in the pharmaceutical industry. He described how working in the pharmaceutical industry meant that he was able to access information he may not have been able to otherwise, with colleagues connecting him with experts across the country, who he consulted with for second opinions. He read research related to his treatment and described how he was more able to make informed

decisions because of this. He also described having access to these resources as potentially a source of distress. He was interviewed three times, each time as an inpatient. The first interview was two days following his admission as an inpatient, the second interview was postponed until the day after he received the stem cells due to him feeling unwell on the day of the interview. Hugo was discharged during a weekend and we were unable to meet for a third interview before he went home. Following his discharge we then lost touch and met for a third interview 79 days following discharge; at this point he had been re-admitted to treat an infection. At this point Hugo was coming up to +100 days following transplant which is a significant milestone for HSCT patients. Hugo wanted to talk freely and openly about his experiences, even though at times this was upsetting and he acknowledged he had found it challenging to express his emotions to people in the past.

5.2.4 James

James was 52 years old when he participated. He was diagnosed with T-Cell Prolymphocytic Leukaemia (T-PLL) and offered a HSCT as the first line of treatment for his condition. T-PLL is a type of Acute Lymphoblastic Leukaemia (ALL) which is a very rare and aggressive disease needing to be treated immediately. It typically responds poorly to conventional chemotherapy, has short survival spans and the only curative treatment is HSCT. James described how because his family were spread across the UK and he had no children, he mainly relied on his partner for support. At the time of participating he owned a successful business consultancy firm, and described working long hours to build this over the years. He reported coming from a poor background and that he worked hard to build his business and a comfortable life for himself and his partner. James agreed to meet for one interview, and did not want to view the testimonies or meet for further interviews. He described finding it difficult to talk about his emotions to strangers, and it may be possible that he found it more difficult to talk fully and openly about his emotional experience. The only interview we met for was the day after he was admitted as an inpatient. James went on to receive the HSCT and was discharged from hospital.

5.2.5 Nathan

Nathan was 60 years old when he participated. He described being separated from his wife, and lived alone. He was diagnosed with Chronic Myelomonocytic Leukemia type 1 (CMML-1). CMML-1 is a blood disorder which develops slowly, and means there are too many monocytes (a type of white blood cell) in the blood. HSCT. Nathan's donor was unrelated and anonymous; he knew the donor was from Germany and he hoped to one day be able to contact them. He described a close relationship with his brother, his ex-wife and step daughter who supported him throughout his treatment. He was retired, and spent his time compering for charity events and being involved with the local masonic organisation. The first interview we arranged was delayed because I was unwell, and therefore took the precaution not to meet with him at this time. The first interview then went ahead when he had been an inpatient for seven days and we met for the second interview four days later which was the day before his transplant. The third interview was the day before he was discharged. At this time Nathan was feeling relieved and described no longer being worried about dying and felt that he had been cured. He was worried about going home and managing medication himself and keeping his home clean. Nathan described how he loved to make people laugh and his ability to do this was a cherished gift. Humour was important during all three interviews, even when Nathan was feeling ill; he always tried to make the interview experience a positive and humorous one for me. Six months after the last interview with Nathan, I received a phone call from him, letting me know that his disease had relapsed and that he was receiving palliative care. It was important to Nathan that he shared his experience for the benefit of others and his situation is an example of how uncertain the outcome of the HSCT as a treatment is, even if a patient survives the initial transplant treatment.

5.2.6 Hayley

Hayley was 61 years old when she participated and described living at home with her partner. She had two grown up children who did not live at home. Hayley was diagnosed with Myelofibrosis (MF) 20 years ago. Myelofibrosis is a rare blood disorder which causes scarring of the bone marrow. Treatment controls the condition for some time, and the amount of time it can be controlled varies from person to person. Eight months prior to

receiving the HSCT, Hayley found out that the treatment was no longer controlling the condition. Hayley received a HSCT from an unrelated donor. She had a significant illness history; following receiving a diagnosis of MF 20 years ago, she also had a brain tumour removed by surgery and has had a small stroke. Hayley participated in three interviews, the first of which was the day after she was admitted as an inpatient. The second interview was the day before she received the HSCT. The third interview was facilitated at her home one month post discharge. During the first interview Hayley spoke about her family, which we both found very emotional. She described how she did not like being tearful in front of strangers and I noticed that during the second interview Hayley held back from talking about emotional aspects of her experience. Prior to the HSCT, Hayley was a partner in a firm. She worked hard and enjoyed this lifestyle very much. Having the HSCT significantly changed Hayley's plans for the future. She said that she did not want to retire fully and however she was considering what she might be able to do post-transplant.

5.2.7 Rosie

Rosie was 29 when she participated. She described how she was originally from Australia, and met an Englishman when she was travelling whom she later married. She was diagnosed with Acute Myeloid Leukaemia (AML) which is cancer of the white blood cells after visiting the doctor with a sore throat that had persisted for more than two weeks. It is a rare type of cancer which is more common in people over 60. I met with Rosie for two interviews, whilst she was an inpatient. The first interview was two days after she was admitted to hospital. Her younger sister who was also her donor was present and contributed to the second interview, although I was unable to gain her sister's consent to include this data and so the second interview has not been included in the analysis. Following the HSCT, Rosie became unwell due to complications associated with the transplant; she was admitted to intensive care and sadly died 48 days after receiving the transplant.

5.3 Results of the IPA from the longitudinal design to meet aim one

All seven participants were interviewed at T1 six of the seven participants took part in interviews at T2. James declined to have further interviews following T1 as he did not wish to view the testimonies. Rosie was interviewed at T2, with her sister. Consent was not given by her sister and therefore this interview was not analysed. Five participants took part in an interview at T3. James did not consent to any further interviews and Rosie had become seriously ill and passed away in hospital, therefore they were not interviewed a third time. Table five below shows the timings for each interview in relation to the participants transplant schedule.

Table 5 Timings for each interview in relation to participant’s transplant schedule.

	T1	T2	T3
Vincent	<i>4 days before admission</i>	<i>2 days before transplant</i>	<i>3 days before discharge</i>
China	<i>31 days before admission</i>	<i>2 days before transplant</i>	<i>2 days before discharge</i>
Hugo	<i>2 days following admission</i>	<i>1 day after transplant</i>	<i>79 days after discharge</i>
James	<i>1 day following admission</i>		
Nathan	<i>7 days following admission</i>	<i>1 day before transplant</i>	<i>1 day before discharge</i>
Hayley	<i>1 day following admission</i>	<i>2 days before transplant</i>	<i>27 days after discharge</i>
Rosie	<i>3 days following admission</i>	<i>7 days after transplant</i>	

Analytic outcomes are presented below as five main themes. Through an iterative process of analysis, described in chapter four ‘4.4 Data analysis procedure’, a single higher-order main theme was generated for each time point, which each coalesced around an overarching and encompassing theme of ‘*Vulnerability*’ that encapsulated the psychological qualities of the experiences that participants recounted. The concept of vulnerability, played out differently at each time point. The main theme for T1 was ‘*Vulnerability exposed*’, for

T2 ‘*Countering vulnerability: Giving myself a fighting chance*’, and for T3 ‘*Recalibrating vulnerability: It wasn’t as bad as I thought but I’m not out of the woods yet*’. Participants initially talked of their vulnerability being exposed; they focussed on finding ways to counter this vulnerability and build resilience and then processing what they have been through and revealing new vulnerabilities. Whilst the main themes broadly mapped onto T1, T2, and T3 respectively, the process of undergoing and recovering from a HSCT was described as dynamic one and there was occasional overlap of these themes across time points (highlighted below). There were a number of sub-themes to each main theme. Two themes ‘*Time: a life on hold*’ and ‘*Relationships: Not quite getting it right*’ are shown as feeding into each main theme, because they appeared to permeate each time point and therefore were ever present. The differences between participants in relation to these themes are discussed throughout results.

The reporting of the analytic outcomes now proceeds by first demonstrating the relationship between the five main themes in Figure 7 below, the contribution of each participant to the each sub-theme (and by default, each main theme) in Table 6, followed by a presentation of each main theme and their related sub-themes.

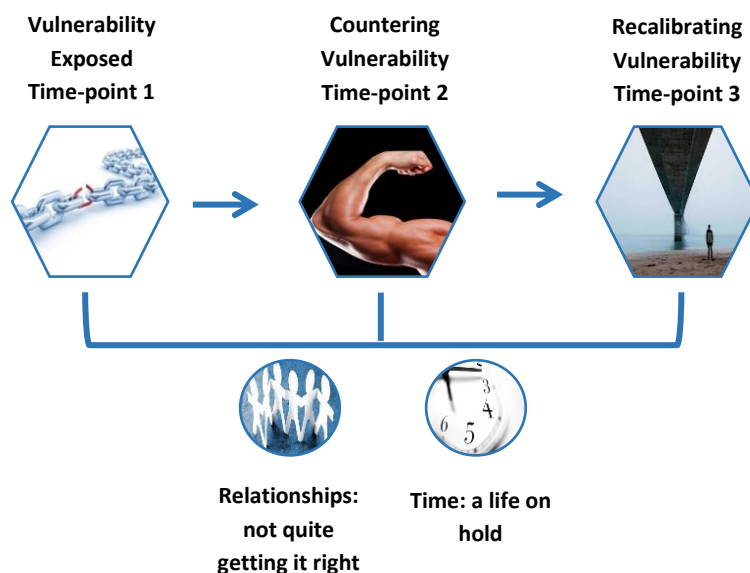


Figure 7 A diagrammatic representation of the relationship between the main themes.

Table 6 Contribution of each participant to the main themes and sub-themes.

Themes/Sub-themes	Vincent	China	Hugo	James	Nathan	Hayley	Rosie
Vulnerability exposed							
Shock, why me?	✓	✓	✓	✓	✓	✓	✓
Being exposed to risk and uncertainty		✓		✓	✓	✓	✓
Giving up control and trusting the experts	✓	✓		✓	✓		✓
Countering Vulnerability							
Information seeking	✓	✓	✓	✓	✓	✓	
Attitude	✓	✓		✓	✓	✓	✓
Recalibrating vulnerability							
Looking back	✓	✓	✓		✓	✓	
Looking forward	✓	✓	✓				✓
Taking responsibility	✓	✓	✓		✓	✓	
Relationships	✓	✓	✓	✓	✓	✓	✓
Time	✓	✓	✓	✓	✓	✓	✓

5.3.1 Theme 1: ‘Vulnerability exposed’

This main theme refers to the overwhelming sense of being exposed, in alarming and unexpected ways, to a frightening and uncertain experience. In being faced with the need for a transplant, the participants were made aware of their own vulnerability to harm, both physical and psychological, and had a sense that they could do little to mitigate this. They had seen themselves as fit and healthy individuals, with dreams and plans for the future; therefore, being diagnosed with a life threatening illness came out of the blue and threw

their lives into turmoil, which some experienced as unjust and wrong. Vulnerability is the state of being exposed to something which might cause harm (emotional or physical) and this theme emerged strongly at T1, although the process of having a HSCT is a dynamic one and participants experienced being exposed and vulnerable at all time points. This theme may have been less strong at T2 because participants were part way through their treatment and had started to experience that they could cope with the side effects of treatment and, as time progressed, they were still well and experienced less uncertainty. At T3, the theme of vulnerability emerged again and this is discussed later in the report.

The shock the participants felt is described in the sub-theme '*shock, why me?*' As well as feelings of shock and unfairness at the diagnosis, three sources of vulnerability were identified as; being exposed to risks, the uncertainty of the outcome and giving up control to the 'experts'. These sources of vulnerability are discussed in the sub-themes below.

5.3.1.1 Sub-theme: 'Shock, why me?'

Most participants experienced shock around the time of diagnosis or when they were offered a HSCT. They never thought this would happen to them. They considered themselves fit and healthy but were exposed to a new truth about their self, leaving them feeling confused and vulnerable. The vulnerability they felt came from beliefs they held about themselves, that they were healthy, safe and in control being threatened by the diagnosis. Hayley had been living with her condition for over 20 years and was shocked when she was told that the disease could no longer be managed with medication;

I never thought it would come to this...I knew there was something wrong but I didn't know to what extent because I thought that I would be on tablets and medication for the rest of my life, I just thought I could keep it under control and basically they told me...if we don't do a stem cell transplant then you'll die within two to three years which was a real shock, because I've always been really active and I worked full time (11).

Here, Hayley described how her assumptions that her condition could be managed were revealed to be false, and that she would die in two to three years without help, leaving her feeling shocked. Other participants also described feeling shocked when they were

diagnosed and a HSCT was discussed. They had also held assumptions about their health and invulnerability, as Hugo described;

I've always been very fit and healthy. I've always you know, exercised, I've never been overweight, never smoked, never you know, and it's just kind of in the end think bang, you just think...it just seems very, very unfair. So part of me is that kind of "Why the hell did this happen to me in the first place?" (160).

Here we see Hugo's reaction to the diagnosis was one of shock ("bang"), and a sense of injustice as he had put effort into being a good healthy citizen, to prevent being unwell – yet his commitment to the mandated preventative action transpired as being misplaced. China explained a similar jarring given she had been a responsible healthy citizen;

You could have knocked me down with a feather...at the time of the diagnosis. I mean you know because I thought I was doing everything right, I'd stopped smoking, cut down on drinking, went to gym, exercised regularly, ate well you know it was very kind of into my health, alternative health and things like that (666).

China's statement "you could have knocked me down with a feather" suggests she felt so unstable after the news; you could have knocked her over. She had done "everything right", therefore she felt that she had been short changed. These accounts collectively point to the beliefs that participants held about how they had inoculated themselves against poor health and also their belief in a just world. That their 'good behaviour' had not protected them was a double whammy of insult and threat. The diagnosis had been so unexpected, and threatened so many things they took for granted, that they felt newly and alarmingly vulnerable.

5.3.1.2 Sub-theme: 'Being exposed to risk and uncertainty'

Participants talked about specific events on which they could pin their new experiences of vulnerability. A key event was when medical staff made them aware that they may die either from the disease or from treatment complications such as stem cell rejection or infection. Participants were left feeling wholly uncertain and extremely anxious about their future and their chances of surviving the treatment. This meeting was experienced by most

participants as extremely negative, as it was perceived to focus on threat rather than protection. It left participants feeling exposed to harm, unsafe and with little chance of survival. Nathan described the meeting as “a bit like saying you’re going to die, just pick a way” (127). Hayley stated “that was just a horrendous meeting because basically she said I’ve got a 40% chance of it being successful...she told it as it was and that was a very hard hitting meeting” (15). Here Hayley focussed on the statistics presented to her during the meeting that indicated she had more chance of dying than of surviving the treatment. In the following extract, China described her meeting and the fear she felt;

The other doctor who I just went to see the other, the other day to, to consent for the stem cell transplant, went through, you know the risks... ..um and everything um, that she went through and what, what I could end up getting and you know, the, the, just everything that...it...that it involved, it just completely put me off really. It, it, it was fear, it was, it was fear. I was, I was very scared. And, and just didn't want anything to, to do with it really (135-147).

China described that the meeting felt too much, and that it was overwhelming and unnecessary. She had gone to the meeting to consent to the procedure, and expected the meeting to be informative, realistic and supportive; however, she found the meeting to be alarming and frightening and she no longer felt okay in consenting. She had become paralysed by the ways the treatment had been framed and “didn’t want to do anything”. The intensity of fear she experienced is highlighted by her repetition of the word, and the use of pauses and filler words, emphasising that she was recalling something which was still distressing or painful. China also described how she had expected the meeting to meet her needs;

It scared me to death so what would have been helpful would have, you know, just to have a few huge massive reminders that in amongst them risks, about the benefits as well because it was, you know, obvious. I mean I know it sounds obvious, you’re going to live; you know you’re going to have your life back, it's going to be cured (439).

Here China described the absence of positivity during the meeting; they did not tap into her optimism to help her, but instead tapped into her fear and vulnerability. Her optimism and hope were taken away giving rise to a heightened sense of vulnerability. It emerged that during these initial meetings other participants also experienced the presentation of risks in the absence of benefits, the focus was on the risks and that the odds were not in their favour. The focus was on what they had to lose rather than what they may gain from the treatment, which exacerbated their vulnerability.

When James said; “they must think they have a chance of doing it, otherwise why spend all this money on me” (151), he was describing that it was not made explicit that the medical staff thought he had a chance of surviving. By ‘reading between the lines’, that others must think he has a chance of surviving, he attempted to rationalise the risk, to decrease the vulnerability he felt and increase hope. Hayley felt that the meeting was more beneficial to the medical team, designed to protect them if patients tried to sue them, she said; “I know there is a protocol that they have to go through but, I think sometimes the empathy is not there” (31), suggesting she felt as though there was something missing in the meeting and her needs were not being responded to. When discussing the same meeting James and China experienced the feeling of being reduced to a statistic in the eyes of the medical team. James likened himself to a “lab rat” (143) and China said;

[Doctor] said “We need so many stem cell transplants in one year to continue to get the funding.” And I turned round and said “Well you won't be getting me this year” (211).

Here, China was wary of others’ intentions, questioning ‘who is this right for?’ wanting to protect herself from being a statistic. In a similar vein, Vincent used the phrase “just a piece of meat” (394) when he described the medical procedures leading up to the HSCT and also in anticipation of further procedures. He suggested that, to the medical team, he is ‘just a body to get better’. Thus, it appeared that there was a disconnect between the participants and the medical team at T1. Participants did not experience this process as dignified, supportive and optimistic but felt reduced to a highly vulnerable statistic.

The second way in which participants reported vulnerability at T1 was the uncertainty of the treatment outcome. Participants described how they had planned their future which created an illusion of safety and certainty, which their diagnosis revealed to be false. For some, the choices they thought they would make in the future were taken away from them; for example, the treatment forced them into early retirement or they knew they would experience an early menopause and therefore would not be able to have children naturally. This moved participants from a powerful position of being in control to a vulnerable and powerless position of having no choice. Rosie described how, prior to diagnosis, she had her life planned, but that this plan, and she, were then thrown into chaos when she was diagnosed with AML and was told she needed a HSCT to survive. She said;

You know where your life is going, you can see it all, it's all out there for you to do it and then all of a sudden someone just jumbles it all up and goes “Well you’re going to have to start again” and you just go “Oh god!” Like you’re telling me I’m either going to be thrown into early menopause, I’m going to be infertile, I could die (66).

Rosie explained how “you” know where your life is going, appealing to the shared human activity of envisaging a certain future. Being told about the need for treatment is compared, by Rosie, to an outsider cold-heartedly fracturing those plans and expecting you to immediately accept that change and convene a new future, even in the face of extreme danger. This felt more important to Rosie than to other participants and was possibly related to her young age by comparison. She had not yet done many of things she expected to in her life, she was newly married and had not yet achieved her career goals.

Thus, participants reported how vulnerability was triggered in the early consenting meeting, which served to extinguish the participant’s hope about the outcome of treatment and left them feeling their imagine future was gone. This sense of vulnerability left some participants feeling ‘on guard’ and that they did not want to be treated as a statistic or a “piece of meat”.

5.3.1.3 Sub-theme: ‘Giving up control and trusting the experts’

Not being in control exposed participants to further feelings of vulnerability; for example in

at T1 Vincent recalled a story about which his current situation had reminded him. He described a traumatic experience of visiting the dentist when he was three years old, which had themes of feeling out of control, fear and vulnerability. This is how Vincent described the experience;

So I went to the dentist and I got taken in, put in this chair that was far too big and they...held me down, you know I didn't want to be there, they held me down and they had this mask, they didn't have one small enough, I was only three, and they just come with this big black rubber mask, covering right over your face...and then the gas comes and you wake up and your mouth is full of blood... I wasn't in control, I was being held down (184).

Here he described his feelings of fear as he was held down, and of being out of control as the procedure is done 'to' him rather than 'with' him. He felt vulnerable and had not consented to what was happening. He recalled this experience as he described how he felt he had no choice but to accept the help of others, as he knew he could not do the transplant alone. He described wanting to administer the treatment to himself and be in control of everything that happened to him. He felt he was relying on the medical team to both cure him and at the same time not cause him harm.

Fear of being harmed by medical interventions was particularly salient for three participants (China, Hugo and Hayley) who had received prior treatments to manage their condition which had failed, before being offered a transplant. These participants, who had a longer time between diagnosis and transplant, were more vigilant of treatment failure and being cheated by the medical system than those participants who were told after diagnosis that their only option was a transplant. This may be because these three participants identified, were more fatigued by failures and setbacks and therefore more vigilant of this happening again.

Participants described reluctantly giving over control to the 'experts' and that this required having trust in those professionals. They felt they had no choice in whether to undergo a HSCT and felt reliant on others who were the ones in control. At the mercy of

the disease and putting their lives in the hands of others, they felt exposed and vulnerable to being harmed by the treatment they were about to receive.

Giving away control and trusting that they would not be harmed was more difficult for some. China described how she checked her medication every time it was administered, and challenged nursing staff if she thought there were medications missing. She was vigilant for and anticipated mistakes. She asked for a timetable of her treatment regime, which was promised, but not delivered. On the other hand, Nathan described being happy to give over control to the ‘experts’ and he felt safe in doing this.

5.3.2 Theme 2: ‘Countering vulnerability: Giving myself a fighting chance’

The second main theme of ‘*countering vulnerability*’ emerged most strongly at T2 but also at T1 where participants appeared motivated to counter the vulnerability that emerged as the main theme at T1 and change their situation, to fight back against the odds that were stacked against them. Given the extent of the vulnerability and fear described in theme one, one might have expected that participants would have been paralysed by this fear or felt stuck in their situation. However, it emerged that vulnerability was not a state that participants were resigned to and they seemed to almost automatically attempt to mitigate this vulnerability and become stronger.

How each participant responded in order to regain strength differed according to the resources available to them, what was important to them and also lifelong patterns of coping. For example the way in which participants responded to the hospital environment was different. Nathan had lots of cards on display, so many cards he ran out of space to put them and they seemed to fill the room. It was extremely important to him to have the support of others and was proud of his connections to his local community and how well he got on socially with others. Being with people, and making them laugh was, he described, a way in which coped with his life experiences. Hugo, on the other hand, did not have any cards up and his room was sparse of personal belongings; he commented that he did not want to make the room more personal because he did not want to get comfortable there. He saw it as a transitional place and did not want to settle. China responded to her environment by altering it, in ways nobody else did, to fit her needs and what was important to her. She

put pictures up at the window to maintain privacy and to make the room darker at night. Having no privacy and being disturbed in the night by noise and light was a common complaint, although other participants accepted this as part of the inconvenience and difficulty of having the transplant. China's actions were closely aligned with how she had described and represented herself, as someone who challenges authority and wants to be able to do things in the way that is right for her.

Two ways to counter vulnerability emerged; information seeking and determination in attitude and behaviour, described in the sub-themes below.

5.3.2.1 Sub-theme: 'Information Seeking'

Knowledge appeared important to participants in reducing vulnerability, and the absence or restriction of knowledge which was experienced, served to increase the feeling of vulnerability for participants. Four participants described their relationship with information and knowledge about the HSCT they were about to undergo. Participants described whether they sought information or not, what types of information they found useful and why. This sub-theme may have emerged as particularly strong at T1 and T2 as these were before the transplant and seeking information was related to building readiness and preparing for the procedure. Participants sought ways to actively move themselves from a position of not knowing or being sceptical to wanting to know more in order to participate more fully, to be in a more powerful and less vulnerable position. Some participants described how they had been in touch with others who had previously received a HSCT. Vincent described how speaking to a HSCT survivor helped him;

If you know what's, what can happen you can in some ways deal with it or, or be aware of it, it makes you "Oh right so this is what they're talking about, okay, this is what's going on. This is what could happen but I know." (326).

Vincent described that seeking information was a way to turn the uncertain into the certain. He experienced this awareness as helpful and not frightening and did not want information to be withheld from him, even if it was perceived by others as worrying or upsetting. Hayley spoke to others who were also undergoing a HSCT online and said "I took comfort from that, talking to other people that had been through the same experience" (391). She

also spoke of her desire to hear survivor stories, particularly from those who she perceived as older and therefore similar to her. I do not know exactly what it was that provided comfort to Hayley; however, because Hayley experienced her age as stacking the odds of survival against her we might deduce that Hayley liked to see examples of older people having survived the transplant which served to redress the odds of her surviving in her mind.

Hugo's job in the pharmaceutical industry enabled him to access research and experts in the field. He said;

You want to make sure that you are getting you know, the treatment which is, which is the one that is going to give you the best outcome potentially. You don't want some maverick playing round the edges of what's accepted and what's not, you want you know the, the bog standard you know, efficacious treatment that's going to give you the best outcome (88)... that's good because you know I can ask the right questions and you know, he can, he knows that he's talking to someone who isn't, does understand what he's talking about (72).

Hugo described that having this knowledge enabled him to “ask the right questions” (72) and shifted his position of being vulnerable through not knowing to being less vulnerable and more powerful because he can spot a “maverick” (88) who may do him harm. Acquiring this knowledge moved him to ‘a level playing field’ with the experts who provided his treatment. For Hugo, this knowledge and evidence countered the threat of harm and therefore lessened his vulnerability. However, he also described the downside to having this specialist knowledge, the potential for knowledge to become a burden, that “ignorance is bliss” (11).

Not all participants were able to access the information they wanted easily. China described how during previous treatments for her condition she did not receive all of the information she needed before having the treatment. It was only after one medication or treatment failed that she was offered a ‘better’ treatment. She was left questioning why she had not been offered the ‘better’ option in the first place. This feeling of being ‘duped’ led her to feel like an outsider, having to rely on others who she was not sure she could trust.

She was wary and questioning, and she attempted to understand what was being done to her, and she felt “ignored” (329) and dismissed. China described;

When I asked for a report on one of the scans and then questioned something that was on this report this particular surgeon turned round, he’d only come to check on me over the weekend and he said “have you got any questions?” and I thought actually “Yes I have” I said “You know this little bit on the report, what does that mean?” he said “That takes us 14 years to learn that terminology” and he said “What are you doing with that report?” And he, he couldn’t believe that I had a copy of this report and he just got, you know so like up his own profession that he couldn’t even bring himself to explain (611).

China was not able to access the information she needed, she was refused because she was not deemed able to understand. She felt aggrieved, that he should have found a way to explain it to her. It also seemed that China understood she was challenging the surgeon and he was surprised that she requested something she should not have. She was made to feel that she had done something wrong, because he questioned why she had the report. This fed into China’s belief that she needed to be on her guard and hold professionals to account because of the continual let downs, failures and setbacks she had experienced in the medical system. It was a recurring theme for China that medical professionals withheld vital information from her and dismissed her and that she therefore needed to be on constant guard to prevent this.

Not all participants wanted to gain more knowledge or pursued more information. James decided to only take part in one interview and not view the survivor testimonies. He described his decision as an attempt to be “self-contained” (448). He stated that every person who undergoes a HSCT is different in terms of their chances of survival, their experience and expectations and he was concerned that he did not want the film “clouding my mind” (420). He was worried that there may be something in the film that would “stick” in his mind and alter it, from the comfortable place he was at that time. He did not want to be given “unduly high expectations” (457). He also described himself as a very “private person” (465) and wanted to be able to deal with his emotional experience on his own and with the support of close family. Similarly, Nathan said that he did not seek more

information from the medical staff than he already had been given. He was happy that he could ask if he wanted to but he left certain things to the experts: “I don’t ask what they do, I just take it if they tell me to take it” (123). This may have indicated that Nathan felt there were things about his treatment that he could not understand, that this knowledge was not easily accessible to him. However, his resilience seemed to come from deciding not to worry about things that he did not understand, that he could put into the hands of others, the experts. He also described how he would like to use his experience to help others: “I’d like to do like a talk at the church or something like that you know, and tell them just what it's like, what this is. And because I’ve got a bit more information” (372). He desired something positive to come from this experience, for others and himself. This appeared to fit with how he saw himself, as positive and likeable, as a good person who helped others.

This sub-theme has demonstrated that one way participants responded to being vulnerable was to seek information to: a) become more aware of what was happening to them, and what to expect so they feel more in control; b) witness the experience of similar others, which reassured participants; and c) understand the medical aspects of transplant so they could oversee what was happening to them and protect themselves from harm. The differences between participants demonstrated that some participants sought more information, some actively avoided receiving more information than they felt they needed, and some also wanted to give information to others, or were happy knowing that others (experts) were using information.

5.3.2.2 Sub-theme: Determination in attitude and behaviour

Some participants described how they countered their vulnerability by doing certain things to give themselves ‘a fighting chance’. This included being active in getting themselves physically ready or ‘getting their affairs in order’ by sorting out financial arrangements and funeral plans in case they did not survive the transplant. Participants were willing to do whatever they could to be ready, to be in “the best state” (Vincent, 135) even if that was just to change their attitude towards the treatment. This ‘attitude’ referred to a willingness to ‘go through it’ and included a sense of acceptance but also positivity and optimism. It was a non-defeatist outlook and a readiness for what they were going to experience. This sub-theme emerged most strongly at T2 but also T1 when participants described their

preparation for the transplant and how they responded to their vulnerability. At T1, participants described how they prepared for the challenges they faced, and by T2 they had already experienced some of the challenges they had anticipated. At T2, they were unable to prepare themselves physically any longer as they were now in isolation and undergoing pre-transplant conditioning treatment (usually chemotherapy); however, they were able to change their attitude and this is what they talked about in the interview.

Five participants described at T1 how they prepared themselves for the procedure and in what ways this helped them. Vincent described “trying to get myself in the best state I can be” (135) by eating well, taking vitamins and walking. James also described keeping fit by walking and Hayley talked about a personal trainer she had hired and also how she attempted to gain weight (and therefore strength) to counter the weight loss she expected during the procedure, which she perceived to make her weaker. As well as ways to get physically stronger, attitude was also important to participants. Positivity and keeping a sense of humour was described by some participants including Nathan who said: “I’m quite a positive person, I think it ain’t going to beat me” (111). This was a lifelong pattern of coping described by Nathan; he described how he had always used humour and positivity and that was the sort of person he was. Rosie also described how she supported others, who she described as not coping as well as she was, by encouraging them to adopt a similar attitude to hers which she perceived was helpful to her. In turn, helping others was beneficial for her mood and she described;

I love making people laugh and I like making people meditate which is what I did with a couple of patients when I was in hospital in [place removed]. You know I liked going to see other people...there was another guy in there who was 30, he ran his own business and then all of a sudden he, you know he was Italian, he was in a foreign country, didn't understand, took all the treatments really hard and I was like “[name removed] don't get angry about it, just come on, let's go and do something or let's go and play pool....(53).

Rosie encouraged others to adopt her attitude of acceptance when she said “don’t get angry about it” and also used distraction and positivity. Rosie had previously described herself as a person who had always cared for and helped others, and she described how in some ways

she had lost that role and found it difficult to accept care from others. We see in the extract above that she described how she retained that role of caring for others who were having a more difficult time than her.

The participants described the procedure as something they must go through, that they could not halt or avoid, which indicated that they felt it was difficult to endure. In order to counter this, they described balancing their fear and uncertainty with optimism about the future and also an attitude that indicated a resolution to simply get through the task of the transplant. China described this task of ‘getting through’ as similar to the children’s story ‘*We’re Going on a Bear Hunt*’ (87). In this story, the characters encountered many scary and threatening obstacles on their bear hunt adventure. In tackling these obstacles, the words “We can’t go over it, we can’t go under it, we’ve got to go through it” are repeated. In likening her experience to the children’s story China acknowledged her fear, her lack of choice and her courage in facing it.

As well as physically going through the procedure, China also described what it was like emotionally to ‘go through’ the procedure. She used the term “emotionally bypassing” (63) to describe the temptation to avoid ‘going through’ the emotional experience of the procedure and she said;

Personally I’m recognising the need now yes, to, to not bypass those emotions. I think having spent a lifetime bypassing emotions ... I think it's very important to acknowledge when you’re angry or when you’re fearful rather than just leaping into a state of hope and positivity because where do those emotions go? (63).

She described how she viewed experiencing the emotions and not “bypassing” them as a way to help her physically. Her concern was that, if she did not allow herself to experience or acknowledge a full range of emotions, that this may have a detrimental impact upon her physical health. This was a way of responding to and countering the negative feelings of fear she experienced, by adopting an attitude of acceptance rather than avoidance in order to build resilience. This was an example of a mind-body connection which was a recurring theme for China. She placed importance on nourishing and healing her mind, as well as her body and that this was necessary because they were connected. China used a variety of

ways to help heal her mind and body including Emotional Freedom Technique (EFT) and homeopathy. Seeing some connection between the mind and body was implicit in the participants' narratives as they talked of adopting the right attitude and that this would help them to get better.

This sub-theme has demonstrated a second way in which participants responded to vulnerability and countered it by making preparations, getting physically ready and when this was done and they were in hospital, they concentrated on their attitude and directed this to one of acceptance, readiness, positivity and optimism in order to build resilience.

5.3.3 Theme 3: 'Recalibrating vulnerability: It wasn't as bad as I thought but I'm not out of the woods yet'

'*Recalibrating vulnerability*' refers to how participants processed their experience of the HSCT at T3. It involved participants '*Looking back*' over the procedure they had been through and assessing what state they were in and what that meant for them. They also anticipated what was to come for them; they were '*Looking forward*' as they were discharged from hospital and continued to recover at home. The theme of '*Recalibrating vulnerability*' emerged strongly at T3 as this interview was held at a major milestone in their HSCT, as participants transitioned from hospital to home. For some, this signified that the transplant had been successful, if they had anticipated that they may die before they reached this stage. Because of this, they seemed to recalibrate their ideas about how vulnerable they had really been. Some of the vulnerability and uncertainty participants experienced regarding the HSCT had been resolved because they had survived the transplant and were leaving hospital. Most participants experienced joy and a reduction in feelings of vulnerability; however, they were vigilant of new sources of vulnerability that lay ahead. There were echoes of recalibrating at other time points, as adjustment and adaptation is not a linear, but a dynamic process and participants were constantly adjusting to changes. These three activities of recalibrating vulnerability described above emerged as; '*Looking back*', '*Looking forward*' and '*Taking responsibility*' which are described in detail in the sub-themes below.

5.3.3.1 Sub-theme: 'Looking Back'

In looking back over the procedure, participants appeared to be processing what had happened to them. They tended to minimise the side effects of the treatment. Every participant talked about having felt unwell since the last interview, but they nonetheless described themselves as 'one of the lucky ones'. Indeed, every participant who took part in a T3 interview described themselves as 'lucky'. Each participant had been given statistics on their chances of survival which seemed low at the outset, so at T3 they felt they had beaten the odds. Participants seemed to credit the reason they were alive to chance. For example, Hugo said;

I was really lucky. Actually I didn't suffer as badly as some people did. I think I was very fortunate that I didn't get a lot of the...you know, I got some side effects but nothing too horrendous. So I was fairly fortunate in a lot of respects. I know some people had a really tough time (42).

In this extract Hugo reported side effects, but felt that others had suffered more than him. He described himself as only "fairly fortunate" because he still felt unlucky for having developed the disease and been in need of the transplant. His comparisons to others who fared less well, rather than to those who had never become ill, secured his view of being fortunate. It may be that memories of side effects become shaped by the meaning participants ascribed to their overall experience; that a HSCT was hard becomes irrelevant in comparison to the pursuit of survival. When participants perceived themselves as lucky, this appeared to shift them away from the original feelings of vulnerability. The benefit of seeing oneself as lucky might be that there is the potential to be lucky again in the future, thus re-calibrating their sense of vulnerability to misfortune. As well as participants seeing themselves as having been 'lucky', there was also a sense of gratitude to the staff who had cared for them.

Three out of five participants at T3 described that the transplant was not as bad as they were expecting. Hayley stated: "because of what the consultants said I was expecting it to be a lot worse" (19), and thus re-framed her experience as less injurious than anticipated. Perhaps in doing so, she simultaneously recalibrated how vulnerable she had been. Hugo described that he focussed on "getting over what had happened" (30),

suggesting that he felt he needed to process what he had been through. It was potentially too difficult for participants to tolerate thinking how close they came to death and so framing the experience as better than they expected may have served to shift participants from a place of vulnerability (being close to death) to one of less vulnerability (they had over-estimated the danger).

In summary, in processing the trauma of being made aware of their vulnerability, their fear of dying, and the side effects of the treatment, participants reframed their experience to one of not being in as much danger as they had thought, or that they were particularly lucky people. In this way they recalibrated the original vulnerability they experienced and this served as a way to self soothe or comfort themselves and to build resilience for further challenges involved in recovery.

5.3.3.2 Sub-theme: 'Looking Forward'

In the process of recalibrating vulnerability, it emerged that participants thought about the future as well as looking back over what they had experienced. They revelled in the joy that their hopes of getting to this point in the HSCT procedure had been realised and they looked forward to being out of hospital and their lives returning to normal. China and Nathan looked forward with abandon, both stating they felt they have been cured, whereas Hugo and Vincent were a little more cautious about whether they were cured and out of danger. China described the opportunities that she could take advantage of, and made plans as the cloud of uncertainty over her future lifted. In looking forward, they also acknowledged that they had changed as a result of the HSCT; they felt physically different, their lives had changed and they became vigilant for new sources of vulnerability as they transitioned into this new phase of their recovery.

Hugo revealed how he had been unable previously to think about the future in the following extract;

you kind of get so involved in the actual transplant itself and then the treatment and all the risk of infection and all the stuff that goes on with...around it, and actually at the end of the day the reason you're having the transplant is to stop your disease from coming back again. And that you don't really...that kind of is not forgotten at

this moment in time but it's not the kind of biggest kind of thing at this moment in time. It's kind of that's something which is probably more for the future. At the moment it's just about getting through everything that you've been through kind of thing (19).

He described how his focus had shifted throughout the HSCT, for example he was unable to look to the future in the earlier stages. It was potentially too difficult to tolerate a future that appeared so uncertain and in order to protect himself, he focused on the task of the HSCT procedure. This appeared to distract him from thinking too far ahead, which was protectively restrictive. Looking back he realised he lost sight of why he was going through the procedure because he focused on the day to day. We see from Hugo's quote above that how far ahead participants look into the future shifts in different stages of the procedure.

At T1, participants were not able to look too far into the future, as it seemed so uncertain. They described not making plans beyond getting out of hospital. By T3 the HSCT procedure was complete, they were recovering, and they started to look further into the future and began to make tentative plans. Vincent and China described how they had been researching where to go on holiday. Vincent said; "looking ahead to the new, to the next summer as well, seeing where we might go" (233). Vincent felt that he had moved into a new phase in his life, and he was happy and looked forward to the things he might do. He had been unable up until this point in the procedure to plan for the future as it had previously been more uncertain.

Some of the excitement participants described feeling about the future was tempered by some uncertainty still remaining about their recovery. There was a sense that they were not 'out of the woods yet'. Participants described worrying about whether the procedure had worked. China said;

I'm absolutely thrilled to bits, so to be here, now, a couple of days away from going home and the bloods rising all on their own, is just amazing, it's a great feeling to have got through that. I know I've not got through it completely and there's a way to go, but I'm, yes I'm really pleased (21)

In this extract, China described balancing her feelings of joy and optimism about the future with the reality of the risks and uncertainty still present as she prepared for discharge from hospital and continued her recovery. Patients undergoing a HSCT are particularly vulnerable for the first 100 days post-transplant, whilst their immune system rebuilds and grows in strength. Until this time they are at higher risk of life threatening infections and they will feel weaker. They are also at risk of transplant complications such as GvHD and relapse. This uncertainty tempered any future plans participants were tentatively making. China said this about her plans to go on holiday;

I was told categorically that I shouldn't be going away for the first 100 days and forget about going abroad for the next year, so that put things in perspective for me which I was glad I was told (25)

China's expectation of what she could do once she was discharged had been unrealistic and she recalibrated this following advice from the medical team. Vincent, Hayley and Hugo spoke of their expectations of what they would be able to do changed, as their body changed over the course of the procedure. Hayley said;

I were very weak for first two weeks, I couldn't do hardly anything. It just takes it out of you, you think you're alright but you're not really. I'm like an old woman going up steps and things (105)...sometimes your expectations of yourself are more, you know, you think well I should be able to do that (109).

In these extracts, Hayley described feeling weakness and tiredness in her body, as did other participants. This change in her physical capabilities placed restrictions on what she was able to do, and she had to lower her expectations. She indicated that she felt frustrated by her reduced capability and that it pointed to an underlying sense that she was still vulnerable. Vincent described how he felt when he went for a walk out of his room for the first time;

Yes, you're more aware of what's going on around you. And that will probably last quite a while I think and possibly when I get, pick up something that will reinforce it, you know just how vulnerable you are (156).

Vincent described being vigilant for danger in places he was not previously. He indicated he felt he was more vulnerable following the HSCT, capturing how the HSCT had changed his sense of self and his body.

At T3 participants were looking forward to the future, which they had felt unable to do previously and in looking forward they experienced joy and excitement about the opportunities for getting back to normal and enjoying the nice things in life. In recalibrating how they thought about themselves and what they were able to do in the future, they did not experience their sense of vulnerability disappearing, but noticed new sources of vulnerability emerging. They experienced being changed both physically and mentally by the HSCT and this highlighted to them how their weakened immune system rendered them vulnerable to infection, and further illness.

5.3.3.3 Sub-theme: 'Taking Responsibility'

'Taking responsibility' refers to a theme that emerged at T3 where participants talked about their responsibility to get well or stay well as they were discharged from hospital to continue their recovery from home. Participants described their duty to continue the good work that the medical team had done to that point in keeping them well, and participants varied in how much this duty weighed on them with and how much they wanted to be seen as a 'good patient'. For some, leaving the safety of the ward felt daunting because even though it had felt uncomfortable to hand over control to the medical professionals in the beginning, in some ways they had become used to this. They faced having more control over their lives and therefore more responsibility over their health and this opened up the opportunity to fail at this task with life-threatening consequences. At this stage, medical advice was given to the participants who were about to be discharged, on infection control in their homes, how to manage the risk from infection from others, managing their own medication and foods that they should not eat. This medical advice is open to interpretation as each patient decided what information they take on board as important and relevant and which bits to dismiss. Individual differences were noted in participant's descriptions of their intentions once they were discharged from hospital, which will be described below.

In taking responsibility for their health, participants described increased health vigilance. Vincent described “looking for signs” (164) of infection and rejection;

Well I guess it's something like a lot of diabetics who self-inject, it's their responsibility. If they don't, if they miss one or they hit the wrong thing, then they have to recognise the signs of going into diabetic shock, you know and do something about it. Otherwise you know, they'll come round in hospital on various drips (172).

In the above extract, Vincent described his feeling of responsibility, to recognise if he was becoming unwell. This may have felt difficult for Vincent, without the monitoring equipment and specialist training that the medical team had. This responsibility is no longer shared between him and the medical team and the burden or onus was on him. It appeared that the consequences of not recognising an infection was weighing on his mind, as he described what may happen to a diabetic, the idea that they might “come round in hospital on various drips” (172) seemed to be a vision of what may happen to him should he “miss” (172) the signs of an infection. One can imagine that whilst Vincent did not explicitly describe being anxious about this, anxiety may be part of his experience. In some ways, participants lost the safety and protection of the ward, a sentiment echoed by China when she described how being in hospital helped her to manage boundaries with visitors;

I can sit here and it's all safe and I'm very protected you know, and I've got these boundaries in place, I've only got one set of visitors coming each day and that's been great and I've been able to manage that. But when I get home you see, it will...that will be different because people will automatically assume (53).

This extract revealed that China experienced leaving the ward as a loss. She was losing the protection that was offered by the boundaries the medical team put in place. The ward was seen by participants as a safe place where threats to health were managed by others. Whilst she was in hospital she described being able to put boundaries in place when family and friends wanted to visit and she did not feel up to it by shifting the responsibility to the medical team. She anticipated that leaving the ward would expose her to others' expectations which she worried she could not live up to.

The hospital was also described as a clean environment and when participants thought about going home, they described that the responsibility to keep the risk of infection low by maintaining a clean environment was with them. This was experienced as daunting, particularly because participants felt physically weakened and did not feel able to clean their home as they previously might have, and they expected that taking on this task themselves may put them at further risk. Some participants did not express concern about this, and this may be down to those participants having others at home who either normally took responsibility of these tasks, or who were able to.

Nathan, China and Hayley described how they had been shocked when they received a large amount of medication to take home which they had previously received intravenously as an inpatient. Nathan said; “One of the things that I have struggled with...is I’ve struggled terribly to take tablets...and I’ve 19 tablets” (104). He was taken aback by the number of tablets and we see below that it felt like a daunting task to self-administer these without making a mistake. Nathan said;

I’ve organised that bag since I got it last night. She only showed me once how to do it but I’ve gone through it and I’ve done it and then to make sure I had got them all I counted the number of tablets that I’ve got... so I knew I’d got it right. And then...I thought I’d wait while the nurse came but as it happened she popped in and I said “Can you just count these with me, have I got the right ones (148).

Nathan described in the extract above his anxiety around whether he was able to manage his medication regime independently when he left hospital and how his anxiety motivated him to check with the nurses. He found benefit in checking with the nursing staff that he had administered his medication correctly, and this gave him confidence and reassured him that he could achieve this independently at home. He was pleased that the nursing staff only had to show him once before he mastered this. He also described organising his bag, which was a strategy he had described at other time points to help him manage his anxiety.

Being a ‘good’ patient was particularly important to Nathan and emerged across his interviews. It was more relevant to other participants at T3 and can be described as the steps taken by participants to take advice on their health and take responsibility for strictly

adhering to this advice. In this way it is close to the theme of '*countering vulnerability*' that emerged at T2, as it is a way that participants took action in order to redress their vulnerability, to actively do something to give themselves the best chance possible. However, there is also an element of being seen to be doing the right things also. It is a public show of responsibility to their health, as Nathan said; "I've done exactly what they told me" (57). This is demonstrated in the extract below from Nathan's T3 interview;

I'm just convinced that I've done what was in that book to prepare, to come in, I did, I got all the gear, I've done everything they told me to do while I've been in here. I don't think I've caused them any bother, I've done everything they told me to do and I'm convinced it's helped.

In this extract Nathan asserted that he followed the medical advice strictly. The book he referred to was an information pack that patients are given before they came into hospital for the HSCT. Actively engaging in preparing to be an inpatient, for example buying the 'right' toiletries and enough pyjamas to have a clean pair every day, helped Nathan feel less anxious and more in control of what was about to happen to him. Now, looking back at T3 he is "convinced it's helped" the transplant to be successful, in terms of surviving to this point and having "minor" side effects compared to what he expected. In this way he attributed the success of the transplant to something tangible, which was within his control, rather than the randomness of luck which is also a theme that emerged at this time point. He also referred to having not "caused them any bother" and it is important for him to be seen to be co-operating and being a good patient. In this way, if the transplant was not successful, he would not be to blame and others would know that he was not responsible for an unsuccessful outcome.

There were individual differences in the way participants managed the task of being discharged and taking responsibility of their recovery at home. Hugo described managing others' expectations, for example turning down invitations to go to the pub. He said "the advice we've been given is you still need to be very, very careful about, you know, social interactions and stuff like that. So we've been very...taking it seriously I suppose and have, retained what's felt like quite a degree of social isolation really" (94). In contrast, Hayley had visitors when she was discharged from hospital and described going out socialising

when she felt she had enough energy to do so. This illustrated the difference in what each participant saw as a risk, and what risks were worth taking. This difference may be explained by the participant's contexts and history. Hayley has a history of serious illness, she was diagnosed with Myelofibrosis 20 years ago and had managed this condition over that time, she also had a brain tumour removed and had what she described as a mini-stroke. She had survived more life-threatening illnesses than most people have experienced and therefore may have processed this in a different way to Hugo, who had less experience of adversity due to ill health. Hayley's tolerance of potential 'risk' situations may be higher as she had overcome the odds many times before and maybe felt immune to situations others perceived as harmful. In contrast, Hugo described that he had been told his there was a higher chance of relapse at later stages with the disease he had. Therefore, Hugo perceived himself as 'not out of the woods yet' and was still anxious about whether his disease had been cured or not. This may impact on the risks he was willing to take, it did not seem worth it to Hugo to risk catching an infection by socialising. This may have seemed like a small price to pay to Hayley, who was less worried about relapse and who had also described her feelings of loss when she left her job to have the transplant and how she missed being with people and socialising.

At T3 it emerged that participants showed individual differences in how they managed the task of leaving hospital and becoming more responsible for their own health. What seemed risky to one person was a risk worth taking for another. It emerged that every participant felt the weight of the responsibility for their health being placed on them as the protection of the ward felt like it was being withdrawn. Participants felt anxious about doing the 'right' things and maintaining the standards set by the hospital.

'Vulnerability' is an overarching theme which helped to explain the participants' experience. I may be sensitive to feelings of vulnerability for reasons which are discussed in 'Reflexive Box 2' below.

Reflexive Box 2 – becoming aware of feeling vulnerable too

Interviewing participants who were feeling very unwell and at times distressed about whether they were going to die was incredibly emotional. I thought I was prepared for this, because I was aware before I started that hearing these stories would be difficult and that some participants would die during the study, but I was not always aware of how it impacted me and the study until much later. The first participant I recruited died before he was able to have the transplant, and this shocked me, but I told myself that I should have expected this and I pushed away my feelings because I thought they were ‘over the top’. When I began interviewing, the first participants told me about how they were diagnosed out of the blue and that they were told their chances of surviving were low. All the optimism I felt from filming the survivor testimonies disappeared and I felt frightened that there was little hope or chance for the participants I was meeting and I was scared about how many other people I met would die. I thought about them, and hoped everything was going okay between interviews and I looked forward to our next meeting so I could find out about how it was going and check that they were still okay.

I still did not like admitting how much the experience was affecting me, because I thought that I should be more robust, because I am a trainee clinical psychologist and it is part of my job to hear distressing stories. I was ashamed, and thought others might think I was not coping and so I kept it mostly to myself, even though I would have encouraged my therapy clients to do the opposite and I would have told them that it is normal and okay to feel this way. Because I tried hard to reject my emotional experience, it came spilling out when I least expected it, but luckily this was in a supervision session and I was treated with compassion and had time to process how I was feeling and how I could respond in ways that were more helpful for me. I was able to continue with the interviews and feel okay about feeling sad and worried about participants and even sharing this with them.

I became more aware of my feelings and responses as time passed. When Rosie died in hospital, I was shocked again; I never thought that she would die because she seemed so young and healthy. Having some distance from the interviews and analysis I have come to realise that I felt vulnerable and exposed, like the participants did. I identified with Rosie because we were similar in age and outlook, we had much in common and so her vulnerability revealed my vulnerability in a way I've never been exposed to before. I've been lucky enough never to have experienced someone close to me having cancer, now I was thinking "if that could happen to her the way it did, it could happen to me or someone I love" and it frightened me. This may have sensitised me to vulnerability during the analysis stage, it is difficult to know for sure. It has made me aware that it is not always easy to 'bracket' my experiences or understand how they affect the analysis because my understanding of myself changes over time.

5.3.4 Theme 4: 'Time: A life on hold'

Participants described the effect the diagnosis, and having the HSCT had on how they experienced time. Participants experienced having more time when they became ill because most participants had stopped working when they were diagnosed or started treatment. They experienced time differently than they had prior to becoming unwell because their usual routine was disrupted. One participant chose to take early retirement, although she felt forced into this decision and worried about how she may fill her time after the transplant. Some participants had taken a break from working, not knowing when they would feel well enough to return or what job they might be able to do. Some participants were able to take sick leave and wondered when they might be recovered enough to return, knowing the estimated time it takes to have and recover fully from a HSCT is one to two years. For some participants their focus was not on life after the transplant, but on getting through the treatment, because the future, whether they would survive and what state they would be in physically, was so uncertain. Participants described the strange effects this disruption in their lives had on their experience of time; for some it slowed down, and they wished they could fast forward time through this experience or for some it felt like they

were stuck in a limbo. Participants described how it felt as though their life was on hold, that they were not living, as if time had paused and they were just waiting for this experience to be over so they could live again. The theme of distorted time emerged mainly at T1 and T2, when the disruption in their routine was most evident because they were in hospital, and in hospital they experienced having a lot of ‘time on their hands’. Some participants described how they planned to make use of this extra time by reading or learning a language. By T3 participants talked less about distorted time, as they were being discharged from hospital and starting to think about how they could start to get back to normal, at least being in their house, eating the food they normally eat and sleeping in their own bed.

At T1 Nathan described that once he had made the decision to have the transplant, he found waiting for a donor to be found and for a hospital bed to become available was slow and painful; he described just wanting to get on with it as quickly as possible. In this period, before coming into hospital to have the HSCT, time appeared to slow down for some participants, described by Hugo as “treading water” (184). Rosie found that she was living only in the present moment; “you can't think...in the future and you can't think in the past, you're only literally living for like, okay well today I've got treatment” (27). This was a common experience amongst participants, of not being able to plan future events and only living for today and the next treatment that is happening. This is how Rosie described the effect on time for her at T1;

Time is insatiable, like you can't find enough time, where's the time, time, time, time, time. And when you're faced with time either being non-existent or your time is slowed, you feel in some sort of void that you can't escape. And so when you're driving along like your...like my husband will be driving me to hospital, I'll watch all these people, I love people watching, I've always loved people watching even before I got in here. It's nice to watch people when they're busy and about and they're doing things. I miss that part of my life, I miss being busy, I miss going to work (91).

Rosie described how prior to being diagnosed and having the treatment she had felt as though she never had enough time, she was working hard to build a life with her new

husband. She described being very future focussed, working to build a better future for herself, moving towards her goals of buying a house, starting a business and having children. Following the diagnosis, her outlook changed, she was no longer future focussed and described just living for today. She no longer thought about the future because her future was so uncertain. Her experience of time was different, it felt as though it had slowed down, she had a new relationship with it, she was no longer rushing around. Facing the threat of dying and “time being non-existent”, she described getting more of what she wanted, ‘time’ because she was not going to work anymore and she had more time to people watch, but she was missing what she was not able to do, being busy and striving.

Hugo was also used to being busy and not having time on his hands. At T1 he described having many outpatient appointments to attend and even though he was not at work, he felt busy doing this and seeing friends and family he expected not to see whilst he was an inpatient. At T3, Hugo described how the change in his routine had impacted upon him once he was discharged from hospital;

there’s no split between the week and weekend, so every day just becomes the same...from someone who’s usually extremely busy and has to be on the top of everything it's quite interesting how you can just get into the mind-set of “Oh I’ll just do it tomorrow” when I always used to do it today! (110).

He described how each day had become the same, in the absence of the usual markers that signify a working day from a weekend. He described being surprised because he thought he would be able to keep on top of the smaller number of things he had to do, with more available time, but the urgency to complete tasks disappeared and he therefore had less motivation to do them, and had let things “drift” (110). This was something that Hugo experienced as negative, it was not a “mind-set” (110) that he found productive or helpful for him, and one can imagine that over time this would impact upon his mood. He was looking forward to getting back to work when he had built his strength and establishing a routine again.

For some participants, life felt as though it was on hold and they are just waiting to have the procedure so their life can begin again. For example At T2 Hugo described “I’m in

transition here. This is a sort of holding area for, for what I'm going through" (47). He experienced being in hospital as limbo, between being unwell and well, diseased and cured, vulnerable and safe. Nathan also described that he was worried he would remain in limbo once the procedure was complete and he was discharged. He said;

I hope that doesn't carry on, you know what I mean? I hope if I am cured, I hope... I hope I don't think, "Well I wonder if I really am" you know what I mean? Am I ever going to be really cured... Am I ever going to think "Yeah I'm alright now, I haven't got that anymore" or "I'm just waiting for it to come back now" (316).

Here Nathan described his worry that he will always be 'stuck' in a sort of limbo where he doesn't know whether he is cured or not. He was wondering whether he would ever feel certain or safe regarding his health again. Would he always experience his life as just waiting? In his response to feeling in limbo, he attempted to balance the uncertainty and fear with optimism, whilst others described acceptance that they must 'go through it' and Hayley described "just taking one day at a time" (19). Vincent described;

Part of me says 'yes go with the flow because there is nothing you can do about it and it's just wasting energy' which I haven't got, as opposed to trying to push it along. 'Come on nurse, why haven't you done this yet?...because I suppose you just go with it, well I can't do anything to make it go faster' (83).

This extract indicated the frustration he felt, that he couldn't make time or the procedure go faster in order to get on with his life, indicating that he felt time was going too slowly and he was helpless in this situation relying on the nurses to do the tasks. His response was to attempt to accept the slow pace of the procedure and go with this rather than fight against it, as doing anything else felt futile. Hayley described a similar experience of wanting to 'fast forward' time;

give you a button, push it and freeze you, do what all they have to do to you and then just wake up in six months' time, but it's not feasible, you've got to be awake for it all (40).

Hayley fantasised about a way to ‘cheat’ the experience by fast forwarding time, which indicated that she found the experience intolerable and did not want to experience it at all, she would rather have the procedure done to her whilst she was not consciously aware, even if that meant losing awareness of six months of her life. In reality she experienced that there was no ‘quick fix’ or way to bypass this procedure that was taking a physical and emotional toll on them.

Each participant’s experience of time was different; however, it was a common experience that the way they perceived time had changed. For some they had desired having more time, and when faced with lots of time on their hands, they missed their old routine of being busy and not feeling they had enough time. A common experience was that they felt in limbo, that life was paused and they were waiting for it to resume and this resulted in time being slowed down.

5.3.5 Theme 5: ‘Relationships’: not quite getting it right’

All participants described how the HSCT affected their relationships with others, in particular those who they were closest to or dependent on for treatment and this emerged across all three time points. The support of family and partners in particular was talked about as particularly important for help with tasks associated with the transplant and also with emotional support. Nathan did not have a partner and he described how this made things more difficult for him, compared to if he did have a partner to ‘share the burden’. Whilst they described that they appreciated the support and love that they received, they were also frustrated within those relationships when the other did not always ‘get it right’. There were two sources of difficulty in relationships that participants described which will be outlined below. Sometimes participants found others’ emotional reactions difficult to deal with and sometimes other people wrongly assumed they knew what would be helpful for the participant. The dependency they felt on others created a tension, as they needed other people but others did not always meet the participant’s needs.

Whilst participants were often touched by gestures of support and love from others, not all offers of support were experienced as helpful. Hayley, Nathan and China described the burden of visitors, who wrongly assumed that participants would experience their visit

as positive. Hayley and Nathan described how they often felt too tired for visitors or ran out of things to say. James found others' offers of support to be misjudged and described how he found it difficult to be supported emotionally by people he did not know well, and he said;

I was thinking I don't want that, and I think yes they're doctors and nurses but they don't know me, they're strangers to me. I'm not going to feel I'm getting any emotional support from them, I need it from people who are close friends and family (67).

In this extract he described how he rejected support offered by the doctors and nurses, and that his preference was at odds with a general assumption that patients should receive emotional support from nurses in particular. He appeared frustrated and whilst it is unclear exactly why he was frustrated it could be that there was an expectation by the nursing staff or others that he would make use of emotional support offered, which he did not want. He could be frustrated at the assumptions of others which were at odds with his own preferences and needs.

Similarly to James above, Rosie experienced frustration at the incorrect assumptions of others. She described how she found it difficult to manage others' reactions to her illness and treatment, because others assumed she would die. She was positive about having the HSCT, because her mother had also had a HSCT and had been in remission since and so she saw a HSCT as a positive curative treatment. She experienced others offering their commiserations, being very sad or crying in front of her, as difficult and it jarred with her own outlook. Rosie also described in the following extract that although many people showed concern she felt that this was not always genuine;

there are few who care and the rest are curious...there are so many people that just want to be tagged along in the journey because it's very interesting to them, because cancer is..." (244).

This extract signified that she found relationships with others difficult. Outside of her immediate family, she interpreted people's questions and reactions as negative and them wanting to be 'tagged along', as taking advantage or gaining something from her situation.

Her experience of cancer led people to comment on her situation or be involved with her life where they normally would not. She described people being curious as if she was an oddity or something to marvel at. This exacerbated her experience of being different, which she already experienced as an Australian living in the UK. She had described how she was usually the person caring for others and that she no longer had that role, which indicated that she found being dependent on others created tension in her relationships.

Rosie also noticed that when she told her story to a cancer charity, they selected the “sad part of my story” (230) to go on their social media platform and she believed this was to increase donations. She said “I want people to see that even something so horrible, that people think “Oh my god that's the most horrible thing”, it hasn't been the most horrible thing to me” (249). This again indicated that she felt others made assumptions about how she felt about her situation, that she experienced it as the most horrible thing. The reactions of others to Rosie being ill and having a transplant was a source of frustration for her because it was different to how she perceived her own situation, and she wondered whether others found her situation more stressful than she did. China also described how it was difficult to deal with the emotional impact that her illness and treatment had on others, as she tried to manage her own emotions;

their fear operating in such a way when I'm dealing with my own fears, and remain optimistic, it's just entering into a completely different game play that actually I don't want to play right now...I don't want to be playing this game. Go sort your own shit out, I've got stuff to do. That's how I feel like saying it, I would never say that, but, because I play the game, because I'm a good girl (168).

In the extract above she described “playing the game” and “being a good girl” which evoked the idea that she experienced feeling a duty to others and therefore found it difficult to assert her needs and wishes. She was particularly concerned with how to manage boundaries with family and friends when she was discharged as she had been able to use the hospital environment to put in protective barriers (by saying she was not allowed visitors) between herself and others whose fear and emotional reaction to her situation she found unhelpful.

Similarly to Rosie and China above, Vincent also experienced the reaction of a family member as challenging. He described how he thought the procedure had been “just as traumatic” (27) for his wife as it had been for him. He described their different coping styles, he being laid back and she being organised and it seemed that fortunately for them they complemented each other. However, they had to be aware of how each other coped and the difference in their styles in order to avoid tension. He described allowing his wife to do things for him and take responsibility for certain tasks in order to “give her something to focus on” (27). In the following quote Vincent described the stress that his wife was feeling when he was being admitted to hospital;

You can't rush these things. You'd just get stressed out, [wife's name] doesn't understand, if she's given a time she goes with that time and God help you if you're not on time, so she was just getting more and more apoplectic during the day. She, she drove me in though (19).

Vincent indicated that his wife's stress was at odds with his own experience, as he was not 'stressed' that the hospital were delaying him, and there was a tension between their strategies of dealing with this setback. At the end of the quote, Vincent comments “she drove me in though” indicating that whilst it was at time difficult and frustrating to deal with others' emotions and the relational impact of the procedure, he recognised that he did need her support, particularly in this case to complete practical tasks, such as driving him to hospital.

Vincent and Nathan both described feeling uncomfortable with relying on others. Vincent described that he would rather do the procedure himself if he could rather than be reliant on others. Nathan is the only participant who lived alone and he described himself as very independent, although he described becoming more dependent on support from his family. He also experienced living alone as an extra burden, making comparisons between himself and others who have partners to split the burden of tasks he had to complete before coming into hospital. Whilst participants recognised that they needed the support of others at this time, others often got it wrong and were the source of further frustration or stress.

This results chapter has so far set out pen portraits of each participant and the findings related to the first research aim regarding the experience of undergoing a HSCT. In ‘Reflexive Box 3’ below, a discussion of how it was to analyse the data and the potential biases noted will be presented. Following this, the findings related to the second research aim regarding the experience of viewing the filmed testimonies will be presented.

Reflexive Box 3 – finding myself in a position of power and not wanting to misuse it

Over the course of interviewing participants and analysing their words I found myself in a position of power, in terms of deciding how to represent the participants’ experiences. This is a position that I felt uncomfortable with and pushed against, which influenced the process of analysis and how I interpreted the data.

When facilitating the research interviews I was aware that what I was going to do with the recordings must have seemed quite mysterious to participants, particularly when I said I was going to ‘analyse’ it. I noticed I was often asked questions about that and also what motivated me to do the research. If I was in the participant’s position I would probably be a little concerned about how I would be represented and because of this I was keen to do a good job of the analysis and not misrepresent participants in any way. This became even more salient, after Rosie described telling her story to a charity, who put this on social media and she felt they misrepresented her. It appeared to me, that I had a lot of power at this point, as the data had been gathered in collaboration with the participants, however the analysis and write up of the report had been done in isolation from the participants.

At the end of an interview with a participant which I remember to be particularly emotional, we started talking about my work, where I went to university, where I had worked before my career had taken a turn into clinical psychology and why I was motivated to do such work.

Partly I understood this participant to be interested on behalf of his daughter who was also considering a career in psychology, and partly it felt as though he was ‘weighing me up’, what were my intentions and could I be trusted after he had allowed himself to be vulnerable with me in the interview. As we were chatting he said “I trust you to do the right thing with this information”.

This trust placed in me by participants further strengthened my determination not to misrepresent participants and I spent a lot of time thinking during the analysis stage, “is this what they really meant?”. I found myself dwelling on whether participants would be happy with how the analysis had turned out, whether they would consider that I had represented them well, and stayed close to what they were trying to convey.

As noted by Karnieli-Miller, Strier, and Pessach (2009), the role of the researcher is often seen as a detective, aiming to discover something which has not been understood by others including the participant. I felt uncomfortable in this position, a position that implied I knew more about the participant than they did about themselves, and I avoided doing this. Avoiding what I considered to be over interpreting the data, may have helped me to stay close to the participants’ meaning, although I think at times this led me to be overly cautious in interpreting what was going on for participants and it took time and support from my supervisor for me to become familiar with using IPA methods and for me to feel more comfortable with going beyond purely describing what the participants had said and for my interpretations to feel less like I was misusing a position of power.

5.4 Results of the content analysis of the data pertaining to the patient testimonies

The filmed testimonies were shown to all six participants who participated in interviews at T2; however, Rosie’s T2 interview was not analysed (see 5.2 Results). The participant and interviewer watched the film together and then the participant was interviewed about their experience of watching the film.

Nine themes emerged from the analysis, five of which describe what was found to be positive or helpful about the film and three which suggest alterations. Whilst a few alterations were suggested, the participants’ experienced the film as helpful in fostering hope, informative, and interesting. The themes that emerged, and the frequency they appear, are set out below in figure 8 and following this a description of the findings will be set out below according to theme.

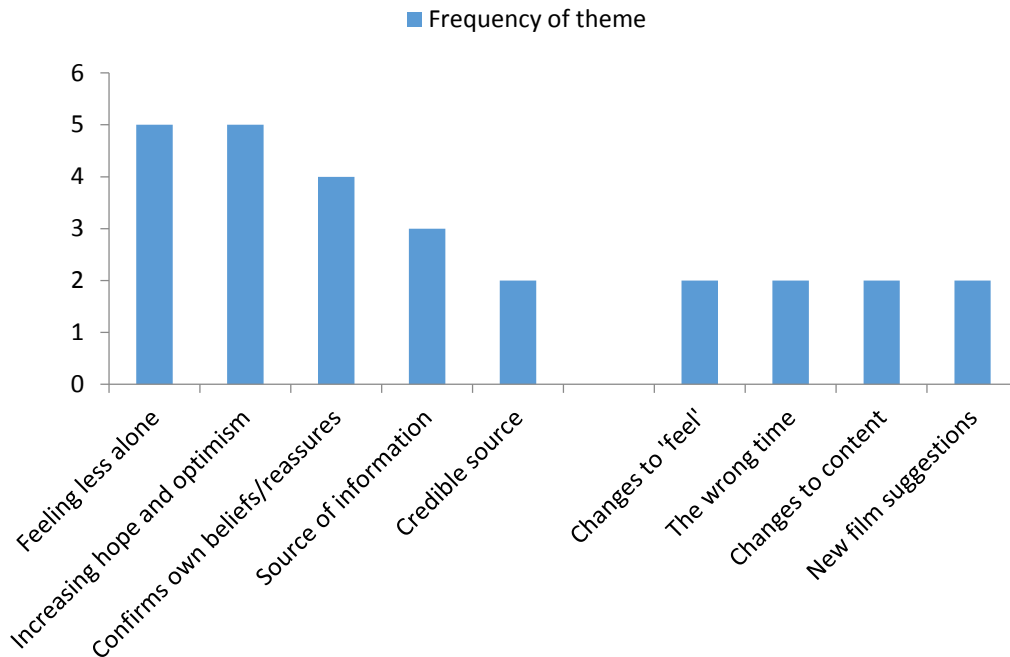


Figure 8 A bar chart showing themes relating to the testimonies and for how many participants these themes emerged.

5.3.6.1 *Feeling less alone*

All five participants described that in watching the film they felt less alone. Vincent described a tendency to feel “it’s you and the disease” (197) and that is a lonely place to be. The participants felt like they were similar to the people giving the testimonies “sometimes using the same words” (193) therefore he felt close to the people on the film and watching the testimonies highlighted to him that “you’re not the only one, that, that’s been a great thing, particularly when you’re in isolation for a long time” (185). China described “I could see myself in every single in each and every one of them” (115) and this indicated to her

that what she was experiencing and how she was managing it was ‘okay’ which she found reassuring. Hayley also found it reassuring to see others like her, similar in age and who had similar experiences. Vincent said “he’s someone who’s almost in my situation, he’s been through it, you can get through it” (221). Seeing others who they considered similar to themselves reassured participants that they can also get through the HSCT, that it is manageable. Watching the film prompted participants to reflect on their own experiences and it encouraged participants to explore how their experience was similar or different, and what was important to them.

5.3.6.2 Increasing hope and optimism

As well as providing the reassurance of seeing similar others having survived the HSCT, participants experienced the film as hopeful and optimistic. Vincent said; “it can cheer up up...she got through it” (259); he experienced others talking about their experience in a positive way as providing hope that he can also get through it. After watching the film Hugo commented; “this is what the future could look like” (119). Some participants described the film as providing a welcome balance from either the negative information they had received before this point or the negative experiences they had had themselves when treatment had not been successful. China described that the initial meetings she had where she was presented with her options and the statistical chance of her surviving the treatment were difficult for her, as she experienced them as cold and distant, but of the film she said; “I think something more humane like the DVD is more beneficial than looking at statistics and thinking well which am I going to pin my hopes on?” (128). To China it did not matter about the statistical odds of her surviving the transplant because she did not feel as though she had a choice, the alternative was a shortened life and death anyway, and so she looked for something hopeful that she could “pin her hopes on”. Hayley and Nathan also liked the contrast the testimonies gave them. Nathan described how he noticed the medical staff tended to “look on the black side” (261), whilst he wanted to be more positive. Hayley said; “I think seeing that video you showed me...I realised yes it can be done” (85). Participants were given a copy of the testimonies at T2 so they could watch the film again if they wished. China described that she had watched it again and she had felt enthused by it and she also showed it to her family.

5.3.6.3 Changes to the 'feel' of the film

Whilst some participants liked the overall message of the film being hopeful and realistic, Vincent commented that he thought it was too optimistic and that he would have liked it to be more realistic. He said the advantage of the film being more realistic would be that he was “forewarned” (365) of what was to come. He experienced ‘forewarned as forearmed’ and sought to make the uncertain aspects of the transplant more certain. This comment was made at T3, whereas at T2 he had described finding the positivity of the film beneficial and also not enjoying the “darker bits” (229) which had reminded him of the possibility that he might die. Perhaps at T3, after he had experienced the transplant for himself, he felt that the film did not do justice to the experience and how difficult it had been for him.

5.3.6.4 Credible source, information seeking and confirms own beliefs/reassures

The testimonies were described as a credible source by two participants, and this was because they came from people who had been through the experience, and in this way they were experts and trusted to give a true account of what it was like. Whilst participants thought it was credible and a good way to share information that they “wouldn’t have been able to get anywhere else” (China, 365), participants also described filtering out information that resonated with them and dismissing the rest. This involved participants paying more attention to people who seemed similar to them, or seeking information that confirmed their beliefs and dismissing information that was different from the way they already viewed their experience and how they intended to manage it. For example Hugo said; “you are always look at things to reconfirm your own kind of beliefs I suppose” (51). He described that the variety of testimonies was useful in terms of having enough of a range for people to find something “to hook onto” (59). This indicated that participants had already prepared somewhat for the transplant by T2 when the film was shown and that they had beliefs about what it was going to be like and what was the best way for them to manage the process. It followed that some participants described the film being shown too late in the process, and that being shown at the very beginning, when participants were deciding whether to have the transplant would have been more useful.

5.3.6.5 Changes to timing, content and suggestions of new films

The film achieved its aim of providing a hopeful but realistic message. It is not clear whether it supported participants by preparing them for the emotional aspects of the HSCT and it was commented by a couple of participants commented that the film was shown too late in the process. There were small additions that were suggested by participants, such as adding information on the film about the people who were giving their testimony such as; their age, their diagnosis and how long they are from transplant. Having a more equal balance between the genders was also suggested as well as another film for when participants are being discharged and one for friends and family to watch. Two participants suggested that their family members would find it helpful or informative and one participant suggested that a new film could be made about the post-transplant experience.

CHAPTER SIX: DISCUSSION

This study aimed to increase understanding of the patients' experience before, during and at the end of a HSCT transplant, and additionally, how viewing a film of survivor testimonies was experienced during the treatment. Knowledge of the patient experience is essential to the provision of medical, nursing and psychological care which is patient-centred, supportive and which minimises distress. In this final chapter, the discussion begins by setting out the findings in relation to the two research aims. It then considers the key findings relative to the literature discussed in chapter two and other theoretical areas not yet discussed. The clinical implications will then be considered. Finally, the study will be evaluated before conclusions and further implications are offered.

6.1 Summary of findings

The first research aim was to explore the experience of participants preparing for and undergoing a HSCT. Findings suggested the experience was one of temporal shifts in one's sense of vulnerability and strength. The second research aim was to explore how participants experienced viewing survivor testimonies whilst undergoing a HSCT. The effect of the testimonies appeared overwhelmingly positive. Participants found the resource a hopeful and optimistic counterbalance to the fear and uncertainty they were experiencing.

6.2 Discussion of findings from the longitudinal component

Key issues raised by the findings from the five themes and related sub-themes from the longitudinal component of the study. Findings from the survivor testimony component of the study will be discussed in '6.3 Patient testimony findings'. All findings will be discussed in relation to existing studies (described and reviewed in chapter two) and new theoretical and empirical work relevant to the findings will be introduced.

6.2.1 Vulnerability exposed

The finding that participants experienced a new, intense and traumatic sense of personal vulnerability is a relatively new finding, with one other study indicating that patients experienced ‘technology induced vulnerability’ from undergoing a simultaneously lifesaving and life threatening procedure (Cooper & Powell, 1998). Other studies described concepts which may be similar to vulnerability, for example ‘perceived threat’ (Farsi, Nayeri, & Negarandeh, 2013). Vulnerability experienced by patients is also described in the wider research. For example, patients in intensive care described vulnerability related to extreme physical and emotional dependency (McKinley, Nagy, Stein-Parbury, Bramwell, & Hudson, 2002), not unlike some participants’ experience of HSCT. That this overwhelming sense of vulnerability was fuelled by the risks associated with the transplant, facing mortality and the uncertainty of their future, has also been corroborated in other studies (de Carvalho et al., 2000; Gaskill et al., 1997; Persson et al., 1995; Sherman et al., 2005; Thain & Gibbon, 1996; Xuereb & Dunlop, 2003). Vulnerability predominated at T1 in the present study, which Fife et al. (2000) report as the time of greatest emotional distress in a HSCT. A consensus is therefore emerging across a number of studies that helps explain the emotional distress experienced by HSCT patients at this stage of treatment.

6.2.1.1 Shock, why me?

Participants described feeling shock after receiving the news of their diagnosis and/or that they needed a HSCT. This supports the findings of Xuereb and Dunlop (2003) that the experience of HSCT centred around two significant events, diagnosis and receiving the transplant. The initial impact of the diagnosis is one of shock, fear, uncertainty and helplessness. This shock was a result of their beliefs about how they had inoculated themselves against poor health and also because their belief in a just world was exposed as misplaced. The diagnosis and resulting need for treatment had therefore been so unexpected that they felt exposed and threatened and unable to view their future as predictable. The ‘shattered assumptions’ theory developed by Ronnie Janoff-Bulman in 1992 may help understand these findings further. She proposed that people commonly hold three assumptions about themselves and the world, but that they are not aware of these

assumptions until they are threatened or challenged by a major life event, such as being diagnosed with a life threatening disease. These assumptions are; the world is benevolent, the world is meaningful and the self is worthy. Janoff-Bulman argues that their purpose is to protect the holder psychologically from all the possible tragedies that could befall them, as this is too disturbing to think about (Janoff-Bulman, 1992). A further two assumptions; the world is predictable and the self is invulnerable, were added by Brewin and Holmes (2003). In the present study, three particular assumptions participant's may hold were challenged; that they could predict what would happen to them, that the world was just, and that they were invulnerable. According to Janoff-Bulman's theory, the unarticulated assumptions act as a buffer against a person's vulnerability because they provide an illusion of competence, stability and invulnerability. Therefore, the participants in the present study, experienced not only being afraid of dying as a result of their diagnosis and need for treatment, but felt terrified, confused and shocked by the new awareness of their invulnerability.

6.2.1.2 Risk and uncertainty

A unique finding of this study was that the initial meetings between the consultant and the participant were identified as contributing significantly to their experience of vulnerability. These meetings outlined the risks of the procedure and the statistical chance of participants surviving so that they could give their informed consent. Participants described these meetings as overwhelmingly negative, frightening, cold and inhumane as they were given information which was detached from their individuality and humanness and they felt reduced to a demoralising negative statistic.

The meetings described by the participants have been researched in the context of HSCT patient's making decisions and consenting to medical procedures (Bywater & Atkins, 2001; Jacoby et al., 1999). Jacoby et al. (1999) concluded that the concept of informed consent is meaningless for HSCT patients as the treatment is usually offered as a last resort; it is their only option for a cure or a longer life, therefore they do not have a choice and informed consent means nothing when there is only one option. It was suggested by Jacoby et al. that a more important task in these meetings was attending to the patient's emotional rather than cognitive needs. This resonates with the findings of the

present study that participants were seeking information that would foster hope and optimism during these meetings, rather than statistical information that would focus on the risks. A study by Lee, Fairclough, Antin, and Weeks (2001) found that when given information that the statistical chance of survival is low, patients fail to recognise the high risk and overestimated the probability of positive outcomes. This suggests that the information communicated in these meetings is difficult to tolerate, therefore rejected or changed to fit the patient's desire to foster hope and optimism. This calls into question the notion of informed consent in this context. The patient may understand the risks, however feel that they have no choice and therefore choose to ignore them and not discuss them (Cooke et al., 2009).

The clinical implications of these findings are that patients undergoing a HSCT need support in maintaining hope and optimism in the face of the fear and vulnerability experienced at the early stages of treatment. Each patient is likely to be different in their ability to hear and process information about their odds of survival and some patients may choose not to engage with this information as some participants said it was not helpful for them to hear it in this way. Therefore, there is more work that could be done in engaging patients in how this initial information is presented and is tailored to their needs. Some patients will want to know everything, the 'hard facts' so to speak as Vincent and James did and this should be facilitated; equally if a patient does not want to engage with statistical information as China and Hayley described then they should not be forced to hear this in order to satisfy the idea of informed consent. The fact that there are risks involved in the treatment should be acknowledged and then the way in which the patient wants to engage with this information could be a more collaborative process, with the patient deciding what information they would like to know and how they would like this presented. Buckman (1992) likens telling patients 'bad news' to pharmacological dosing: too little truth is like taking too little of a medication, it is ineffective and weakens the patient's trust in the physician, but too much is likely to be overwhelming to the system, and may produce tolerance effects or even resistance in some people. As discussed in chapter two, distress during treatment in HSCT patients is related to poorer survival outcomes and post treatment quality of life and therefore it is imperative that steps are taken to minimise as far as

possible patient distress, and the findings of this study suggest that reducing fear and increasing hope and optimism is one way this could be achieved.

6.2.1.3 Giving up control and trusting the experts

As well as experiencing a lack of choice as to whether to undergo the transplant, participants also reported experiencing a lack of choice and control during the procedure. Many participants had never experienced being reliant on others for care and had little choice in their daily routine as the treatment regime was being controlled by the medical staff and they were confined to a hospital room. These findings support those of Haberman (1995) and Persson et al. (1995).

Participants described that in giving over control to the ‘experts’ they gave themselves the best chance at being cured, because they could not treat themselves. This control ranged from not being in charge of daily routines, for example when nursing staff came in to administer treatment and when they ate lunch to having ‘blind trust’ in the ‘experts’ that they were not going to harm them. Giving up control was more difficult for some participants than others depending partly on their past experiences.

Haberman (1995) suggested that the act of giving up control to others who are trusted was a way that patients remained in control. In the present study, giving over control to the ‘experts’ was perceived as the only way participants would survive or be cured. Haberman hypothesised that giving over control to a stable external force (the medical team) was seen as a way to align oneself with a powerful other as a way to maximise the chances of a favourable outcome, and therefore a way to stay in control or regain control as much as possible over treatment uncertainty (Haberman, 1995). This may have been used as a strategy by some participants in the present study. Putting their trust in others and apparently relinquishing control may be a psychological response to either feeling reliant on others and out of control or as a way to gain control by maximising their chances of the best treatment outcome. Whilst this was seen as necessary by participants in this study, it is clear that participants found putting their trust in others challenging and the lack of choice and control impacted on their wellbeing.

Participants in this study commented on unexpectedly experiencing being given choice and control, for example China described that she met with the dietician who designed a bespoke menu based on what she ate at home and her preferences and this was sent to the hospital kitchen. In this way China experienced choice and control in what she ate which was very important to her, and it illustrates the role of exploring patient's values and context to find out what is important to them whilst they are in hospital, therefore preserving agency in valued areas. The potential clinical implications of these findings are that patient wellbeing can be supported by encouraging choice and control if this is part of the patient's needs. This should be performed in a patient centred way, as some patients may choose purposely to relinquish control.

6.2.2 Countering vulnerability

This is the first study to show that HSCT patients' relationship to vulnerability shifts over time during the treatment. Whilst it is not surprising that people's experience of something changes over time, this study has highlighted what changes, namely the participant's concept of vulnerability. Participants instinctively responded to vulnerability with determination which will be discussed further below in '6.2.2 Countering vulnerability'.

Following the initial impact of the threat of diagnosis and news that a HSCT was needed, participants quickly got on with the task of adjusting to their new situation and preparing for the transplant. The participants reported agency and determination in preserving their life and maximising their chances of surviving or having a good outcome from transplant. The ways in which participants demonstrated this appeared to vary according to their resources or disposition; however, participants commonly employed a determined, hopeful, optimistic or positive attitude in order to protect themselves from the psychological ramifications of the threat they experienced. Their response to their vulnerability was aimed at shifting them to a less vulnerable position, conceptualised as having greater odds stacked in their favour of being able to endure the transplant and enjoy a healthy life post-transplant. Xuereb and Dunlop (2003) reported similar findings in their interview study where participants undergoing a transplant described activities designed to maximise psychological and physical preparation for the transplant in order to foster the best possible outcomes. Whilst both Xuereb and Dunlop (2003) and the present study found

that how patients responded to the task of the transplant stemmed from their values and resources, Xuereb and Dunlop (2003) found their participants were emphatic about their strategies, that they were the right ones and others would be unhelpful. On the contrary, the present study found participants were more flexible in their thinking and stated that “everyone is different”. This could be as a result of viewing the testimonies in which people described coping in different ways to the viewer, they were therefore confronted with other ideas of successful coping strategies. Whilst there was no indication that participants thought about changing their strategies after viewing the testimonies, Hugo commented that they were shown too late when he was already wedded to his way of dealing with things, indicating he might have been more open to others’ ideas in the earlier stages of transplant.

A picture is emerging from the present study and wider literature that HSCT patients demonstrate intuitive expertise in coping with life threatening illness and invasive, uncertain treatment. It is intriguing that the findings of the present study indicate that people in this difficult situation often err towards agency (engaging in tasks that help them to prepare and be in the best state possible physically) and also attempt to adopt attitudes of positivity and optimism aimed at lifting their mood, rather than responding to their suffering in other ways, for example feeling resigned, paralysed and helpless. Participants did not question their own ability to recover, and, after an early stage of shock, reported to have gotten on with the task. In contrast Persson et al. (1995) found that some participants described more hopelessness and wanting to ‘give up’. This was not found in the present study, and whilst participants alluded to feelings of anxiety and sadness, they reported adjusting to their situation. The level of distress of participants in the present study is unknown, as psychological measures of distress, anxiety or depression were not taken. Whilst participants did not explicitly describe that they were feeling stuck or hopeless, it is possible that they did feel this way, some of the time. The relational design of the study may have impacted upon the findings, as participants may have wanted to present themselves in a certain light, which might not have been consistent with their internal state of mind.

There are three reasons why the present study may not have found themes of feeling stuck, resignation or hopelessness: because this is not how patients experience the transplant; because whilst participants did not speak of it, they did experience these feelings

sometimes; or it may be a feature of the sample, which was a group of people who cope in the same way, which includes telling their story.

6.2.2.1 Information seeking

The findings from the present study were that seeking information about the transplant was a common action taken by many participants in response to threat, as a way to move them from a vulnerable position to one which was perceived as more knowledgeable and more aware of potential pitfalls or dangers therefore potentially more able to prevent this. Participants did not want to be surprised by what was going to happen to them and recruited many different sources of information, such as medical experts, contact with survivors, support groups and internet forums. When participants were denied information by medical staff or were told they would receive information that was then not provided, they experienced this as being excluded and dismissed, which was frustrating but could also increase feelings of vulnerability. Xuereb and Dunlop (2003) found that patients responded positively when the response in terms of empathy, amount and type of information given by the medical or care team was matched to the patient's needs. Participants in the Xuereb and Dunlop (2003) study described wanting to have their fears acknowledged and not dismissed. Often when participants asked for details, they were actually looking to gain some agency and hope in a situation that felt helpless, so they could plan and prepare rather than gain medical facts (Xuereb & Dunlop, 2003).

Not all participants found more information helpful in the present study and at least one participant actively avoided receiving more information than he thought necessary and did not want to view the film of survivor testimonies. These findings link with existing knowledge about the role of information seeking in coping as a way to increase feelings of security (Averill, 1973; Haberman, 1995; Persson et al., 1995; Rutten et al., 2005). The individual differences between participants in the amount or type of information sought could be explained in terms of the employment of different coping styles. In the coping literature, two types of patients, 'monitors' and 'blunters', are described in relation to their response to information. 'Monitors' readily seek and consume information from many sources, whereas 'blunters' avoid sources of information as a way to avoid or deny what was happening, or to slow down the rate at which they had to process information. Evidence shows that both strategies are linked with adaptive coping (Brennan & Moynihan, 2004). It

is possible that in the present study, there was a higher representation of ‘monitors’ than ‘blunters’ because the study offered participants the opportunity to view a film of survivor testimonies, which itself is a source of information.

The implication of these findings is that patients’ requests for information need to be responded to in a timely manner. In order to maximise benefit, information should be given in a patient centred, rather than a ‘one size fits all’ way. The participants in the study received information booklets about the transplant and what to expect. They had opportunities to ask questions and request information from their consultants and specialist nursing staff. It is clear that HSCT patients have individual needs when it comes to information seeking and this should be addressed on an individual basis. Working in collaboration would be the best way to approach individuals information needs, asking patients what information they would like, how they would like to receive this i.e. written, verbal or meeting with experts by experience. The emotional response of patients can also be monitored to inform medical and nursing staff of their levels of anxiety and therefore whether offering some information may be helpful in reducing distress and increasing security or whether the rate of information needs to be slowed down, and given in stages.

6.2.2.2 Determination in attitude and behaviour

The findings were that participants actively engaged with ways to reduce their vulnerability and give themselves a fighting chance, described by one participant as “getting myself in the best possible state”. This can be viewed as preparation for something they perceived as threatening and arduous and also an attempt to reduce distress and increase hope. Some preparation involved getting themselves physically in shape, by eating well and exercising. However, more often, it was related to getting one’s mind in the best shape, by having a positive outlook, which includes maintaining hope and optimism for the future, accepting the situation and using humour. This could be related to a belief in a mind-body connection and the idea that in changing their perception of the experience they could improve or at least not hinder their body’s ability to heal. It may also be because there are limited ways in which participants can have agency or attempt to impact upon the outcome and this is one such way they believe they can influence it. When a patient is in hospital, in isolation and not able to leave the room, they are limited in what they can do. Adopting and maintaining

a positive outlook did not mean participants did not expect to experience difficulties, however they maintained a belief that it would be okay in the end. When investigating the process of keeping courage in HSCT, Coolbrandt and Grypdonck (2010) found that patients invest in the idea of a happy ending to give meaning to the suffering they endure “patients do everything they can for a happy ending” (Coolbrandt & Grypdonck, 2010, p. 218). Whilst the present study did not find that participants adopted certain attitudes to give meaning to their suffering, it did find that participants adopted this attitude in order to help them get through the task.

Cohen and Ley (2000) found in their study of 20 adult survivors of HSCT that fear came from feeling unprepared physically and emotionally. Therefore, the findings in the present study that participants were concerned with preparing both physically and emotionally could be interpreted as a response to this fear and an effort to reduce this. There is only one other study by Shuster, Steeves, Onega, and Richardson (1996) in which attitude was a theme of participant experience. In Shuster et al. (1996), participants described that they could alter their experience by altering their attitudes about the HSCT tasks they faced. In addition to this, they found that participants believed that the mind could produce an attitude that would not interfere with the body healing. This fits with the findings of the present study that participants held beliefs in a connection between the mind and the body. It was not made explicit by participants in the present study whether they believed that certain mind sets would help the body to heal or that a negative mind set would hinder.

There are three possible benefits to having a positive outlook identified in the literature. The first is that having a positive outlook increases hope and reduces fear (Saleh & Brockopp, 2001). Secondly, having a positive outlook may also give patients some control over their mood by distracting them from thoughts of dying (Thain & Gibbon, 1996). Thirdly, as discussed above, belief in a mind-body connection and the effect of thinking positively on survival is widely held. Thinking positively, not about the disease or the treatment but about recovery is believed by many to motivate the body to ‘fight it’ (Wilkinson & Kitzinger, 2000). It is also possible that participants used ‘positive talk’ in the relational context of the interview. This may not necessarily have been an indication of

their internal state of mind. Through a discursive analysis of cancer patients' talk of positive thinking, Wilkinson and Kitzinger (2000) found that when cancer patients talked about "being positive" or "thinking positive", it was often in the context of expressing negative emotions. By expressing negative emotions in the context of describing themselves as generally a positive person, they were able to express to the person listening disturbing feelings without unsettling the listener. Because of the potential vagueness of language used around thinking positively, Wilkinson and Kitzinger (2000) purport that it can be used as a "conversational device which is internationally useful in allowing cancer patients to talk about suffering and distress" (Wilkinson & Kitzinger, 2000, p. 806). Whilst in the present study, descriptions of positive attitude could be vague, it was not found that participants then went on to discuss difficulties or suffering after they talked about having a positive outlook, so this may not be true in this sample of participants. They were describing their experience of how they managed the potential for negative thoughts and feelings, by avoiding dwelling on those and shifting to a 'positive attitude' instead.

6.2.3 Recalibrating vulnerability

The longitudinal approach of the present study allowed a unique insight into what changes over time as participants undergo a HSCT. A major finding was that their relationship to vulnerability shifted. Being diagnosed and informed of the risks and uncertainty of treatment left participants fearful and vulnerable, and Janoff-Bulman's theory of shattered assumptions can be used to understand these findings, as set out above in '6.2.1 Vulnerability exposed'. At T3 interviews the theme of vulnerability emerged once again, as when participants were nearing discharge from hospital and their transplant was complete, they looked back and began to process what they had been through. They also looked forward to a life out of hospital, and they felt the loss of the protection they had come to know on the ward. As they looked to the future, they considered new opportunities they had not been able to think about before when the future had seemed so uncertain. As well as opportunities, new sources of vulnerability emerged. One response to this was to minimise the new vulnerabilities by taking responsibility for their health, being good, following advice and doing everything right. Below, Janoff-Bulman's theory will be revisited to illustrate one way in which the findings can be understood.

6.2.3.1 Looking back

Participants spontaneously looked back over the transplant procedure in the final interview and whilst they might have been expected to describe how difficult it had been and how unwell they had felt, instead they minimised the burden of the physical effects of the transplant. Severe side effects of the treatment were minimised and every participant described themselves as ‘lucky’. They described how they did not suffer as much as others had, although it was unclear where their ideas came from about others’ experience. The finding that participants minimised the physical impact of the treatment links with the literature that patients undergoing a HSCT reported physical symptoms as secondary to the psychosocial and spiritual challenges (Adelstein et al., 2014; Persson et al., 1995; Thain & Gibbon, 1996).

Going beyond the literature, that patients not only saw the symptom burden as secondary to the psychosocial aspects of the HSCT, it emerged that participants in the present study actually downplayed the physical impact of the treatment side effects. They described how it had not been as challenging as they had expected, comparing their experience to others who ‘had it worse’. In comparing their experience to others (real or fantasised) and viewing their experience as ‘lucky’ or not as difficult, they were perhaps shifting themselves away from the danger and threat they had perceived and were then perhaps likely to feel less anxiety about what they have been through, more confident about their ability to cope, and more resilient about the future. It could be that participants found it intolerable to think how close they came to death, and so recalibrated this experience as one in which they were in less danger, in order to feel safer and less anxious about their experience.

This understanding of participants engaging knowingly or unknowingly in a process of recalibration in order to move them away from a state of anxiety to one of safety is concordant with Janoff-Bulman’s ‘shattered assumptions theory’ and also ‘terror management theory’ (Greenberg et al., 1986; Solomon, Greenberg, & Pyszczynski, 1991). Shattered assumptions theory proposes that when a person has experienced trauma, there is a need for them to rebuild their assumptions by modifying old ones or creating new ones. Participants’ ascribed meaning to their experience that they were ‘lucky’ or that they were not in as much danger as they had previously thought, which could be interpreted as a way

for them to modify their assumptions which had been threatened by the events of the HSCT. If they had survived, and they knew that others did not, this (according to the theory) threatened their assumption of a 'just world'. Therefore they may have reconciled this dilemma by finding meaning in their experience that they survived because they were 'lucky' or that they were not as ill as others. Being a 'lucky' person may also protect the participant going forward, as it therefore signified that they may also be lucky in the future when they face other challenges. Focusing on the positive and comparing themselves to others worse off also served to distract participants from dwelling on how difficult the HSCT was and how close they came to death which protected the participant from feelings of anxiety or depression and led them to feel more content with their experience (Thompson, 1985).

6.2.3.2 Looking forward

In looking forward participants described new opportunities that presented themselves and also new sources of vulnerability. Participants experienced leaving the ward as exciting but also as challenging and experienced this as a loss. Patient fears at the time of discharge have been highlighted in other studies (Baker, Zabora, Polland, & Wingard, 1999; Cohen & Ley, 2000). The current findings support these studies as the same tension emerged in the participants' narratives between longing for the outside world and the ambivalence of leaving the security of the hospital, where experts kept watch for signs of infection or relapse. Participants identified risk of infection from others, from food and from an unclean home environment as new sources of vulnerability which had not been present before they were admitted to hospital. Some participants in the present study also described their fears of relapse which were described as a lingering sense of vulnerability.

6.2.3.3 Taking responsibility

Participants responded to the threat of infection and relapse once they are discharged by finding ways to offset this risk. Again we see a drive to counter their vulnerability, when participants experience fear and feel anxious about the risks in leaving hospital. They also experienced managing their own health as daunting and taking over the tasks that nurses previously did as burdensome, however there is not a sense that participants were stuck in in this experience, or unable to move forward. They described taking responsibility for their

health by continuing the good work done by the medical staff in the hospital, and felt that if they did this, it followed that they would be safe. Ways to counterbalance the risks they faced included, looking for signs of infection, keeping their homes ultra clean and isolating themselves from others who could be sources of infection. The extent to which participants described following the advice of the medical staff and being a 'good patient' differed according to their contexts and how vulnerable they perceived themselves to be. This response to being discharged from hospital following a HSCT has not been described elsewhere in the literature and can be understood in the context of terror management theory developed by Greenberg et al. (1986). Terror management theory describes how humans fear death and are preoccupied with this as they live with the conflict of having a desire to live but knowing that they will inevitably die. As a defence against this terror, the theory proposes that people adopt a variety of tactics to impose meaning and value on their life. Some defences employed are unconsciously driven; however, when death is in immediate awareness, as it was for the participants in this study, defences can be conscious and appear rational and logical. Arndt, Schimel, and Goldenberg (2003) found that following being reminded of death, young people are more likely to engage in health-promoting behaviours as a defence against death, to keep death away (Straker, 2013). This can be likened to the participants' response in this study and their engagement in behaviours designed to improve or protect health.

6.2.4 Relationships

Relationships were viewed as generally supportive by participants. Families and friends provided a range of support from practical to emotional which participants described as essential to get them through the treatment. Nursing staff were also seen as a resource of support which could be called upon when needed, and some participants described developing enjoyable relationships with staff over their time in hospital, consistent with the findings of Thain and Gibbon (1996).

A noteworthy finding is that the data also highlighted the existence of tension and frustration within relationships with family, friends and nursing staff. Participants reported difficulty in negotiating the boundaries between private and public space whilst in hospital and described frequently feeling intruded upon by medical staff and family. One participant

felt pressure to share their feelings with nursing staff which seemed to emerge from a societal view that the role of nurses is to provide emotional support and be there to comfort suffering patients. Support from others was not always perceived as helpful as participant's interpersonal needs shifted. They found it difficult to keep family and friends from visiting, and experienced witnessing the distress of their family and friends as burdening. It is not clear how much support patients undergoing a HSCT have in managing difficult conversations with carers, family and friends, but this is one area in which patients can be supported by nursing, psychology or social work staff.

The impact of a HSCT on relationships is more likely to be researched in the context of post-transplant quality of life, which may be because the long term nature of illness and recovery in HSCT may impose significant stressors on relationships. There is evidence that relationship dysfunction is a feature of chronic illness (Haberman, Bush, Young, & Sullivan, 1993; Zabora, Smith, Baker, Wingard, & Curbow, 1992)

The clinical implication of these findings is that families are essential to supporting HSCT patients through the procedure, providing both support with daily tasks and emotional support in the form of motivation and morale boosting. Participants described the process being difficult and burdensome for families as well as families being an extra source frustration or tension at times, therefore support for the families and carers of the patient is essential to avoid carer 'burnout' and additional stress being placed on the patient via the family. Some participants suggested that their family could watch the film of survivor testimonies used in this study to support them to understand what the participant is going through and to prepare them. Overall participants described that they appreciated the support they received from nursing staff, and that they could be called upon if needed. Tension and frustration was described when participants felt that there was a lack of boundaries between personal and private space and when they were expected to seek support from the nursing staff in a certain way. It is therefore important to take into account a person's context and individual interpersonal needs. Nursing staff can assist patients through conversations to express their needs and make them known to others.

6.2.5 Time

The impact of having a HSCT on a patient's perception of time has not had much attention in the literature and so this is an interesting theme to emerge from the data in the present study. Participants described that their perception of time had changed in undesirable ways and their sense of time being distorted was largely influenced by the disruption of one's routine, particularly not attending work. Whilst most participants felt that in becoming ill they had gained more time, they were not able to use it in productive ways. When they had been well they had wished for more time and therefore it felt cruel that when they found themselves with the wished for time, they resented it. Time seemed to pass more slowly for some, who were used to rushing around, and they wished that they could fast forward time to the future when the transplant was over.

The findings in the present study were related to the concept of the speed of time passing and also to how participants felt confined in the present, not being able to think about or plan the future. It is a common experience that when people are well and happy they perceive time as going fast. It is also true that the opposite is experienced when a person is experiencing distress or suffering through illness (Bayes, Limonero, Barreto, & Comas, 1997). Perception of time has been studied in relation to emotion and it has been suggested that time slows down when people experience a frightening or threatening event, as this provides the evolutionary advantage of being able to make decisions quickly or memories are more densely packed in these situations. This makes sense in an acute frightening event such as a robbery, however, it does not adequately explain why patients undergoing a HSCT experience a similar effect, and further investigation of time perception in chronic illness is needed. During a HSCT patients are in isolation and disconnected from their normal daily routine, they described having more time, therefore potential more time to watch the clock. A clinical implication of this finding is that patients may benefit from being helped to stay busy, which is difficult when a person must avoid social contact.

6.3 Discussion of findings from the patient testimonies component

The film of survivor testimonies was produced following an identified need for there to be a resource which was helpful for patients in the preparation stage, the aim was that it would

foster hope and be informative, but it would not focus on the medical aspects of the procedure, and would speak to the emotional experience of undergoing a HSCT, and how people coped with the experience. The findings suggested that the testimonies had addressed the needs identified in the preliminary stages of this study. The participants' experience of viewing the testimonies was largely a positive one and was described as a relational experience, as participants compared themselves to the survivors and felt less alone in their experience. Watching the film allowed the participants' hope and optimism to surface that 'if they can get through it, so can I'. This was described as a helpful counterbalance to the information on treatment risks and statistical chance of survival they had received prior to undergoing the transplant. It is likely that the film was shown to participants too late, as participants wanted the film to be available around the same time as the initial transplant meetings, when they needed support in fostering hope and optimism. Possibly due to the film being shown too late, it was less likely to bring new ideas to the participants on how to cope, and more likely to confirm their own beliefs about how to cope or reassure them that it is okay to feel the way they do and that their experience is normal. In keeping with research on using cancer survivor stories with patients, they found them an attractive and legitimate source of information (Kreuter et al., 2008).

Most participants described the film as having the right balance between positive stories and stories of difficulty or suffering. The film was designed to include themes of hope, but also to foster realistic expectations of the experience. When the film was tested for appropriateness, the film was described by one reviewer as overly positive. During the interviews, one participant also said that the film could be more realistic, implying that he experienced the film as overselling the positive and this did not match his experience of the transplant. From the descriptions of the initial meetings when the risks of undergoing a transplant are discussed, it seems that if the film was shown around this time, there would be an adequate balance of information that presented risks alongside hope.

Whilst participants described that the film increased their hope and optimism and they found this beneficial in reducing distress, we do not know whether the resource impacted on levels of distress in a way that would be quantifiable. We also do not know if there is any difference in levels of hope and optimism or measures of coping or distress

compared to patients who did not view the testimonies. Only moderate support for the use of hope enhancement strategies in clinical and community settings has been found according to a meta-analysis by Weiss and Speridakos (2011); however, this meta-analysis reviewed studies that were providing interventions aimed at increasing hope usually with psychiatric outpatients rather than in a health setting, and as far as is known, none of these reviewed studies used similar methods to the present study.

When viewing the film, participants used it and the interviewer as vehicles for self-reflection. The film prompted participants to think about their own experience in relation to the survivors and they talked about similarities and differences and what was more important or less important to them. It is not known what difference it would have made if participants viewed the film alone, whether it would have had the same effect on hope and optimism or not.

The clinical implication of these findings is that the film can be used to foster hope and optimism in the early stages of undergoing a HSCT. It is recommended that the resource is viewed with a member of nursing, psychology or social work staff in a way to capitalise on the relational aspects of the intervention.

6.4 Evaluating the study

The quality, strengths and limitations of the present study will be discussed in the following section.

6.4.1 Quality

In keeping with Yardley's four principles of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2008) to ensure quality and credibility in the present study, the following processes were undertaken:

Sensitivity to context was demonstrated in how the data was analysed and in the interview setting, which is one of the reasons why three time points were chosen, to give participants time to tell their story and feel at ease with the interviewer by building trust. Interactional difficulties were noticed and attended to, for example treatment side effects

(i.e. tiredness), interruptions or other tasks demanding the participant's attention. Power differences between myself as the researcher and participants were also taken into account, given that I was both controlling much of the data collection context and also being in a participant's home or personal space in hospital. Sensitivity to context was also demonstrated in the way the data was interpreted, paying attention to who the participants were and why they might tell their story this way. Pen portraits aimed to give the reader an account of the background and context of participants and the context in which the data is generated.

Commitment and rigour was demonstrated in both the development of quality materials to be used in the study, and the thoroughness of data generation and analysis. Having two researchers edit the filmed testimonies separately and then together took a considerable amount of time; however, it demonstrated commitment to quality. Recruiting a sample of participants who were difficult to access but crucial in order to say anything of value about this population also demonstrated commitment as did the use of repeat, in-depth interviews which required paying close attention to the participant for up to an hour thus demonstrating thoroughness. It is necessary to be immersed in qualitative work to really be able to see the world from another's perspective, hence analysing the transcripts line by line, paying close attention to the data and presenting transcript extracts to support themes demonstrates the rigor and sensitivity of the analysis.

Transparency and coherence was established by setting out detailed accounts of all procedures, of material development, recruitment, data generation and analysis. The impact and importance of the study was established by placing the study within the wider research in the literature review section and setting out in detail what knowledge has been ascertained in the results and discussion section.

6.4.2 Strengths

The findings of this study have contributed to the literature on the experience of patients undergoing a HSCT. The findings have sometimes supported existing research and sometimes added unique contributions. In evaluating the present study, four strengths were identified; the unique longitudinal approach to data generation, the creative use of a

stimulus in interviews to elicit data, the depth and richness of the data, and the development of a novel resource for use in clinical practice, which will be discussed below.

Interviewing participants at three times points was challenging, especially when participants were likely to be unwell and were undergoing an intensive treatment regime. However, the longitudinal design of the data generation enabled a picture to emerge of what changed in a patient's experience over the course of a HSCT, which so far as is known is unique in the current literature on the experience of undergoing a HSCT. If one interview had been used, after the transplant, some insight into the experience of the participants may have been lost to hindsight. Interviewing seven participants a maximum of three times generated a large amount of rich data and maximised the chance of including a variety of people with different life experiences. Meeting repeatedly with participants also allowed time for an alliance to be built between the interviewer and participant and facilitated a more in-depth exploration of their experience.

Using a film of survivor testimonies as a stimulus in a research interview was a novel way of generating data. Using the film within the interview context, rather than separately, supported the participants' recollection of their experience of watching it. So far as is known, this is the first time a film has been used as a stimulus in this way in a research study and it yielded findings which can be used to inform future research. The participant used the interviewer to explore their internal experience of thoughts and feelings that had been prompted by the film. The film reminded them of their own experience, what was important to them and their own hopes and fears. The implication for using this property of the resource as part of a clinical intervention will be discussed in '6.5 Further directions for research'.

The film developed for the study will now be used with transplant patients going forward, and so the research has directly impacted clinical practice, as well as contributed to the literature. Other findings, regarding the experience of patients will also be used to support recommendations, which will be disseminated to the transplant centre involved in the research, with the aim of improving clinical practice.

6.4.3 Limitations

In reviewing the design of the present research with hindsight, four limitations have become apparent; biases within the sample, imposing time points creating artificial stages of treatment, unexpected effects of using novel interview stimulus and relational context of interviews affecting data generated, which will be discussed below.

The context of recruitment meant that the sample could be biased in several ways. All the participants were recruited from one transplant centre; therefore the findings can not necessarily be generalised across all patients undergoing a HSCT in the UK. As transplant procedures are standardised across the UK then the experience of patients may be found to be similar, although there could be differences in experience for patients if the ‘culture’ within the system differs across transplant centres. The study did not compare the experience of patients across different countries and so I cannot be sure how the findings would generalise across countries, although studies that have been completed across the world have corroborated the findings of this study in many instances, therefore there may be elements that are unique to having a HSCT that can be generalised to patients across the world.

A further limitation of the participant sample is that there may be biases inherent in who chose to participate. The recruited sample may represent a homogenous group of individuals who are highly motivated to tell their story and to view a resource aimed at providing support and information, therefore they may have similar characteristics in terms of motivation and a preference for ‘information seeking’ coping styles. This is relatively unknown as these constructs were not measured during the study. Taking part in the study involved viewing a resource of survivor testimonies, and those who do not view this as beneficial or view it as harmful will therefore not be represented. This was highlighted when one participant requested not to view the testimonies, but was willing to be interviewed about his experience at one time point, which indicated that some people feel able to say no to this, and are sufficiently self-aware to know this is not what they need.

Little control could be exerted over the recruitment process, as the treating team acted as gatekeepers. During recruitment it was reported that one patient who declined to

participate had stated they wanted to “take one day at a time”. This indicated that for at least one person, taking part in the study represented planning or engaging in future oriented activities which this patient did not want to do. The gatekeeping for recruitment was initially a frustrating process, with patients sometimes being ‘protected’ from the study in a paternalistic way. At least one participant was deemed not appropriate to ask by the treating team because she was too young, even though she was 18, and unfortunately she was never approached. At times potential participants were missed because they were not identified as eligible, or sent information in time. The difficulty in recruiting participants in health research due to research governance and practitioner control over participants was discussed by Ewing et al. (2004) who described their concerns that these processes can impact the validity of studies if some patients are not given equal access and recruitment numbers remain small.

The design of the research imposed three time points for data generation. Whilst these time points were selected because they were felt intuitively to demarcate different stages of treatment, it is possible that these represent artificial stages. The findings indicated a change in the participants’ experience over time; should different time points have been selected, the findings may not have indicated the same change in experience over time.

The relational aspects of the interview situation may have impacted on what participants say, for example ‘positive talk’ may have been employed, which I had interpreted as an insight into their state of mind, however it may actually be a discursive tool, employed to ensure the interview was comfortable. As the interviewer I used myself as a research tool, and in doing this shaped the data generated. Because the interviewer was using their personality, and their skills in rapport building and questioning participants in the interview, as well as bringing their prior knowledge and experience to the analysis, different researchers may have generated different findings. I attempted to provide transparency through a process of reflexivity; however, there are undoubtedly biases, assumptions and agendas of which I was unaware of. In hindsight, it would have been useful to have a feedback session with participants, after the analysis process, to share findings with them. This triangulation technique has been used in health research to validate findings (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014) and for

completeness, to secure an in depth understanding of the phenomena in question (Adami & Kiger, 2005) and in the present study may have provided two benefits, to be able to check whether I had stayed close to the participant meaning and experience and give the opportunity to shape the analysis further but also it would have the benefit of giving the participant a more active role in the research, therefore reducing feelings of powerlessness.

6.5 Further directions for research

Further research in the use of the film of survivor testimonies as a relational clinical intervention to support patients has been identified as useful from the findings of the present study. Participants found the film of survivor testimonies useful in fostering hope and optimism and recommended that the film would be best used in the early stages of transplant preparation when participants experience fear and vulnerability as they are made aware of the necessity and the risks of the transplant treatment. Based on the findings of this study, modifications to the intervention are suggested and further research is necessary to realise the impact of the intervention. It is proposed that the film be shown as early as possible in the transplant preparation process. Preferably, the film should be shown alongside the initial meetings with the consultant to discuss the risks and benefits of the procedure in the process of gaining informed consent. It was found that this is the time that participants described feeling distressed about the risks and uncertainty of the transplant treatment and it is hypothesised the film would increase hope and optimism and reduce fear and distress. The effect of the film as a resource to increase hope and reduce distress could be measured and compared using a control group, and measures of hope, anxiety and distress. Measures of coping styles could also be used to ascertain whether there is any difference in the impact of the film across participants who adopt differing coping styles.

It is recommended that in further investigation of the efficacy of the film as a resource to support patients, it be used in a relational context. The findings of the present study were that the film was a vehicle for self-reflection and this property can be capitalised on in future interventions, therefore it is recommended that the film be watched with a member of staff who then facilitates a discussion about the patient's experience of watching the film, whether it highlighted any fears or concerns for the patient and how they might be able to manage these. It is unknown at present what the impact would be if patients

watched the film alone. It is hypothesised that without the relational context of having somebody to watch the film with, and to discuss any issues that the film highlighted, it may be at worst overwhelming for patients and at best not as effective in reducing distress. This could be compared in future research. As discussed in ‘Chapter Two: Literature Review’, Perry (2000) designed and studied an intervention aimed at preparing patients for HSCT. The intervention was a checklist of factors considered important in transplant preparation and the participants were encouraged verbally to take an active part in preparation by completing the checklist and contacting various members of staff to discuss issues raised. The findings were promising in terms of showing a difference between the checklist group and a control group, with the checklist group showing improvement in preparation, post-transplant problems and anxiety measures. It is hypothesised that the proposed further research may have similar mechanisms to the Perry (2000) study by encouraging patients to actively engage in preparing for transplant.

6.6 Conclusion

This research study used interviews to explore the experience of seven patients undergoing a HSCT, longitudinally across the course of treatment. The research showed that vulnerability is an important part of the experience of having a transplant and over time the patient’s relationship to vulnerability changes as they respond to this with a determination to counter this vulnerability, increase their chances of survival and reduce their distress. By the time the patients are being discharged from hospital, they are beginning to process this experience, evaluate their vulnerability going forward, and protect themselves from distress caused by coming close to death and from future vulnerabilities. Relationships with others, on whom they relied on for support were also important and at times challenging, as was their experience of time. The study also explored their experience of viewing a film of survivor testimonies, designed as a resource to support patients whilst they were in hospital having pre-treatment prior to receiving the stem cells. They experienced the film as helpful in surfacing their hope that the transplant will have a good outcome for them which boosted their moral. An understanding of what it was like for a group of patients to view a film of survivor testimonies, in the context of undergoing a HSCT was generated, with clinical implications providing some ways in which the findings could influence clinical practice

for consultants, nurse, psychologists and social workers who provide care for haematology transplant patients.

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APPENDICES

- Appendix 1 First page of the NHS Ethical Approval for the testimonies component.
- Appendix 2 Interview schedule for testimony filming.
- Appendix 3 One page example of initial coding and editing the film of testimonies completed separately by the two researchers.
- Appendix 4 An example page of the second edit cross checking between both raters.
- Appendix 5 An example of sections of transcribed footage selected during the editing grouped into themes and ordered to appear in the film.
- Appendix 6 Ethical approval email for testing the appropriateness of the film.
(University of Leeds School of Psychology Amendment Reference No.16-0223)
- Appendix 7 Survey questions when testing the appropriateness of the film.
- Appendix 8 Invitation email when testing the appropriateness of the film.
- Appendix 9 Participation email with link to film and survey when testing the appropriateness of the film.
- Appendix 10 Social media advertisements for participants when testing the appropriateness of the film.
- Appendix 11 First page of ethical approval for the longitudinal component of the study.
(NHS HRA Ethical Approval Amendment 3 Reference No. 14/YH/0155)
- Appendix 12 Consent form for the longitudinal component of the study.
- Appendix 13 Patient information sheet (version 3) for the longitudinal component of the study.
- Appendix 14 Contextual information sheet for the longitudinal component of the study.

Appendix 1 – First page of the NHS Ethical Approval for the testimonies component.



Health Research Authority
NRES Committee Yorkshire & The Humber - Bradford Leeds

Room 002
TEDCO Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3384

09 October 2014

Dr Merry Hill
Senior Clinical Psychologist
Leeds Teaching Hospitals NHS Trust
Clinical Psycho-Oncology, Rehabilitation
Level One
Bexley Wing
St James's University Hospital
Leeds
LS9 7TF

Dear Dr Hill

Study title:	How do stories of survival help patients going through bone marrow transplant?
REC reference:	14/YH/0155
Protocol number:	N/A
IRAS project ID:	108853

Thank you for your letter of 3 October 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Gillian Mayer, nrescommittee.yorkandhumber-bradfordleeds@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

A Research Ethics Committee established by the Health Research Authority

Appendix 2 – Interview schedule for testimony filming.

Introduction “Thank you for agreeing to take part in this study. We are interested in gathering people’s experiences of transplant and life afterwards as a tool to help people to get through the procedure. Particularly we think people might be inspired by hearing how other people have survived the procedure emotionally. We hope that this will help people cope with what we understand can be a very stressful time”

1. Could you start by telling me what you remember of how the transplant was for you?
2. Was it what you expected?
3. What helped you get through the transplant?
4. How do you feel about having the transplant now?
5. What do you wish you’d known beforehand?
6. What would you tell someone who was about to have a transplant?

Ending “ Thank you for taking part in the testimony interview. This part is over now and I have stopped filming but before we finish...

[De-brief with 2nd investigator]

“How has it been talking about your experiences today”

Appendix 3 – One page example of initial coding and editing of the film of testimonies completed separately by the two researchers.

Researcher 1

Common 7th Code # Dec 2015 lot 6

CD No.	File No.	Start	End	Quote	Keep/Cut (Bold if didn't agree inter-rater)	Theme
7.007	DSC-0797	00:00	0:16	Question	Cut	
		00:17	1:04	"I knew I would need a transplant" "transplant was just a procedure I was going to do" "it's the (long) way I was coming to get (batter)"	Cut	Decision
		1:05	1:14	Question	Cut	
		1:15	2:52	"I was fortunate" "because move in late class" "before transplant" "difficult to know what to expect" "knowing" "was going to be in isolation was hardest part"	Keep	Lucky / comparison expectation death possibility / isolation
		2:53	4:32	Mean question	Cut	
		4:34	7:53	"Everyone has an individual room" "it is quite isolating" "Not allowed to leave the room" "At first it's new, and it's happening" "They're all hanging on with their sleep outside" "How to block out the"	Keep	Environment / Isolation Dependence / Novelty Effect / Loneliness Coping / Empathy / Understanding

Researcher 2

lot 5

CD No.	File No.	Time	Topic/Theme - BCT	Keep/Cut	Reason/Notes
7.007	0783	00:00-00:16	Interview beginning - transplant. Same time as 7. Only way to get	cut	know ✓
		0:16-1:05	BCT	cut	✓
		1:05-1:14	BCT	cut	✓
		1:14-2:34	Really fortunate. Became more med. A big thing. Choosing trans.	Keep	✓
		2:34-2:52	being in hospital, being in isolation, the hardest part	Keep	✓
		2:52-4:34	BCT.	Cut	✓
		4:34-7:54	Individual room, nice but isolating. depend on people coming, poor view. here going on during recovery. Visitors coming on 2 levels.	Keep	✓
			Lonely existence. No understanding of how you feel. Puzzles to block out being on my own. Didn't feel ill. Just wanted to go home. Didn't get over that	↓	
		7:54-8:01	BCT	Cut	✓
		8:01-8:59	Something I had to deal & myself. I did it. Coping by switching off. Depends who you are	Keep	✓

Document1

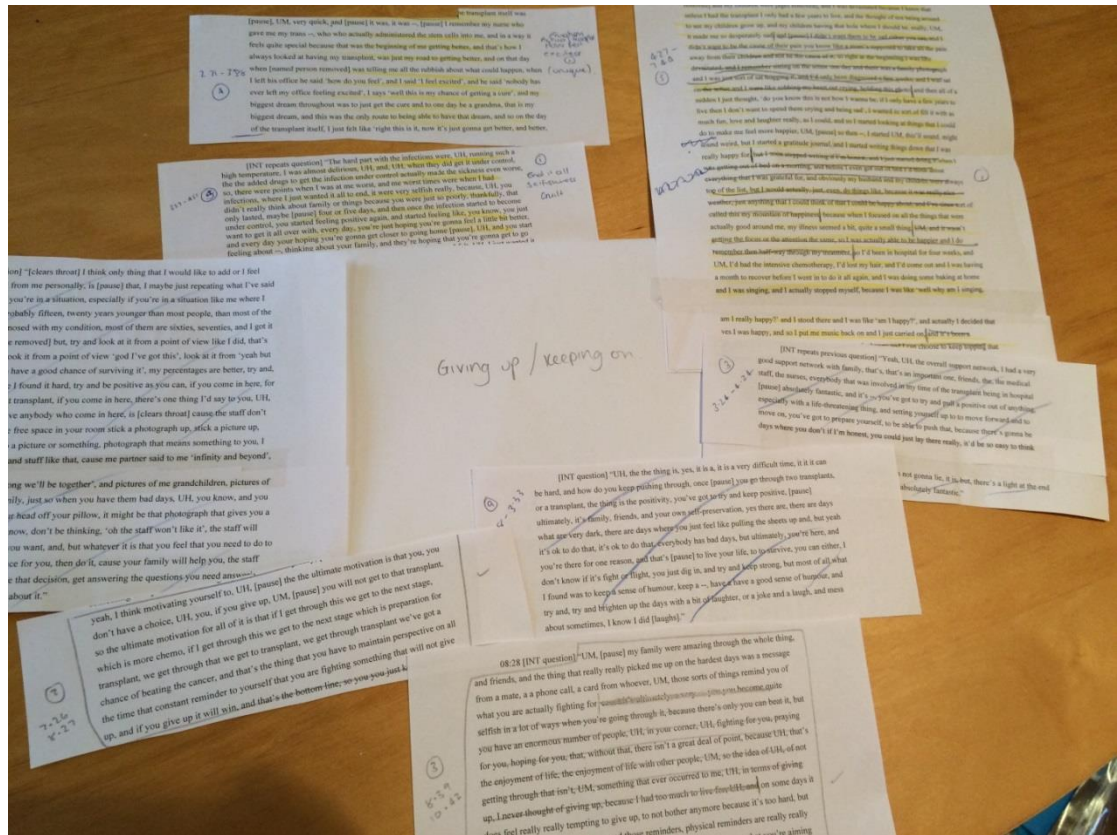
Appendix 4 – An example page of the second edit cross checking between both raters.

Testimony 4

EDIT DECISION LIST							
Job Number : M20150601_011 Client Name Merry Hill							
FILE NAME	TIMECODE		Number	Theme	Rating (1-3)	Reason for Rating	Total Time
	IN POINT	OUT POINT					
DSC_0789	0.31	1.10	1	1.Not as bad as expected	1	Hopeful	39s
	1.11	1.54	2	1.Another phase	3	Unnecessary	
	1.55	2.30	3	1.Emotion, sadness at radiation	1	Could be unexpected	35s
	2.31	3.38	4	1.Emotion, excited for BMT	1	Unique experience	1m 07s
	4.27	7.44	5	1.Ways of coping (emotionality, gratitude, allowing self to be happy)	1	Ways of Coping	3m 17s
	7.45	9.25	6	1.Ways of Coping (meditation, keeping calm)	1	Ways of Coping	1m 40s
	9.26	10.00	7	1.Book recommendation	3	Not necessary	
DSC_0790	0.13	1.19	8	1.Ways of coping (visualisation)	1	Ways of Coping	1m 06s
	6.03	8.23	4	1.Ways of Coping (routine, good stories)	1	Ways of Coping & Hope	2m 20s
	8.45	9.55	5	1.Ways of coping	3	Repeated	
DSC_0791	0.17	0.54	6	1.Ways of Coping	3	Repeated	
	2.22	2.27	7	1.Ways of coping	3	Repeated	
							10m 44s

✓
disagree
✓
✓
✓
✓
✓
✓

Appendix 5 – An example of sections of transcribed footage selected during the editing grouped into themes and ordered to appear in the film.



Appendix 6 – Ethical approval email for testing the appropriateness of the film.

(University of Leeds School of Psychology Amendment Reference No.16-0223).

-----Original Message-----

From: Ethics.Committee@webhost02h.leeds.ac.uk

[mailto:Ethics.Committee@webhost02h.leeds.ac.uk]

Sent: 08 September 2016 10:12

To: Siobhan Hugh-Jones

Subject: Ethics form decision

Siobhan Hugh-Jones

Institute of Psychological Sciences

University of Leeds

Leeds LS2 9JT

08-Sep-2016

Dear Siobhan Hugh-Jones,

Title of study: Perspectives of former bone marrow transplant patients on a short film of testimonies designed to support current patients

Ethics reference: 16-0223

I am pleased to inform you that the above research application has been reviewed by the IPS Research Ethics Committee and has been approved.

Please note that this approval only relates to the particular version of documentation supplied in this specific application (ref no: 16-0223; date approved: 08-Sep-2016). If you wish to make any amendments to the approved documentation, please note that all changes require ethical approval prior to implementation.

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. There is a checklist listing examples of documents to be kept which is available at <http://ris.leeds.ac.uk/EthicsAudits>

Yours sincerely,

IPS Research Ethics Committee
(Chair: Donna Lloyd)

Feedback from the Ethics Committee:

All requested changes have been made.

Appendix 7 – Survey questions when testing the appropriateness of the film.

1. What is your age?
2. What gender do you identify with?
3. What is your country of residence?
4. Have you had a bone marrow transplant?
5. What type of transplant have you had?
6. Approximately how long ago was your transplant?
7. Are you in the video recording?
8. How would you describe the tone or message of the video recording?
9. Do you think the video recording makes people aware of the most important aspects of having a bone marrow transplant?
10. Please tell us more about your answer (including any important aspects you think are missing)
11. Do you think the video recording is okay to show patients who are about to undergo a bone marrow transplant? (i.e. is the video recording is okay or too distressing/worrying for people)
12. Please tell us more about your answer (including any parts of the video recording you think should be removed or changed)
13. Did you ever see anything like this video recording when you had your bone marrow transplant?
14. Would you have found this video recording or anything else useful around the time you had your bone marrow transplant?

Appendix 8 – Invitation email when testing the appropriateness of the film.

Dear...

Do you have 45 minutes to spare to help future bone marrow transplant patients?

We are looking for volunteers to watch an online video recording of people talking about their experience of having a bone marrow transplant and tell us what you think of it.

The video recording is 30 minutes long and the survey should take approximately 15 minutes to complete. A full study information letter is attached. Please read this and consider if you would be willing to take part.

If you are willing to take part, please email the researcher, Gemma Smith, at umgls@leeds.ac.uk. She will then send you the link to the video recording and the survey.

The data collected will form part of a Doctorate in Clinical Psychology research project conducted at the University of Leeds. The researchers are investigating how best to support people as they go through a bone marrow transplant.

Regards,

Gemma Smith (Psychologist in Clinical Training, Univeristy of Leeds)



Research Title; Perspectives of former bone marrow transplant patients on a short film of testimonies designed to support current patients

This has been approved by the School of Psychology Research Ethics Committee.

Ethics Reference; 16-0223

Approval Date; 19/08/2016

Appendix 9 – Participation email with link to film and survey when testing the appropriateness of the film.

Dear...

Thank you for agreeing to take part in this research. The link to the short film and the survey are below, please watch the film and then complete the survey.

Advice...

The 30 minute film contains testimonies of people's experience of having a bone marrow transplant. These stories are not designed to be distressing, but to represent as accurately as possible the experience of the individuals telling their story. They therefore contain a mix of positive and negative experiences. The survey should take approximately 15 minutes and contains questions relating to your views of the content and tone of the film.

Where can I find support?

If at any time you feel you would like some support, here are some contact details of various organisations that may be able to help. You may also want to contact your specialist transplant nurse who may be able to offer support or refer you to the relevant service.

Anthony Nolan Charity

Patient Experience Team (Contact for advice & Support)

0303 303 0303

Thank you for agreeing to take part in this research.

Here is the link for the 30 minute film 'link'

Please watch it and complete the survey

Here is the link for the survey 'link'

If you have any questions please get in touch with either the researcher Gemma Smith umgls@leeds.ac.uk or the research supervisor Dr Siobhan Hugh-Jones s.hugh-jones@leeds.ac.uk

Regards,

Gemma Smith (Psychologist in Clinical Training, Univeristy of Leeds)

A handwritten signature in black ink, appearing to read 'G S' with a flourish.

Research Title; Perspectives of former bone marrow transplant patients on a short film of testimonies designed to support current patients

This has been approved by the School of Psychology Research Ethics Committee.

Ethics Reference; 16-0223

Approval Date; 19/08/2016

Appendix 10 – Social media advertisements for participants when testing the appropriateness of the film.

“Have you had a Bone Marrow Transplant?...

Would you like to use your experience to help others?...

Would you be willing to watch a 30 minute online video and complete a survey about it...

We are currently researching how to help patients undergoing a bone marrow transplant, and we are looking for people to watch a video of people’s experiences of having a bone marrow transplant and give us your feedback.

If you are willing to help, please contact the researcher Gemma Smith by email umgls@leeds.ac.uk for the links to the video and survey.

Thank you for helping us to support transplant patients of the future

Research Title; Perspectives of former bone marrow transplant patients on a short film of testimonies designed to support current patients.

This has been approved by the School of Psychology Research Ethics Committee.

Ethics Reference; 16-0223

Approval Date; 19/08/2016

Post to go on Twitter

Have you had a bone marrow transplant and would like to take part in research to help others, contact umgls@leeds.ac.uk for more details.

Appendix 11 – First page of ethical approval for the longitudinal component of the study. (NHS HRA Ethical Approval Amendment 3 Reference No. 14/YH/0155)



Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Tel: 0207 1048 088

29 June 2016

Dr Merry Hill
Senior Clinical Psychologist
Leeds Teaching Hospitals NHS Trust
Clinical Psycho-Oncology, Rehabilitation, Level One, Bexley Wing
St James's University Hospital
Leeds
LS9 7TF

Dear Dr Hill

Study title: How do stories of survival help patients going through bone marrow transplant?
REC reference: 14/YH/0155
Protocol number: N/A
Amendment number: Substantial Amendment 3, 19/03/16
Amendment date: 01 June 2016
IRAS project ID: 108853

The above amendment was reviewed at the meeting of the Sub-Committee held by correspondence.

Summary of Amendment

This amendment was submitted in order to change from using a mixed quantitative/qualitative methodology to involving qualitative methods only.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

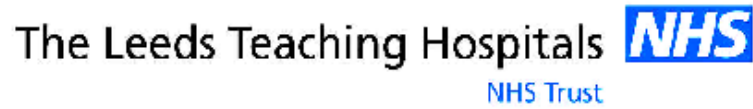
Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 3, 19/03/16	01 June 2016
Participant information sheet (PIS)	3	21 March 2016
Research protocol or project proposal	4	21 March 2016

A Research Ethics Committee established by the Health Research Authority

Appendix 12 – Consent form for the longitudinal component of the study.



PATIENT CONSENT FORM
Experiencing Transplant with Stories from Survivors: Part 2 - Intervention

Patient ID: Initials: Date of Birth:

Patient initial each point

- 1. I confirm that I have read and understand the information sheet dated 11/02/2014 (version 2) for the above study and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected. I agree to take part in the study. _____
- 2. I understand that my medical records may be looked at by authorised individuals from the Sponsor for the study, the UK Regulatory Authority or the Independent Ethics Committee in order to check that the study is being carried out correctly. I give permission, provided that strict confidentiality is maintained, for these bodies to have access to my medical records for the above study and any further research that may be conducted in relation to it. I also give permission for a copy of my consent form to be sent to the Sponsor for the study. _____
- 3. I understand that even if I withdraw from the above study, the data collected from me will be used in analysing the results of the trial, unless I specifically withdraw consent for this. I understand that my identity will remain anonymous. _____
- 4. I consent to the storage including electronic, of personal information for the purposes of this study. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publication. _____

Name of the patient

Patient's signature and the date the patient signed the Consent form

Name of the Investigator taking written consent

Investigator's signature and date the Investigator signed the consent form

Original to be retained and filed in the site file. 1 copy to patient, 1 copy to be filed in patient's notes, 1 copy for Sponsor

Appendix 13 – Patient information sheet (version 3) for the longitudinal component of the study.



PATIENT INFORMATION SHEET

Experiencing Transplant with Stories from Survivors - Part 2: Intervention

Part 1

1. Invitation

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

2. What is the purpose of the study?

This is an exploratory study to investigate the psychological impact of hearing testimonials from survivors of transplants on those undergoing the procedure.

3. Why have I been chosen?

You have been chosen as a decision has been made for you to have an allograft transplant under the Leeds Haematology Transplant team.

4. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form to confirm that you understand what is involved when taking part in this study. If you decide to take part you are free to leave the study at any time and without giving a reason. If you withdraw, unless you object, we will still keep records relating to the treatment given to you, as this is valuable to the study. A decision to withdraw at any time, or a decision not to take part, will not affect the quality of care you receive.

5. What will happen to me if I take part?

You will be asked to sign a consent form prior to taking part in the study. You will be asked to watch a short film of testimonials from people who have undergone a bone marrow transplant and to complete three short interviews (from 10 mins up to 1 hour each) over the course of your bone marrow transplant treatment. Your interviews will be digitally recorded but any identifying material will be removed afterwards. We hope to involve up to eight people participating in this study and so anticipate that it will take one to two years to complete and will be completed by 2017.

6. What do I have to do?

If you agree to take part, the researcher will contact you to arrange a convenient time to come and visit you at home or a convenient location to sign the consent form which will take about 10 minutes and also to complete the first interview, the researcher will ask you questions about your experience before your BMT. The researcher will then make contact with you to arrange to come visit you once you are admitted to hospital for the transplant and will give you the short film of testimonies from people who have been through the procedure to watch. After you have watched the testimonies with the researcher you will be interviewed. The researcher will be interested in your experience of being in hospital as well as your experience of watching the testimonies. Whilst you are in hospital, after you have had the transplant you will be asked to complete another interview, where you will be asked questions about your experience of having a BMT. Each interview is likely to be between 10 minutes and an hour, depending on how long you wish the interview to last.

7. What is the procedure that is being tested?

A collection of testimonies from people who have experienced allograft transplant.

8. What are the alternatives for diagnosis or treatment?

Treatment as usual.

9. What are the possible disadvantages and risks of taking part?

Sharing your experiences of coping with the transplant might be emotionally challenging at a time when your resources might be low. If, at any point during the study, you feel it is too difficult to continue to participate, you will be able to withdraw, or suspend your involvement. It is important for you to tell a member of the research or clinical team if you feel your participation has particularly affected your mood and you feel you need further support. One of the researchers might ask you directly about this if they become concerned about you.

10. What are the possible benefits of taking part?

It is hoped that hearing the stories of people who have survived the transplant may help you to cope with the experience, but we do not know if this is the case or how it will work. We cannot promise that this intervention will help, but by taking part in this study, we hope that the information we get will help improve the psychological care of people going through transplant in the future.

11. What happens when the research study stops?

The findings will be written up and may be published but your responses will be made anonymous. You will be asked if you would like to be contacted with the findings when these are available.

12. Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

13. Contact Details

Researcher	Telephone Number
<i>Dr Merry Hill (Chief Investigator)</i>	0113 2065897
<i>Gemma Smith (Researcher)</i>	<i>umgls@leeds.ac.uk</i>
<i>Dr Siobhan Hugh-Jones (Supervisor)</i>	0113 34 35744

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making a decision.

Part 2

14. What will happen if I don't want to carry on with the study?

If you decide that you do not want to continue to participate in the study then you should inform one of the researchers. You will not be contacted again by the researchers unless you want to be but any responses you have given at that point will be retained unless you ask for them to be destroyed. Your care will not be affected by a decision to withdraw from the study.

15. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

16. Will my part in this study be kept confidential?

If you consent to take part in this study, the records obtained while you are in this study as well as related health records will remain strictly confidential at all times. The information will be held securely on paper and electronically at your treating hospital under the provisions of the 1998 Data Protection Act. Your name will not be passed to anyone else outside the research team or the sponsor, who is not involved in the trial. You will be allocated a research number, which will be used as a code to identify you on all research forms.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised.

Your records will be available to people authorised to work on the research but may also need to be made available to people authorised by the Research Sponsor, which is the organisation responsible for ensuring that the study is carried out correctly. A copy of your consent form may be sent to the Research Sponsor during the course of the study. By signing the consent form you agree to this access for the current study and any further research that may be conducted in relation to it, even if you withdraw from the current study.

The information collected about you may also be shown to authorised people from the UK Regulatory Authority and Independent Ethics Committee; this is to ensure that the study is carried out to the highest possible scientific standards. All will have a duty of confidentiality to you as a research participant.

If you withdraw consent from further study treatment, unless you object, your data will remain on file and will be included in the final study analysis.

In line with Good Clinical Practice guidelines, at the end of the study, your data will be securely archived for a minimum of 15 years. Arrangements for confidential destruction will then be made.

17. What will happen to the results of this study?

The study forms part of a Doctorate of Clinical Psychology qualification from Leeds University which will be awarded to the researcher Gemma Smith. The study will be made available to the University of Leeds. The results of the study will be available after it finishes and will usually be published in a psychology journal and/or presented at a conference. The data will be anonymous and none of the participants involved will be identified in any report or publication.

You will be asked in due course whether you would like to be contacted with the findings of the study when they are available.

18. Who has reviewed the study?

This study was given favourable ethical opinion for conduct in the NHS by Yorkshire & The Humber - Bradford Leeds Research Ethics Committee Research Ethics Committee.

19. Contact for further information

You are encouraged to ask any questions you wish, before, during or after your treatment. If you or your relatives have any questions about this study you may wish to contact the following organisation that are independent of the hospital at which you are being treated:

Robert Ogden Macmillan Cancer Information and Support Centre,

St. James's University Hospital, Beckett St, Leeds, LS9 7TF,

0113 2066498

cancerpatientinformation@leedsth.nhs.uk

Opening hours 10am to 4pm Monday to Friday.

If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed in your patient notes, one will be filed with the study records and one may be sent to the Research Sponsor.

You can have more time to think this over if you are at all unsure. Thank you for taking the time to read this information sheet and to consider this study.

Appendix 14 – Contextual information sheet for the longitudinal component of the study.

Contextual Information

Pseudonym _____

- What is your age?
- How would you describe your ethnicity?
- Who do you live with?
- Where do you live and did you grow up in this area?
- When were you diagnosed?
- What is the name of your diagnosis?
- What treatment did you receive prior to having a HSCT?
- Is your donor known or unknown to you?