Safe in the bubble, out into the unknown: returning home following allogeneic stem cell transplantation. A phenomenological study

by

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Statement of Originality

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ABSTRACT

Aim

This paper reports a study exploring the lived experience of fifteen men and women treated with allogeneic stem cell transplant (SCT) for haematological malignancy.

Background

Evidence suggests that treatment of haematological malignancy including allogeneic stem cell transplant has a significant impact on the quality of life (QoL) of recipients and quantitative studies have measured dimensions such as physical function and psycho-social and spiritual domains. Fewer studies have considered individual’s lived experience of allogeneic stem cell transplant (SCT) and their subsequent recovery.

Methods

The study followed an interpretive phenomenological methodology using semi-structured interviews. Fifteen participants aged between 22-68 years were purposively recruited from two specialist treatment centres and were interviewed within three months to one year post SCT between April and September 2013. Data were then analysed using interpretive phenomenological methodology to gain insights into their lived experience including their personal and social experience of the world following treatment.

Findings

Two overarching themes emerged from the data: The Immediacy of Illness & Existential Crisis and The Recovery Journey. The Immediacy of Illness and Existential Crisis illustrate the participants’ experiences of critical events in relation to disease onset, diagnosis and treatment and the enduring uncertainty which continues into recovery including facing their own mortality. Participants suffer major disruption to their lives physically, psychosocially and emotionally as a result of illness without a sense of when they may resume the normality of their former life.

Returning home after several months of hospitalisation is a particularly daunting and challenging time for patients. Participants expressed their fear of being suddenly left in
charge of their own health needs and the stark reality of the outside world compared to being cared for in the relative safety of their protective isolation facility in hospital. The responsibility for self monitoring and vigilance in the light of on-going treatment effects such as graft versus host disease (GVHD) and the threat of viral infections warrants increased support from health care professionals. Social support in order to cope with isolation, financial hardship and employment issues similarly deserves attention.

Processing traumatic experiences such as life threatening diagnoses, critical events and harsh treatments can be difficult when faced with the immediacy of illness. Participants feel guilty of burdening their loved ones but could benefit from the opportunity to talk to other patients in order to gain perspective and share strategies for coping and adjustment.

**Conclusion**

Ambiguity and uncertainty characterise the illness and recovery journey for those with haematological malignancy. Whilst participants have access to specialist teams, there are opportunities for health and social care professionals to provide more support for individual’s returning home after prolonged hospitalisation and in the months that follow. In particular the development of a community based Advanced Nurse Practitioner, skilled in early recognition of treatment effects, could significantly enhance the care of patients in their first year post SCT.
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**Glossary of terms**

**Androgen:** is the broad term for any natural or synthetic compound, usually a steroid hormone that stimulates or controls the development and maintenance of male characteristics.

**Aplastic Anaemia:** is a disease in which the bone marrow and the blood stem cells are damaged causing a deficiency in all three blood cell types (pancytopenia); red blood cells (anaemia), white blood cells (leukopenia) and platelets (thrombocytopenia). Aplastic refers to the inability of the stem cells to generate mature blood cells.

**Acute Lymphoblastic Leukaemia:** is an acute form of leukaemia, or cancer of the white blood cells, characterized by the overproduction of cancerous, immature white blood cells known as lymphoblasts. In ALL, lymphoblasts are overproduced in the bone marrow and continuously multiply, causing damage and death by inhibiting the production of normal red and white blood cells and platelets in the bone marrow and infiltrating to other organs.

**Acute Myeloid Leukaemia:** is a cancer of the myeloid line of blood cells, characterized by the rapid growth of abnormal white blood cells that accumulate in the bone marrow and interfere with the production of normal blood cells. AML is the most common acute leukaemia affecting adults.

**Autologous stem cell transplant (AHST):** transplantation in which stem cells (undifferentiated cells from which other cell types develop) are removed, stored, and later given back to the same person through a transfusion.

**Allogeneic stem cell transplant:** transplantation in which stem cells donated from another individual are provided to the recipient through a transfusion.
**Antithymocyte globulin:** is an infusion of horse or rabbit-derived antibodies against human T cells used in the prevention and treatment of acute rejection in organ transplantation and therapy of aplastic anaemia.

**Blasts:** new immature blood cells

**Bone marrow transplant (BMT):** the original term used for a stem cell transplant when stem cells are collected from the bone marrow itself by aspirating stem cells from the hip bone using a specially designed needle and syringe.

**Cognitive Behavioural Therapy:** types of therapy, often delivered by psychologists, usually based on talking and practising specific types of voluntary activity. This group of interventions can include relaxation training, counselling and psychological approaches to pain control.

**Cyclophosphamide:** an agent used to treat cancers and autoimmune disease.

**Cyclosporin:** a drug widely used in organ transplantation to prevent rejection by reducing the activity of the immune system.

**Cytogenetics:** a branch of genetics concerned with the study of the structure and function of the cell, especially the chromosomes.

**Cytology:** the study of cells in terms of structure, function and chemistry.

**Granulocyte colony stimulating factor (G-CSF):** used to stimulate the production of stem cells in the bone marrow.
Graft versus host disease (GVHD): occurs when particular white blood cells (T cells) in the tissue (the graft) recognize the recipient (the host) as "foreign". The transplanted immune cells then attack the host's body cells.

Acute graft versus host disease (aGVHD): Acute GVHD usually happens within the first 3 months after a transplant. Common acute symptoms include:

- Abdominal pain or cramps, nausea, vomiting, and diarrhoea
- Dry or irritated eyes
- Jaundice (yellow colouring of the skin or eyes)
- Skin rash, itching, redness on areas of the skin

Chronic graft versus host disease (cGVHD): Chronic GVHD usually starts more than 3 months after a transplant, and can last a lifetime. Chronic symptoms may include:

- Dry eyes or vision changes
- Dry mouth, white patches inside the mouth, and sensitivity to spicy foods
- Fatigue, muscle weakness, and chronic pain
- Skin rash with raised, discoloured areas, as well as skin tightening or thickening
- Shortness of breath
- Vaginal dryness
- Weight loss

Haematopoietic cell transplant (HCT): stem cell transplant using blood stem cells (haematopoietic stem cells are produced in the bone marrow and either divide to form more blood-forming stem cells, or mature into one of the three types of blood cells)

Haematopoietic stem cell transplant (HSCT): as above
Health Related Quality of Life (HRQoL): a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life. A related concept of HRQoL is well-being, which assesses the positive aspects of a person’s life, such as positive emotions and life satisfaction.

Histology: a branch of anatomy concerned with the study of microscopic structures of human tissue.

Hodgkin Lymphoma: is a cancer that develops in the lymphatic system (part of the immune system). In Hodgkin lymphoma, B-lymphocytes (a particular type of lymphocyte multiply in an abnormal way and collect in certain parts of the lymphatic system such as the lymph nodes (glands). The affected lymphocytes lose their immune properties increasing vulnerability to infection.

Human leukocyte antigen tissue types: genes that encode for proteins on the surface of cells responsible for regulation of the immune system.

Imaging: making a visual representation with an electromagnetic beam.

Immunophenotyping: a technique used to study the protein expressed by cells. This can be performed on tissue section or cell suspension. An example is the detection of tumour marker such as the diagnosis of leukaemia and involves the labelling of white blood cells with antibodies directed against surface proteins on their membrane. The labelled cells are processed in a flow cytometer, a laser-based instrument capable of analysing thousands of cells per second.
Intrathecally: route of administration for drugs via an injection into the spinal canal (subarachnoid space)

JAK2 gene: a gene present in the bone marrow, a mutation of which can cause myeloproliferative neoplasm

Myelodysplastic Syndrome: a group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells. MDS is often referred to as a bone marrow failure disorder.

Myelofibrosis: a bone marrow disorder disrupting the body’s normal production of blood cells. It causes extensive scarring in the bone marrow

Myeloablative therapy: Conventional full intensity therapy aimed to kill as many cancer cells as possible and to suppress the immune system of the recipient to allow engraftment of the donated stem cells

Non-myeloablative transplants: reduced intensity transplant using less aggressive chemotherapy and radiation. This treatment aims to suppress the immune system of the recipient to allow engraftment of the donated stem cells and relies on the graft versus host reaction to kill cancerous cells

Peripheral blood stem cell transplant (PBSCT): stem cells are collected from the peripheral blood

Peripheral T Cell Lymphoma: a group of rare and usually aggressive Non Hodgkin Lymphomas that develop from mature T-cells
Quality of life (QoL): An evaluation of health status, relative to a person's age, expectations and physical and mental capabilities

T cells: a type of lymphocyte (white blood cell) that play a central role in cell-mediated immunity

Thalidomide: is in a class of medications known as immunomodulatory agents and can be used to treat certain cancers by strengthening the immune system
CHAPTER 1

Introduction

1.1 This introductory chapter begins to build the rationale for the thesis including its contextual and clinical origins. An explanation of the researcher’s role and interest in this area is followed by a short summary of the background to the study and an outline of the chapters.

1.2 Researcher’s role and personal transcript

My initial fascination regarding the experiences of patients undergoing stem cell transplant (SCT) for haematological malignancies began when I became a Matron in Haematology in 2008. It is where I learned about this specialised field for the first time and was responsible for the in-patient ward, the haematology day unit and associated out-patient clinics. Once a decision has been made to treat the patient with SCT they spend several weeks in a protective isolation facility receiving high dose chemotherapy, radiotherapy and sometimes total body irradiation prior to undergoing their SCT. Whilst my role combined both clinical and managerial components, I was conscious not only of the impact of a long period of hospital stay on in-patient bed capacity but most importantly to the individuals’ experience of treatments, the impact of chemotherapy and radiotherapy, associated side effects, social isolation and their subsequent recovery.

I found it hard to decide which part of the patient’s journey would form the focus of my research since the progression from diagnosis through treatment to returning home were all areas of significant interest to me. In particular, my attention was drawn to people’s ability to cope with life threatening diagnoses, toxic and invasive treatments and the experience of receiving often “last chance” life saving treatments when these were not necessarily guaranteed. This in turn led me to consider the challenges lying ahead for these patients after hospital treatment, for example physical effects, psychosocial adaptation and the
adequacy of on-going support and after much deliberation chose this area for my research. What has been rewarding is that participant’s narratives have incorporated significant experiences from their initial symptoms, diagnosis, treatment and recovery phases through to their return home resulting in unique accounts of their individual journey.

1.3 Background

Initially, a literature review was conducted examining studies published between 1995 and 2012. Rationale for this is because HSCT was becoming increasingly the treatment of choice for patients with haematological malignancy in the 1990’s. In the United Kingdom haematopoietic stem cell transplants using donor cells were progressively more prolific following the establishment of a stem cell donor registry in the mid 1980’s. As will be seen in the literature review a host of quality of life studies emanated from stem cell transplant centres and therefore served as a useful background to this study. The search was subsequently narrowed down to focus on the period between 2000 to 2012 for a number of reasons. Firstly, patients’ need for support in their cancer journey was highlighted by Sanson-Fisher (2000), corroborated by Cardy (2006) in a large scale study of the emotional impact of cancer, sponsored by Macmillan Cancer Support, where a quarter of the participants reported feeling “abandoned” and unsupported by the health system when they are not receiving care in hospital. Specific to haemato-oncology the government paper, Improving Outcomes in Haematological Cancers (NICE 2003) called for particular attention to be given to helping patients to adjust back to daily life, and to management and monitoring long-term side effects. Issues relating to cancer survivorship and on-going care for all cancer survivors have also gained attention in recent years and led to policy development (DoH 2010, DoH 2007). Secondly, researchers began to consider the wider context of the psychosocial and emotional impact of stem cell transplant as patients’ survival rates improved. Finally, nurse-led follow-up arrangements are evolving (Beaver 2005, Cox et al 2008, Cox & Wilson 2003) and it is pertinent to investigate how nurses and other health
and social care professionals can best support patients in the aftermath of lengthy and aggressive treatments involving stem cell transplantation.

1.4 Overview of Chapters

Literature review
Chapter 2 presents the current knowledge and substantive findings relating to patients under-going haematopoietic stem cell transplantation and their subsequent recovery. Consideration is given to the theoretical and methodological contributions within this field and also to the wider related literature concerning cancer and survivorship.

Methodology and methods
Chapter 3 provides an overview of interpretive phenomenology and the rationale for it’s choice as a suitable methodology for this study in eliciting patient’s experiences of stem cell transplant. The research methods are outlined including the ethical considerations.

Findings and analysis
Chapter 4 presents the findings in two overarching themes; the immediacy of illness and existential crisis and the recovery journey. The participant narratives are analysed and supported by in vivo data extracts to provide evidence for the themes which emerged. References are also made to relevant research in the field.

Discussion
Chapter 5 presents a discussion of the findings.

Conclusion
Chapter 6 concludes the study making recommendations for informing clinical practice and future research. The limitations of the study are discussed.

1.5 Summary of Chapter
This introductory chapter has presented the rationale for this study by providing a synopsis of its context and background. The researcher’s clinical and managerial experiences have
been described to illustrate how the research idea evolved from observations in practice. The chosen methodology has been identified with a brief overview of the forthcoming chapters.
CHAPTER 2

Literature Review

2.1 Introduction
This chapter presents an overview of the supporting literature for this study. The review summarises the current incidence and treatment of haematological malignancies including haematopoietic stem cell transplantation (HSCT). Studies evaluating quality of life during and after HSCT treatment are presented followed by research exploring the patient experience. A major complication associated with the treatment, that is, graft versus host disease is also discussed. Key texts from the cancer literature are reviewed to inform and illustrate a broader focus to the patient’s illness and recovery experience. The limitations of current knowledge are described to provide the rationale for this study.

2.2 Search strategy
The databases used to obtain relevant studies between 1995-2012 for this review are: The Cochrane Controlled Trials Register; Medline; CINAHL; British Nursing Index and PSYCHLIT. The search strategy utilised for this review included the use of key words and phrases in each database: autologous stem cell transplant, allogeneic stem cell transplant, haematopoietic stem cell transplant (HSCT), bone marrow transplant (BMT). All of these terms were used singly and in conjunction with health and quality of life, patients’ attitudes and experiences, coping and psychosocial factors, survivorship, follow up, consultations, out-patient appointments, post discharge care, transition care, home care and hospital at home using Boolean operators. The search revealed limited publications relating directly to follow up after stem cell transplantation and patient experience therefore literature focusing on quality of life and post-transplant experience was reviewed. Reference lists of all studies, reviews and articles obtained were checked for secondary references.
Allogeneic haematopoietic stem cell transplantation is often referred to as allogeneic HSCT, HSCT, HCT, SCT, peripheral blood stem cell transplant (PBSCT) or bone marrow transplant (BMT). When studies are referenced, the author’s abbreviation will be utilised but in the main body of this thesis the term HSCT and SCT will be used interchangeably. A glossary of terms is presented to explain medical and technical terminology on page 7.

2.3 Classification and incidence of haematological malignancy

Haematological malignancies are tumours affecting the haematopoietic and lymphoid tissues affecting the bone marrow, blood, and lymph nodes (Vardiman et al 2009, World Health Organisation 2014). A disease affecting one of these areas often affects the others due to their intimate connection through the immune system. Lymphoma, a disease of the lymphoid system often spreads to the bone marrow, thereby also affecting the blood. According to the World Health Organisation (WHO 2001) classification of haematological malignancy is dependent on cell lineages, that is the myeloid and lymphoid lines. Lymphomas and lymphocytic leukaemias are derived from the lymphoid line whilst acute and chronic myelogenous leukaemia, myelodysplastic syndromes and myeloproliferative diseases are myeloid in origin.

A quality appraisal comparing data from the National Cancer Data Repository with the population-based Haematological Malignancy Research Network (2012) states that there are no precise or reliable figures for incidence and survival rates for the range of haematological cancers in England and Wales. Complexities surrounding the multiple parameters required for diagnosis are considered key to this problem such as a combination of histology, cytology, immunophenotyping, cytogenetics, imaging (see glossary of terms) and clinical data (Swerdlow 2008). However, according to Leukaemia and Lymphoma Research (2014) around 30 000 people in the United Kingdom from infancy to adulthood are diagnosed with a haematological malignancy (blood cancer) every year. Cancer Research UK (2014) report average survival statistics for certain haematological malignancies
acknowledging that individual cases vary significantly according to stage and severity of disease, type of blood cell affected and age. Treated at an early stage, survival of at least five years is reported as 91-94% for Hodgkin lymphomas, 40% for acute lymphoblastic leukaemia and 25% for acute myeloid leukaemia. In the latter case survival for more than five years in those under 45 years is 50% reducing to only 12% for those over 65 years.

2.4 Initial treatment of haematological malignancy

The primary aim of treatment for haematological malignancies is to achieve disease remission. For diseases such as lymphoma, leukaemia and Hodgkin lymphoma the instigation of a suitable chemotherapy regime is commenced as soon as possible after diagnosis and a requirement for radiotherapy may also be indicated. The duration of this treatment, referred to as induction therapy can take up to a month and aims to destroy all of the malignant cells (Cancer Research UK 2014). This is proceeded by consolidation therapy consisting of more chemotherapy aimed to prevent malignant cells from returning and subsequently maintenance treatment consisting of low dose chemotherapy and short courses of steroids for up to two years or stem cell transplant (Cancer Research UK 2014). Both induction and consolidation therapy regimens are intense and require periods of hospitalisation in a protected isolation facility due to the risk of infection caused by the disease and the treatment. The intensity of therapy is necessary to destroy the rapid production of immature and ineffective white blood cells which in turn limit the production of normal functioning white and red blood cells and platelets. Chemotherapy is administered through an indwelling intravenous device placed into one of the larger ‘central’ veins or in the case of acute lymphoblastic leukaemia, intrathecally when malignant cells have penetrated the central nervous system. It is often necessary to also give blood and or platelet transfusions due to the depletion of red blood cells and platelets resulting from both disease and treatment. For other malignant diseases, different treatments are indicated prior to consideration of allogeneic SCT. Myelofibrosis is treated with medications that target the JAK2 gene mutation thought to be responsible for the disease combined with steroids,
androgen (male hormone) therapy and thalidomide related medications (Killick et al 2013). The main treatment for myelodysplastic syndrome is supportive care including the use of antibiotics, blood transfusions to treat severe anaemia and in some cases growth factors to promote normal blood cell production in the bone marrow (Killick et al 2013). In more severe or progressive disease, chemotherapy may be used to control a rising blast count and allow the bone marrow to resume normal blood cell production. This can involve low dose oral chemotherapy or more intensive treatment using a combination of drugs given intravenously, similar to those used to treat acute myeloid leukaemia. Medical therapy for aplastic anaemia involves suppression of the immune system and in more severe cases, a stem cell transplant (Locasciulli et al 2007).

2.5 Haematopoietic stem cell transplant

Haematopoietic stem cell transplant (HSCT) is increasingly considered the treatment of choice for patients with a range of malignant haematological diseases including leukaemia, non-Hodgkin lymphoma, Hodgkin lymphoma and myeloma (Rizzo et al 2006). Globally, 10,000 patients are treated in this way annually (Gratwohl et al 2008). As mentioned above, HSCT is also used to treat patients with aggressive forms of aplastic anaemia, myelodysplastic syndrome and myelofibrosis. Significant morbidity and mortality are associated with the underlying diseases and their treatments, including transplantation, and extend well into the post transplant recovery phase (Lee et al 2001, Andrykowski 2005). A study (Hahn et al 2013) included 38,060 patients with haematological malignancies or disorders who underwent a first allogeneic HSCT in a United States or Canadian Centre between 1994-2005 and were reported to the Centre for International Blood and Marrow Transplant Research. Diseases included acute lymphoblastic leukaemias, myeloid leukaemias, myelodysplastic syndrome and Hodgkin and non-Hodgkin lymphomas. Survival rates for those undergoing allogeneic SCT from both related and unrelated donors have shown an overall increase since the inception of this procedure. This can be largely attributed to advances in HLA tissue typing, improved supportive care and earlier treatment
with transplantation. Yet Hahn et al (2013) advocate further development of innovative approaches to increase the overall survival to more than one year.

The decision to undertake HSCT is taken when attempts to otherwise treat the disease have failed or when certitude that this will ultimately be the case exists. The purpose of HSCT is to replace the recipient’s diseased or damaged stem cells by replacing them with healthy ones. Haematopoietic stem cells are the blood forming component of bone marrow responsible for the production of red blood cells, white blood cells and platelets which in turn carry oxygen to body tissues, prevent infection and prevent bleeding respectively. There are two main types of stem cell transplantation. The first is autologous - when the patient’s own stem cells are collected during a period of disease remission, stored and re-infused at a later time. The second is allogeneic - when the stem cells are obtained from a related or unrelated donor. Once the decision is made to progress to an allogeneic SCT the process of establishing a donor of a tissue type compatible with the recipient commences. A related donor is more likely to have matching human leukocyte antigen tissue types (see glossary on p 7) to that of the recipient which plays a significant role in transplant success (US Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation National Cancer Institute 2015). Historically the stem cell collection involved aspirating the bone marrow but has largely been replaced by a process known as apheresis. The donor is treated with the hormone, granulocyte colony stimulating factor (G-CSF) to increase the production of their stem cells (Cancer Research UK 2015). The apheresis procedure involves being attached to a machine with an intravenous device which draws off and filters the donor’s blood in order to preserve the stem cells for transplantation to the recipient. Stem cells may also be collected from umbilical cord blood (Cells4life 2015).

2.6 Conditioning therapy

Conditioning is the term used to describe the chemotherapy or irradiation regimen employed to eradicate the patient’s disease and to suppress immune reactions preceding the infusion
of healthy stem cells. The bone marrow is ablated with dose levels that cause minimal injury to other tissues. In allogeneic SCTs a combination of cyclophosphamide or similar agent in addition to total body irradiation is conventionally employed Socie et al (2001). Whilst SCTs allow higher strength conditioning treatments to treat aggressive disease, the associated toxicities can result in painful stomatitis, chemotherapy induced colitis and life threatening infections (Larson et al 1993). More recently, novel treatment approaches use lower doses of chemotherapy and radiation and whilst insufficient to eradicate all the bone marrow cells of the recipient, non-myeloablative transplants reduce the risk of serious infections and transplant related mortality and instead rely on the graft versus tumour effect to resist the inherent risk of cancer relapse (Alyea et al 2005, Aleya et al 2006). Also, whilst requiring elevated doses of immuno-suppressive agents (drugs used to prevent rejection of the donated stem cells) in the early stages of treatment they are less than for conventional transplants (Mielcarek et al 2003). This results in a state of dual chimerism1 in the early stages following transplant where both host and donor stem cells are present in the marrow space. By decreasing doses of immuno-suppressant’s the donor T-cells are allowed to eradicate the remaining recipient’s stem cells and to induce the graft versus tumour effect. The relatively common appearance of mild graft-versus-host disease is indicative of the more desirable graft versus tumour effect and serves to inform future dosage levels of immuno-suppressive agents. Less aggressive conditioning regimes tend to be undertaken in elderly patients or for those considered too high risk for conventional allogeneic STC (Alyea 2005).

2.7 Graft-versus-host disease

Graft-versus-host disease (GVHD) commonly occurs in people undergoing allogeneic HSCT for haematological malignancies with 30-70% suffering an acute or chronic form (Lee et al 2003). The disease occurs as a result of the donors stem cells recognition of host tissues as antigenically foreign. Although the risk of GVHD is reduced by deoxyribonucleic acid (DNA)

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1 Chimerism is the term normally used to describe the status of donor marrow in the patient
based tissue typing, allowing for more precise matching between donors and transplant patients, it can still manifest. Even human leucocyte antigens (HLA) identical unrelated donors have genetically different proteins known as histocompatibility antigens causing the donors T-cells to mount an immune response. The acute form of GVHD is typically experienced in the first one hundred days post-transplant (National Marrow Donor Programme 2014) and poses a major challenge associated with morbidity and mortality (Goker, Haznedaroglu & Chao 2001). The chronic form normally occurs after a hundred days and can present on-going challenges to transplant patients long into their recovery phase, adversely affecting long term survival (Lee et al 2003). The clinical manifestations of acute GVHD include selective damage to the liver, lungs, skin and mucosal membranes and the gastro-intestinal tract. Chronic GVHD also attacks these organs and over the longer term can cause damage to the connective tissue and exocrine glands. Patients can experience rashes, itching, diarrhoea, nausea, mucositis, loss of appetite and jaundice. Standard treatment of both acute and chronic GVHD is the administration of intravenous glucocorticoids such as prednisolone designed to suppress the T-cell-mediated immune response of host tissues. Risks associated with the treatment are infections due to this immune suppression. Depending on the severity of the GVHD, quality of life may decrease significantly (Pidala et al 2009) and exacerbation result in hospitalisation for therapeutic intervention or dose adjustment of the patient’s existing medications (Grant et al 2005).

2.8 Quality of Life Measures

For patients undergoing HSCT there are numerous severe physical, psychological, social and emotional challenges to be faced (Cooke et al 2009, Sherman et al 2005, Hacker & Ferrans 2003, Hacker et al 2002, Hendricks & Schouten 2002, Fife et al 2000). Considerable attention has been dedicated to the assessment of quality of life (QoL) for patient’s undergoing HSCT and is important in order to compliment data regarding survival statistics, treatment outcomes and disease free intervals. Conceptualising QoL, however, is not straightforward since definitions vary (Ferrans 2000) and researchers strive to identify
and develop the most appropriate instrument to reflect their own conceptualisation. Clearly, the validity and reliability of the measurements used in relation to QoL is imperative but equally if an agreed definition of quality of life is not reached, interpretation, comparison and synthesis of research findings will be compromised (Hacker 2003). In the thirty-two studies included in an integrative review (Hacker 2003) investigating quality of life in adult patients undergoing bone marrow transplant or peripheral blood stem cell transplant over a decade, only five stipulated a definition of quality of life. Liptrott (2007) similarly acknowledges the difficulties of applying quality of life assessment to clinical practice in view of the wide variation of measures used and the relative importance attached to their specific domains. Her review (Liptrott 2007) examines both the qualitative and quantitative methods of assessing the impact of HSCT on QoL and notes both the multidimensional nature of the measures and the multiple separate scales. The outcomes of the studies appear to be influenced considerably by the context of the methodology and perception of quality of life from the instruments used. Table 1 summarises a range of QoL studies a number of which are reviewed in more detail in the following sections.
2.9 Table 1: Quality of life studies and reviews during haematopoietic stem cell transplantation

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<thead>
<tr>
<th>Authors</th>
<th>Objective of study</th>
<th>Sample</th>
<th>Measures</th>
<th>Results</th>
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<tbody>
<tr>
<td>Anderson et al</td>
<td>To describe health related QoL (HRQoL) after autologous versus allogeneic SCT during the first year post transplant. Also to compare allogeneic SCT after reduced intensive conditioning (RIC) and allogeneic SCT after myeloablative conditioning (MAC)</td>
<td>139 patients between 2000-2004</td>
<td>European Organization for Research and Training for Quality of Life Questionnaire-Core30. (EORTC QoLQ-C30) Questionnaires completed on six occasions from inclusion to 12 months post SCT</td>
<td>The RIC group recovered in a similar way to the autologous group and were closer in scoring compared with the MAC group. After 1 year levels of symptoms and functioning were back to baseline or better for the autologous and RIC group. The MAC group perceived more symptoms and lower levels of functioning during the whole period and were still impaired in 10 out of 29 scales 1 year after SCT</td>
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<tr>
<td>Andrykowski et al</td>
<td>To examine health-related quality of life (HRQoL) and growth, and spiritual well-being in adult survivors of hematopoietic stem-cell transplantation (HSCT) for a malignant disease</td>
<td>HSCT survivors (n = 662) recruited through the International Bone Marrow Transplant Registry/Autologous Blood and Marrow Transplant Registry from 40 transplant centres Age- and sex-matched healthy comparison (HC) group (n = 158) Mean age approx 50 yrs in both groups Breast cancer (n=154) and haematological malignancy (n= 497) Autologous (n=386) Allogeneic (n=267) Mean 7 years post HSCT (range 1.8-22.6)</td>
<td>A variety of standardized measures of HRQoL and growth and spiritual well-being: Physical Functioning (SF-36-PF) and pain (SF-36-Pain) subscales of the SF-36 Physical Well-Being subscale of the Functional Assessment of Cancer therapy scale (FACT-PWB) Functional Assessment of Cancer Illness Therapy Fatigue subscale (FACIT-Fatigue) Medical Outcomes Study Sexual Problems (MOS-Sex) and Sleep Problems (MOS-sleep) scales Alertness Behaviour subscale of the Sickness Impact profile (SIP-AB)</td>
<td>HSCT survivor group reported poorer status relative to the HC group for all HRQoL outcome clusters including physical health, physical functioning, social functioning, psychological adjustment, and dyadic adjustment. HSCT survivor group reported more psychological and interpersonal growth</td>
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<tr>
<td>Bevans 2010</td>
<td>To define HRQL, highlight the major HRQL during allogeneic HSCT and discuss the clinical application of the evidence and gaps that require further research</td>
<td>Case study of one 28 year old female</td>
<td>Patient reported outcomes (PROs)</td>
<td>Inclusion of PROs should be incorporated into patient assessment and clinical care. Psychological and social needs are less often addressed than physical function and symptoms</td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Participants</td>
<td>Measures</td>
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<td>Bird et al 2010</td>
<td>Randomised controlled trial (RTC) to compare the effect of two methods of rehabilitation after SCT on health and QoL</td>
<td>58 patients between 2005-2006. Median age 55 years. Autologous and allogeneic. 28 randomised to intervention and 29 control patients</td>
<td>36-item Short Form Health Survey. General Health Questionnaire Graham and Longman QoL Scale Shuttle Walk Test Data collected at baseline, 12 weeks and 6 months</td>
<td>There was no difference in Short Form 36 physical functioning scores between the two groups at follow-up. No evidence of a difference between the two modes of rehabilitation was observed for any of the trail outcomes</td>
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<tr>
<td>Byar et al 2005</td>
<td>To evaluate QoL 5 or more years post autologous HSCT</td>
<td>197 individuals post BMSCT between 1983-1992 for haematological malignancy</td>
<td>Medical Outcomes Study-Short Form (MOS SF-36); City of Hope-Quality of Life-Bone Marrow Transplant (COH-BMT) and the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT)</td>
<td>MOS-SF-36 scores for physical functioning, role-physical, bodily pain and general health sub-scales lower than values for the general population</td>
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<tr>
<td>Frick et al 2004</td>
<td>To compare individual QoL (iQoL) with health related QoL (HRQoL) and functional status of patients before high dosed therapy/PBSCT</td>
<td>79 patients aged between 10-70 years</td>
<td>Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) and the EORTC QLQ-C30</td>
<td>Patient nominated domains included family (89%), hobbies/pastimes (74%), health (physical including mobility) (70%), profession/occupation (51%), social life/friends (47%) and marriage/partnership (33%). Patient perceived iQoL depends on areas other than health and physical functioning</td>
</tr>
<tr>
<td>Hacker &amp; Ferran 2003</td>
<td>To investigate the QoL among patients immediately after undergoing peripheral blood stem cell transplantation</td>
<td>16 patients Autologous and allogeneic</td>
<td>European Organization for Research and Training for Quality of Life Questionnaire-Core30 and the Ferrans and Powers Quality of Life Index. Assessed before transplantation (n=16), immediately before hospital discharge (n=10), 2 weeks after hospital discharge (n=10), and at 6 weeks post hospital discharge. Brief telephone interview at 6 weeks after discharge from hospital</td>
<td>Patients experienced diminished functional ability, increased symptoms and poorer quality of life immediately after the marrow ablative regimen. Deviations from pre transplantation functioning did not necessarily result in life dissatisfaction. Findings suggest some patients can return to baseline status in terms of perceived health and functioning, decreased symptoms and overall QoL 6 weeks after hospital discharge</td>
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<tr>
<td>Author(s)</td>
<td>Study Objective</td>
<td>Sample Characteristics</td>
<td>Outcome Measures</td>
<td>Key Findings</td>
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<td>Hacker 2003</td>
<td>To critically evaluate a decade of quantitative QoL measurement in adult patients undergoing bone marrow transplant (BMT) or peripheral blood stem cell transplant (PBSCT)</td>
<td>Quantitative research studies published between 1990-2000 in the nursing and medical literature (N=32)</td>
<td>Single or multiple instruments to assess QoL</td>
<td>Nurses can select from a variety of tools to measure QoL in the BMT and PBSCT patient populations. No gold standard exists for measuring QoL in research or clinical practice. Clinicians must consider the clinical meaningfulness of changes in QoL before implementing changes in their practice.</td>
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<td>Hendriks &amp; Schouten 2002</td>
<td>To measure QoL after stem cell transplantation from a patient, partner and physician perspective</td>
<td>SCT survivors with no recurrent disease. Autologous and allogeneic</td>
<td>EORTC QLQ-C30 at 2.5 years (n=52) and at 4.5 years (n=33) post SCT</td>
<td>SCT has long term impact on QoL issues such as fatigue, sleep disturbance, dyspnoea and financial problems. Partner’s assessment of the patient’s QoL was more aligned with the patient’s own assessment. Physicians tend to overestimate QoL and underestimate symptoms in their patients.</td>
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<tr>
<td>Jarden et al 2009</td>
<td>Randomised controlled trial (RTC) to explore the effect of a multimodal (exercise, relaxation training and psychoeducation) intervention on treat-related symptoms in patients undergoing allogeneic haematopoietic SCT</td>
<td>42 patients aged 16-65 years Allogeneic. 21 randomised to intervention 21 control</td>
<td>24 item symptom assessment questionnaire weekly in hospital and at 3 and 6 months post SCT</td>
<td>Overall significant decrease in symptom intensity in all but the affective symptom cluster (affective symptoms = nervousness, anxiety and stress). The study begins to support an exercise-based multi-modal intervention programme.</td>
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<td>Lee et al 2006</td>
<td>To measure QoL of patients undergoing allogeneic transplantation</td>
<td>96 subjects between 1999-2004. Median age 46 years</td>
<td>Self assessment surveys pre HCT and at 6 months and 1 year post HCT including the Medical Outcomes Study Short From 12 (SF12) and the Functional Assessment of Cancer Therapy-Bone Marrow Transplant scale (FACT-BMT)</td>
<td>Physical and mental functioning assessed by the SF12 was not associated with acute or chronic GVHD. In contrast the trial outcome index (TOI) of the FACT-BMT was sensitive to occurrence of acute and chronic GVHD. GVHD is a major determinant of the QoL of survivors. Chronic GVHD is most strongly correlated with worse QL after 6 months post transplantation.</td>
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<tr>
<td>Liptrott 2007</td>
<td>To provide an overview of themes and issues arising from a literature review of QoL for patients undergoing HSCT</td>
<td>Qualitative and quantitative QoL studies</td>
<td>Single or multiple instruments to assess QoL</td>
<td>Definitions of QoL variable; instruments used to measure QoL variable. Aspects of QoL identified as both positive and negative at varying times throughout the HSCT journey. Few studies report interventions and outcomes</td>
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<tr>
<td>Mosher et al 2008</td>
<td>To review current literature on adult's QoL following HSCT</td>
<td>Review of 22 prospective reports with 20 or &gt;20 participants between 2002-2007</td>
<td>Single or multiple instruments to assess QoL at baseline and post HSCT</td>
<td>Although physical, psychological and social aspects of QoL improve over the years following HSCT, survivors experience persistent anxiety and depressive symptoms, fatigue, sexual dysfunction and fertility concerns. Despite ongoing treatment side effects, the majority of HSCT survivors resume work, school or household activities</td>
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<tr>
<td>Pidala et al 2009</td>
<td>To review the current literature on QoL following allogeneic HCT in adults</td>
<td>Review of 37 studies examining QoL after HCT</td>
<td>Single or multiple instruments to assess QoL</td>
<td>Statistically and clinically significant adverse impact of allogeneic HCT on QoL. Improvements over time from baseline. Some studies suggest greater impairments to QoL in allogeneic HCT compared with autologous HCT and chemotherapy but others do not. Acute and chronic GVHD pose threats to QoL. Behavioural interventions have demonstrated efficacy in improving QoL</td>
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<td>Study</td>
<td>Objective</td>
<td>Participants</td>
<td>Instrument/Method</td>
<td>Findings/Conclusion</td>
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<td>Saleh &amp; Brockopp 2001</td>
<td>To examine a comprehensive view of QoL post BMT and to evaluate the psychometric properties of an instrument designed to measure QoL in this population</td>
<td>41 BMT survivors with an age range of 18-71 years Autologous and allogeneic BMT</td>
<td>Quality of Life in Bone Marrow Transplant Survivors Tool (QoL-BMT-ST) An average of 30 months post-BMT</td>
<td>Global QoL good (x=6.7 on 0-10 scale. Subjects experienced long-term areas of concern including physical strength, sexual activities, fear of cancer recurrence, fear of developing a secondary cancer, unemployment, family distress and uncertainty toward the future. Psychometric testing of the QoL-BMT-ST revealed adequate to excellent reliability and validity</td>
</tr>
<tr>
<td>Schulmeister et al 2005</td>
<td>To expand the limited body of knowledge of the perceptions of QoL, quality of care and patient satisfaction among patients receiving high-dose chemotherapy with an autologous SCT on an outpatient basis</td>
<td>36 patients</td>
<td>FACT-BMT before chemotherapy and 2-4 weeks and 6 months post chemotherapy and SCT</td>
<td>FACT-BMT scores were lower 1 month post-treatment than at baseline and highest six months post treatment. Subjects with progressive disease reported lower QoL at one and six months post treatment and ranked satisfaction with care lower than subjects with no evidence of disease</td>
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<tr>
<td>Tierney et al 2007</td>
<td>Exploration of the theoretical model of response shift in relation to QoL following HSCT</td>
<td>Review of 25 QoL studies</td>
<td>Only 3 studies stated the theoretical framework on which the study was grounded</td>
<td>HSCT recipients report good to excellent QoL following treatment despite ongoing physical and psychological sequelae. The theoretical model, response shift offers a compelling explanation for the paradoxical findings. Response shift proposes that individuals redefine QoL based on alterations in health status</td>
</tr>
<tr>
<td>Wettergren et al 2008</td>
<td>To prospectively measure QoL in patients with malignant blood disorders following SCT using an individualised and a standardised measure</td>
<td>22 patients assessed</td>
<td>Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) and the EORTC QLQ-C30 Before and 1 year post SCT and the standardised measure was compared to Swedish norm values</td>
<td>The majority of patients reported concerns related to health before and 1 year post SCT recorded by both instruments. QoL improved after a year. SCT recipients reported worse functioning in comparison to Swedish norm values</td>
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2.10 Patient’s experience and QoL including the period of undergoing SCT

This section reviews a qualitative study of patients undergoing allogeneic and autologous stem cell transplant in hospital (Shuster et al 1996), a personal account of the stem cell transplant experience (Morstyn 2009) and a descriptive longitudinal study (Schulmeister et al 2005) exploring patients’ perceptions of QoL, quality of care and patient satisfaction whilst undergoing autologous SCT for a variety of conditions including haematological malignancy on an outpatient basis. The studies are summarised in Table 1.

Shuster et al (1996) interviewed patients (n=11) during their hospitalisation for SCT including one who had an autologous and ten who had an allogeneic SCT. Informants were interviewed between one and four times a week whilst in hospital and once a week for four weeks post discharge. Five themes emerged from the study which were physiological functioning, alertness, attitude, social relationships and spirituality. Physiological functioning concerned numerous severe challenges such as pain, nausea, itching, fevers, sweats, chills and seizures along with difficulties in eating and the discomfort of tubes such as intravenous devices. The authors (Shuster et al 1996) identified a thread between all five core themes which led them to describe the ‘dialectic of patient coping experience’ (Shuster et al 1996 p 5). In essence the informant’s vacillated between two poles; a desire for connectedness and a sense of disconnection in order to deal with their experience. For example they alternated between striving to be alert and the desire to sleep through unpleasant events, or a desire to plan for the future countered with dealing with the immediacy of daily life.

Making sense of the transplant experience is eloquently described by Morstyn (2009) in his personal reflections of his bone marrow transplant. As a practising psychiatrist, he endeavours to conceptualise his experiences of diagnosis and treatment within a medical or psychiatric framework but finds neither of these approaches suitable in addressing his feelings or understanding. Spending weeks in isolation undergoing harsh treatments Morstyn (2009) found that he was no longer able to consider the world as a separate entity from his own existence in it. Whereas his body was largely taken for granted and generally
invisible to him, the threat of death and deterioration coupled with physical changes, disruptions, pain and fatigue necessarily created a new and frightening awareness. He describes new forms of spacial and temporal experience such as noticing the ceiling as he spent hours staring up at it as if re-learning to look at the world. Further discomfort was suffered by self-alienation resulting from physical pain and the ambiguity of existence and solitude experienced at this very difficult time. He describes how Merleau-Ponty’s (2002 p237) explication of the phenomenology of perception helped him to make sense of his “overwhelming existential crisis” and as a consequence felt better able to understand his own experience. Furthermore, he could identify individuals who were able to relate to him in his altered existential state and contribute invaluably to his recovery. Whilst a number of these were health care professionals, he found that their ability was variable and that the most significant person to understand his predicament was his wife.

A descriptive longitudinal study (n=36) was carried out by Schulmeister et al (2005) to explore patients’ perceptions of QoL, quality of care and patient satisfaction whilst undergoing autologous SCT on an outpatient basis. Of the thirty-six patients, twenty one had breast cancer, one ovarian and fourteen haematological malignancy and whilst 64% lived at home, 3% stayed in a residential facility and 33% in an apartment near to the out-patient site. Subjects completed the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) before high-dose chemotherapy, four to six weeks after and six months post-chemotherapy. In addition, telephone interviews were conducted to gain the patient’s perspective on their treatment experience, quality of care received and satisfaction of care and the qualitative data were analysed using Giorgi’s methodologic reduction. Findings revealed that those reporting a negative experience were associated with severe or life threatening effects including neutropenic sepsis as a result of high dose chemotherapy and almost half of the patients in the study required hospitalisation (Schulmeister et al 2005). Recommendations for improvement of the autologous SCT programme included more effective communication, better information and implications for
nursing care, ancillary needs and survivor support. Specific comments relating to communication and information related to offering rationales for symptom management advice and offering personalised information tailored to an individuals’ needs. Participants also suggested that they would appreciate conversations regarding spirituality, sexuality, effects of treatment on fertility, long-term effects and complementary therapies (Schulmeister et al 2005 p64).

2.11 Quality of Life Studies post stem cell transplant

This section reviews a number of studies investigating QoL pre SCT up to twenty two years post SCT. It should be noted that patients involved in the studies have a range of diseases including breast cancer and haematological malignancy and are treated with both autologous and allogeneic SCT. Patients undergoing autologous SCT do not suffer from GVHD and therefore this potentially reduces the number of side effects post SCT. A study by Wettergren et al (2008) found that quality of life improved a year post compared to pre-transplant state. Most notable were improvements in the domains of role function, social function and physical function. The authors advocate the use of a standardised instrument to measure QoL in combination with an individualised measure. The latter allows participants to nominate preference-based domains, thereby increasing the likelihood of reflecting a patient’s personal perceptions and priorities at specific times. In an earlier study, carried out by Whedon et al (1995), the QoL-BMT-ST was supplemented with an open-ended qualitative questionnaire allowing patients to report additional data which highlighted additional themes of pain, uncertainty and fear of disease recurrence.

Saleh and Brockopp (2001) examined a comprehensive view of quality of life post BMT and evaluated an instrument to measure quality of life in this population. The Quality of Life in Bone Marrow Transplant Survivors Tool (QoL-BMT-ST) was found to be reliable and valid through comparison and high correlation with similar measures and the authors (Saleh & Brockopp 2001) promote its value over other instruments for two reasons. Firstly, its design
is specific to BMT survivors on previous QoL evaluation and secondly, certain questions are generated directly from the content analysis of interviews with BMT survivors though the authors do not state specifically what these questions were. The study included patients who had been treated with either allogeneic or autologous transplantation. The BMT survivors (n=41) with an age range of 18-71 years who were an average of thirty months post BMT in Saleh & Brockopp’s (2001) study reported good quality of life. However, areas of concern included physical strength, sexual activities, fear of cancer recurrence, fear of the development of a secondary cancer, unemployment, family distress and uncertainties about the future and are reported with high incidence during the first year post transplant. Uncertainty was found to be conceptually distinct from fear of recurrence but closely associated with the unpredictable nature of their primary cancer. 56% of the allogeneic BMT survivors experienced graft versus host disease, causing changes in physical appearance accounting for the psychological distress reported.

Tierney et al (2007) note the paradoxical findings of a large number of QoL life investigations where SCT recipients report good to excellent QoL following treatment despite ongoing physical and psychological sequelae. Corroborating this evidence are studies reporting positive outcomes such as enhanced appreciation of life and relationships, personal growth and a re-ordering of life priorities as perceived by the individual (Andrykowski et al 2005, Dew et al 1997, Fromm et al 1996). The theoretical model of response shift into QoL research (Sprangers & Schwartz 1999) helps to explain how patients redefine their quality of life based on alterations in health status. The response shift model offers an explanation of how individuals perceive their quality of life in the face of ongoing physical and emotional sequelae. The concept of response shift accounts for a change in meaning an individual assigns to their own perception of their QoL resulting from a reappraisal of values, internal standards or re-conceptualisation of the target construct. Similarly, Tierney et al (2007) acknowledge that social factors may also affect individuals’ perceptions of their QoL and for some, survival itself, given the limited treatment options
available, may be synonymous with life quality. Tierney et al (2007) effectively demonstrate the phenomena of response shift in their case study. Despite enduring problems with chronic GVHD following STC, resulting in significant physical manifestations, loss of sexual desire and eventually abandoned sexual activity the individual studied rated her QoL higher at these times than at others when health issues were not so challenging.

In a large (n=662) multi-centre study Andrykowski et al (2005) compared patients who had received an HSCT with a healthy control group to illicit their health related QoL (HRQoL) a mean of seven years post treatment. The HSCT survivor group reported poorer status relative to the healthy control group for all HRQoL outcome clusters including physical health, physical functioning, social functioning, psychological adjustment, and dyadic adjustment. In contrast, the HSCT survivor group reported more psychological and interpersonal growth corroborated by Tierney et al’s (2007) findings. A study investigating quality of life after SCT at around 2.5 (n=52) and 4.5 (n=33) years, Hendriks & Schouten (2002) found that survivors experienced long term impact on QoL issues such as fatigue, sleep disturbance, dyspnoea and financial problems. Whilst recognising the value of the tool in analysing overall quality of life the authors (Hendriks and Schouten 2002) point to the importance of factors such as sexuality and unemployment which are not included but potentially have significant impact on quality of life.

Although increasing data are available addressing QoL issues after stem cell transplantation, a number of important challenges remain for investigators. Whilst the concept of QoL is an important consideration in the aftermath of arduous treatments for life-threatening illness (Pidala et al 2009), its definitions remain varied, synonymous with the heterogeneity of the instruments utilised to measure it. These range from general quality of life instruments such as the 36-item Short Form Health Survey to cancer-related measures such as the Functional Assessment of Cancer Therapy General and disease specific and treatment related measures such as the FACT-BMT outcome measures. Whilst the disease
specific and treatment related measures are more sensitive to specific patient groups, interpretations and comparisons of studies using heterogenous instruments are problematic. Patient attrition can also affect the validity of longitudinal studies along with potential response shift in relation to self-reported QoL. It is also recognised that further work is required to enhance the researchers, clinicians and patients understanding of the clinical relevance of QoL throughout the treatment and recovery trajectory (Pidala 2009, Bevans 2010).

2.12 Social context of quality of life

In their study of forty-four cancer patients in two treatment centres, Schou and Hewison (1999) examine factors affecting quality of life whilst undergoing radiotherapy and or chemotherapy. Unlike other studies which, they argue, ignore or under-examine the social nature of treatment Schou and Hewison (1999) draw attention to the importance of the individual's social reality in relation to their experience. Contrary to the perception of patients' being passive recipients of treatment Schou and Hewison (1999) highlight the significant, interpretive and practical work that patients undertake in order to manage complex treatment and their daily lives. The important role of language in the social construction of treatment and patients' accounts of treatment experience places social context as an integral part of their cognitive-behavioural mechanisms and processes. Therefore the authors caution against assumptions being made regarding patients' coping and adjustment styles in isolation of their social context and reality. Developing this argument further, Schou and Hewison (1999) explore the concept of time and treatment calendars in relation to experiencing cancer. Surviving a cancer diagnosis for five years or more whilst living with the effects of treatment and the possibility of recurrence has led to it being considered a chronic illness (Witter & LeBas 2008). As a consequence there is a requirement for patients to reconstruct their personal calendars according to frequent disruptions and deviations from their pre-diagnostic situation.
In terms of developing strategies to deal with their cancer experience, Corbin and Strauss (1988) refer to three focal areas for patients and families, these being illness related, biographical and everyday life-work. Schou and Hewison (1999) conceptualise these three areas in terms of organisation of time so that the work of patients and families is to balance the illness and treatment calendar with their biographical life calendar and their personal or private calendar. The authors contend that this work is hindered by the ambiguity of dialogue between health care professionals where prognostic and treatment detail is rarely discussed and the language used is tempered to inspire the notion of cure and survival. Van der Waal (1996) found continuity of care to be one of the most important aspects of QoL for patients with chronic illness, whilst this appeared to be a lower priority to providers. Changes in schedules or alterations to treatment plans gave rise to patients’ anxiety, particularly when news of these was delivered by a junior or unknown person. Concurring with this evidence, Schou and Hewison (1999) found that lack of a dependable contact with an identifiable central treatment professional or professional treatment team is a distinct feature of a confusing treatment context. The lack of a central figure gave rise to communication deficits and interfered with relationship building between professionals and patients. Questions regarding treatment and surveillance as well as explanations regarding test results and procedures tended to be unaddressed by the less experienced clinical staff and impacted on patient choice and consequent control of their treatment programme. Patients commented on the confusion caused by receiving conflicting information. An example of this arose when a patient reported fatigue and received a lecture on the benefits of positive thinking at one consultation, but at the next was told that this was understandable (Schou and Hewison 1999).

The displacement of the personal and life calendar is arguably the most important effect of the treatment calendar and the disease process on the ill person’s Quality of Life, (Schou and Hewison 1999). To this end, they argue the importance of professional contact and advice in managing the treatment calendar and rehabilitation phase so that patients and
families can assess if and when normality will be resumed. In summary the illness calendar and treatment calendar expressed by the term ‘patienthood’ (p153) is considered by Schou and Hewison (1999) to be key to illness related quality of life but is often underestimated and overpowered by the functional living perspective associated with the biomedical model. Whereas QoL in oncology originated in ideas about impairment and disability and their assessment, treatment processes themselves impact seriously on social functioning.

2.13 The lived experience of autologous stem cell transplantation

Two studies (Jones & Chapman 2000, Stephens 2005) are discussed here exploring the lived experience of patients undergoing SCT, (see Table 2). A third study is presented in a later section examining patient’s coping strategies (Cohen & Ley 2000). At the beginning of the 21st century Jones and Chapman (2000) acknowledged that stem cell transplantation was still in its relative infancy and therefore attention necessarily focussed on the technical and scientific aspects of the treatment. Whilst medical research was concerned with the biological efficacy of this treatment for an increasing number of haematological and other cancers, nursing studies sought to address the multiple side effects of treatment. The authors highlight a paucity of research uncovering the lived experiences of patients undergoing stem cell transplantation and the associated physical, psychosocial and emotional consequences and implications. Jones and Chapman (2000) own small in depth study of seven individuals undergoing autologous stem cell transplantation seeks to address this gap through hermeneutical phenomenological enquiry. The aims of the study were to elicit, value and learn from their personal experiences and thereby inform nursing practice regarding appropriate support and care. Themes that emerged from the participants’ stories included changing concepts of self, the significance of relationships, being different from the past and temporality. The changing concept of self resulted from physical and emotional changes including the recognition of their own mortality often in alien environments due to treatment in specialist centres. The narratives of two patients speak powerfully about their
experience and fight for survival as demonstrated in the following concluding statements
from patients in the study:

“If I had to describe in one sentence what it was like, it was like a sheer trip to hell and back.
A very quick trip there and an awfully slow trip back”

And,

“I’ll tell you what boys, you’ve got to be awful bloody sick before you die.”

(Taken from Jones & Chapman 2000 p159)

The importance of close connection with significant family and friends provided strength and
comfort during treatment and extended during the transition from hospital to home. Participants in this study reported feelings of uncertainty and turmoil in trying to resume their
normal lifestyle characterised by the theme of ‘being different from the past’. The theme of
temporality found by Jones & Chapman (2000) refers to the lived time connecting past, present and future experiences giving meaning to our being-in-the-world and according to
Heidegger(1962) gains meaning in the face of a finite future.

Certain limitations are highlighted (Jones & Chapman 2000) acknowledging that critics of
phenomenology may question how an understanding of patient experience can translate
into changes in practice. However, the authors demonstrate how a number of
recommendations to change and support practice were accepted locally on the basis of the
study and it can be argued that these valuable findings are transferable to other transplant
centres. Recommendations included active measures to reduce patient and family anxiety
including orientation to personnel and the environment in the treatment facility, inclusion of
family members and friends in the care of patients whilst in hospital and support for these
individuals too. Trust in people and processes were recognised as all important particularly
when test results went missing or the competence of practitioners was called into question. This latter finding had implications for staff education and training both within the transplant centre and in diagnostic departments in the hospital.

In a subsequent phenomenological study, Stephens (2005) interviewed five patients following autologous stem cell transplant. Findings illustrated that the transplant experience impacted on their lives for an undetermined time and that through experiencing physical, psychological and emotional changes felt they had altered as people supporting the findings of Jones and Chapman (2000). All five participants described reprioritisation and changes in their outlook and values and whilst this was perceived as positive in some cases, two participants described an increase in emotional vulnerability (Stephens 2005). An emergent theme from the participants (Stephens 2005) was one of discovering the gift of a new life and not wanting to waste it. Whilst this view is upheld by a number of participants in the study by Jones and Chapman (2000), emotions are adversely affected in the analysis of why their cancer developed, reflections on the aggressive treatment regimens and a resulting anger and bitterness towards life articulated by one of the participants.
### Table 2: Patients lived experience of autologous stem cell transplant

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<thead>
<tr>
<th>Authors</th>
<th>Study aims and design</th>
<th>Sample</th>
<th>Data collection and analysis</th>
<th>Results</th>
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<tr>
<td>Cohen and Ley</td>
<td>To describe patients’ experience of having an autologous bone marrow transplant</td>
<td>20 adults; 15 females, 5 males; mean age 46 years</td>
<td>Interviews and hermeneutic phenomenological analysis (descriptive and interpretive). Mean number of months post autologous BMT 16 months (range 2-49.5)</td>
<td>Patients experienced fears including that of death, recurrence of disease and being physically and emotionally unprepared. Loss of control and trust in one’s body was experienced. Fear was associated with leaving hospital and not having someone ‘constantly looking at you to make sure the cancer isn’t back’</td>
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<tr>
<td>Jones &amp; Chapman</td>
<td>To explore the lived experience of people treated with autologous bone marrow/peripheral blood stem cell transplant</td>
<td>7 people; 2 females, 5 males</td>
<td>Interviews and hermeneutic analysis. At least one year post autologous SCT</td>
<td>Four themes identified: Changing concepts of self Significance of relationships Being different from the past Temporality</td>
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<tr>
<td>2000</td>
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<tr>
<td>Stephens</td>
<td>To explore the lived experience of people treated with autologous HSCT</td>
<td>5 informants; 2 males, 3 females; mean age 53.8 years</td>
<td>Interviews and analysed using Giorgi’s method of phenomenological analysis. At least 6 months post HSCT</td>
<td>Nine themes identified: Changes on various levels; fear; isolation; concern about others’ well being and coping skills; adaptation, adjustment and recovery; changes in values, outlook and priorities; transplant is a separate and discrete experience from that of diagnosis and initial treatment; new life; bereavement</td>
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<td>2005</td>
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2.15 Survivorship

Definitions of survival following cancer vary. For the purpose of statistics oncologists consider survival as commencing from the time of cancer diagnosis and henceforth defined as disease-free survival or survival with recurrence (Little et al 2000). Others use the term survivor to refer to those for whom treatment has been successful and there is no evidence of the original malignancy and no recurrent disease. Increased survival rates largely due to screening and improved treatments have resulted in research statistics reporting survival periods of five and ten years from the time of diagnosis. A number of adult patients with cancer survived because of the aggressive nature of treatment including HSTC and the subsequent screening and preventive practices for long term survivors (Rizzo et al 2006).

The experiences of cancer survivors include a number of physical, social and psychological challenges relating to their altered life circumstances (Welch-McCaffrey et al 1989). Studies reveal some of the challenges faced by cancer survivors for example, those with colorectal cancer (Beech et al 2012, Little et al 2000), breast cancer (Crouch & McKenzie 2000) acute leukaemia and Wilms’ tumour (Mackie et al 2000). Other illnesses can develop as a result of treatment including heart disease, renal impairment, hypertension, osteoporosis and sexual dysfunction (Dubbleman et al 2006, Tichellie & Socie 2005), and cognitive impairments (Tannock et al 2004). Altered physical functioning and fatigue can have a major impact on resuming normal activity post allogeneic SCT (Anderson et al 2010, Syrjala et al 2004) and cancer related fatigue can increase in severity when other chronic conditions are present (Wright et al 2014). Psychosocial challenges include uncertainties about the future (Holland & Reznik 2005), feelings of isolation (Little et al 2000) and an inability to return to work (Short et al 2005, 2007).

Cancer survivorship research aims to identify diagnosis and treatment related outcomes to contribute to a knowledge base informing appropriate follow up care including screening and surveillance, thereby optimising the future health of cancer survivors (Aziz 2002). These authors (Aziz 2002) acknowledge that for patients with malignant haematological disease
the most significant treatment related therapies affecting health status in long-term survivors are irradiation, chemotherapy and allogeneic stem cell transplantation. The so called ‘late effects’ manifest in specific organ or tissue complications requiring on-going monitoring and interventions as required. For patients with acute and chronic graft versus host disease, late effects are associated with long term high-dose glucocorticoid treatment. This prolongs the period of immunosuppression with consequent adverse effects on health and survival (Tichelli & Socié 2005).

Fatigue is one of the most prevalent and distressing symptoms experienced by those treated for cancer (Barton-Burke 2006, Lawrence et al 2004) including haematological malignancy (Jarden 2009, Hacker et al 2011). Whilst Hacker et al’s (2011) study involved the immediate post transplant period they highlight the fact that decreased activity may result in long-term functional consequences affecting patients’ ability to return to their previously held roles.

Saegrov & Halding (2004) conducted a three part investigation in Norway to ascertain the experiences of twelve adults living with cancer and diagnosed six months to three years earlier. The informants aged from 43-70 years included those diagnosed with breast, prostate and colon cancer, non-Hodgkin lymphoma and myeloma. Initially a mapping process identified the follow up and post treatment programmes offered in the region closest to the patients’ home. The second part of the investigation involved mapping how the participants evaluated their own health, quality of life and views regarding their post treatment programmes and follow up. Finally, in depth interviews were carried out to gain further insight into how the individuals experienced having cancer. The major findings highlighted three specific times of stress and difficulty; that of awaiting a definitive diagnosis following a suspicion of cancer, waiting for treatment to commence and the period following treatment. Participants felt that this latter phase of recovery and rehabilitation was neglected and would have welcomed the opportunity to discuss their new and altered life situation as a
result of the disease and associated challenges faced. They highlighted the need for a rehabilitation programme to provide information regarding physical activity and fatigue management and the opportunity to address psychological and social issues with a health care professional. Consultancy follow ups tended to focus on the medical themes as opposed to health related quality of life issues.

2.16 Therapeutic rehabilitation intervention

Bird et al (2010) compared the effect of a professional-led and a self-managed rehabilitation programme after stem cell transplantation on health and quality of life. The randomised controlled trial incorporated exercise, relaxation and information. No evidence of a difference in outcomes between the programmes was observed using a number of trial outcome measures. One of the limitations identified was the small sample size and is synonymous with earlier studies investigating the effectiveness of exercise programmes to maintain physical functioning both during and following SCT (Courneya et al 2000, Hayes et al 2003). In Bird et al’s study (2010) recruitment was adversely affected by the entry criteria which meant that potential participants who felt that they did not require rehabilitation were excluded at a later date when this may have been beneficial. The most frequently cited reasons for declining to take part were the distance from home to the hospital and that the programme did not feel relevant for their needs. The authors conclude that programmes with variable content to suit individual requirements at a time appropriate to them and with creative methods of evaluation appropriate to increasingly complex and less standardised interventions are required in the future. Conversely, Jarden et al’s study (2009) found overall significant decrease in symptom intensity with a supervised structured exercise programme, relaxation training and psycho-education intervention compared with standard treatment. However, symptom intensity in the affective cluster, including nervousness, anxiety and stress was not decreased and fatigue was reported most frequently as the most distressing symptom in both the intervention and control groups (Jarden at al 2009). Findings (Jarden
et al 2009) do however provide some evidence of the efficacy of an exercise-based multimodal intervention.

2.17 Psychosocial issues and survival

The areas of distress most common amongst individuals undergoing treatment for cancer include uncertainty regarding treatment outcome, recurrence and mortality; acute symptoms such as nausea, vomiting, mouth sores and pain; reduced functional status; changes in appearance and sexuality; family distress; contact with health services including communication and information sources and financial considerations (Syrjala et al 2004). There is currently a growing body of research focussing on the psychological aspects of SCT, particularly in the post-transplant rehabilitation phase (Table 3). A pilot study by De Marinis (2008) aimed to compare the presence of post-transplantation depression disorders by gender and to compare the outcomes amongst those with and without depressive disorders from a health psychology standpoint. Twenty three adult participants completed a number of self-report measures including the Short Form (SF)-12 Health Anxiety Inventory (HAI) and Somatosensory Amplification Scale (SAS) and this data was supplemented with medical and psychiatric records detailing medical problems and medications. Findings showed that female survivors have a higher rate of depressive disorders and that survivors with treated depressive disorders are similar to those without depression based on the outcome measures of health related quality of life and health anxiety due to success of their anti-depressant treatment. A number of limitations were highlighted including sample size, sample bias, uncertainty regarding definitive diagnoses and adherence to treatments in addition to the validity of the instruments used to measure anxiety and distress. However, the findings were consistent with Syrjala et al’s (2004) findings, where those suffering depressive disorders were significantly more likely to be female.
### Table 3: Studies investigating the physical, psychological and psychosocial sequelae of HSCT

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study aims and design</th>
<th>Sample</th>
<th>Data collection and analysis</th>
<th>Results</th>
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</thead>
<tbody>
<tr>
<td>Coolbrandt &amp; Grypdonck 2010</td>
<td>To explore how patients undergoing SCT keep courage and pull through the demanding therapy</td>
<td>15 patients from three hospitals, 8 males and 7 females. 8 nurses.</td>
<td>Grounded theory, Participant observation, Patient interviews, Nurse interviews</td>
<td>Patients ‘keep courage’ by protecting their positive story from the assaults of negative information and threatening signals. The most vulnerable time is during aplasia (following conditioning therapy) when physical and mental strength are lost. Doctors and nurses help them to muster up courage and nurses carry them through the most despondent moments</td>
</tr>
<tr>
<td>De Marinis et al 2009</td>
<td>To compare the presence of post-transplantation depression disorders by gender and to compare outcomes amongst those with and without depressive disorders using a health psychology focus</td>
<td>23 HSCT recipients</td>
<td>Cross-sectional pilot study, Depression disorders health status measure (Short Form-12), Health Anxiety Inventory (HAI), Somatosensory Amplification Scale (SAS), At mid-term survivor stage</td>
<td>Females had a higher rate of depression disorders. Those with treated depressive disorders were similar to those without depression on health-related quality of life and health anxiety. Neither age nor time since HSCT was associated with depressive disorders</td>
</tr>
<tr>
<td>Gruber et al 2003</td>
<td>To identify long-term psychosocial effects of allogeneic, syngenic and autologous HSCT</td>
<td>163 patients</td>
<td>Herschbach Questionnaire on Stress in Cancer Patients (QSC). Three additional items added specific to HSCT. Up to 16 years post HSCT between 1979-1996</td>
<td>Somatic and psychosocial problems of HSCT can have long-term effects on patients’ QoL. Serious problems were associated with fitness, pain and fear/emotional stress. Professional reintegration is an important factor in patients’ well-being</td>
</tr>
<tr>
<td>Hochhausen et al 2007</td>
<td>To examine whether three psychosocial variables (social support, self-efficacy and optimism) assessed prior to BMT predicted physical and emotional well being one year post BMT</td>
<td>87 participants</td>
<td>Rand Medical Outcomes Study Social Support Survey, Life Orientation Test (LOT) to measure optimism, Cancer Behaviour Inventory Long From (CBI-L) to measure self-efficacy, HRQL assessed with the Functional Assessment of Cancer Therapy General (FACT-G) and the FACT-BMT disease specific outcome measures</td>
<td>Social support, self-efficacy and optimism significantly predicted emotional and physical well being one year post BMT</td>
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<tr>
<td>Study</td>
<td>Objective</td>
<td>Participants</td>
<td>Assessment Tools</td>
<td>Findings</td>
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<tr>
<td>Jenks Kettmann &amp; Altmaier 2008</td>
<td>To assess prevalence of depression among patients receiving an allogeneic transplant over a 1 year period. To investigate the role of social support in mitigating depression. To assess whether age and/or gender influenced depression or its relationship to social support</td>
<td>86 participants, 47 males and 39 females between the ages of 18-55 at the time of transplant</td>
<td>Medical Outcomes Study Social Support Scale (MOS-SSS) Centres for Epidemiological Studies of Depression Scale (CES-D)</td>
<td>Patients experienced a reduced level of depression post compared to pre-BMT. Females reported more depression than males. Social support pre-BMT predicted depression levels post-BMT</td>
</tr>
<tr>
<td>Sherman et al 2005</td>
<td>To describe issues discussed by participants in a monthly post-HCT</td>
<td>6-8 participants each month but not necessarily the same people; males and females; 1-12 years post HCT. Young adults to middle age. Autologous and allogeneic</td>
<td>Topics of discussion emanating from a monthly support group over a two year period. Issues raised were accompanied by examples from participants</td>
<td>Issues raised were categorised into three major themes: physical, psychological and social with subthemes and specific examples</td>
</tr>
<tr>
<td>Siegal 2008</td>
<td>To review the evidence regarding psychosocial considerations in HSCT and implications for patient QoL and post transplant survival</td>
<td>Literature review</td>
<td>Studies investigating psychosocial considerations in HSCT.</td>
<td>Evidence reviewed points to the need for psychosocial services on transplant units and psychological evaluations in the pre-transplant workup. Psychosocial screening and intervention should be offered early in the treatment process</td>
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Siegal (2008) reviewed evidence of psychological considerations of haematopoietic stem cell transplantation in relation to patient’s quality of life and post-transplant survival and concluded that psychosocial services should be available on transplant units offering screenings and interventions early in the treatment process. Psychosocial factors have been shown to predict health outcomes and mortality in chronic illnesses such as heart disease and immune-deficient disorders (Schneiderman et al 2005). Though such an association has proved controversial in cancer, studies have supported a link between psychosocial factors and survival (Foster 2004, Hoodin 2006). Whilst Foster’s (2004) study produced significant data showing a correlation between in-patient lay carer presence and survival, a limitation was that the quality of the relationship between the care-partner was not considered. Frick et al (2005) demonstrated a relationship between problematic support and increased risk of mortality in a prospective study of patients before and four years following autologous stem cell transplantation. The psychosocial sequelae associated with HSCT can extend to the patient’s informal caregiver, partner or spouse as evidenced in a study by Langer et al (2003). This prospective longitudinal investigation revealed higher levels of depression, anxiety and marital dissatisfaction in caregivers compared to the patients as long as one year post transplant (Langer et al 2003).

A prospective longitudinal cohort study, Syrjala et al (2004) examined the course of recovery and return to work after haematopoietic cell transplantation for leukaemia and lymphoma patients (n=335). Findings show that cancer treatment distress peaked prior to and up to ninety days post transplant. Whilst declining steadily over subsequent assessments however, 79% of patients reported a clinically significant level of cancer treatment distress at 1 year follow-up assessment. The authors conclude that physical recovery occurred earlier than psychological or work recovery and that recovery might be accelerated by more effective interventions to increase work-related capabilities, improve social support and manage depression.
A study by Sherman et al (2005) elicited themes generated from dialogue among survivors of HSCT in a designated patient support group. The purpose of this investigation was to provide a foundation regarding long term effects that can be investigated more closely in order to develop interventions to assist in improving quality of life. Sherman et al’s (2005) findings concord with quality of life research eliciting patients’ concerns within the spheres of physical, psychological and social changes. In particular a discordance between pre-transplant expectations for returning to normal and the reality of altered functional status associated with greater psychological distress was indentified. However, both positive and negative post-transplant issues were highlighted by participants. Physical themes included coping with long-term physical changes or complications, fatigue, cognitive changes, medications and side effects and sexuality. Psychological themes comprised of feelings of uncertainty and the search for meaning and whilst many expressed a struggle relating to redefining themselves and a sense of identity, there was also acknowledgement that they had received a second chance and an increased ability to deal with other life stresses. Depression occurring many months after discharge from hospital was also experienced. The social themes discussed related to roles and relationship changes, work and study issues and interpersonal communication. Recommendations from this study (Sherman et al 2005) include the promotion of support groups to provide information and contacts for patients, an explanation of the normal disease trajectory and emotional support. An earlier study, (Weis 2003), demonstrated the benefit of learning strategies for coping with long term effects of SCT within a patient support group.

In a study of eighty-seven participants receiving allogeneic stem cell transplantation for leukaemia in a multi centre randomised controlled trial, Hochhausen et al (2007) found a correlation between social support, optimism and self-efficacy and post transplant emotional well-being one year post procedure. Limitations to the study include the poor representation of diverse racial and ethnic groups and potential selection bias resulting from potentially physically healthier patients agreeing to participate. Whilst social support and self-efficacy

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may be enhanced through intervention Hochhausen et al (2007) advocate that future research should explore the predictive value of optimism further along with other psychosocial factors such as coping style.

In a longitudinal prospective study, Jenks Kettmann & Altmaier (2008) considered the role of social support in mitigating depression among bone marrow transplant patients pre and post hospitalisation and up to a year into the recovery phase. Eighty-six patients completed the Medical Outcomes Study Social Support Scale (MOS-SSS) and the Centres for Epidemiological Studies of depression Scale (CES-D) before and one year post-transplant. The authors (Jenks Kettmann & Altmaier 2008) acknowledge that whilst this was part of a larger study (n=398) a relatively low number of patients were able to complete both social support and depression measures at pre-BMT and one year later mainly due to death and severe illness. Results showed moderate levels of depressive symptoms with 29.1% and 27.6% meeting the suggested criterion for clinical depression at pre and post BMT respectively. Females reported more depression than males pre BMT, though this levelled out at one year post BMT. Social support status pre BMT influenced depression levels post BMT controlling for existing levels of depression. The authors recommend that health care professionals encourage patients to build social support pre-transplant and to maintain this post BMT. Although Jenks Kettmann & Altmaier (2008) acknowledge the challenges of maintaining social support during weeks of hospitalisation in an isolation facility and advocate inclusion of informal caregivers, family and friends, this does not necessarily address the challenges throughout the disease trajectory. BMT often follows months of treatments which have already impacted on the patients’ ability to sustain a social network or employment and Grassi et al (1996) found that post-transplant depression is linked with pre-transplant depression, low social support and external locus of control.
2.19 Patients' coping strategies

Several authors endeavour to distinguish strategies used by patients to cope with their diagnosis and ensuing disease trajectory (Cohen & Ley 2000, Bulsara et al 2004, Frick et al 2005, Shuster 1996, Coolbrandt & Grypdonck 2010). Cohen & Ley's (2000) study of twenty adult survivors of autologous stem cell transplant (see Table 2) begins to explore the relationship between hope and fear and the role that nurses can play in preparing and supporting patients throughout their journey. Although the twenty patient interviews were conducted a mean number of sixteen months post-transplant, the focus was their reflections of undergoing the treatment as opposed to their return home. The patients’ need for realistic information was countered by a fear of knowing too much and potentially diminishing their hope of survival.

In a study of haematological cancer patients (n=7) Bulsara et al (2004) set out to identify the common factors which patients and spouses believed would enable them to achieve a level of control in managing their illness. Interviews included patients and three spouses included at the discretion of the patients. Findings highlighted the importance of feeling in control of their illness and treatments, acceptance of their condition, maintaining hope and the support of family and significant others as fundamental elements for their sense of empowerment.

Frick et al (2007) sought to determine associations between health locus of control, causal attribution and coping prior to stem cell transplantation using three questionnaires to measure these factors (Lohaus & Schmitt 1989, Muthny 1998, Muthny 1992). In addition, ratings of Karnovsky’s index was used to measure performance status (Karnofsky & Burchenal 1949). Frick et al (2007) identified four homogenous subgroups of patients (total n=126) in respect to their locus of control convictions which are outlined in Table 4 below:
2.20 Table 4: Adapted from Frick et al (2007 p159)

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<tbody>
<tr>
<td>1</td>
<td>'not internal' (n=30) patients seem to believe that situations relevant to their health or illness are not under their control</td>
</tr>
<tr>
<td>2</td>
<td>'powerful others' (n=21) patients seem to perceive that doctors, nurses, spouses and others are relevant for managing their disease</td>
</tr>
<tr>
<td>3</td>
<td>'yeah sayers' (n=35) patients score highly on all three internal, external and fatalistic subscales</td>
</tr>
<tr>
<td>4</td>
<td>'double external' (n=38) patients have very high external expectations relating to powerful others and fate control</td>
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Frick et al’s (2007) findings support the theory that adjustment to cancer can be related to external factors such as medical care, financial stability and social integration alongside internal factors such as coping resources or spirituality supported by other studies (Folkman & Greer 2000, Grulke et al 2005, Farsi 2010).

Research into patients’ coping mechanisms during stem cell transplantation (Coolbrandt & Grypdonck 2010) explores the concept of keeping courage in order to pull through the considerable physical, emotional and psychological demands of their treatment. A distinction between this active strategy and the purveyance of a ‘positive story’ (p218) as opposed to the passive concept of hope is recognised. Patients were found to think only optimistic thoughts believing that a positive attitude may affect the outcome of their treatment (Coolbrandt & Grypdonck 2010). Interestingly, Morstyn (2009), in his personal reflection of stem cell transplant experience describes his feeling of anger towards a nurse’s recommendation to ‘think positive’, an approach also questioned by McGrath et al (2004). Farsi et al (2010) uphold the notion that nurses should actively seek to understand their patients’ coping strategies and also be cognisant as to how these vary according to individuals at different stages of the disease. The authors recommend further research to investigate the effect of religious and cultural orientation in relation to coping with life threatening and challenging situations.
2.21 The paediatric and adolescent experience

This section reviews three studies pertaining to the experiences of children under the age of eighteen and their parents to illustrate some of the psychological issues raised throughout stem cell transplant treatment. Parental experience of family stress during HSCT of paediatric patients is examined by Wu et al (2005). Eleven parents of children under the age of eighteen were interviewed and through content analysis four emergent themes were identified including parental psychological distress, family lifestyle disturbances, parents’ coping patterns and family resources. Though a small study (n=11) the effects on direct family care-givers at the beginning of the transplant process are worthy of consideration in the arena of adult HSCT and the potential effects of carer distress during the recovery phase. Wu et al (2005) highlight the role of the nurse in teaching parents about the potential reactions of their children during the transplant process. Guidance is recommended concerning adjustment and coping of both parent and child with a focus on sharing experiences with other families and health and social care professionals. It is pertinent to consider the cumulative effects of being a care-giver from disease onset, diagnosis, treatment and recovery trajectory since care-giver support is an important factor affecting SCT recipient’s recovery (Bulsara 2004).

The importance of considering both parental and child assessments of quality of life is advocated by Feichtl et al (2010). Longitudinal quality of life data were obtained from sixty-eight paediatric patients-parent dyads prior to and up to two years post-transplant. Findings showed that children typically rated their quality of life as high at all time points and virtually all domains. Quality of life agreement was less aligned where dyads did not speak the same language and concordance was more disparate among female-patient dyads than male-patient dyads.

In a retrospective study of seven adolescents Forinder and Posse (2008) examined data collected from the patient’s medical records pertaining specifically to psychosocial
interventions and their subsequent responses to these. The theoretical frame of reference used was Erikson's (1968) socio-emotional model for psychological development. Erikson (1968) upholds the notion that each phase of a person's development is associated with an inherent crisis to be managed. For adolescents, he argues, it is a conflict between plural identities which need to be untangled. Seeking an identity is considered a basic human need by Erikson (1968) where identity is defined as a subjective experience consisting of three components: biological identity, psychological identity and social identity. Interacting with peers is seen as critical to this development as young people compare themselves to others and endeavour to find social roles and groups compatible to their own biological and psychological make-up.

Literature concerning adolescent development describes a process of psychological emancipation from parental dependence through to independence and adulthood (Erikson 1968, Marcia 1994). The seven adolescents in Forinder & Posse's (2008) study had sought psychotherapeutic support several years after HSCT and were identified as being a particularly vulnerable group. The participants' describe how they are affected by the feeling of being different, suffer isolation from their peers and have an on-going dependence on their parents. The authors suggest that the loneliness and in some cases fear disclosed by these young people could represent a grieving process associated with the limitations imposed by illness and also the loss of an imagined future. Conversely, other studies have demonstrated the positive outcomes experienced by children and adolescents who have suffered from cancer including valuing life in a more positive way, achieving emotional growth, life satisfaction and hope for the future (Meeske et al. 2001, Zebrack & Chesler 2002, Chao et al 2003, Patenaude & Kupst 2005).

It is useful to consider the paediatric and adolescent literature because the experience of paediatric haematopoietic stem cell transplant preceded that in the adult field. Whilst there are specific issues relating to younger people such as a disturbance to identity development,
it can be argued that biographical disruptions caused by illness have a similar effect on adult self perceptions and identity. Valuable knowledge may therefore be transferable across the age groups. Considering this literature is also important because the effects of HSCT on paediatric patients can be long lasting and may inform implications for adults post treatment. Two participants in the current study experienced isolation from their peers during their young adult years and significant uncertainty related to resuming their future plans.

2.22 Summary of chapter

This chapter has reviewed the literature regarding haematopoietic stem cell transplant and the associated physical and psychosocial sequelae both during and following treatment. Some studies adopt a biomedical framework to measure patient’s quality of life at certain time points throughout their journey and form an extremely valuable body of knowledge for understanding the implications for patients of haematological disease and both autologous and allogeneic stem cell transplants. Physical symptoms such as fatigue and susceptibility to infections are common and persist for many months post SCT. In spite of this on-going disruption and challenging side effects such as GVHD patients often report an acceptable quality of life. At the time of commencing the current research relatively few studies explore the patient’s lived experience. Whilst psychosocial issues such as depression, uncertainty, fear of disease recurrence, isolation and financial insecurity have been highlighted exploration of how patients experience returning home following treatment with allogeneic SCT has not been specifically addressed. It is therefore important to elucidate participant responses regarding this transition and their initial recovery journey in order to identify their longer term health and social needs.
CHAPTER 3
Methodology and Methods

3.1 Introduction
This chapter provides a rationale for the methodology chosen for the study. The philosophical and theoretical underpinnings of interpretive phenomenology are presented including its antecedents. Decisions regarding the study design, choice of sample sites, recruitment strategies, participant inclusion and exclusion criteria, data collection and ethical considerations are discussed.

3.2 Study Design
This study is designed to explore the experiences of fifteen adult participants who were treated with allogeneic stem cell transplantation (cells from a donor) for haematological cancer. The focus of the study is concerned with participants’ experiences of returning home following this treatment. Participants were recruited from two major specialist treatment centres and the study followed an interpretive phenomenological methodology using semi-structured interviews on one occasion only between three months and one year post transplantation. Data were then analysed using interpretive phenomenological methodology to gain insights into participants lived experience following the transplant including their personal and social experience of the world following treatment.

3.3 Research Methodology
Interpretative phenomenological analysis (IPA) is a qualitative approach committed to the examination of how people make sense of major life experiences (Smith et al 2009). It is phenomenological because it allows expression of things in their own terms (Husserl in Smith 2009) as opposed to attempting to fit them into predefined categories. Since individual interpretation of an event is both personal and dependent on many contextual factors (Scott 1990), this feels to be a highly appropriate philosophical stance for the current study.
all participants underwent allogeneic stem cell transplant, their diseases varied in type, complexity and onset and their ages and social circumstances varied considerably. A major theoretical axis of interpretative phenomenological analysis is hermeneutics (Smith et al 2009), that is, the theory of interpretation, where both participants and researcher reflect on and make sense of events and experiences. It is argued (Smith et al 2009) that the active thinking involved in this sense making is applied in a self-conscious and systematic fashion in order to reach a deeper level of understanding. The idiopathic nature of IPA recognises the uniqueness of an individuals’ experiences as interpreted by themselves whilst acknowledging the researchers contribution as second order. The term second order is used since the researcher only has access to the participants’ experience through their personal account of it. Thus, IPA can be viewed as a shared process of researcher and participant seeking to shed light on an experience through story telling and active listening.

In the analysis of patient stories, Van Manen (1990) argues that similarities and differences between cases may be explored but only for comprehensive interpretations of individual accounts. The overall aim is not to generalise (Van Manen 1990 p22) as this may distort the uniqueness of the events. Conversely, Smith et al (2009) advocate the study of a homogenous sample so that convergence and divergence can be examined in some detail. Whilst immediate claims are bounded by the group of participants under study Smith et al (2009) support the notion that these may be extended through theoretical generalisability, where the reader of the research is able to consider the evidence in relation to their existing professional and experiential knowledge. As noted earlier, the participants in this study formed a homogenous sample by virtue of their treatment with SCT whilst their experiences, personal characteristics and contexts were unique. It was therefore envisaged that there may be some common themes and others that would be exceptional.
3.4 Antecedents of interpretative phenomenology

As an academic discipline, philosophy is ‘the study of the fundamental nature of knowledge, reality and existence’ (New Oxford Dictionary 2010). In turn, phenomenology forms a broad philosophical movement having at its core, the study of the structure of experience. The prime concern of phenomenology is the systematic reflection on and study of the structures of consciousness Husserl (1970). The technical term ‘intentionality’ is invoked by Husserl (1970) to describe the process occurring in consciousness and the object of attention for that process (Smith et al 2009). Phenomenologists assume human existence is meaningful and interesting as a result of this consciousness and that ‘being’ in the world or embodiment is a concept of acknowledging peoples’ ties with their world (Polit & Hungler 1997). A clear differentiation exists between Husserl’s conception and the Cartesian method of analysis which sees the world as objects, sets of objects and objects acting and reacting upon one another. The Husserlian approach to phenomenology adopts a descriptive stance where the process of bracketing off the outside world and subsequent phenomenological reduction supports the notion of objectivity towards the study subjects. In direct contrast, Heidegger (1954) asserts the importance of man’s capacity to understand himself and the world and thereby introduces the notion of interpretation. This ontological position is responsible for the shift from description to that of social constructivism and IPA is therefore the chosen methodology for this study.

3.5 Embodiment

The concept of embodiment has recently gained focus in a range of human sciences including sociology and qualitative approaches to psychology (Finlay & Langdriddle 2007, Nightingale & Cromby 1999, Burkitt 1999). In sociological terms the concept is useful in developing social constructions of the human condition such as disability and gender issues whilst for psychologists it is critical to understand embodied experiences on an individual level. From a phenomenological perspective, embodiment encapsulates the physical and biologic body at the same time as recognising its inherently individual expressive and
experiential potential (Smith et al 2009). As suggested by Ratner (2000) emotional qualities and expressions are determined by cultural rather than biologic processes. The body is therefore perceived as a vehicle through which individuals actively engage with the world both physically and emotionally (Merleau-Ponty 1962). IPA research has addressed the notion of embodiment in terms of the ailing body and how individuals endeavour to understand their altered bodily state. As articulated by Ainley (1989):

“A person's experience of the world and self are bound up with her/his body...The body anchors the individual in a world of things and other people...A person's ties to her/his body are perhaps made most clear when something about the body goes awry...Most people are aware then - whether they view their bodies as enabling or limiting – of both being and having a body”. (Ainley 1989 pp21-22).

This concept of developing an increased consciousness of the body as a result of illness resonates with the experiences of individuals undergoing haematopoietic stem cell transplantation found in the literature (Morstyn 2009, Stephens 2004, Jones & Chapman 2000). As highlighted in the literature review, participants in Stephen’s (2004) and Jones and Chapman’s (2000) studies underwent autologous stem cell transplants and in Morstyn’s (2009) personal account the type of transplant is not specified.

3.6 Methodological choice

Academic teaching and authors of research methodology promote the notion that research questions should guide decisions about research design and methods (Blaikie 2000, de Vaus 2001, Mason 2002). In a paper addressing the role of the research question in social research, Bryman (2007) poses challenges to this conventional view and how this position pertains to actual research practice. Citing the example of Glaser and Strauss’ (1967) original formulation of grounded theory approach, she acknowledges that research questions are necessarily secondary to the course of this type of investigation. Whilst
advocating the naturalistic paradigm, Kleinman and Kopp (1993) recognise the uncertainty experienced by even experienced fieldworkers when challenged to define their research question at the outset. In such cases, however, the research topic is identified and specific questions emerge as the study progresses. Beyond the methodological debate in its own right exist other tensions and factors influencing the ultimate choice of research design. Included are issues of research credibility or preference in relation to policy gatekeepers, journal referees and editors, chosen audience and funding bodies (Bryman 2007). Likewise, an important consideration is the epistemological beliefs of the researcher and their own strengths and analytical skills. Whilst the author is a relative novice in pure research terms, she is aware of the relatively low value that some critics would attach to the chosen methodology particularly in the hierarchy of research acclaim. However, as advocated by Frank (1995) the importance of listening to patients stories is one which is worthy of renewed focus in the post modern era. Further, the advancement of communication and interpretive skills from a philosophical and ethical viewpoint through the research process itself can only serve to enhance a deeper understanding of the patient’s lived experience.

Phenomenology does not argue for the abolition of traditional science (Benner 1994) but rather for its apposite use. Clearly, where a study does not seek to examine or make sense of the human experience a different approach will be more appropriate, for example, a study researching the efficacy of a novel therapy for malignant conditions demands scientific investigation. As Baron (1985) argues however, accomplishments of traditional science derive their significance from what this means for human beings. Consequently, it could be argued that research conducted with both positivist and social constructivist paradigms may be viewed as complimentary as opposed to diametrically disparate. Scientific knowledge and medical know-how regarding stem cell transplantation (SCT) for haematological malignancy is an experimental and highly technical developing field of medicine. As new treatment regimens are developed and their efficacy tested with traditional positivist scientific methods, it is important that qualitative methods are used simultaneously to
explore the effects that such treatments have on patients' lives. The current study is concerned with participant's lived experience of life-threatening illness, arduous treatments and its long term effects. Consideration of blood cancer as both an acute and chronic illness further recognises the value of medical and social research in gaining a greater knowledge of novel treatments for haematological malignancies alongside developing an enhanced understanding of people's health and social needs.

3.7 Data collection

Data collection is usually through semi-structured interview or can arguably take place with an interview guide rather than formal questions. Since the essence of interpretive phenomenological enquiry is to understand the experience through participants accounts (Smith & Osborne 2007) an opening question could be all that is required supported by probes and affirmations of understanding (Kvale 1996) as the dialogue progresses. The role of the researcher is to check out meanings with the respondents by seeking examples and clarification of their feelings towards the experience. Subsequently adding their perspective and subjective judgement (Polit & Hungler 1991) is considered an important element of the research process. Conversely, this perspective is contended by Jasper (1994) who challenges the skilled researcher adopting a phenomenological approach to avoid contamination of the data in their pursuit of the true lived experience. Proponents of this latter view advocate the descriptive form of phenomenology where the system of bracketing is undertaken so that preconceptions and presuppositions are put aside (Crotty 1996).

The adoption of a detached position where a priori assumptions are suspended has a parallel to the grounded theory methodology of Glaser and Strauss (1967) whereby emerging theory drives the inquiry and emanates directly from the participant. In contrast, however, the phenomenologist centres on eliciting the experience of individuals to identify the phenomenon whereas the grounded theorist seeks to develop the emerging theory using interviews and other data collection methods (Wimpenny & Gass 2000). Whatever the
ontological perspective, the skilled interviewer should be sensitive to the respondent to ensure important data is not missed and be aware when to provide direction such as probing or asking the participant to give an example. As cautioned by Charmaz (1994), however, being too directive and basing questions on assumptions should be avoided. Similarly, a true representation of the interview data is dependent on the integrity of the researcher ensuring important detail is not overlooked in favour of biased selection of material for personal gain.

3.8 The study population

The population for this study are patients who have been treated with allogeneic SCT for haematological malignancy. The participant cohort (see Table 5) were recruited from two major treatment centres in South East England referred to as Centre A and Centre B. Each centre treats approximately one hundred and fifty people with this procedure annually and therefore provided a sufficient number of participants, despite the possibility of attrition during the study for reasons such as ill health, fatigue or death. A sample of up to twenty patients was intended with the final number being fifteen in all. Rationale for choosing the two specialist centres was two-fold. Firstly, each is a designated facility for SCT and secondly, the researcher has professional contacts at both centres and it was anticipated that their support would impact on gaining access to potential participants. Gaining access to institutions for the purpose of research is important since professional gate-keeping has been noted to restrict access for a number of reasons including that of protecting patients and staff groups (Holloway & Wheeler 2002). Conversely however, other studies (Corbin & Morse 2003, Alexander 2010) have demonstrated the willingness of vulnerable patients to participate in research with the potential to benefit others. The therapeutic value of articulating physically and emotionally painful experiences is powerfully described by Kleinman (1998: xiii) subsequently corroborated by researchers in palliative care (Barnett 2001: 158, Dickson-Swift et al 2006: 859, Alexander 2010).
3.9 Sample size

Sandelowski (1995, p180) points out that any hard and fast rules concerning sample size is inappropriate given the inquiry nature of qualitative research, and states that: “A good principle to follow is: An adequate sample size in qualitative research is one that permits - by virtue of not being too large - the deep, case orientated analysis that is the hallmark of all qualitative inquiry, and that results in – by virtue of not being too small - a new and richly textured understanding of experience”. Smith and Osborne (2007 p56) concur with this view and state that ‘there is no right answer to the question of the sample size’ and that it is dependent on factors such as availability and willingness of participants, the richness of the individual cases, the depth of analysis and the constraints of the study’s resources. Rationale for aiming to interview up to twenty participants in this study is based on a number of factors including the likelihood of gleaning sufficient in depth data in order to answer the research questions; time resource to conduct this number of interviews given the geographical location of the specialist centres and participants homes and also the time taken to analyse the data in sufficient depth. Many more experienced researchers postulate their opinions as to sample size in a paper written by Baker & Edwards (2012) supporting the notion that ‘how many qualitative interviews is enough’ is dependent on a range of arguments including those stated for this current study.

3.10 Inclusion and exclusion criteria

Participants in this study had returned home following hospitalisation for allogeneic SCT for between three months and a year. Eligibility was also dependent on the participant being an English speaking adult (or the availability of a translator), aged eighteen or above and with capacity to provide informed consent and to participate in an interview process. Patient exclusion criteria includes those who have any cognitive dysfunction, impairing their ability to provide informed consent or respond to questions. The full inclusion and exclusion criteria are summarised in Figure 1 below:
Figure 1: Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Male or female patients who have undergone allogeneic stem cell transplant for haematological malignancy between 3 months-1 year previously.</td>
</tr>
<tr>
<td>2. Adult patients above the age of eighteen.</td>
</tr>
<tr>
<td>3. Able to understand the participant information provided.</td>
</tr>
<tr>
<td>4. Capacity to provide informed consent and to participate in the interview process.</td>
</tr>
<tr>
<td>5. English speaking or translator available.</td>
</tr>
<tr>
<td>6. Patients have sufficient time to read the information sheet and to ask any questions prior to agreeing to participate.</td>
</tr>
<tr>
<td>7. Patients whose hospital teams and General Practitioner had been informed of their participation in the study and consideration given to any concerns to be raised.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patients who lack capacity.</td>
</tr>
<tr>
<td>2. Patients who were too weak or unwell to participate.</td>
</tr>
</tbody>
</table>

Whilst sixteen patients were interviewed, it transpired that P13 had received an autologous SCT and therefore did not fit the inclusion criteria. His data was therefore excluded from the study.

Methods

3.11 Recruitment of participants

The clinical nurse specialists and the consultant haematologists at each specialist centre were named on the site specific information of the ethical application for the study and were kept informed of its progress. Site visits provided the opportunity to meet members of the team and discussions took place regarding recruitment strategies. Permission to attend the patient support group at Centre B was initially requested in order for the researcher to introduce the idea of the study and potentially recruit participants. However the group had made a decision to exclude external speakers at that time. The clinical nurse specialist sent a flyer explaining the research to all the stem cell transplant patients eligible to take part as she was posting other information to them regarding the support group she led. The Matron
for stem cell transplant at Centre A displayed research flyers at the out-patient clinic and agreed to answer questions on behalf of the researcher. Those who were prepared to participate were requested to inform a member of their clinical team or to contact the researcher directly. Rationale for recruiting potential participants to the study through their clinical teams included the following considerations:

(i) The researcher felt that patients would be reassured by research that was approved by their clinicians.

(ii) That patient’s would feel confident about the credibility and authenticity of the researcher if endorsed by their clinical team.

(iii) That potential participant's would feel better able to decline inclusion following discussion with a third party rather than directly with the researcher.

After several weeks, when this strategy yielded no patient interest, two former haematology consultant colleagues were approached at Centre B to ask if they would promote the study at their SCT follow up clinics which they readily agreed to do. Reminders were sent a day before their clinic at their request along with flyers and participant information sheets. The researcher also made contact with their secretaries in the case of busy schedules preventing information transmission by e-mail. Again, this strategy did not result in patient interest being communicated to the researcher. It was at this point that the researcher requested to attend the out-patient follow up clinics at centre A and following excellent recruitment replicated this strategy at centre B.

Potential patient participants were identified during a pre-clinic multidisciplinary meeting at both hospital sites to which the researcher was invited. The researcher was introduced acknowledging her professional relationship with colleagues in the hospital and wider network which undoubtedly had a positive impact on the researcher’s inclusion within the clinical team. Following the conclusion of the meeting, one of the clinical nurse specialists
volunteered to make introductions to the patients though very quickly this proceeded to the researcher introducing herself due to clinical staff being busy and feeling at ease to do so. The clinic administrative staff were invaluable in identifying the patients in the clinic to the researcher and assisting in communicating what stage they were at in their appointment in order to minimise disruption. The potential participants were approached by the researcher and the purpose of the research explained including the intention to conduct recorded interviews and how long these may last. Initial questions were answered and they were supplied with the participant information sheet (Appendix I) with an arrangement for the researcher to make contact at a mutually convenient time to establish if they were happy to take part. Apart from one gentleman who entered the clinic and expressed his requirement to rest, all of the patients approached agreed to consider participation. Over the subsequent few days follow up calls were made to the potential research subjects and their willingness to participate established. The researcher offered to interview patients on a day that coincided with their clinic appointment or in their own homes depending on their preference. Several potential participants began to tell their story right away which was promising and they were asked to retain their thoughts or to make some notes as an interim measure to inform the interview. Often several calls were necessary due to scheduling of the participant’s clinic and other hospital appointments, health status, work and other commitments which served to enhance an initial relationship and rapport between the participants and the researcher.
Figure 2: Flow Chart of Recruitment Process

1. Potential participants identified during haematology clinic multi-disciplinary meeting

2. Potential participant approached by researcher in the out-patient clinic and the aims of the study are explained

3. Patient expresses willingness to participate and a patient information sheet is supplied

4. Arrangement made for the researcher to contact the patient to establish if they are still willing to participate

5. Interview arranged at the venue convenient to the participant (at the treatment centre to coincide with the participant’s follow-up appointment or in their home)

6. Written consent obtained on the day of the interview
3.12 Table 5: Participant details

Fifteen participants aged between twenty two and sixty eight years who were treated with allogeneic stem cell transplantation were recruited to the study. Eight participants were treated at specialist centre A and seven at specialist treatment centre B. Details of the sample are given in the following table and brief pen portraits of each of the participants can be found in Appendix II.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Specialist Treatment Centre</th>
<th>Marital status</th>
<th>Living Context</th>
<th>Diagnosis</th>
<th>Date of Transplant</th>
<th>Time Since T’plant at Time of Interview</th>
<th>Donor and GVHD Status</th>
<th>Interview Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1*</td>
<td>22</td>
<td>M</td>
<td>A</td>
<td>S</td>
<td>With mother</td>
<td>Hodgkin Lymphoma</td>
<td>29.11.2012</td>
<td>(2ⁿᵈ transplant)</td>
<td>Unrelated donor Gut GVHD May 2013 now resolved</td>
<td>STC A</td>
</tr>
<tr>
<td>2</td>
<td>67</td>
<td>F</td>
<td>A</td>
<td>Ma</td>
<td>With husband</td>
<td>AML</td>
<td>22.08.2012</td>
<td>8 months</td>
<td>Unrelated donor No GVHD</td>
<td>H</td>
</tr>
<tr>
<td>3*</td>
<td>29</td>
<td>F</td>
<td>A</td>
<td>S</td>
<td>On own/boyfriend</td>
<td>AML</td>
<td>June 2012</td>
<td>11 months</td>
<td>Unrelated donor Skin GVHD now resolved</td>
<td>STC A</td>
</tr>
<tr>
<td>4*</td>
<td>59</td>
<td>F</td>
<td>A</td>
<td>Ma on own</td>
<td>With son</td>
<td>ALL</td>
<td>Feb 2013</td>
<td>3 months (2ⁿᵈ transplant)</td>
<td>Sibling donor Chronic GVHD gut and liver</td>
<td>STC A</td>
</tr>
<tr>
<td>5*</td>
<td>24</td>
<td>F</td>
<td>B</td>
<td>S</td>
<td>On own/mother</td>
<td>AA</td>
<td>01.08.2012</td>
<td>9 months</td>
<td>Sibling donor No GVHD</td>
<td>STC B</td>
</tr>
<tr>
<td>6*</td>
<td>63</td>
<td>M</td>
<td>B</td>
<td>Ma</td>
<td>With wife</td>
<td>AML</td>
<td>Feb 2013</td>
<td>3 months</td>
<td>Son donor GVHD</td>
<td>STC B</td>
</tr>
<tr>
<td>7</td>
<td>68</td>
<td>M</td>
<td>A</td>
<td>Ma on own</td>
<td>With wife and 2 adult daughters</td>
<td>AML</td>
<td>August 2012</td>
<td>11 months nearly 12</td>
<td>Cord x 2 Skin GVHD</td>
<td>H</td>
</tr>
<tr>
<td>8*</td>
<td>63</td>
<td>F</td>
<td>B</td>
<td>Ma</td>
<td>With husband</td>
<td>AML (from CML)</td>
<td>17.01.2013</td>
<td>4 months 11days</td>
<td>Unrelated donor GVHD</td>
<td>STC B</td>
</tr>
<tr>
<td>9</td>
<td>68</td>
<td>F</td>
<td>B</td>
<td>W</td>
<td>On own but son in adjoining house</td>
<td>AML (from MDS)</td>
<td>12.07.2012</td>
<td>11 months</td>
<td>Unrelated donor No GVHD</td>
<td>H</td>
</tr>
<tr>
<td>10</td>
<td>62</td>
<td>M</td>
<td>B</td>
<td>Ma</td>
<td>With wife</td>
<td>Myelofibrosis</td>
<td>20.09.2012</td>
<td>8 mths 14 days</td>
<td>Unrelated donor GVHD</td>
<td>STC B</td>
</tr>
<tr>
<td>11*</td>
<td>50</td>
<td>M</td>
<td>B</td>
<td>Ma</td>
<td>With wife and son</td>
<td>Myelodysplastic syndrome</td>
<td>19.02.2013</td>
<td>3 months 18 days</td>
<td>Unrelated donor GVHD</td>
<td>H</td>
</tr>
<tr>
<td>12*</td>
<td>28 or 38</td>
<td>M</td>
<td>A</td>
<td>Ma</td>
<td>With wife and 2 children</td>
<td>Lymphoma peripheral T cell</td>
<td>15.03.2013</td>
<td>3 months</td>
<td>Sibling donor No GVHD</td>
<td>STC A</td>
</tr>
<tr>
<td>14</td>
<td>67</td>
<td>M</td>
<td>A</td>
<td>Ma</td>
<td>With wife</td>
<td>Myelofibrosis</td>
<td>01.11.2012</td>
<td>8 months</td>
<td>Unrelated donor GVHD</td>
<td>STC A</td>
</tr>
<tr>
<td>15*</td>
<td>33</td>
<td>Ma</td>
<td>A</td>
<td>M</td>
<td>With wife and 2 children</td>
<td>ALL</td>
<td>13.12.2012</td>
<td>6 months 21 days</td>
<td>Unrelated donor No GVHD</td>
<td>W</td>
</tr>
<tr>
<td>16*</td>
<td>62</td>
<td>M</td>
<td>B</td>
<td>M</td>
<td>With wife</td>
<td>AML</td>
<td>23.02.2013</td>
<td>7 months</td>
<td>Unrelated donor No GVHD</td>
<td>STC B</td>
</tr>
</tbody>
</table>

**Key:** Gender: M = male, F = female; STC A = specialist treatment centre A, STC B = specialist treatment centre B; Status: Ma = married, S = single, W = widow; Diagnosis: AML = acute myeloid leukaemia, ALL = acute lymphoblastic leukaemia, AA = aplastic anaemia; Interview location: STC A = specialist treatment centre A, STC B = specialist treatment centre B, H = home, W = work
3.13 Narrative interviews

Narrative inquiry aims to elicit the participant’s story, incorporating ‘plots and structures’ (Kvale & Brinkmann 2009) and their interpretation of these through temporal and social frameworks (Mishler 1986). Whilst Mishler (1986) supports the view that narratives are one of the cognitive and linguistic forms through which individuals attempt to organise and express meaning and knowledge, Riessman (2008) alludes to the complex relationship between narrative, time and memory in an individual’s attempt to reify their past and present identity. For an interview to be truly narrative in nature, the interviewer seeks information from the participant in the form of an initial question (Kvale & Brinkmann 2009). Thenceforth, the interviewer will actively listen to the account using verbal and non-verbal signs to encourage the storyteller. It may be necessary to pose an occasional question to seek clarity or further information whilst noting the content, structure and potential tensions and resolutions within the story. If a situation arises where a participant experiences difficulty in telling their story, gentle probing based on the topic guide or non-directional facilitative support is employed (Wengraf 2001). Gordon, (1980 in Sorrell & Redmond 1995) suggests two forms of probing: recapitulation – where the respondent is taken back to the beginning of their story to re-establish their flow of narrative or to add more detail and silence – allowing the interviewee time to gather their thoughts and formulate the next stage of their account. Probing is also an important aspect for the researcher in that it serves to clarify understanding and to resist making assumptions (McConnell-Henry et al 2011).

Questions may include the following:

Could you remind me about how you felt when….?

How did you come to terms with that?

Was there anyone there to support you?

The opening question used for this study was “Could you tell me about your experiences of undergoing a stem cell transplant and in particular about returning home from hospital”. 
Although a topic guide was devised (Appendix III), subsequent questions and probes followed the content and issues raised by the participant’s in their narrative.

The interview was non directive other than the opening question “Can you tell me about your experience of being treated with allogeneic SCT for your blood disorder and what it's been like trying to resume a normal life at home?” supported by probes and affirmations of understanding (Kvale1996). The narrative style of interview enabled the participants to tell their story and to talk about experiences which are important to them in relation to the overall purpose of the study. Whilst the lack of structure poses certain risks, for example, participants veering away from the phenomena being studied, the benefits are a collection of unique accounts borne out of their willingness to reconstruct and attempt to ascribe meaning to their experiences. The validity of such data may be called into question, since participants have a choice what to disclose or not as the case may be and their accounts change over time. However, it is argued by Frank (1995 p22) that there is no such thing as a false account:

“If calling stories true requires some category of stories called false, I confess to being unsure what a ‘false’ personal account would be. I have read personal accounts I considered evasive but that evasion was their truth. The more reconstructed the story the more powerful the truth of the desire for what is being told, as the corrected version of what was lived.”

In accordance with this view, Charmaz (1997 p219) conceives that the telling and retelling of stories by those suffering illness serves to solidify and reify their stance on the event, themselves and their future selves. Observations and field notes accompanied each interview and were reflected upon alongside analysis of the interviews. Following the interviews when points of clinical clarification were required the researcher sought this information from the Clinical Nurse Specialists for example their GVHD status immediately
post SCT (acute GVHD) and at the time of the interview (chronic GVHD) as this could have an impact on their physical and psychological state.

Five participants requested family members to be present during the interview and their contributions are recognised in the analysis. A pilot interview was undertaken involving a volunteer following his experience of head and neck cancer and the challenges he faced during his recovery phase. This served as valuable practice for the researcher of narrative interview technique and familiarity with the electronic recording device.

The interviews took place over a period of six months and each one lasted between thirty five minutes and one hour and fifteen minutes. On initial meeting to conduct the interview, there was a period of preamble including the purpose of the study, consent and general conversation aimed at gaining a rapport and putting the participants at ease.

3.14 Follow up to interviews

At the end of the interview participants were asked if they were willing to be contacted at a later date for the purposes of verification, and clarification of points within their narrative. Initially it was planned that the participants would be supplied with a short summary of the interview transcript and asked to comment on its validity. However after much discussion, deliberation and reading on this strategy a decision was made not to do so. The reasons were both ethically and methodologically motivated. Ethically, the participants interviewed had already given a significant amount of their time to be interviewed during the early stages of their recovery and the researcher did not want to add to this burden. Whilst some authors (Lincoln & Guba 1985, Colaizzi 1978) advocate the process of checking interpretations of data between researchers and participants as a final step in data validation, Giorgi (2006) adopts the view that the use of participants as evaluators of findings is theoretically flawed. He argues that whilst participants describe their experiences from the perspective of a natural attitude, analysis is conducted from the perspective of the phenomenological
attitude. Central to his concerns (Giorgi 2006) are firstly that if precedence is given to the individual undergoing the experience then the rationale for analysis is invalid and secondly that if discrepancy exists between the researcher and the participant, problems arise in determining which perspective takes priority. He therefore proposes a greater trust in subjectivity and the safeguards that the method and phenomenological attitude provide. Whilst this view could imply an imbalance of power between the researcher and the participant Giorgi’s (2006) reference to method and phenomenological attitude are crucial in dispelling this notion. Proponents of interpretive phenomenological method and analysis, Smith and Osborne (2007 p53) argue that whilst IPA is concerned with ‘trying to understand what it is like, from the point of view of the participants, to take their side’, of equal importance is the interrogation of the text and asking critical questions to establish deeper meaning. By combining these two aspects of understanding through empathy and interpretation Smith & Osborne (2007) suggest that the inquiry is likely to achieve a richer analysis at the same time as respecting the totality of the person. In this study, the researcher had the opportunity to check meanings with participants at the time of the interview and witnessed participants making sense of their experiences through their narratives. All participants were invited to contribute further thoughts if they recollected any detail they considered relevant and important during the period of the study, though no further contact was made.

3.15 Demographic and clinical data

Demographic and clinical information was obtained from the participants and access to their medical record was granted if required. The participant’s age, marital and employment status, their underlying disease, date of their SCT and GVHD status are collated in Table 5.
3.16 Ethical Considerations

Ethical approval for the study was obtained following submission to the National Research Ethics Committee, Surrey University Ethics, and the local Research and Development Departments at the two specialist treatment centres in accordance with the NHS Research Governance Framework. The researcher obtained an honorary contract from specialist centres A and B for the duration of the study involving employment checks including occupational health clearance, Criminal Record Bureau checks and references. The chief focus of the occupational health check was to ensure the researcher had no infections which could have posed a risk to the participants. The patients’ general practitioners were notified (Appendix IV) and asked to inform the researcher of any contraindications to their participation, though no concerns were raised.

Each potential participant was comprehensively informed of the aims, methods, anticipated benefits and risks of the research and any discomfort it may entail prior to seeking written consent. Participants were assured that any issues of concern that may be raised would be communicated to their clinical teams or relevant agencies as required and in discussion with them. The procedure for making complaints or raising concerns independently including those concerned directly with the researcher was communicated to all participants with details of who to contact on the participant information sheet.

The primary ethical issue which was considered in relation to the purpose and design of the study concerned the possibility of causing distress to a vulnerable group of people. The researcher was mindful that recollection of events throughout their illness trajectory from disease onset through to chemotherapy, radiotherapy, stem cell transplantation and rehabilitation could potentially be challenging to the participants and require an intervention to alleviate the anxiety caused. A significant number of studies suggest that people treated for cancer including blood cancers fear the recurrence of disease (Stephens 2005, Cesario et al 2010, Williams 2012) and suffer on-going side effects relating to treatments in addition
to facing a slow and debilitating recovery (Sherman et al 2005). Since participants were recruited between three months and a year post SCT it was envisaged they would still be experiencing the physical, psychological and emotional effects of their harsh treatment regimes and be in the stage of relatively early recovery. Conversely however, studies have demonstrated that whilst telling stories of illness can be painful, it may be a unique opportunity to share the emotional burden of such experiences and to endeavour to make sense of them as well as providing an opportunity to help somebody (Alexander 2010). In accordance with this view Frank (1995) advocates listening to illness stories as a fundamental moral act, a duty and as such refers to a post-modern requirement for an ‘ethic of listening’ (Frank 1995 p 25).

The most important strategy put in place to mitigate distress is the researcher’s sensitivity in recognising verbal and non-verbal signs of distress and in being prepared to discontinue the interview in such circumstances. The participant’s specialist teams were aware of the research and details of the study were communicated to their general practitioners in order that any concerns could be raised by the participants or by the researcher on their behalf. The participant information sheet stated that the researcher could make referrals for professional support should this be required. Two participants were visibly distressed during the interview. One young gentleman signalled for the recording to be stopped temporarily and apologised for being upset. However, he was subsequently keen to resume despite reassurances that he should not continue if he felt uncomfortable to do so. He had made notes about the areas he wanted to cover in the interview in the days leading up to meeting and it was suggested that these could be used rather than continuing but he was earnest in his desire to continue. A second gentleman had experienced significant health challenges in the week before the scheduled interview and had to cancel it once. Despite this, he also was insistent on fulfilling his commitment to share his experiences.
As Kvale & Brinkmann (2009 p 74) note, ‘morally responsible research behaviour is more than abstract ethical knowledge and cognitive choices; it involves the moral integrity of the researcher, his or her sensitivity and commitment to moral issues and action’. Field notes were kept relating to each interview in order to learn from each what went well and not so well including contextual factors such as how the participant appeared in terms of their health and general demeanour. The researcher’s years of nursing experience were of value in making these physical and psychological assessments and in respecting each individual’s circumstances. Environmental factors such as securing a comfortable venue for the interviews or arranging to visit the participant at their home were also important factors.

3.17 Consent

Participants were asked to sign a consent form and advised again that they could withdraw at any time without giving a reason nor affecting their future care (Appendix V). Verbal consent was repeated at the beginning of the taped interview. The participant information sheet stated that the research would not result in a direct benefit to them but that it could help others undergoing SCT in the future.

3.18 Confidentiality

The participants were assured that all data would be treated as confidential unless it was disclosed that they or another person was at risk of serious harm. The electronic recordings and interview transcripts were kept securely in a locked place when not being used solely by the researcher for the purpose of analysis.

3.19 Anonymity

The participants were assured that their interviews would not be related to their personal identity nor discussed with anyone other than anonymised versions being discussed with the researcher’s academic supervisors prior to dissemination of the findings to themselves, presentation at conferences and publication in an academic journal.
3.20 Potential risks and learning for the researcher

There is a possibility that the researcher may be affected by the narratives told by the participants or if she feels that they have been adversely affected by the process. Reflecting on the interviews including reference to the transcript and field notes helped to further refine the art of effective listening and genuine solicitude. Sharing data excerpts with academic supervisors also helped to point to instances where a leading question was asked or an opportunity to probe missed. A second issue for the researcher concerned interviews conducted in the participant’s home. The principles outlined in the Hospital Trust and University of Surrey Lone Worker Policies were applied to ensure safety in entering an unknown environment and informing a colleague or family member of her whereabouts.

3.21 Data Analysis

The researcher made the decision to transcribe the interviews herself for several reasons. Firstly to gain familiarity and subsequent in depth knowledge of each participant’s interview by repeated listening which was ensured due to the slow speed of typing relative to the spoken word. Secondly, in order to pick up any nuances such as silences, pauses, laughter, repetition of certain words and tone as advocated by McLellan et al (2003) which may otherwise have been overlooked and finally because this formed the first stage of data analysis. Whilst developing a heightened consciousness of both content and context, the process of transcription can also be viewed as a function of reflexivity, uncovering more detail and thereby increasing the depth of understanding (McLellan et al 2003).

Transcribing the interviews without involving a third party also supported the ethical principles of confidentiality of the data, though the possibility of doing so was built into the ethics application for the study in the event of constraints on time resources. Although the researcher undertook training in the software package NVIVO on two separate occasions,
and the transcripts uploaded, capabilities within other more familiar programmes proved to be sufficient for the organisation of data.

In order to enhance the depth and quality of the data analysis three approaches were considered valuable. Thematic analysis of the interview transcriptions was conducted using the procedural steps outlined by Colaizzi (1978) and Smith et al (2009) as a guide. Rationale for this method is twofold. Firstly that a logical procedure is followed so that all interviews are subjected to the same steps to identify statements and significant phenomena which could then be drawn together across all participant data. Secondly, adopting interpretive phenomenological analysis recognises and accepts that a researcher’s previous knowledge and experience are included as part of the analysis (Colaizzi 1978, Crist & Tanner 2003, Smith 2009).

1. Read all of the participants descriptions of their experiences to acquire an overall feeling for them
2. Return to each transcript and extract phrases or sentences that directly pertain to the investigated phenomena, that is, extract significant statements. Acknowledge common themes and condense responses by eliminating repetition.
3. Formulate meanings from the significant statements. The result should be closely connected to the original accounts whilst illuminating meanings hidden in the various contexts and horizons of the investigated phenomenon.
4. Repeat step three for each transcript and organise the aggregate formulated meanings into clusters of themes. Refer these back to the original transcripts to validate them.
5. Integrate the results into an exhaustive description of the investigated topic.
6. Formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible.

7. A final validating step may be achieved by returning to the participants.

Adapted from Colaizzi’s procedural steps in Valle & King 1978

3.22 Reading the participants descriptions of their experiences

As mentioned earlier, the participant interviews were listened to in detail whilst being transcribed verbatim. Following each interview notes were made contemporaneously and whilst these included demographic data, the venue and context of the meeting, an initial overall sense of meaning was ascribed (see Pen Portraits Appendix III). During the process of the initial line by line analysis, comments and themes were annotated in the margin of each interview transcript (Appendix VI). On subsequent readings preliminary interpretations of the data were also noted and summarised in table format (Appendix VII). The box below shows an example of one of the participant transcripts with preliminary themes identified:

<table>
<thead>
<tr>
<th>Themes: physical manifestations, identity and self-image</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I was really puffed out and my arms were like sausages. I was quite a keen gym goer before I went in (to hospital) ‘cos I wanted to be really fit and I was going in three times a week doing weights and cardio and its just all gone (laughs), you know it’s like being the ten stone weakling on the beach again.” (P11)</td>
</tr>
<tr>
<td>“You don’t even want to watch TV because you compare yourself with the people who are well and you think look at me, I’ve blown up and I’ve got no hair and I’m not the way I should be.” (P1)</td>
</tr>
</tbody>
</table>
Theme: facing own mortality and therefore feeling grateful for any hope regarding treatment options.

“I feel quite lucky ‘cos you know, on the 1st January the doctors in Brighton essentially said game over, you know, you’ve had this seizure so if it’s in your spine or central nervous system … nothing’s going to happen, we won’t be doing the transplant.” (P12)

This process was performed for each interview and a further table designed to represent some of the cross cutting themes (Appendix VIII). At each stage of the analysis the preliminary findings were discussed with academic supervisors and excerpts of the data shared to promote consistency of interpretations. When these differed, in depth discussions ensued allowing possible construals of meaning to be considered. This process was invaluable in achieving consensus with the researcher being able to lend context to the narrative and the academic supervisors to challenge unintentional but none the less potential bias and preconceptions to influence the interpretation. An example of such discussion related to the researchers interpretation of a number of participants appearing positive about their experiences. Whilst there were data to support their adoption of this attitude it was perhaps more of a conscious strategy to deal with experiences which were on many occasions overwhelming. It is important therefore that the researcher’s interpretations were questioned and that a deeper level of understanding achieved. In this way the researcher acts as a resource to make sense of the data thereby increasing the reliability of the findings. As Hammersley and Atkinson (2007) state:

“This requires the exercise of some analytic nerve, tolerating uncertainty and ambiguity in one’s interpretations and resisting the temptation to rush to determinate conclusions” (Hammersley and Atkinson 2007 p163)
Since the foundations of the analysis lies deep within the data, re-visiting and re-checking interpretations with the original data is an important and repetitive process as the findings emerge.

### 3.23 Extracting Significant Statements

A process was followed for each interview transcript which involved extracting significant statements (Appendix IX). This differed from the line by line analysis because it allowed for larger pieces of text to be examined. In a number of interviews these statements were repeated but in a slightly different way allowing the researcher to discover events which were particularly significant for the participant or that they appeared to be making sense of.

An example of this related to the theme of uncertainty which had already emerged in one form or another in all the participant’s narratives. The example shown in the box below catalogues significant statements relating to the uncertainty about whether a second stem cell transplant had been successful for a particular lady.

---

**Significant statements relating to uncertainty about disease recurrence:**

“If I have a pain, I think oh, is that the leukaemia back as soon as I get sort of over tired like I have been recently, I immediately think it’s back, you know” (P4)

“I’m still at the stage where I’m waiting for it to come back and I think I’ve got to really sort of get over that. The doctor said today my blood levels are fine. There’s one or two things that are slightly out of kilter but they’re not worried so, so I think it’s, it is good because I trust them” (P4)

---

A subsequent method of analysis advocated the viewing of data through four lenses McCormack (2000a, 2000b) including language, narrative processes, context and significant moments in order to uncover different aspects of understanding resulting in a contextually rich interpretation. An explanation of the lenses is outlined below:
(i) The lens of language guides the researcher to focus on the specific words used by participants in the telling of their unique story.

(ii) The lens of narrative process focuses on the structure and pattern of words used. Noting a hesitant, disjointed use of words may suggest a different meaning than an easier, flowing account and enables the researcher to sense emotions and meaning attached to what is being discussed.

(iii) The lens of context acknowledges the individual’s understanding of how their experience is influenced by the context in which the experience takes place. In this study, contextual factors include the researchers understanding of the aggressive treatments undertaken by the participants through clinical experience and review of the literature.

(iv) The lens of moments refers to a new understanding of an event or experience captured through the process of storytelling.

Whilst this process was rigorously applied to several interview transcripts thenceforth the overarching principles were applied in a more general way as the researcher became familiar with the analytical method. For example, a heightened awareness of language and the structure of the narratives such as the repetition of certain events and feelings led to an enhanced understanding of the participant’s experience. A male participant who experienced significant physical challenges stated that he was not depressed “just hugely pissed off” which revealed his strength of feeling but his language also characterises a masculine tendency to display anger rather than distress.

Furthermore, increased attentiveness and sensitivity to the participant’s discursive style enabled a deeper level of analysis of the data and the meaning attached to it. McCormack’s (2000a) lens of significant moments refers to a person’s new understanding of an event or experience, also referred to as an epiphany captured through the process of storytelling.
whilst Colaizzi’s (1978) collection of significant statements implies interpretation by the researcher. The researcher’s experience was that both processes occurred, that is, during participant’s story telling when it was evident that they gained new understanding and again as the researcher analysed these statements in the context of the whole narrative.

The use of metaphor has also been suggested as an effective vehicle both to communicate and present human experience (Wiklund 2010). Their use may originate from the participants within their narrative (Jairath 1999) or be applied by researchers (Kangas, Warren & Byrne 1998, Wiklund 2010). Since metaphors were apparent in the language of participants in studies reviewed in the literature the use of such an approach was considered appropriate if they arose in the current study. According to Lakoff and Johnson (2003) Western philosophy and language is often inadequate in expressing the meaning of everyday realities and argue that the use of metaphor plays a critical role in purveying meaning and understanding of our stories:

“Metaphor is for most people a device of the poetic imagination.... a matter of the extraordinary rather than ordinary language.” (p3 Lakoff and Johnson 2003)

Participants in the current study used metaphors such as ‘in limbo’ or ‘having no satnav’ to describe the uncertainty they felt about their recovery experience and these are discussed further in the findings. One of the participants used the following metaphor to illustrate how he felt about being told that he could go home revealing the enormity of how this felt to him:

“you’re being given a key that unlocks certain doors back to your normal life but not fully understanding the consequences of being left to stand on your own two feet after such a journey. It’s a huge, huge thing”.

83
3.24 Rigour

Whilst quantitative research is dependent on the reliability and validity of the instrument (Polit & Hungler 1997) qualitative research is judged in terms of trustworthiness, transferability, transparency and depth of analysis to uphold its rigour. Van Manen (1990 p22) argues against generalisation as an aim of phenomenological research in favour of capturing the uniqueness of the individual and associated events. However, Van Manen (1990) also cautions against reflection on such events whereas Conroy (2003) advocates the incorporation of Heideggerian (1954) philosophy into an interpretive phenomenological research design. Qualitative methodology involving such an interpretive naturalistic approach to its subject matter is considered by Denzin & Lincoln (1994) to be more valid and less reliable than quantitative methods. Establishing rigour in both methodological congruence and in the interview process is one of the principle tenets of phenomenological inquiry (Wimpenny & Gass 2000). Kvale & Brinkmann (2009) promote the concept of interviewing as a craft whereby the interviewer becomes skilled with practice and is subsequently able to apply educated judgements to inform the data collection process. This contrasts with the positivist approach advocating formulaic ‘rule-governed’ methods (Kvale & Brinkmann 2009). Burns (1989) outlines the requirements for procedural rigour in qualitative research consistent with Glaser & Strauss’ (1967) view that the researcher should describe the social world with such vividness that you could almost believe you were there.

3.25 Researcher credibility

Researcher credibility (Patton 1990) as the data collecting instrument and analytic agent is dependent on their knowledge, qualifications, skills and experience. Any connection to the topic and the participants should also be transparent as recommended by Koch (1994) outlining how a decision trail can assist the reader to regard the interview in its wider context. All of these factors are important in establishing confidence in the data (Polit & Hungler 1997 p306) and are incorporated into the final thesis and related publications. The researcher’s professional role at the time of undertaking this study was largely a managerial
one and also the area of specialism relatively new. This has distinct advantages in that
knowledge in the field was gained through working in the area and by what was learnt from
the participants throughout the duration of the study as opposed to having any preconceived
ideas or views. This position of naivety in relation to the speciality reduced the risk of bias
and any associated conflict of interest pertaining to clinical and managerial matters.

3.26 Trust in narrative inquiry

As mentioned earlier the researcher gained access to patients through a network of
professional colleagues. It is hoped that patients were reassured regarding the authenticity
of the researcher since the study was approved by their clinical team. Establishing a
relationship of trust with participants throughout the inquiry is critical (Cartwright & Limandri
1997, Polit and Beck 2004), particularly when emotive topics may be discussed (Speziale &
Carpenter 2003). The researcher remained cognisant of her responsibility to protect the best
interests of participants and to consider the needs of those who may be more vulnerable, for
example, those with a limited social support network, advanced age and compromised
functional or psychological status (Castledine 2003). The concept of trust has implications
for the nature and quality of information participants are willing to disclose and the
researcher made every effort to ensure that their shared experiences were valued. Certain
characteristics are advocated for the investigator such as reliability, the ability to inspire
confidence and consistency (Meize-Grochowski 1984), empathetic understanding
(Cartwright & Limandri 1984) and the ability to work in partnership with participants (Shuster
1984). The initial face to face contact and thereafter by telephone or text message
communication between the researcher and the participants led to a shared familiarity, trust
and respect.

3.27 Reflexivity

The role of reflexivity in qualitative methodologies is highly significant (Dowling 2006)
refuting the belief that distance between researcher and participant is paramount. Whilst
some authors promote its value in sustaining objectivity in phenomenological methods (Koch & Harrington 1998), others acknowledge the participatory nature of narrative research whereby reflexivity embraces a reciprocal process of interpretation between researcher and the researched (Fontana 2004). From an epistemological standpoint reflexivity encourages a critical appraisal of the research design and methods in conjunction with the investigators reflections on their prior assumptions about how knowledge and truth are acquired. In philosophical hermeneutics Gadamer (1989) asserts that predispositions are an essential component of interpretation and should be recognised accordingly (Pascoe 1996). A number of strategies were employed to support the authenticity and trustworthiness of the interpreted data. As mentioned earlier, the researcher kept field notes to record nuances and impressions from the narratives directly after the interviews were completed to support the subsequent interpretation and analysis. A research log was maintained to record the researcher's reflections on the interview process and to maintain a decision trail thereby ensuring transparency of the research process and the analysis.

3.28 Confirmability
Confirmability refers to the neutrality or objectivity of the data achieved through an agreement between two or more independent people about the relevance and meaning of the data (Polit & Hungler 1997). In this study, the researcher’s academic supervisors worked collaboratively with the researcher in the analysis and interpretation of the data.

3.29 Transferability and implications for practice
Lincoln & Guba (1985) utilise the term transferability to denote the applicability of the data to other contexts. The clarity of the research design and sampling will influence this in combination with the thick or rich description provided by the investigator. Whilst critics of phenomenology argue that gaining insights into the lived experiences of the participants does not result in practice change, as highlighted in the literature review Jones & Chapman
(2000) claim that recommendations to change and support practice were accepted on the basis of their phenomenological inquiry.

3.30 Dissemination and reporting

Preliminary findings from this study have been shared with a group of Doctoral students and academic staff and a poster was presented at the post-graduate conference in February 2014 at the University of Surrey. An abstract was accepted for an oral presentation at the British Sociological Association conference in September 2014. Following a travel scholarship awarded by the European Bone Marrow Transplant European Bone Marrow Transplant (United Kingdom) Nurses and Allied Professions Group in 2009 to attend the annual conference, presentation at a subsequent European Bone Marrow Transplant meeting has been invited. A paper has been submitted to the Journal of Advanced Nursing. Appropriate methods of dissemination to the patient groups and staff at both specialist treatment centres will be discussed with the clinical teams on completion of the thesis.

3.31 Summary of chapter

This chapter has offered a rationale for the chosen methodology of interpretive phenomenology in order to investigate participant’s experiences of returning home following allogeneic stem cell transplant. Since interpretive phenomenological methodology is based on an acceptance that the researcher is able to consider the evidence in relation to their existing professional and experiential knowledge, it is not value free. IPA acknowledges the human contribution to the process which would not be acceptable to researchers favouring a positivist paradigm. In order to gain a greater insight and understanding of what patients go through and what life holds following SCT it is important to explore the issues directly from the patient’s perspective. The study methods and the procedural steps followed for analytical purposes have been outlined and the emergent themes will be discussed in the findings chapter.
CHAPTER 4

Data Analysis and Findings

4.1 Introduction

The purpose of the following chapter is to present the findings from the study in accordance with interpretive phenomenological method (Munhall 2012, Smith 2009). The two overarching concepts which emerged from the data are: The Immediacy of Illness and Existential Crisis and The Recovery Journey. Arriving at this conceptual stance was a lengthy and complex process of analysis, moving backwards and forwards between the data and what was emerging. The aim was to narrow the scope of enquiry to the most significant convergent characteristics of the participant’s experiences, whilst endeavouring to preserve some of their unique features. As mentioned in the previous chapter, the early themes were assembled in a series of mind-mapping diagrams and tables (Appendices VII & VIII). Revisiting the data and looking for relationships between the emerging themes and sub-themes was an iterative - inductive process (Ezzy 2002). Excerpts from participant narratives are used to illustrate the themes with data extracts denoted in speech marks and italic and the participant number in brackets, for example participant 1 is (P1). Where a spouse or parent were present and contributed to the interview the participant to whom they relate is entered into the brackets with a W for wife, an H for husband and M for mother for example the wife of participant 14 would be shown as (P14W). Words or statements specifically emphasised by participants are shown in bold type within the data extracts. References are made to the literature to support the findings, some of which originated from the primary literature review and others introduced as themes from the data emerged and further reading took place.

4.2 The Immediacy of Illness and Existential Crisis

This overarching concept illustrates the immediacy of illness and existential crisis experienced by the participants in relation to disease onset, diagnosis, treatment and
continuing into recovery. The sudden or insidious onset of haematological malignancy throws the participant’s lives into an existential crisis in both an immediate and enduring sense. Challenges include their literal fight for survival through uncompromising chemotherapy and radiotherapy treatments with stem cell transplantation as the only remaining option available to them to treat aggressive or relapsing disease. The participant’s experiences have resonance with Bury’s suggestion that “illness and especially chronic illness is the kind of experience where structures of everyday life and the forms of knowledge that underpin them are disrupted” and that “chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death which are normally only seen as distant possibilities or the plight of others” (Bury 1982 p169). The immediacy of illness and existential crisis includes themes of: critical events and uncertainty (Table 6).

Table 6: Themes and subthemes of the immediacy of illness and existential crisis

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical Events</td>
<td>Onset of illness and diagnosis</td>
</tr>
<tr>
<td></td>
<td>Disease and treatment effects</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>Safe in the bubble and being left to stand on your own two feet</td>
</tr>
<tr>
<td></td>
<td>Progress isn’t linear, waiting for it to come back</td>
</tr>
<tr>
<td></td>
<td>I can never relax: the emotional strain of caring</td>
</tr>
<tr>
<td></td>
<td>Left to fight and fend and work it out for yourself: financial issues</td>
</tr>
</tbody>
</table>

4.3 Critical Events

The illness journey is characterised by critical events resulting from the underlying disease and the effects of treatments including impaired immunity, damage to vital organs and the possibility of stem cell rejection. Systemic infections and in some cases reaction to trial chemotherapeutic agents pose life threatening risks with the pre-transplant conditioning therapy being one of the most physically and mentally challenging. This section will follow the participants chronologically through these stages commencing with their diagnosis.
4.3.1 Onset of illness and diagnosis

Several participants described how feelings of tiredness and weakness (p 11, p14 and p16) and symptoms suggestive of viral illness (p12, p14, p16) precipitated their decision to seek medical help. Participants 3, 12, 14 and 16 acknowledge the speed of events following their diagnosis and the experience of participant sixteen, a sixty three year old man, employed on a full time basis until his illness serves to illustrate this point. Both this gentleman and his wife were increasingly concerned about symptoms such as “pains in his stomach, incredible night sweats and the fact that he was getting weaker and weaker and sleeping constantly and stopping breathing.” Initially told that they he could see a doctor “in a fortnight” prompted his wife to “row with the receptionists” in order to have her concerns taken seriously and expedite an emergency appointment. Her concerns were well founded as she describes below:

“They actually told my husband when he was brought into the hospital he had a fortnight, it was that close. I mean we just about got him out of the car into the hospital before he collapsed, it was that bad.” (P16W)

In this data extract the patient’s wife is describing how close to death her husband was before he was admitted to hospital where he was confirmed to have acute myeloid leukaemia. At the specialist treatment centre, developments progressed rapidly as demonstrated in his wife’s explanation of the situation and his affirmation (in brackets) in the following quote:

“It was like being thrown into a cement mixer and wondering what was going to come out at the other end (it was just a haze really, yea, so much going on P16).” (P16W)

The “cement mixer” analogy portrays a sense of the complete disruption that was occurring with little conception of what was going to happen at the other end of treatment. Participant
twelve, a thirty-eight year old gentleman described the shock of learning that he had a
diagnosis of peripheral T cell lymphoma having experienced several weeks of respiratory
symptoms prior to his GP organising investigations at the hospital:

“It was a bit of a shock, I wasn’t expecting it at all. I’d had trouble breathing and
sweats, like a virus and then they called me next day and I thought right, well that’s not
good and I thought it was because of the chest x-ray, probably because of the
wheezing, I couldn’t properly inflate my lungs I was thinking this is like lung cancer or
something like that but then they took me away to the quiet room as they do and sort
of mentioned it but it was kind of like a whole new world it’s not something I was, blood
cancers isn’t anything I know anything about” (P12)

Though he had not anticipated a serious cause for his symptoms, assuming he had a virus,
his suspicions were aroused when he was called back to the hospital urgently following
diagnostic investigations. The immediacy of the life and death situation and the complete
uncertainty was an overwhelming experience. Not only was the diagnosis a surprise but the
nature of the disease itself was not one which was familiar to him. Since haematological
malignancies are relatively rare it is not surprising that lay knowledge is sparse in
comparison to the more common forms of cancers. The urgency of this call alerts him to
contemplate a more sinister explanation for his condition coupled with the severity of his
pain and breathing difficulties. Reaching a conclusion that something is seriously wrong
suggests that he is processing external cues at the same time as beginning to interpret
changes in his altered bodily state. These interpretations signal his heightened awareness
and resonate with the notion of embodied intelligence as described by Benner (1994) and
the primacy of embodiment proposed by Merleau-Ponty (2002). His lack of awareness
about blood cancers is apparent in his articulation “a whole new world” encapsulating the
notion of entering the world of the sick (Bury 1982, Mishler 1994, Frank 1995). Participant
four was similarly shocked to learn of her diagnosis of acute lymphoblastic leukaemia:
“I was actually in denial at first. I mean I even told the consultant that he’d got it wrong. I said people in my family don’t get things like this, I think you’re wrong. Bless him, he just smiled nicely at me and said, no I think I’m right.” (P4)

In searching for the meaning of illness events, there is evidence that patients consider possible causes for disease incidence including familial transmission (Bury 1982 p 174). This particular lady articulates disbelief at her diagnosis because there is no family history of “things like this”.

For the participants treated with supportive therapies for myelodysplastic disorders (P11 and P 14) there is a period of a less critical nature following diagnosis as symptoms are treated and plans for eventual SCT are made. The young lady with aplastic anaemia (P5) is also treated conservatively though she suffered a critical event five months after diagnosis when she contracted a klebsiella bacterial infection and required life support. Serious complications of avascular necrosis and osteomyelitis rendered her severely debilitated and at risk of amputation of her arm and leg. Participants diagnosed with leukaemia and lymphoma had several months of chemotherapy or a combination of chemotherapy and radiotherapy prior to their SCT. Describing their experiences of chemotherapy and radiotherapy leading up to SCT, participants liken the time spent in a protective isolation facility as feeling like a ‘caged animal’ (P15) or “serving a prison sentence” (P11 and P15). Participant fifteen found these times particularly frustrating, “when you’re feeling mentally ok, it just drags” and kept a calendar to cross out the days until he was able to come out of isolation. The temporal aspects to which this gentleman refers accord with the ‘treatment calendar’ as portrayed by Schou & Hewison (1999 p49) over which he has little control and which conflicts with his personal and life calendar enforcing a sudden disruption to his day to
day life.

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2 Avascular necrosis is a condition whereby a compromised blood supply results in the death of bone tissue and there is evidence to show that it can occur as a result of high dose methylprednisolone therapy used in the treatment of aplastic anaemia (Marsh 1993).
day plans. Conversely, for participant twelve, a thirty eight year old gentleman whose hospitalisation at the point of diagnosis and initial treatment lasted several weeks, the period in isolation during the transplant experience appeared to be less daunting.

“I’d been in hospital in Brighton for seven weeks at the start, then I knew that however long I was in here was for less time than that, so it was doable, I know that I’d done worse do you know what I mean, it was almost like training” (P12)

Knowing that he had managed a long period of time in hospital at the time of diagnosis helped him to prepare mentally for the challenges ahead coupled with the chances of achieving disease remission from undergoing the SCT.

4.3.2 Disease and treatment effects

Despite relatively mild physical effects during the initial two cycles of chemotherapy, which he described as “being in limbo” participant six acknowledges the rapid deterioration of his physical condition during the time of his pre-transplant conditioning. He questions whether his “vegetative state” was due to tiredness relating to both the treatment and the fact that he suffered heart failure caused by the chemotherapy or if this was a psychological reaction to his circumstances. He appeared to feel more comfortable with the former explanation. His experience of being in hospital, characterised by his use of the metaphor “being in limbo” is evocative of the concept of liminality identified by Turner (1969) and encountered by cancer patients as evidenced in a number of studies (Little et al 1998 McKenzie 2004, Thompson 2007, Cayless et al 2010). Turner (1969 p 97) uses the concept of liminality to explain the process of transition between roles and positions in society where the liminal phase is viewed as particularly ambiguous ‘betwixt and between structural classification’. In the context of illness, Molzahn et al (2008 p15) suggests that ‘liminality refers to the ambiguous experience of one’s life story being interrupted by illness’. For this gentleman being “in limbo” relates to the time in hospital receiving his initial chemotherapy where the implications
of illness and uncertain outcomes are realised. A number of the participants describe the conditioning phase of the transplant experience as being particularly distressing and the inherent risk to survival is also evident. As participant sixteen explains:

“I had my transplant in February but before that I had to have the conditioning chemotherapy and I found that the worst ... it affected me most, I was getting infections, also I had a problem with very low blood pressure which nearly put me into intensive care.” (P16)

It appears that this gentleman suffered a critical event as a result of infection and effect on his blood pressure caused by the conditioning therapy and that he narrowly escaped an episode of intensive care. Similarly, participant nine, a sixty eight year old lady, eleven months post SCT for acute myeloid leukaemia recalls:

“And I landed up with one platelet! God knows how I survived. They’re now a hundred and sixty-six, whoopee! Put the flags out! I mean ok, I laugh about it but it was... I’m going to say this, you probably won’t put it in but I was knocking on death’s door...the professor said to me it’s going to be like nothing you’ve had before. I know you’ve had three lots of chemo, he said and in different stages it’s got stronger and stronger, but this one is the ultimate. He said you can never have any more. He said if this comes back I’m afraid it’s curtains.” (P9)

Whilst this lady appears to speak fairly light-heartedly about her experience, it was obviously one which carried very real and potentially life threatening consequences illustrated by her reference to “knocking on death’s door”. Furthermore, the professor’s sobering advice that if the “ultimate” treatment failed it would be “curtains”. The fact that she feels able to laugh about it now suggests her relief to have survived or perhaps the use of humour was a deliberate strategy to underplay the seriousness of the situation. Fox (1979) suggests that
humour is a key strategy to mask the stress that uncertainty brings. Participant eleven’s powerful description of conditioning therapy and SCT is articulated in the following data extract:

“you’ve had the core of your body killed and brought back to life again and you can’t just shrug that off and bounce back” (P11)

This gentleman’s description of “the core of your body being killed” and being “brought back to life again” correlates with findings in Potrata et al’s (2010) study aimed at understanding distress and distressing experiences in patients living with multiple myeloma. Potrata et al (2010 p127) found that the conditioning phase of allogeneic stem cell transplant was particularly stressful and considered a ‘violation to the body’, where several participants associated chemotherapy and specifically the conditioning chemotherapy with the beginning of death. This temporary state of ‘death’ ceased when the stem cells were infused and there was evidence of successful engraftment. Though not specifically referring to any one part of the SCT process another participant in the current study affirmed “you’ve had a huge bang to your body” and “you’ve been stripped down from your whole”. Whilst other participants in the current study refer to distressing symptoms at this time, the majority also focus on the life giving qualities of the stem cell treatment. This view is both significant and poignant for participant four who had already had a SCT and explained how she felt about undertaking a second one:

“in a way it was easier because I knew what to expect with the transplant, having been through it before but also it was harder because I knew what to expect” (P4)

She described having different side effects with both lots of chemotherapy treatments in that pain was a feature the first time and diarrhoea the second which though “terrible” was dealt with well, “you only have to say, you know this hurts or I’m really feeling sick and they look
after you”. Clearly, prompt alleviation of unpleasant symptoms relieved the situation and as she explained the “reassurance” she received likewise reduced her anxiety. At the time of our meeting this lady was feeling concerned about a possible relapse of her acute lymphoblastic leukaemia. In the face of this, though the transplant experiences in their totality had not been pleasant, she expressed a preference for the opportunity to receive more treatment in order to increase her chances of survival:

“they told me I couldn’t have another transplant now because I’ve had two and I think it’s my age and whatever, but if someone said to me ‘well we can give you another transplant you know, it’s come back but you can have another one’, I wouldn’t think twice, you know,…it wasn’t a terrible experience, you know, by any means.” (P4)

These sentiments contrast significantly with a participant with disease relapse in Potrata et al’s (2010) study who felt that she could not face the experience of a second SCT. Potrata et al’s (2010) findings however, concord with the sentiments of participant eleven who stated:

“I went in there sort of you know quite roughty toughty and well muscled and weighing about thirteen stone and it really kicked my arse… if I’d been another twenty years older and known what I know now, I bloody wouldn’t have it. I’d go with transfusions.” (P11)

The strength of his language “I bloody wouldn’t have it” reflects his emotional response to how challenging the experience has been for him and that he would certainly not be keen to contemplate a second SCT. Two participants described critical events leading to a significant period of time in intensive care. Participant seven required life support due to a chemotherapy related infection prior to his transplant. The critical nature of his experience and his feelings of confusion due to lack of memory regarding how or why he was there are exemplified in the data extract below:
“That was a nightmare when I was in Intensive Care, really. I’ve got a vision, I’ve got memories of being aware that I was somewhere, I didn’t know why I was there, I didn’t know where I was. All I knew was I couldn’t move. Was I a prisoner, you know I just didn’t know, my mind was going round in circles and it was horrible, you know it was awful. All I could see was strange people walking past that I didn’t know. I could hear people talking occasionally but it was, well, I just couldn’t make out what was going on and it was frightening to me, because my mind was working normally in a sense, but I just couldn’t work out what was happening at all.” (P7)

Memories remain vivid for this participant and he emphasises the magnitude, duration and effect that the confusion had on him. The incident clearly caused him much distress evident by the strength of feeling articulated in his narrative and his lasting memory of the experience as illustrated further in his words:

“I just didn’t know what was going on and my mind was playing awful tricks on me and well at least I felt it was, it must’ve been because I just didn’t know what to think at the time and it was awful and I can’t forget that, you know, it is still stuck in my memory... it took me about five days to find out what had happened” (P7)

The immediate effect of being provided with an explanation and making sense of the situation however was perceived by this participant to improve his mental attitude immediately:

“once I knew what had happened to me, I was actually a lot happier, because, I was just so confused, so confused, so confused it was awful but anyway once I knew what had happened to me I was, it made life a lot simpler and everything and I concentrated on getting better” (P7)
The experience related by participant seven almost a year post transplant illustrates the speed at which life threatening infections can occur and also the profound and lasting effect of the distress he felt. Similarly participant eight, a sixty three year old lady treated for leukaemia recollects the time when she was “rushed” to intensive care following an acute reaction to a trial drug:

“I was on a trial and they gave me really strong chemo and it caused monocytes in the skin, they were attached to my skin, they were attached to my lungs and gut and everything and when the chemo...worked, all that came away and it just left all my lungs and gut and everything and I just bled out, so I was rushed to Intensive Care and they had to put me on a life support machine and I was on that for three weeks.” (P8)

Her recollections remain vivid as she went on to explain:

“...and in my stupid mind I was trapped. I mean my husband said to me, you had tubes everywhere and I couldn’t move. I was just on my back .. and I could hear this music and I could hear, very far away, people talking. And I thought, I’m a prisoner, somebody’s keeping me prisoner and I don’t know why they’re keeping me prisoner ‘cos I haven’t got anything (laughs), you know, as if I’d been kidnapped and I could hear this music and I thought, I’m in Austria, because I kept hearing Strauss’s waltzes” (P8)

It is clear that both participants had a consciousness of their experience. Participant eight subsequently learnt that music was played twenty-four hours a day in the intensive care unit and accounted for her accurate memory of hearing Austrian music. She even remembers thinking that everyone must be having a good time “dancing in the square”. She was only
four months post transplant and she describes how “flashbacks” of this experience affected her during a subsequent admission to her local hospital. She had lost a lot of weight and was being fed by naso-gastric tube. She describes waking up in the night gasping for breath and likens this to the feeling of being trapped whilst in intensive care. She alludes to the reassurance given to her by the night nurses and also her determination to overcome the feeling of panic as shown in the following data extract:

“but after a few days I got through that... I'm a very logical person. I argue with myself. I say you’ve got to stop this. Get on with it. Face it.” (P8)

For both participant seven and eight, it appears that they can apply logic when they are able to make sense of their experiences. It is interesting that they appear to take a tough line with themselves, "you’ve got to stop this. Get on with it” despite the extremely traumatic events they have been through. Conversely, an inability to interpret their situation adequately during their time in intensive care engendered fear and confusion. Similarly, in Parker’s (in Clanidin & Connelly 1999) study of patients’ recollections of their intensive care experience, participants reported a diminished ability to discern dreams and hallucinations from reality. They too told of feeling like a prisoner where their bodies had lost the capacity to move through paralysis, weakness and the constraint of tubes and life supporting equipment. Attempts to communicate were thwarted by respiratory apparatus for participants in both studies in addition to substitutes such as writing or touch being impaired. However, participants reported their awareness of and comfort derived from hearing the familiar voices of loved ones. This was clearly a critical moment in this lady’s treatment and the duration of time spent on life support emphasising the extreme seriousness of the event. Despite the alarming disruption to her body this lady repeatedly spoke about how lucky she felt to receive the treatment and felt more concerned for her close family as shown in the following data extract:
“it obviously affects your life but I think the awful thing is that it affects your loved ones, because my husband and my son and my daughter-in-law really went through it, seeing me the way I was, I mean they say, no don’t be silly, but it makes you feel guilty because you feel that you can cope with it for yourself. I don’t know if other people feel the same, I feel guilty that I’ve ruined their lives...they’re really hurting, they’re really suffering” (P8)

The emotional aspect of the suffering affecting the whole family is evident here particularly her suggestion that she had “ruined their lives” and caused them to suffer. In addition to critical events relating to chemotherapy treatments, two participants experienced atypical and unique complications resulting in further disruption to their physical being. Participant twelve, married with two small children, suffered both a brain seizure between treatments for his lymphoma, compromising his chances of progressing to SCT and also a perforated bowel. The latter was thought to be related to the effect of steroids on a previously weakened area of the lining of the bowel and happened when he was in a neutropenic state following chemotherapy. As he explains:

“I ended up having bowel taken out as well. I had raging lymphoma and they were doing a fairly major operation and when it happened I was neutropenic so they had to wait and once they’d done it the lymphoma came back very quickly so there was this battle about, so well we want to give him treatment, we want to give him steroids and steroids plus healing bowel is not a good combination” (P12)

The careful timing and titration of treatments for conditions with competing requirements and priorities is palpable. From his diagnosis onwards this gentleman suffered a series of life threatening complications and the “battle” he alludes to over what course of action to take in addition to the “raging lymphoma” would inevitably have added to his anxiety. However, the calm attitude displayed by this gentleman as he told his story belied the enormity of what he
had experienced and was perhaps explained by the very fact that he had survived. In his words:

“I've actually felt very lucky to be..., there’s been plenty of times when I’ve wondered if I'll see the end of the football season.” (P12)

Similarly, participant fifteen, a thirty three year old gentleman with acute lymphoblastic leukaemia experienced an extremely rare complication. Despite being treated aggressively with both chemotherapy and radiotherapy, he developed a tumour on his optic nerve:

“I was on chemotherapy and I developed really bad headaches but it was a headache that was all day, all night, every minute, every hour of the day...they were giving me pain killers which didn’t even touch the sides. After about seven to ten days the consultants were doing the rounds and I just had my head under the blanket and I said I can't see and I couldn’t read text messages on my ‘phone anymore, the room went a bit hazy and then I woke up another day and I couldn’t see anything” (P15)

This participant was newly married in the same year that his illness became apparent. He had two small children and after years of working in larger companies had recently set up his own business. The enormous disruption this situation had on his entire family was evident from his narrative. Coming to terms with his underlying diagnosis and subsequently facing possible loss of his sight was clearly an event of inordinate magnitude. He explained that when he was seen by a specialist ophthalmologist, she acknowledged that in her many years in the speciality, she had never seen nor treated a case such as his. Not only was it unusual to experience disease relapse whilst still being treated with chemotherapy but the tumour itself was particularly uncommon. Threatened with the loss of sight in both eyes, his stunned reaction is evident in the following narrative extract:
“but I’ve got two young children and I can’t see anything, I can’t see and I could just hear her talking and she said I think you’ll never be able see again and I was sat with a nurse ‘cos the nurse had to walk me to my ward because I couldn’t see where I was going and I was just thinking, I just couldn’t get my head round it.” (P15)

Whilst the shock of this news and all its implications was difficult to absorb, his immediate thoughts involved not being able to see his children. Not only was this a critical event in this gentleman’s treatment phase but held devastating consequences for his future. As he explained however, after several scans he started targeted radiotherapy to the optic nerve the following day which resulted in a successful outcome:

“the next day I woke up and I could see but only like 10% but I could start to make shapes and over about four or five days it, I came back and I got complete eyesight again.” (P15)

It is worthy of note that the experience of the actual SCT was an anti-climax for the participants directly contrasting with that of the conditioning treatment. The following data extract is testimony to the way several of them viewed the experience:

“Then it was the big day... and I had twenty minutes on one bag (of stem cells) and then twenty minutes on the next bag and they said ‘that’s it, you’re all done’ and you sort of look round, am I in any pain, nothing’s you know, what do you mean, they said that’s it, done and I couldn’t believe it” (P15)

This young man expresses surprise that the experience was different to that which he anticipated imagining the SCT to be a more invasive procedure than it actually is. As mentioned previously, participant four had been treated with a second STC and her
acknowledgement that the cells were literally life giving and her gratitude are evident as she explains:

“one of the things that really shocked me was when I had the transplant, when they actually brought in those stem cells and they treated them sooo carefully as if they were so precious and I thought gosh they really are precious, this is sort of my chance at life...and they treated the whole situation like that and it was quite humbling really. It was really quite a shock for me, it wasn’t just an everyday thing, you know it was really important” (P4)

This lady’s articulation and repetition of how “precious” the stem cells are and how “humbling” the experience felt emphasises the importance of this event, “it wasn’t just an everyday thing”. Overall, it seems that whilst the physical experience of receiving the stem cells was relatively straightforward for the recipients who articulated it, the personal meaning ascribed to it is one of significant magnitude and potentially life changing. In reality, however, many of the participants’ post-transplant experiences illustrate that having a new “chance at life” is not as easy as these words of hope might suggest.

This section has presented the first of the two themes, ‘critical events at diagnosis’ and ‘critical events related to disease and treatment effects’ under the overarching concept of ‘The immediacy of illness and existential crisis’. The second of the themes, ‘uncertainty’ will now be presented.

4.4 Uncertainty

4.4.1 Safe in the bubble and being left to stand on your own two feet

This section focuses on the uncertainty described by participants commencing with their transition from hospital to home, the immediate post transplant period and for others in a more enduring sense. The majority of participants relayed their experiences of leaving the
safety of the hospital to returning home and how it felt. The sense of uncertainty experienced by the participants was particularly acute when they were ready to go home. Some felt psychologically unprepared for making this transition. These feelings are captured in the opening statement of participant three’s narrative:

“I think the first reaction I guess was oh no, I’m leaving hospital, what’s going to happen, because you’re in a very safe environment and as soon as you leave that environment you start to worry, you know any little thing, you check your temperature a few times a day just to make sure because although you really don’t want to go back into hospital, that’s the primary concern.” (P3)

This young lady’s feeling of uncertainty “what’s going to happen” appears to contrast significantly with the feeling of safety within the hospital environment. Nevertheless, she alludes to worrying about little things and checking her temperature “a few times a day” suggesting an increased level of vigilance regarding bodily changes. Her “primary concern” however, is to avoid returning to hospital at all costs. In accordance with this view, participant four refers to the safety of the hospital both in terms of being cared for but also sheltered from life in the outside world.

“It was (pause) all the time I was in hospital actually, it was like you are protected from everything else. Even if I wanted to do something for people at home I couldn’t because I was, you know in some ways it was really nice because I was protected and I was being looked after, you know, I was safe in this bubble, but I also felt a little bit trapped, I couldn’t do things that I wanted to do, you know, try and sort things out at home but it was very nice in some ways, I did feel very protected and very safe” (P4)

Whilst she appreciates feeling “protected...looked after” and “safe in this bubble” these emotions are countered with a sense of duty to “sort things out at home” and result in her
feeling “a little bit trapped”. In the context of her narrative, this dichotomy appears to centre principally on the enormous responsibility she feels towards caring for her mother with dementia and her son with mental health illness versus her own needs in illness and the rare privilege of being cared for herself, “I was being looked after.” Emphasis on the word I and her repetition of how “nice” that felt illustrate this point. Participant sixteen similarly refers to the relative safety of the hospital environment:

“I felt myself very vulnerable. Under the protection of the hospital you feel relatively safe but once you’re put out into the big open world and our local hospital is about half an hour’s drive away I suppose so if anything went wrong, I’d have to be rushed to hospital, so I did feel vulnerable, and I did think that something would go wrong because they, they’d told me many times that I could get infections, high temperature, diarrhoea loads of different things that would be quite serious” (P16)

This gentleman’s prime concern appears to rest on his feeling of vulnerability, “that something would go wrong” and in the event of needing to be “rushed to hospital” the time that this would take. These worries stem from advice that has been given to him “many times” and relate to a multitude of possible complications preparing him for this likelihood. The following extract from participant one’s story illustrates comparable feelings of anxiety and uncertainty about leaving hospital:

“when they tell you to go, that you’re ready to go home you need that psychological support, as soon as they said that your counts have gone up and they tell you that you’re ready to go you get that almost overwhelming feeling inside that you can’t wait to leave the hospital and you almost wonder whether it’s staying in one place all the time that makes you feel weak or if it’s still the treatment that’s kicking in, you’re still not sure, as soon as they tell you you can go home where do I start from there? That’s, a huge, huge thing and being by yourself and being told that, sometimes you
can take those things for granted that you’re being given a key that unlocks certain doors back to your normal life but not fully understanding the consequences of being left to stand on your own two feet after such a … journey.” (P1)

However, for this gentleman it is the “overwhelming” sense of anticipation about going home coupled with feeling weak and not knowing ‘where to start’ psychologically that make the transition difficult to contemplate. When he says he was told by clinicians that “your counts have gone up” and that he is “ready to go”, it is the physiological parameters of his blood test results informing this decision to which he refers. The disparity between the physiological and psychological reality is tangible and powerfully expressed. Whilst acknowledging metaphorically that he is being given a “key that unlocks certain doors back to your normal life” he nonetheless conveys the uncertainty and insecurity he feels. In his work the Wounded Storyteller (Frank 1995 p18) testifies to the importance of people telling stories of illness in order to give voice to an experience that medicine cannot. Reading the professional literature after having cancer himself compounded his belief that the language used failed to describe the immediacy of the embodied suffering he had recently experienced. This notion has a significant resonance with the experience articulated by participant one where the simplicity of the declaration that he is ready to go home, particularly as he was alone when this occurred, totally underestimates the enormity of its implications for him “after such a journey”. These findings concord with Jones and Chapman (2000) where a participant similarly described her emotional turmoil on being discharged home:

“I think it was the fear of facing life again after what you’d been through, because one minute you think you’re so near death and then you’re forced back into society.”

(Jones & Chapman 2000 p157)
“All the instructions, so many things”: the worry about taking responsibility

Participant sixteen comments on the weight of responsibility he felt when he returned home and the uncertainty as to whether he was following instructions correctly:

“I suppose a mental aspect of it was slight paranoia to start with. I just thought, is that an infection, in goes the thermometer. Have I done that right have I done this right. When I’d left hospital it was then my responsibility to keep myself you know within that bubble of you know all the instructions that they gave me when I left hospital and of course you tend to take things by the letter” (P16)

The use of the word “paranoia” suggests the strain he felt regarding self-monitoring his condition and the interpretation of symptoms. Also how diligent he was in following the instructions he was given to the letter. In accordance with this participant’s experience, participant one describes similar feelings as follows:

“Obviously there are infections but here there are many things, it could be GVHD, could be infection, you could have different variables of, different types of medication that you need to go and take, whether you’re taking too much or whether your body’s not absorbing it, or if it’s how severe your GVHD is in your gut or on your skin, anything. There’s so many more things, so many warning signs and on top of that you have to worry about the disease as well.” (P1)

At seven months post SCT he appears to feel overwhelmed by the number of complications requiring his vigilance in addition to being alert for signs of disease relapse. He was suffering both peripheral and systemic effects of graft versus host disease at the time of the interview and mentioned feeling nauseated that morning. Since his gastro-intestinal tract was involved it is understandable that he was also concerned about the absorption of his
medications. Whilst the majority of participants talked about the uncertainty and fear of disease recurrence and other complications post SCT participant three was an exception. Apart from her increased vigilance in monitoring her temperature when she initially returned home she focused on regaining her physical strength. This lady was one of the younger participants and described herself as physically fit prior to developing leukaemia. She had managed to return to work and resume many of her normal activities, albeit in a limited or less strenuous sense than before her illness. In view of this progress and having almost reached one year post SCT her anxieties may well have diminished in comparison with some of the other participants.

4.4.2 Progress isn’t linear, waiting for it to come back

Once the participants return home, challenges associated with a more chronic state become evident with the threat of acute events ever present. As stated by participant six, a sixty three year old gentleman three months post stem cell transplant for leukaemia:

“I’ve been warned by lots of people that progress isn’t linear with this and it’s not, so going through, you think everything’s well not ok because there’s something wrong, but that you’re going in the right direction and then you have a setback, you get a bit lower, then it picks up again, so you pop up and down the change curve several times.” (P6)

Similarly, other participants in this study report fluctuating physical and psychological effects throughout their illness, treatment and post treatment phases which are not necessarily related to the disease itself. Though temporarily reassured by acceptable blood test results, in many cases doubts prevail that this situation may be short-lived due to the possibility of stem cell rejection and disease relapse in addition to longer term side effects and the continued risk of infection. The experiences related by the participants are testimony to the reality of their anxieties resulting in an on-going state of uncertainty for themselves and their families. This reality is exemplified in the following narrative extract from participant one, a
twenty-two year old young man with Hodgkin’s Lymphoma whose initial autologous stem cell transplant failed to combat his disease:

“I went through the first three months and the scan was clear, thank God. Then I started to get symptoms about a month and a half after and I started to panic. I started to get worried and certain diseases, they don’t show through the blood, especially Hodgkins, and the other signs would be sweating, lumps, feeling itchy and there’s only so much that bloods can do and even the chimerism³ within the bloods to say how much is yours and how much is the donor.” (P1)

In his account, this young man clearly faces grave concerns regarding the recurrence of disease related symptoms. Despite the initial clear scan and the normal reliance on blood tests used to monitor disease remission, he is acutely aware of the ubiquitous nature of Hodgkin’s Lymphoma. Undoubtedly, his previous experience of a failed stem cell transplant compounds his anxiety. He goes on to articulate an understandable need for his concerns to be believed and taken seriously following his second donor transplant:

“it’s so good to be rest assured, and to have confidence in the patient that if something is not right at least to order an alternative scan or a CT scan or something or I don’t know. My disease had been acting very, very funny and to go and say ‘oh you can’t be, you look well, you look fine’. If I relied on that then there would be no need to have any scans would there? And I know they cost alot of money, for the NHS to go through all of this but ... I need to be rest assured for their sake as well because it’s easier, it’s good to have the disease under control and know what exactly what is happening with the disease rather than ‘we don’t need one, you look fine, your bloods are fine’.” (P1)

³ “Chimaera”: creature from Greek mythology whose body is made of parts from different animals. In allogeneic transplantation chimerism is normally used to describe the status of donor marrow in the patient i.e. how large a percentage of blood cells constitute that of donor and recipient.
It would appear that the nature of his disease and the outcome of his stem cell transplant are such that he is unable to feel reassured that all is well. He infers that health care professionals are telling him that he ‘is fine’ based on his blood test results and his appearance as opposed to a diagnostic scan to confirm that his disease is ‘under control’. He feels that the cost is justified both to mitigate this uncertainty and to effectively monitor and manage disease relapse. Uncertainty illness theory (Mishel 1981) supports the concept that when illness events such as diagnosis, symptoms, treatments and prognoses are ambiguous, they are unable to be cognitively categorised adequately and uncertainty ensues. Being listened to and the subsequent reassurance and trust built out of this cannot be underestimated and is demonstrated below:

“He (the doctor) made sure that he was going to do one (a PET scan) because he knows the prognosis of your disease and know how everything goes and it’s to rule out any complications, anything. And that is very, very important. Very important. And he did do that and everything was fine and I couldn’t thank him enough because I have trust in him and he listened to me, he didn’t ignore it and that’s also important the doctors do not ignore even the smallest of things, the small things can turn into something big.” (P1)

His relief that the doctor appeared to share his view that further investigations were required to ‘rule out complications’ is apparent and he reiterates the point several times in his account of events at this time. It appears that he can no longer trust in his body and needs evidence from various investigations to reassure him. In accordance with this young man’s apprehension, participant fourteen stated simply “it’s hard to understand what’s going on in your body”. Similarly, in their study of twenty adult survivors of autologous bone marrow transplantation Cohen and Ley (2000) found that patient’s fears were associated with loss of
both physical control and trust in their body. Participant one also alludes to his mother’s anxiety and the need for understanding. For example:

“the worst thing is especially when your mother is there and she’s worried because you know, having a child whose unwell and knowing the disease can come back, ‘oh she’s anxious, she’s an anxious mother, you know, don’t listen to her’. It’s not the case all the time. I don’t like that, I’ve absolutely hated the judgement of that. It makes me feel as if I’m almost paranoid, that I’m getting almost too much into it.” (P1)

In the context of his whole narrative, this participant stressed the weight of responsibility he felt for managing his recovery including recognition of potential problems and also the importance of having the unerring support of his mother. Understandably, diminution or disrespect of their roles perceived as labelling them as anxious is challenging to accept, particularly in the light of such an uncertain future.

“because it’s one thing that ‘oh you’re anxious, you’re over thinking, you’re new to this, it’s only been three months and you’re already thinking about this and getting too much into it.’ How about, how about if I’m not getting too much into it. What about if there really is something there?” (P1)

Participant one’s description of his need to be heard reveals how he felt that not all doctors or nurses were taking his and his mother’s concerns seriously, rendering them powerless, silenced and in turmoil. Frank’s (1995) notion of the chaos story has particular relevance here. His argument centres on the need for clinical staff to develop an enhanced tolerance for chaos as part of a person’s illness or life story rather than attempting to assuage it. This requires the professionals to share the burden of uncertainty by listening and resisting the temptation to control it. In terms of self protection and survival, qualities such as realism and vigilance are advocated by Ehrenreich (2010) and therefore support an attitude of alertness.
as expressed by this young man. Participant nine similarly reports a worry with regard to the
difficulty of recognising if anything is wrong:

“If that’s what’s happening with my body, I don’t know what’s happening in there, you
know, it’s not really telling me and now they’ve found this thing to do with the liver, and
I’m more worried about that.” (P9)

This participant feels uncertainty about the implications of a blood test when she
experiences no physical signs or symptoms:

“she said (the nurse) that yes, the counts are pretty high on your liver and that’s what
they’re worried about, but she said it is curable so she said, don’t worry about it. She
said don’t get all panicky and upset about it and I said no, I’ve got over that bit now.
You know, I went for a long walk and sort of sorted it out in my head and I think that’s
the only way I can do it, go for a long walk.” (P9)

On first meeting this lady at the specialist treatment centre she had been told that her there
were some concerns about her liver and she expressed her own apprehension at that time.
In this example, it appears that the nurse at her local hospital is suggesting she controls her
emotions “don’t get all panicky and upset about it” and whilst her attempt to reassure “it is
curable” were undoubtedly well meant, could in the circumstances have been somewhat
premature. As this lady explained, she needed to find her own way of sorting it out in her
head by going for “a long walk” suggesting the psychological toll this worry is having on her.
She went on to explain:

“I’ve got no husband to talk things over with. In actual fact I’ve got no one so, you
know, it all goes through my head all the time. You know, oh God, what’s going to
happen if I get worse than I am now, who’s going to look after me?” (P9)
It appears that her worry is intensified and going through her head “all the time” because since she lost her husband she has no-one to talk things over with. She also expresses uncertainty and fear about her future and wonders how she will cope if she gets worse. A significant part of her narrative was concerned with her difficult relationship with her grown up children and also the fact that neither could offer any help to her in the future as she said:

“I’ve got a boy and a girl, and they both said oh well when you get past it Mum you’ll have to go in a home, we’re not looking after you. And I thought, well thank you, thank you very much” (P9)

When asked how this made her feel she replied, “it gives me an awful feeling, I feel, a real dark feeling within myself”. Anxious to maintain her independence, this lady fears any future further deterioration in her health which would threaten this, as she said “ooh heck, what am I gonna do then?” Her existential worries and concerns suggest a need for more support and reassurance at the time of meeting with her as well as in the future. Having suffered a seizure during the course of his treatment for T cell Lymphoma, participant twelve alludes to his on-going investigations in relation to suspected involvement of his central nervous system. The following quotes demonstrate the uncertainty experienced with elements of self-reassurance and hope as mentioned earlier:

“actually I think I’ve got off pretty lightly I think in the great scheme of things. I haven’t, touch wood, I haven’t had any complications or anything. My scans came back from a few weeks ago that were, appeared to be clear although I’m having another one today so that seems to be pretty good hopefully…” (P12)

Having said that he has “got off pretty lightly” seems to be a considerable understatement in the context of significant life threatening situations he faced at the beginning of his treatment
which in itself was not guaranteed in view of the highly aggressive nature of his disease. The use and emphasis on the word “appeared” suggests that this young man is not convinced that he can rely on the latest scan results endorsed by the fact that a more specialised scan has been ordered for him. He articulates his doubts further in the following quote:

“I’m slightly suspicious about why I’m having this scan today, I did know deep down I’m having a scan on my brain because neither a standard PET or MRI gives them the kind of comfort that they want over what’s going on in my brain, neither of them are quite clear enough. This particular type of choline PET scan gives them better clarity. I know that. Then you’re sort of thinking have they seen a shadow on a previous scan or something, you know, you can talk yourself into it, so I’m sure when I see them next week and if they say yes, your scan came back and it was fine I’ll just walk along a bit taller, do you know what I mean?” (P12)

This excerpt suggests that he is weighing up whether or not he is being told the truth about his previous scan and the rationale for performing another one. On the one hand he can understand the doctor’s need for assurance given that he has suffered a seizure and that initially this was thought to be linked with his malignancy. On the other, he toys with the idea that there may be something suspicious on the first scan after all. Again, like several other participants he seems to perceive his concerns as rather tenuous, whilst his attitude appears to be both reasonable and shrewd. Despite this, he does admit to the fact that he will feel relieved to be in receipt of a clear scan. His reference to being able to “walk a bit taller” also suggests that this will have a positive effect on his self concept and underscores the effect that illness and uncertainty can have on one’s identity (Charmaz 1997). Reflecting on the uncertainty he has felt since his SCT he explained:

“‖I imagine it’s the same as when you’ve had a heart attack or anything is, is I don’t have the luxury to have twinges or aches and pains..if I feel something in my head I
think ooh is it coming back in my head...if I feel a twinge in my stomach I don't just think I might have had a dodgy prawn sandwich or something you think ooh is this lymphoma or something like that, but I haven't had any of the big signs that I had initially which is like night sweats and fevers and that kind of thing, so, it isn't but it's hard to er, it's only time actually heals that er, I'm a great believer you know. The first couple of weeks after my seizure, anything I was just like ooh, is it another one coming, you know?” (P12)

Participant twelve’s experiences demonstrate his heightened awareness of any bodily symptoms such as “twinges or aches and pains” that could indicate that all is not well in his body. His continued concerns are that any physical symptom must be related to the original lymphoma disease. Whilst the fear maybe unfounded, it is never the less real and given the multitude of possible side effects or potential relapse is highly significant. He does however acknowledge that these worries are lessened by the degree of symptoms and the passage of time. Participant four had been treated with two SCTs due to recurrence of her acute lymphoblastic leukaemia and following her return home explains her prevailing uncertainty regarding potential disease relapse:

“I’m still at the stage where I’m waiting for it to come back and I think I’ve got to really sort of get over that because the doctor said today my blood levels are fine. There’s one or two things that are slightly out of kilter but they’re not worried so I think it’s good because I trust them and they don’t mislead you so you feel very safe in a way that they’re not going to tell you one thing and then you know, a surprise is going to pop up” (P4)

At just three months after the most recent SCT this lady describes herself as “still at the stage” of waiting for her disease to return. Her narrative followed a consultation in the out-patient’s clinic and she reflects back on what has been said. Here the focus is on her blood
results and whilst “one or two things are slightly out of kilter”, she appears reassured by the doctor’s assertion that her “blood levels are fine”. The notion of trust is important in helping her to feel safe. She also alludes to pain and her fear that this may be linked with “your leukaemia or the medication or the transplant” and describes this as “quite a scary thing really”. She went on to assert:

“I am in remission, and I have to keep telling myself that, I have to keep telling myself that. I am in remission, I don’t have active leukaemia cells at the moment and so that’s something I need to really hold onto really, sort of, you know, keep telling myself that, so I almost feel like I’ve got to stop thinking about ‘what ifs’ and you know, maybe and just work with that” (P4)

Her repetition of being “in remission” and that she has to ‘keep telling herself that’ suggest the effort it is taking her to adequately convince herself that her disease is under control. In a study (Baker et al 2005) involving participants who had been diagnosed with one of the ten most prevalent cancers, 68% continued to fear recurrence more than one year after treatment was completed. Similarly, in a study of forty-three women with a diagnosis of ovarian cancer at some time in their lives Cesario et al (2010 p615) found that the ‘Damocles Sword’ of ovarian cancer seems to be the constant threat of recurrence and subsequent health deterioration or death. Similarly, participant fourteen questions whether he is clear of disease declaring an ever present “element of doubt”:

“Yea... there’s always that element of doubt as to whether they’ve got it all. They keep saying oh your blood counts are great but you know your lymphocytes... If we get rid of that ‘but’ we’d be a 100% you know” (P14)

This gentleman’s comments infer that whilst being assured by the doctors on the one hand that your “blood counts are great” another level of clinical uncertainty exists in relation to his
lymphocytes and “whether they’ve got it all”. An exceptional case is participant three who did not allude to any fear of disease recurrence and for participant two who stated:

“You get confidence from the, just the time really...six months seemed to be quite a critical time. I think you know after that I think I started to feel more positive and able to do more.”

This example suggests that survival time since the SCT is an all-important marker of recovery progress and consequent reduction in existential uncertainty.

4.4.3 I can never relax: the emotional strain of caring

The husband of participant eight echoes the sentiment of uncertainty illustrating the strain felt by care-givers regarding his wife’s on-going symptoms though refutes the notion that these feelings can be dispelled in the near future as shown in the examples below:

“I can never relax, I can never feel good about things, even if there’s good news, I don’t feel like it is good news. The doctors say oh, everything’s going well, but as far as I’m concerned it’s only going well today, up to this point, tomorrow it could change, and so I’m just on my guard all the time.” (P8H)

These words illustrate his reasoning that he is only able to live for today and takes no comfort in good news as everything can change tomorrow. His reference to being on his “guard all the time” suggests the degree of strain he is experiencing. In the following data extract he expresses his concern about how quickly an infection can take hold and become life threatening:

“I make sure she’s done the temperature and if she gets up in the night, I’m awake, I can hear her, I’m alert for her all the time, you know, because they say that it can
come on so quickly. Your temperature can go from normal to forty within such a short
time and that’s at danger point and they said be alert, because people that aren’t
alert don’t wake up in the morning.” (P8H)

The emotional burden felt by participant eight’s husband is evident. Because he has been
warned how quickly an infection can develop he is constantly “alert for her” which
undoubtedly interrupts his sleep too. He goes onto describe such an experience when his
wife’s temperature was very high but she “felt fine” which adds another dimension of worry
when symptoms which should be acted upon may be ignored:

“That really worries me at the moment, that’s why I was checking the temperature and
it was thirty nine point nine and I thought wow, you know and she felt fine, oh, I’ll be
alright, you know, but we can’t take the chance, so you know normal things that your
body would normally fight off wouldn’t it, you know, I’ve got a bit of a bit of a sore
throat there, that’s ok, be gone in the morning, could be disastrous for her” (P8H).

This gentleman was acutely aware of the risks associated with stem cell rejection, disease
relapse and infection, taking his responsibility to act quickly extremely seriously. Given the
life threatening complications during his wife’s treatment when he had been warned on
several occasions that she may not survive are compounded by on-going health concerns
and uncertainty. In addition to the above concerns he is witness to many physical changes
and disturbances to his wife’s bodily state and questions what these might mean:

“Why’s her nose running all the time? Why’s she blowing blood out of her nose, you
know, this type of thing, is she breathless? Is she clearing her throat? The hearing’s
gone a bit hasn’t it? Your eyes have gone a bit, deteriorated, your teeth, all your fillings
in your teeth, they’re hurting... now her nails all cracked off and became brittle.” (P8H)
These signs and symptoms are diverse and hard to comprehend and it is difficult for him to know how to react. As he continued:

“then I saw this rash coming back and this big black bruise came up so I said well have you knocked it, no I haven't knocked it, well why's it come up then, why's that, is it blood problems?” (P8H)

As experienced by other participants, it is unclear as to the specific cause of participant 8’s signs and symptoms but she did have GVHD which would account for the skin rash. It is likely that her platelet count was still low accounting for her bruising and it appears that her husband feared this was an indication of on-going “blood problems”. He went on to explain that whilst some complications are outlined in the transplant information booklet others are not which causes more worry, particularly when experienced at home.

4.4.4 You're left to fight and fend and try and work it out for yourself: financial issues

The following quote from participant four demonstrates the worry she experiences through lack of agency as a result of an uncertain prognosis following her second SCT:

“they didn’t actually say they couldn’t hold my job any longer but they did things like employ someone on a long term contract to cover my class (pause) because there was no clear prognosis, and I realise now they can't give you a clear prognosis, so I took early retirement on medical grounds but of course, then my income dropped so dramatically and you can’t pay your mortgage and things like that. So it's things like that that have made coming home more difficult. I think that’s why in hospital, in my little bubble, I didn’t think about the horrors of the financial thing but when you come out and suddenly you’re faced with all these things to have to try and sort out and because you can’t give a definite, you know, well, I'm in remission and everything’s
going to be alright now, you can’t sort of really organise things properly so, it’s just difficult, it is difficult." (P4)

Her account clearly portrays the difficulties of coming home and facing the realities of a “dramatically” reduced income and inability to pay the mortgage and how these factors have added to her distress. Again this lady alludes to the protective environment she experienced in hospital “my little bubble” compared with “the horrors of the financial things” and the immediacy with which things need sorting on return home. Although she refers to her remission state and that “everything’s going to be alright now” it appears that her concerns are compounded by the uncertainty of her prognosis, “you can’t give a definite...” suggesting that remission itself is a fragile and uncertain position to be in. She goes on to articulate the seriousness of the threat to her home and her anxieties in relation to her son who is unable to work due to mental illness:

“I think I may lose the house. I’ve written to the mortgage company again, I’ve used all my savings now to keep paying the mortgage, but of course, my son with his situation, because he is depressed, he doesn’t work and if anything happens to me he’s going to be homeless, so that’s a huge issue for me and you know I just think people don’t realise the impact, not just on your health, that leukaemia has such an effect on those around you, you know, so that’s still ongoing and I’m still trying to sort that out and I’m sure I will but maybe not how I want to, but get sorted” (P4)

Ensuring that her son is going to be alright is stated repeatedly by this participant, particularly in the context of her having time to “get sorted”. The impact of her disease on the lives of others is powerfully described, “it’s a huge issue for me... not just on your health” but “those around you”. Since her disease relapsed following her first transplant and success of the second one is not guaranteed she has to cope with the fact that she has reached the
limit of available treatments and that her future is therefore uncertain. Her effort to make sense of this situation is illustrated in the following extract from her narrative:

“I said to them, what if this one doesn’t work because obviously the last one didn’t, well it did but only for a short time and they said well you couldn’t have another one so it would just be palliative care and you think, you know, well I’ve just been thinking, what happens then, you know, how, what does it all mean?” (P4)

Throughout her narrative this lady reflects on her current position and seems to fluctuate between states of despair and hope as she endeavours to comprehend the concept of remission, afforded to her for a second time and eluding her so quickly previously. The following excerpt appears to illustrate her belief that she may have another year in which to leave things in order for her surviving family:

“I’ve been given a chance and I’ve got at least another year I hope that I can do things and try and get things sorted, you know, make sure my son’s alright, that my Mum’s ok. I’ve got time to do things so I am lucky.” (P4)

The notion of being lucky in relation to having the SCT and in this lady’s case valuable “time” is alluded to by most of the participants and is discussed in a previous section. It is unfortunate however that whilst recognising her own and her son’s need for support on return home this participant was unable to access it.

“I did contact Macmillan because I felt I needed support for me to deal with how I was feeling about the leukaemia but also to help my son cope with it all..., but apparently you have to be referred by the hospital. I was hoping someone would come to my home talk to us together, but they couldn’t do that so its, you know it isn’t that long
since the transplant, and I think you find it, I found it hard to cope with, really, on my own” (P4)

When the researcher enquired as to whether she felt able to ask the medical staff to make a referral she replied:

“They are so incredibly busy, and I thought you know they’re really to treat my leukaemia, and the other problems are something that I’ve got to sort out, rather than, you know, try to rely on them again.” (P4)

This sentiment was echoed by many of the participants who felt they should endeavour to be as brief as possible at their consultation to ensure others were not kept waiting too long. A number of other participants mention the financial burden associated with loss of earnings, reliance on a single wage and the costs of travelling to a specialist centres (P5, P10, P14, P15, P16). The length of time they were in hospital and the intensity of follow up appointments had an impact on the financial and emotional strain felt by both participants and their family members. Participant fifteen, a thirty three year old self employed gentleman highlighted the considerable strain caused by sustained interruption to his employment. This interview took place in his business location where he and his wife were self-employed, though he had not yet resumed work. A significant proportion of his narrative was concerned with the financial problems they faced and their perceived lack of meaningful advice in this regard:

“I honestly thought that there would be somebody, a team of people, Macmillan nurses or whatever who would come and sit with you and just say, tell me about your situation, what do you need help with, where are you at financially, how does this impact on your life... but there was nothing and you’re left to fight and fend and try and work it out for yourself “ (P15)
It appears that this young man and his wife did not receive the information they required to understand what if any benefits they were entitled to and were left to “fight and fend” to work it out for themselves. This, at a time when he felt as his most vulnerable and unsure about his prognosis took valuable time and added to their anxiety and uncertainty. As he stated “I was more stressed about the finances than I was about the treatment”. Supporting this view, his wife pointed to the irony of the advice they received:

“that's the one thing they say, stay as relaxed and calm as possible, no stress and then you've got other stuff like this to deal with.” (P15W)

The anxiety experienced by this young man and his wife is similar to that of participant four and suggests a significant lack of attention to these important social aspects of illness. This finding reflected precisely that of an explorative study of financial concerns, advice, support and coping in people diagnosed with cancer and their carers carried out by Wilson et al (2011) on behalf of Macmillan. Whilst Macmillan grants are available, (Macmillan 2012) and health care professionals eligible to apply on behalf of patients, it is possible that the participants in the current study were either not eligible or that this aspect of support was overlooked.

4.5  Summary of the immediacy of illness and existential crisis

This section has served to illustrate the severe disruption caused to the participants both in terms of their physical, psychosocial and emotional being and their everyday lives. Critical events concerning diagnosis, systemic infections and the conditioning therapy including trial drugs remain at the forefront of their minds, with two participants describing flashbacks related to their intensive care experience suggestive of the negative recall associated with post-traumatic stress disorder. The participants also describe periods of being ‘in limbo’ between treatment cycles and feeling frustrated about being in protective isolation,
particularly during periods when they feel relatively well. All of the participants describe significant aspects of their illness journey which relate to uncertainty. Uncertainty is evident at the time of becoming ill and at diagnosis and on-going insecurities are experienced on their return home. Anxieties concern the responsibility for self-monitoring, the fear of disease relapse, the strain felt by care givers and social aspects such as employment and financial issues. Though some recovery progress is acknowledged no participants have reached a point where the full benefits of their treatment is realised. These aspects will now be discussed in the recovery journey theme which follows.

4.6 The Recovery Journey

The overarching concept of the recovery journey presents the participants’ experiences of life following their return home after treatment between three months and a year post SCT. Whilst most of the participants begin to recover some physical strength, problems such as infections, GVHD and associated side effects prevail, giving rise to on-going health issues of both an acute and chronic nature. The recovery journey includes themes of physical, psychosocial and emotional disruption; coping strategies and communication and information matters (Table 7).
### Table 7: Themes and sub-themes of The Recovery Journey

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td><strong>Physical, Psychosocial and Emotional Disruption</strong></td>
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<td>Treatment effects</td>
<td>Groundhog Day</td>
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<td></td>
<td>Altered appearance, identity and self-concept</td>
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<tr>
<td><strong>Coping Strategies</strong></td>
<td>Keeping occupied</td>
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<td>Being positive and determined</td>
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<td></td>
<td>Being lucky and rethinking the way I see life</td>
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<tr>
<td><strong>Communication and information matters</strong></td>
<td>The desire for knowledge versus 'not wanting to know'</td>
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<td></td>
<td><em>Your blood counts are fantastic: the biomedical focus</em></td>
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<td></td>
<td>Autonomy, trust and encouragement</td>
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### 4.7 Physical, Psychosocial and Emotional Disruption

#### 4.7.1 Treatment effects

A common theme emerged which was the participant’s shock about the degree and duration of fatigue, tiredness and physical weakness they felt on return home. Whilst some described feeling debilitated and sleeping for much of the day (P6, P10 and P11), one lady was unable to go upstairs to bed (P8) and others described limitations such as being unable to socialise for long (P2, P3, P4, P5, P9, P10, P11, P12, P14 and P16), do the shopping without feeling “*dead on his feet*” (P11) and unable to care for young children as they had previously (P11, P12 and P15). Fatigue has been found to be a common long term effect of SCT (Marks et al 1999, Molassiotis & Morris 1999) and difficulties in physical functioning exacerbated by conditions such as GVHD, infections, secondary malignancies, organ damage and endocrine dysfunction (Mosher et al 2009). The intensity of fatigue experienced is evident from all participants and the effect that this has on their ability to contemplate the normal activities of daily life including social pursuits is considerable.
P3, the young female teacher played a lot of sport including touch rugby before her illness and experienced a loss of muscle tone and P2, P6, P8 and P11 were unable to pursue their former sporting activities including golf, keep fit, dancing and gymnastics. Symptoms experienced by the participants are shown in Table 8.

Participant eleven, a fifty year old gentleman had experienced a steady but incapacitating decline in physical fitness following his diagnosis of myelodysplastic syndrome four years previously. He was treated with supportive therapy for some time knowing that a SCT was imminent and spent some time preparing for it with exercise aimed at “bulking up” and “improving his chances on the other side”. The following data extract illustrates the expectations he associates with this treatment:

“\textit{I'd only looked as far as T day, let's get this transplant out the way and everything's going to be alright. But of course everything's not going to be alright, that's just the start of it. I hadn't really let myself look any further than that and even when I was in hospital I was thinking oh yea, by three months I'll be back down the gym again and in six months, it'll all be sorted, you know and of course I've had to come to terms with the fact that that's not even slightly realistic.}” (P11)

The fact that he could no longer rely on his body to respond to exercise in the same way as it had done prior to his illness exemplifies the disparity between his expectations and the reality, or in other words, what he previously took for granted (Bury 1982). His determination is clear along with his initial expectation that “\textit{everything’s going to be alright}” following treatment and that he would be resuming activities in the gym within a three to six month time frame. He admits to the fact that these hopes were unrealistic, though at the time his perception was that following his SCT “\textit{it'll all be sorted}”. 
Table 8: Participants’ self-reported symptoms

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<th>Presenting symptoms</th>
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All participants in the study reported on-going issues relating to infections (see Table 8), several of which necessitated admission to hospital. For some participants, though the duration of the disruption caused by infection was more protracted due to their immune-compromised state, it was not severe enough to necessitate admission to hospital. In contrast others experienced considerable disruption to their physical state due to more severe infections requiring re-admission to hospital. In some cases this was to their local hospital and in others they returned to the specialist treatment centre where their SCT had been carried out. Participant nine’s experience involved re-admission to the specialist hospital following assessment at one of her routine follow-up appointments. In part, she feels that the burden of the journey and time taken to attend these appointments is responsible for an infection occurring:

“It was such a long day, and I think in a lot of ways that pulled me down and that’s why I ended up with pneumonia (pause) I had pneumonia about three weeks before they grabbed me and said right, you’ve got to come in and I said, no, I’m not, I’m going
home and I went home. Then they did some cultures and they found out I had a chest infection on top of pneumonia so that’s why I got dragged in” (P9)

This lady’s reluctance to be re-admitted at all costs is apparent in her initial refusal to stay in hospital as advised. It is possible that general fatigue in the early days post-transplant masked the threat of a more acute problem or that she simply underplayed her symptoms in order to avoid returning to hospital. A feature of most of the participant’s experiences was being unable to fully rely on their interpretations of what was happening to their body throughout their illness trajectory as stated by participant ten:

“things happen, your body, everyone’s body is different, and everything changes in you your body, from losing your hair to growing new nails to, it er, everything changes.” (P10)

Adapting to changes in the body and accepting limitations in recovery was found to be the experience of individuals following colorectal cancer (Beech et al 2011) and has resonance with Breadon’s (1997 p978) finding that the women in her study described a survival process that includes viewing ‘the body as a house of suspicion’. Participant fifteen experienced several infections on his return home which appeared to be linked to viruses carried by his small children and were complicated by other treatment side effects as illustrated in the following data extract:

“So I went home and I was ok, not too bad and then I picked up a couple of viruses, I think I had adenovirus, rhinovirus twice…so I went back in as I was ill and then all the side effects of treatment sort of started for me from then on ‘cos they said the radiotherapy, and even the chemotherapy, the methotrexate, everything, and alot of it you won’t get until you know, it could be three months later and something happens to you and it’s all at different stages and different times, so when you’re immediately after
transplant and you feeling ok and then another week and you’re feeling ok and you’re sort of like, what are they talking about, like I don’t feel too bad and then I’d pick up a virus that completely wiped me out” (P15)

His narrative suggests an ambiguity in the post-transplant period when the first few months of anticipated recovery takes on a different sequence of events and complications. Treatment side effects including weight loss also became a major concern “the loss of appetite I didn’t really expect, I lost four and a half stone”. In spite of the potentially serious nature of his infections, and the necessity to be readmitted to hospital they appeared to be relatively easily resolved with antibiotic therapy whilst his poor nutritional state persisted. As he went on to explain:

“I knew it was a direct relation between eating a bowl of pasta or porridge and feeling healthy and not eating it and feeling crap, but you couldn’t physically do it. It’s like you’re in bed with the worst flu ever and you don’t even want to talk to anyone and someone’s trying to keep feeding you a bowl of porridge, you’re just like go away.” (P12)

This gentleman had resisted having a naso-gastric tube inserted for feeding purposes despite advice to the contrary and at almost five months post-transplant was just beginning to be able to eat small but regular meals. It appears that the lasting effects of radiotherapy and chemotherapy played a part in his on-going problems and recurrent viral infections compounded the situation. Participant ten, the sixty-two year old gentleman, eight months post SCT for myelofibrosis similarly experienced a number of occasions when a high temperature indicated underlying infection as he describes:

“it was the third time I’d had the rigors which is the violent shakes that you get with the temperature that keeps spiking and I keep saying to the wife, I’m not going to the
hospital it's gone down to 35 and then quarter of an hour later, she'd take my temperature again and it's gone up to 38. I mean the highest one I've had so far is 42.2 and I shook for three hours, solid." (P10)

Despite the extreme symptoms he strongly resisted going to hospital. His symptoms of chronic GVHD including colitis had a significant effect on his recovery at around seven months post SCT and regular episodes of diarrhoea throughout the day and night disturbed his sleep and further increased his fatigue and weight loss. His medication regime at this stage, up to forty tablets a day, impacted negatively on his appetite compounding an already extreme situation as he explains in the following moving data extract:

“I think last Saturday was the first time that I've thought that I could just give up and not bother any more but you can't go back. You've gone this far, there is no return. It's not as if you'd say, oh I'll go back and then I'll be as I am because you never will be, because you haven't got your own cells in you anymore. And it's your life you're fighting for so you've got to keep going. You know for the wife's sake as well as my sake.” (P10)

This gentleman's distress is evident and he is clearly realistic in acknowledging that it is not possible for him to return to his pre-transplant state. His experience appears to capture the notion of a ‘critical situation’ as identified by Giddens (1979) whereby the seriousness of his circumstance is starkly recognised. Concern for his wife and appreciation of the disruption caused to her life is also apparent. Pidala et al (2009) found that acute and chronic GVHD are associated with worse quality of life after allogeneic SCT and Syrjala et al (2004) found that chronic GVHD was associated with depression.
4.7.2 *Groundhog day*

As evidenced in the previous sections all participants in this study described the significant physical, psychological and emotional disruptions experienced at various stages during their illness trajectory. However, participants also describe instances when they felt reasonably well and rather bored and frustrated regarding their slow progress. The following data extract from participant twelve sums up the continued disruption and tedious nature of illness and recovery:

“I mean the reality is that the day to day is, it’s very **boring** actually you know, it **really** is. It is groundhog day and sometimes you can struggle to remember where things happened because you don’t have specific reference points, you don’t have, oh yes that was the week before Jonny’s wedding or something ‘cos I don’t **have** any of that, it’s just, you know I have ‘countdown’ which is essentially the same every single day, you know, so you have no reference points and things can get a little bit bland, it just sort of rolls on interminably and when I come here, it’s just, it’s just early days or it’s only been three months and I think it just seems like so much **more** but obviously it’s on the back of another eight months **before** it or nine months before it but it still never ceases to amaze me and I can’t imagine certain things. I can’t imagine going back to work, that’ll be **really weird**.” (P12)

Having “no reference points” compounds this young man’s sense of his life’s ‘blandness’ in the first three months post SCT particularly as this follows nine months of disruption since his diagnosis. This typifies the experiences of other participants whose life is on hold until their immunity recovers.
4.7.3 Altered appearance, identity and self-concept

All of the participants made reference to altered appearance due to weight and hair loss, but for some also the ‘bloating’ effect of steroids and manifestations of acute GVHD. A data extract from participant eleven is included here to illustrate this point:

“I’d say a fortnight after the transplant I started to get very ill. I couldn’t sleep which I’ve now been told was probably due to the steroids and I was having alot of water retention. I was a bit of a mess actually... I looked in the mirror and I could see myself falling apart. My skin was falling off my face where I was all bloated with water retention and my eyes were sort of sunk right back in my head and they were bright crimson... I had GVHD as well, very early on, which is kind of fortunate but you know, not so great on another level. I looked like I’d had a month’s cruise round the med or something. I went really, really dark brown and part of the reason I hadn’t wanted to eat was I had GVHD of my gut” P11

Not only were the visual effects on his appearance disturbing to this gentleman but also the physiological consequences of being unable to eat or sleep properly. As he explained “in the end it got to the stage where I hadn’t really eaten or slept for six days and I looked in the mirror and I could see myself falling apart”. In some cases the effect on their appearance was a significant issue because it signified their overall state of ill health and at others because it affected self-image. Accordingly, participant one, a young man whose passion was for design, fashion and jewellery alluded to his altered appearance:

“You don’t even want to watch TV because you compare yourself with the people who are well and you think look at me, I’m blown up and I’ve got no hair and I’m not the way I should be” (P1)
Comparing himself with “people who are well” appeared to compound this young gentleman’s feeling of being different “I’m not the way I should be” and served as an unwelcome reminder of his ill body. Participants also recognised how difficult it was for their close family and friends to bear witness to their altered physical state and appearance and endeavoured to protect those they felt most vulnerable. The wife of participant fourteen said:

“he hadn’t seen the grandchildren for so long except for one of them, the oldest one, but he got so upset about it, we stopped him going but the little ones couldn’t even Facebook because he just looked so dreadful?” (P14W)

This lady’s efforts to minimise the distress caused to their grandchildren is evident though it is conceivable that both participant fourteen and the children experienced significant suffering as a result of the loss of close contact at this time. Participant fifteen similarly wished to protect his family from distress caused by his altered appearance, as illustrated in the following excerpt from his narrative:

“They basically came in to tell me I was going to have a tube fitted and I refused...the tube erm and just said I don’t, I don’t wannit and they said ‘cos I’ve got, you know I’ve got, I’ve lost four and a half stone, I’m bored, I’ve got no eyebrows, no eyelashes, I’ve got two young children, you know, it’s scary enough as it is without Daddy having a tube stuck to his face all the time as well. I thought it just looks horrific and I really didn’t wannit and so I refused” (P15)

It appears that for this gentleman, the suggestion to insert a feeding tube due to severe weight loss was the final assault on his dignity, as illustrated in his list of physical and emotional manifestations, “I’ve lost four and a half stone, I’m bored, I’ve got no eyebrows, no eyelashes”, in addition to recognising the potential effect on his children, “it’s scary enough
as it is without Daddy having a tube stuck in his face”. Conversely, participant seven felt that his experience was less severe than he had imagined:

“Chemotherapy didn’t affect me amazingly. I mean my hair fell out and things like that but I didn’t feel ill as a result of it. Other people I know have been through tremendous things, sickness and diarrhoea… and having terrible times. I sailed through it with virtually nothing at all, I have been so fortunate, and I’ll never, I’ll never forget that I’ve been that lucky, and, thank goodness for that really” (P7)

Comparing his experience with others, he acknowledges relatively few distressing disruptions to his physical state and refers to the virtue of luck. Comparing one’s experience favourably to others perceived to be less well off has been evidenced in other studies (Wood et al 1985) and is a recognised strategy for coping. In addition to altered appearance the participants express their desire to resume some of their former activities such as work, study, exercise and leisure pursuits. Also, to fulfil their roles within the family such as caring for children (P11, P12 and P15), domestic undertakings and pursuing their intended life plans.

4.8 Coping Strategies

The participants reported a number of strategies for coping with their experiences of stem cell transplant and in adapting to their life back at home. Four overriding examples of this are keeping occupied; being positive and determined; being lucky and rethinking life and communication and information matters.

4.8.1 Keeping occupied

A number of the participants described how they capitalised on time spent in hospital when they felt well enough. Much of this time involved keeping in touch with their families and using web-based technology. One gentleman endeavoured to learn a language (P6),
another made plastic models and gave them to the staff for their children (P7) and participant three, the young teacher spent time lesson planning for when she returned to work. Having the rare opportunity to prepare many lessons in advance seemed to preserve a sense of normality and identity for this participant and seemed to signify the confidence she felt about resuming her career and her future. As postulated by Carricaburu & Pierret (1995) retaining control, being active and doing things is a way of projecting one’s life into the future and to refuse being taken prisoner by illness. Sustaining a positive attitude and gauging her progress through incremental steps was a feature of this participants’ recovery strategy. For participant seven, keeping occupied was a coping strategy he said he would recommend to anyone as a diversion from dwelling on their disease and its implications. Being able to give the models to staff for their children could have also have had a positive effect psychologically by virtue of his ability to reciprocate for the care he received. According to Bury (1982) illness and particularly chronic illness disrupts the normal rules of reciprocity and mutual support increasing a sense of dependency on the individual involved. Keeping occupied was as an active strategy also adopted by this gentleman on his return home:

“You know I **needed something** at that stage to do, to get back to **normal life**, to keep myself occupied because the worst thing in the world is if you’ve got nothing to do and of course your thoughts go to what’s been going on.” (P7)

This gentleman decided to build decking in his garden with the help of his family in an effort to resume his “**normal life**”. Johansson et al (2012) found that the goals of patients who had undergone allogeneic SCT within the past year at the time of interview were related to being healthy and participating in a normal life. Whilst similar to this gentleman’s attitude, he also wanted to keep occupied to avoid thinking about his illness experiences. He is the participant referred to earlier who was reliving his memories in intensive care and was experiencing numerous challenges in his recovery including the development of a hemia
and shingles. He admitted to feeling “down”, “depressed” and “morose” at various points since his return home though reiterated the importance of trying to “keep a positive attitude” a number of times throughout his narrative as if challenging himself to uphold the belief that it will help.

4.8.2 Being positive and determined

As previously mentioned, despite apprehension about returning home all participants in the study were anxious to make the transition as soon as possible post SCT. The data extract below reveals participant eight’s sheer determination to overcome the physically testing challenge of walking up stairs after her intensive care experience:

“they said well you can’t go home unless you can walk upstairs... I looked at these stairs and I thought oh my word, it’s like Mount Everest and they said, if you can walk up two or three stairs we’ll let you go home. I walked to the top and back down. Don’t ask me how I did it, ’cos I really don’t know but I thought, I’m determined to show them I can go home. And I think you’ve got to be positive, you’ve got to be determined, you’ve got to tell yourself that you will get through it.” (P8)

This lady’s Mount Everest metaphor captures the enormity of the task ahead of her and her over achievement of it, demonstrating her resolve to prove that she was mentally and physically able to return home. She makes the point that inner strength is something that must come from one’s own determination and positive attitude. Similarly participant one acknowledges that although he received counselling, ultimately he needed to draw on his own reserves to deal with his difficult situation.

“I know I keep on saying, going back to my previous transplant, because I’ve gone through the whole works. I mean I’ve tried everything, I even tried counselling, I tried to have counselling before and after treatment but there is only so much you can
say, and you need to find in your own stride try and keep yourself busy, and try and do things to make you not think too much...and I had to dig up old projects that I did from University and try and get myself back up there again. Whether it’s just five minutes, ten minutes, it was something. I needed to feel normal” (P1)

For this young man, concerning himself with “old projects from University” to get himself “back up there again” appears to be of benefit in two ways. Firstly, because this cognitive dimension enables him to identify with his life prior to illness and possibly helps him to visualise a future. Secondly, that distraction prevents dwelling on less positive thoughts. For participant four, however, anxieties regarding her recovery from a second SCT, her dependent mother and son and her ability to pay her mortgage challenged her ability to think positively as advised by a nurse:

“one of the nurses said to me that your attitude of mind is so important after something like this, after your transplant, you need to be really positive… but it’s really hard when you’ve got these things going on, that you worry about and you wake up in the night and you’re worried about them and I think how can I be sort of positive and think everything’s going to be alright and I’m going to beat this you now, when you just feel like you’re fighting all the time.” (P4)

Whilst, maintaining a positive attitude in the face of illness or adversity may be considered a desirable quality, critics raise some important points for consideration (McGrath et al 2006, Morstyn 2009, Ehrenreich 2009). Morstyn (2009), a consultant in psychiatry, treated with a SCT reflected on his experience of being advised to ‘think positive’ otherwise ‘his cancer would get worse’. He describes his reaction as angry. Rather than expressing resentment, the participant in the current study appeared to be confused about receiving such advice given the ambiguity of her situation. McGrath et al (2006) suggest that health professionals should exercise caution in both prescribing positive thinking and in responding to patients
and carers whose belief systems and feelings of obligation depend on it. A number of participants in this study stated that they tried to keep positive implying that this attitude was beneficial. One gentleman’s belief in the notion that “mind over matter” was capable of affecting outcomes is evident as he explained:

“the human brain is actually a lot more powerful than any of us give it credit for you know in terms of that sort of thing and a positive attitude definitely will help. You know, the feisty people survive better, generally speaking than those who sort of say oh life’s dreadful, I’m going to, you know it’s all going to fall apart on me.” (P7)

Whilst there is evidence to suggest that people with cancer who have an optimistic outlook may experience a better quality of life than those who feel hopeless, less empirical evidence supports a correlation between coping styles and survival (Petticrew et al 2002). In a study which aimed to identify the core strategies used to attain a strong sense of empowerment in coping with their condition (Bulsara 2004) twelve informants with haematological cancer were interviewed. The study highlighted three main ways in which empowerment was achieved including fighting spirit and determination to cope with the illness; a reliance on significant others and acknowledgement and acceptance of their illness. Findings in the current study are consistent with Bulsara et al (2004) in that the majority of participants refer to the importance of relationships as previously discussed and openly strive for a positive and fighting spirit. However, the notion of illness acceptance for some participants is rather more implicit in as much as they do not explicitly articulate non-acceptance or denial of their condition. Also, whilst all participants reveal ways in which they are actively managing their recovery several participants allude to feelings of anger or frustration and endeavours to control their emotions, for example participant nine who stated:

“there are times when I could scream, absolutely scream and I think oh, now come on you can’t do that, take yourself for a walk.” (P9)
Participant three on the other hand felt that being positive was an integral part of her approach to life and its challenges as illustrated below:

“I’ve always been a positive, I’ve always looked at the positives to anything, I always think well, what’s the worst case scenario, can I deal with it, yes ok and let’s get on with it.” (P3)

Rather than dwell on the negative aspects of her treatment such as the slow re-growth of her hair, fatigue, her infertility and the restriction to travel to countries of her choice due to health risks and insurance reasons she actively pursues alternative ways to overcome them. Her attitude towards hair loss and the fact that she was still bald a year post SCT is demonstrated in the following example:

“Finding the positives so my hair hasn’t grown back but that means I don’t have to wash my hair every day so all I have to do is get up and put my wig on and it saves me twenty more minutes in bed!” P3

The mother of participant five believes that being “stubborn” and “a fighter” is what has enabled her daughter to survive from being a premature baby in a neonatal special care baby unit through to her more recent life threatening events in an adult intensive care facility:

“and she’s always had that fighting spirit, otherwise I don’t think she’d have got this far, she really is a fighter.” (P5M)

Similarly, participant nine refers to her whole experience as a “fight” and in the following words demonstrates the mental effort it takes to remain positive in spite of it:
“I’ve come through it. But it was a fight, it is a fight all the time. You’re forever thinking come on be positive, don’t get down in the dumps about this and you know, just hope for the best, you know, get on with your life, go out and do the things that you’ve always done” (P9)

This lady’s desire to return to a normal way of life is evident and whilst acknowledging the metaphorical battle she has been through to reach this state, her words “it is a fight all the time”, suggest that it is on-going in nature. Stating that she must “hope for the best” implies that she is concerned about the success of her treatment and also her ability to return to her former role. ‘Struggle language’ such as ‘fighting’ associated with personal testimonies of people surviving cancer (Seale 2001 p308) has both positive and negative connotations. On the one hand, Sontag (1991 p5) argues that when ‘fighting’ is associated with military metaphor, the resulting effect on many individuals is to view the disease as a demoralising ‘ruthless, secret invasion’. Conversely, however Seale (2001 p325) suggests that reports of heroic struggle and fighting language may in fact be experienced as inspiring and supportive by people with cancer.

4.8.3 Being lucky and rethinking the way I see life

As mentioned earlier, many of the participants refer to how lucky they have been to receive a stem cell transplant and their gratitude for being given a second chance. Despite concerns about her family and her own future participant four reflected:

“I do think, you know I think I’ve been really so lucky because I am in remission, you know, even if it comes back, the same, a year down the line, it’s still an extra year isn’t it? And I think, gosh, you know, my niece’s husband just sort of literally dropped dead and you think gosh, I’ve been given a chance and I’ve got at least another year. I hope that I can do things and try and get things sorted, you know, make sure my son’s alright, that my Mum’s ok. I’ve got time to do things so I am lucky. And I’m lucky
This lady’s acknowledgement of how lucky she has been appeared to be a literal counting of her blessings from her survival “I am in remission... I’ve been given a chance” through to more practical aspects of her post transplant experience. In a study of patients undergoing stem cell transplantation Coolbrandt & Grypdonck (2010) found that patients made concerted efforts to ‘keep courage’ and to sustain a ‘positive story’ in order to make sense of their ordeal. It was suggested that these efforts involved more active strategies than ‘the rather passive concept of hope’ (Coolbrandt & Grypdonck 2010 p218). Findings from the current study accord with those of Coolbrandt & Grypdonck (2010) in that a number of proactive strategies were engaged by participants in order to cope with challenges throughout the illness journey. The personal growth realised by participant one as a result of the experience is conveyed in the following excerpt from his narrative:

“And you try to express that through your work because there’s alot of negativity in cancer and I try to do that as much as possible, and as much as I hate cancer, and I hate what I’ve gone through, it has made me rethink about many things, my work, the way I think, the way I communicate with people, the way I see life. It’s massive, it’s a huge thing. A huge, huge thing. And no-one can take that away from me.” (P1)

For this young man, the enormity of what he has been through is absolutely life-changing, affecting his whole way of operating, communicating and the way he views life. In addition to the four main sub-themes, all participants acknowledged the importance of support from loved ones. In a moving data extract, participant sixteen articulates the encouragement he received from his daughter in the form of digital photographs of his Grandchildren:
“Well yes, the first thing my daughter did she brought in a digital photo frame with pictures of my Grandchildren and she said, ‘get better for them’ and erm, I’m sorry (visibly very emotional). It worked.” (P16)

His daughter’s action and words are a poignant reminder to him of how important he is to his grandchildren encouraging him to draw strength from the relationships of those who love him. Field notes made directly following the interview and notes attached to the interview transcript note the extent of his emotion as he related this.

Field note entry 28/09/2013
Participant 16
He did get tearful when talking about the worst times which were birthdays and significant anniversaries or festivals such as Christmas. Also, the importance of family and recovering for them was a particularly emotive topic. I did not suggest turning the tape off as this was short lived but gave time for him to come through this and recover himself.

4.9 Communication and information matters

4.9.1 The desire for knowledge versus “not wanting to know”

Participants had different experiences of the way in which certain information was communicated to them and mixed views as to what they wished to know or not know. Participant seven, a sixty eight year old gentleman, eleven months post SCT for leukaemia stressed the importance for him of gaining detailed information as articulated in the following narrative:

“I’ve learned an awful lot over the time, you know there are things I knew nothing about, and now, I’m not an authority on it but I’m pretty knowledgeable… the more I understand, the easier I find it to deal with, for me. Everybody’s different in that
He appears to feel more in control with increased knowledge and understanding of the rationale behind his treatment and what this means in terms of his own experience. As well as a desire for detailed information seeming to be a natural trait for this gentleman he also mentions that a lack of suitable donor resulted in him having a cord transplant. The novel nature of his treatment possibly increased his interest and though information was less readily available, he received verbal explanations from his medical team and supplemented this with seeking out information himself. In their study of age and gender in illness narratives, Seale and Charteris-Black (2008) similarly found that older men with cancer demonstrated a greater involvement with medicine as an expert system than younger men and women. This related both to their interest in treating their illness as a problem capable of being fixed with technical expertise and their social confidence when interacting with doctors. With regard to information supplied prior to treatment and in particular SCT, participant fifteen held the following view:

“the information is good that you receive but I just think it’s hard, it’s a bit like reading a text book and then going on a field trip, and practically doing what you’ve been reading, you know the physical part of it, so people can talk to you and tell you and give you sheets of paper, but you never really know what to expect until you’ve experienced it.” (P15)

Whilst finding the information “good” he used the analogy of the practical experience of going on a field trip compared to reading about the subject under study to illustrate how difficult it was to imagine a transplant. This point suggests that sharing experiences with those who have lived through SCT could have potential benefits in supplementing more factual material. In contrast to the participants who felt their coping correlated strongly with
having more information and understanding of their disease and treatment, a number felt that the reverse was true for them. This is demonstrated by the following extract from participant sixteen’s narrative:

“I’m a terrible worrier, always have been and I knew that if I knew what was coming round the corner I’d be constantly worrying, which apart from the fact that you know, was I going to survive or not, I didn’t really have any other worries. I know that sounds strange, apart from my family, I worried about my family, what they were going through and how they were coping” (P16)

This gentleman uses avoidance as a conscious strategy of coping with his existential worries and he also adopts a strategy of living in the present. He remembered vividly being asked if he wanted to know his chances of survival and although he expressly requested not to know his wishes were inadvertently overlooked, causing him and his family considerable distress:

“He told me that I only had a forty per cent chance of getting through the next stage. That hit us all didn’t it?” (P16)

Present throughout the interview, his wife did however express her exasperation at her husband’s lack of interest in any information and explained her own and her daughter’s conflicting attitude:

“Me and my daughter was absolutely desperate for information..., we needed to know so we knew how to handle everything that was going to happen” (P16W)

An explanation for this difference in attitudes could be that when one’s existence is threatened there is little capacity or need for any information beyond concern for their
survival. However, loved ones wish to know potential consequences and what they need to do to prepare for the future. His wife’s language and emphasis on the word “desperate” suggests the anxiety that both she and her daughter felt as a result of their lack of understanding of his situation. Participant six’s attitude towards illness information was similar to participant sixteen in that he was happy for others to acquire knowledge on his behalf. This sixty three year old gentleman was three months post SCT for leukaemia with his son being his donor. He acknowledged that his son received significant amounts of material by virtue of being a donor and that his wife “got herself signed up to receive all the research papers”. As he explained:

“it was just I suppose I didn't want to be reminded of it. You know you’ve got something seriously wrong, you’re in good hands .. there’s not anything I can do that’s going to make any difference to what they know or what they can do, so does it help me to have detailed information about all the stuff that could go wrong and all the possible side effects? I don’t think it does, so that’s my opinion. For other people it may be very helpful.” (P6)

It appears that his preferred way of coping with the situation is to rely on the expertise of the specialists rather than worry unnecessarily about his destiny over which he feels he does not have any control. Employing a ‘language of probability and reasoning logic’ is recognised as a strategy for coping with the uncertainty of a situation (Fox 1979 p46). This gentleman did however acknowledge the value of his wife recognising possible complications once he returned home as illustrated in the following data extract:

“Clearly there’s a point when you do need to know about the potential side effects because if something comes along, you need to know whether to worry about it…so it was probably quite important that she, that one of us was in touch with what could happen, but I preferred that it wasn’t me” (P6)
Again, he repeats his preference for the responsibility of knowledge acquisition to lie with others and was happy for his wife to take on this role. In addition to this being linked to his coping mechanism, he alludes to a gender distinction affecting the wish to discuss serious issues such as the nature of his disease and his chances of survival:

“when you've had a dose of bad news I think there’s a bit of the men from Mars and women from Venus or is the other way round? My wife is certainly more likely to talk about things and it’s more likely to help her whereas I’m more likely to keep things to myself. I think it would have certainly helped her if I’d spoken more. It might even have helped me, I don’t know.” (P6)

He acknowledges how expressing his emotions and perhaps a diversion from the traditional stoical male role could have alleviated these tensions. He went on to convey how “difficult” it was to gauge what information to share with children and grandchildren, particularly due to the fluctuating nature of his changing condition, admitting that this was something he left to his wife to communicate. His own reaction to the information given to him by his consultant is illustrated in the following excerpt from his narrative:

“it’s one of those conversations you remember in the state I was in. There was fifty per cent chance of living fourteen months I think it was, without a transplant, so we might as well go for a cure which has got a forty per cent chance of success and hope it was going to work. So that was the mental position we took.” (P6)

Being given information comparing the percentage chances of survival both with and without a STC enabled him to make an informed choice regarding his treatment options. With a “forty per cent chance of success” he opted to “go for a cure and hope it was going to work” suggesting that whilst cognisant of the fact that there was no guarantee of success, he
consciously adopted the “mental position” of optimism. In a study investigating the process of maintaining hope in adults undergoing bone marrow transplantation Ersek (1992) identified several coping strategies including seeing the disease as a challenge and avoidance of negative thinking which resonate with the attitude of participant six in the current study. These findings are also corroborated by Saleh & Brockopp (2001) who found that participants hospitalised for bone marrow transplantation engendered positive attitudes and thoughts in the face of challenging situations in order to nurture hope.

It is interesting to note that several participants admitted to deliberately avoiding certain information and others felt it had not been discussed. Their rationale however is similar in that they felt that this was a deliberate attempt to focus on the curative aspects of the chemotherapy treatment and the transplant. Participant fourteen, a sixty seven year old gentleman eight months post-transplant for myelofibrosis commented on his perceived lack of information received about the treatment he would be undertaking as demonstrated in his words:

“I’m very positive about having had it done and I got through the other side of it but one thing that did disappoint me. It was never really explained erm, what you have to go through.” (P14)

However, this did not concur with his wife’s recollections who felt that his relief at being given a ‘second chance’ blinded him to the information he was given:

“You seemed to shut your eyes to alot of it because the doctor went into it in such big detail but I think P14 at that point was so pleased that they were going to give him a second chance that he’d shut his mind to all that. He just knew he was going to go in and have it done and his brother was going to be a donor which was a really good match...our son was with us as well and he’d got this huge list of questions and he
was so patient and he answered every one of them and he told you it was going to be no walk in the park.” (P14W)

The relief that this participant felt once a donor was established for his stem cell transplant seemed to overshadow the reality of the treatment challenges ahead and in response to his wife’s explanation “I think in your mind you cut that bit completely out” he conceded:

“Yea, I think you’re probably right, I didn’t want to think about what I was going to go through” (P14)

At sixty eight, this participant was of an age considered to be high risk for the type of treatment required which may well have increased both his gratitude and concern. When he claimed it was “never really explained what you have to go through”, it is possible that this related to not fully comprehending the enormity of the physical and psychological challenge ahead, in other words what the lived experience would actually be like. His perceptions resonate with participant fifteen’s comments earlier, that is, that factual information does not fully prepare you for the experience. This sentiment was echoed by a younger participant who when asked if he felt prepared for what was involved in his treatment explained:

“I’m not sure I would have absorbed it. I was so relieved and so excited about finally getting my stem cell transplant...I think maybe they didn’t impress upon me the seriousness of what could happen because you don’t really want to go in there knowing that. If you’ve got an expectation that you’re going to be absolutely bloody miserable, and, you know, all of the vomiting and all the other side effects that can happen, you don’t wanna know that’s coming, just let it happen, you know, rather than have chance to brood about it in advance.” (P11)
This gentleman suggests that sparing the volume and intensity of information prior to treatment may offer some protection to an individual in terms of reducing anticipatory dread. This attitude is similar to patients in studies (Cohen & Ley 2000, Tarzian et al 1999) where patients were found to want enough information to know what to expect though not too much to provoke a loss of hope. Accordingly, McVey et al (2001) suggest that an individual can reduce fear by limiting the amount of traumatic information processed, and in turn, maximise feelings of personal control.

Several participants commented on the benefits of sharing experiences with others informally or in a patient and carer support group either in person or via the internet. Whilst helpful and reassuring for some, again, views were divided amongst certain participants with two in particular voicing their opinion. As participant six explained:

“I’ve actually avoided support groups, and I keep away from medical programmes on the TV and all that sort of thing. I don’t think it would help me. Everyone’s got something slightly different so it would be a bit like looking on the internet, you’d get half the story and it probably wouldn’t be very helpful.” (P6)

Similarly, participant one shares a reticence to use the internet for fear that the information could make him “feel worse”. He felt he had learned from the experience of his first SCT as illustrated by the data excerpt below:

“after transplant you’re very vulnerable and you want to try and find an answer even after transplant, and especially when you haven’t had a PET scan you want to know what’s going to happen to me, find out other people’s stories and that’s a really, really bad thing to do. If I didn’t have a previous transplant before this one, I’d probably have done that again, I wouldn’t have learnt from my mistakes. I would have made myself even worse.” (P1)
In the context of his narrative, this young man of twenty two years is reflecting on his previous transplant and the need for reassurance that his disease is not relapsing for a second time. He considers that a PET scan would confirm if this was the case as opposed to comparing symptoms by finding out “other people’s stories”. Whilst admitting that looking up symptoms and talking to others on the internet could “scare you silly”, participant eleven did however start his own blog in hospital to share practical tips attracting five thousand views. As he explained:

“I wrote it in a very black humour kind of style, you know, just little odds and sods and tips to bear in mind when you go into hospital. One of the first things I picked up on is that you need lipsil ‘cos the air filters in that place are so concentrated and dry, your lips are the first thing to go, no matter how hydrated you are.” (P11)

Sharing useful information from personal experiences that is easily accessible is likely to be extremely helpful to others and less controversial than offering advice about a particular disease, since everyone’s case is likely to be different. However, participant five remarked on a conversation between two transplant patients which started in the out-patient’s waiting room. Subsequently it extended to a group discussion where consensus was reached on many aspects of their individual experiences:

“Last week in the waiting room and a couple of other transplant patients were just having a chat between themselves and it was quite comical listening to some of the stuff they’re going through. Not because it’s actually funny what they were saying but it was like just one person said something and I’ve never sat in this situation where every single person can agree on so many things about going through their situation.” (P5)
This sharing of experience as described above encapsulates Frank’s (1995 p49) notion of the communicative body whereby ‘when a body that associates with its own contingency turns outward in a dyadic relatedness, it sees reflections of its own suffering in the bodies of others’. Portraying four typologies of bodies in illness (Frank 1995) the communicative body type is one which realises the ethical ideal of existing for the other and in so doing endeavours to fulfil an obligation to relieve the suffering of fellow men and women (Schweitzer 1933).

4.9.2 “Your blood counts are fantastic”: the biomedical focus

A number of participants remark on the nature of their information exchanges at their follow up appointments. The primary focus of the consultation appears to be the blood test results and once discussed other concerns are either forgotten, held in abeyance because there is a perception that these are of secondary importance or not raised in order to minimise the delay for others. These points are illustrated by participant fourteen who said:

“Because the first thing that happens when you go in the room, they go oh yea, you’re blood counts are fantastic so you think oh thank God for that, we’re through another month... and you think well I must be getting better if my counts are good and then you forget what you should be asking, you know, the not overly important things, well they are important things, from your point of view anyway aren’t they, you know, it stops you thinking about them, things you need to know” (P14)

This gentleman’s reference to the “not overly important things” but important “from your point of view” highlights the value of considering investigation results in parallel with complementary information related to the individual’s lived experience. His phrase “I must be getting better if my counts are good” suggests that the results inform how he should be feeling rather than the reverse. This observation conveys the importance of sharing information in the context of understanding and responding appropriately to the illness and
recovery journey. As Mattingly (1994) affirms, treatment that is structured narratively and comprehensively distinguishes it from a mere sequence of medical interventions. However, as participant fourteen also observes entering into a dialogue can mean “you’re in there longer and you feel guilty ‘cos you’re taking up so much time”.

For participant eleven, his initial reluctance to raise concerns was based on his desire to portray a traditionally masculine image rather than minimising his appointment time, as he explained:

“my wife insisted on coming in to see the doctors with me because I used to do the typical bloke thing where, how’re doing, I’m great, I’m fine, all good, you know, no problem at all and then she’d pull me up and say what about this, what about that, aren’t you going to tell him about this and I’d think oh yea, maybe it’s not as rosy as I’m painting it. You know I actually had to make a conscious decision to change the way I portray what’s been happening with me and not try and butch it out or anything like that and actually just say everything that’s happening which is a little bit...erm, just something to get used to really” (P11)

The realisation that his strategy of saying he was fine was not necessarily advantageous occurred as a result of his wife’s insistence on attending his consultation to ensure he presented an accurate as opposed to a “rosy” picture of his situation. Though he refers to his conscious “decision to change” and “not try and butch it out” this was clearly an alien concept for him. The approach, referred to as self-censorship is not limited to the males in this study, and the rationale for adopting it can vary. As previously mentioned, participant five was noted by her mother to not disclose information she felt may be upsetting and participant eight endeavoured to reduce her husband’s anxiety by reassuring him that she was fine. Whilst motives vary, the overarching intention of participant’s in this study appears to be an effort to protect others and in participant eleven’s case to present a positive macho
image. In their discourse analysis of interviews with women with breast cancer Wilkinson and Kitzinger (2000:805) argue that ‘upbeat’ talk such as that used by participant eleven “I’m great, I’m fine, all good” is a conversational device used to fulfil a ‘socially normative moral requirement’ to be positive through the experience of cancer.

4.9.3 Autonomy, trust and encouragement

All of the participants expressed the value they attached to being listened to by the doctors, their trust in clinical expertise, openess and encouragement and the consistency of medical personnel involved in their follow up consultations. The following data extract from participant fourteen’s account illustrates the first of these points:

“he was the one who took notice of me when I said about the cyclosporine. He went to see the consultant to persuade him to change me from that to another drug.” (P14)

This gentleman had deduced which drug in particular was causing his distressing nausea and vomiting and whilst it was important anti-rejection medication, the doctor he spoke to “took notice” and was able to persuade the consultant to change it. Similarly, participant one was able to influence his doctor to order a scan when he was concerned about disease relapse highlighting the importance of being listened to. The following two excerpts from participant five and seven’s narratives illustrate their reaction to the encouragement they received from medical staff:

“She said, P5, I saw you when you were on life support and I thought well this is it. And she said I cannot believe you are here looking so well. She said I really am proud of you and you know, just hearing that and that’s coming from a professor” (P5)
I popped back in there and went up to the ITU to say hello to everybody there and to say thank you and they said ‘good heavens, you’re our miracle patient you are’ and I thought, that’s lovely, that is. Made me feel pretty good anyway.” (P7)

For both participant five and seven, the acknowledgement of their survival by a professor and intensive care staff respectively was extremely significant. There appear to be two specific reasons for this, one being that they are remembered so clearly as individuals and secondly that they are respected and admired for their endurance. It is also worth noting that since this young lady and older gentleman appear to have survived these critical events ‘against the odds’ a sense of praise for the staff themselves is implicit in their words of encouragement. The notion of symbiotic praise in these particular circumstances is noteworthy because treatments which engender both life saving and life threatening outcomes, staff understandably take pride in patients’ survival. The value of knowing and being known by the specialist teams is seen as important to all the participants and the two data excerpts below reflect this:

“as soon as we ‘phone she recognises his name and she realises, I know she’s got hundreds of patients but I think he was in there so long she sort of knows” (P14W)

“I just think it would be nice if you could always see the same doctor because they know what you were like last time, so they can say ooh, you look a lot better today, or whatever, whereas if you have different doctors they tend to sort of ask you all the same questions because obviously they don’t know you” (P8)

Consistency and familiarity of medical staff inspires confidence and obviates the need to repeat information. Participant eight’s reference to a doctor knowing “what you were like last time” is also suggestive of a subjective element to their assessment which could enhance their evaluation of a patient’s progress. It is clear from her account that her experiences of
seeing the same doctor have been mixed. Supporting the notion of consistent contact with a given professional or group of professionals, Schou and Hewison (1999) suggest that when this is the case, patients and family members have a greater opportunity for a coherent treatment experience. Furthermore, Del Vecchio Good et al (1994 p 857) advocate consistent contact for another important reason. This is to ensure that 'attention to the trivia of daily treatment and the focus on technological requirements set the ground for more significant encounters, when difficulties of course and prognosis are addressed'. Given the uncertain recovery journey for participants in the current study, this observation is significant. In stark contrast to the concept of the “miracle patient” several patients remark on less positive comments such as participant four being told that palliative care would be her only option in the case of disease relapse and as mentioned previously in the case of participant nine, that it would be “curtains”.

4.10 Summary of the recovery journey

This section has served to illustrate the experiences of the participants in their recovery journey up to one year post SCT. As physical, psychosocial and emotional disruption continue to affect the lifeworlds of the participants and their families, they employ a number of coping strategies to deal with enduring uncertainties regarding survival and their general health status. Attitudes toward receiving information is varied whilst all of the participants value the expertise and encouragement afforded to them by their clinical teams. The notion of being positive and determined and information matters are explored further in the discussion chapter which follows.
CHAPTER 5

Discussion

5.1 Introduction
This chapter builds on some of the theories and concepts emanating from the themes identified in the findings, drawing on relevant literature both within and external to literature concerning haematological malignancy and stem cell transplant. The study aimed to explore the patients' experience of returning home following allogeneic stem cell transplantation. Research questions included how patients cope on their return home after prolonged hospitalisation; what physical, psychosocial and emotional challenges are faced and what help they require in order to overcome these and the medical, social and psychological support systems in place to meet these needs.

5.2 Biographical disruption
Participant's experiences of the immediacy of illness and existential crisis have resonance with what Gidden's (1979) identified as a 'critical situation'. This critical situation is one which disrupts people's beliefs and assumptions about their everyday lives and 'involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others' (Bury 1982 p 169). For participants in this study, disease onset, the urgent requirement for medical help and subsequent treatment poses an existential crisis. This continues into the post treatment phase and is associated with ongoing threat to survival through infection, acute and chronic GVHD and the risk of disease relapse or secondary malignancy (Potter & Kerridge 2004). Whilst Bury's (1982) conceptualisation of illness as a major disruptive experience was based on empirical evidence of those with chronic disease it is relevant to the experience of participants in the current study. Not only do some of the participants experience a major disruption to their lives at the inception of disease but this continues post SCT as survival now extends beyond one year (Hahn et al 2013). Their disease trajectory incorporates phases of acute and
critical illness situations in tandem with a slow and “non linear” recovery and enduring side effects of a more chronic nature such as fatigue, weight loss, loss of taste and tingling in their hands and feet (peripheral neuropathy). No one participant could be sure what recovery really meant in terms of resuming their former life state, giving credence to Mukherjee’s (2011) observation that those surviving cancer must define and live with a ‘new normal’. In addition to an altered bodily state prompting individuals to seek professional help, Bury (1982) identified two other aspects of disruption; firstly disruption in the explanatory frameworks normally used by people necessitating a fundamental rethinking of the person’s biography and self-concept and secondly the resources that people are able to mobilise in order to respond to the disruption. Key questions arising out of the disruption in the explanatory frameworks involve making sense of why the disease has occurred and why now? As previously mentioned, whilst participants in this study were shocked at the severity of their diagnosis they acknowledged the limited evidence of predisposing factors for haematological malignancy. In addition to the physical manifestations, participants described the major disruption to their psychosocial and emotional well-being. Their ability to fulfil their former roles within the family, resuming work or studies and participation in social activities including sport were significantly compromised due to infection avoidance, fatigue (all participants) and in some cases a loss of confidence (P2 and P5). These findings accord with what Little et al (1998 p1485) refer to as ‘boundedness’ whereby the individual’s social world contracts through an awareness of limits to space, available time and empowerment as a result of cancer.

The mobilisation of resources referred to by Bury (1982) involves people having to reappraise their family and social support network and their on-going access to health services whilst attempting to fulfil the customary human attribute of reciprocity. In this study all the participants with the exception of one widowed lady express how vital family support has been physically, socially and emotionally. Another lady whose son and mother were reliant on her to support them formed a close relationship with her sister following SCT as
she was the sibling donor. However, illness of her own family members limited the support she was able to offer. Other than continuing to access specialist medical services, and one gentleman being involved in a post SCT physiotherapy class, the participants had no other support provided. One gentleman (P11) viewed ill-health retirement as a bonus as it provided an opportunity to leave a job he no longer enjoyed, to “get out of the rat race” and to avoid long commutes with their own associated disruptive effects on his family life. His wife was the primary wage earner and he was able to contemplate less stressful job possibilities in the future, while for others, enforced retirement and disruption to education and apprenticeship had a more detrimental effect on the participant’s lives.

5.3 Haematological malignancy as a chronic illness

Chronic illness and long term conditions are often defined as a physical or mental condition that demands living with disease trajectories over time (Hyman & Corbin 2001). A recent definition (Perrin et al 2007) suggests that any health condition lasting more than twelve months or likely to have a duration of at least twelve months constitutes a chronic illness. Whilst the initial diagnosis and treatment of cancer may be considered an acute phase of illness, it’s often insidious onset and continuing physical and psychological effects over time can define it as a chronic problem. Contesting the notion that cancer should be defined as a chronic illness Tritter & Calnan (2002) argue that whilst a diagnosis of cancer similarly signifies a biographical disruption (Bury 1982) that the associated meaning is considerably different. According to Tritter and Calnan (2002) a major difference concerns the social response to the stigma of cancer compared to that associated with chronic illness (Goffman 1963). Tritter and Calnan (2002) contend that the stigma associated with chronic illness and disability is likely to be characterised by a sense of embarrassment as opposed to that of cancer which is associated with a fear of infection and death. Participants in the current study report very real fears regarding infection and death but neither are they immune to feelings of embarrassment caused by altered appearance such as weight loss, hair loss and skin rashes due to GVHD and severe physical debilitation and fatigue. They too suffer a loss
of identity and altered self-concept as a result of their disrupted lives in a similar way to those with chronic illness as portrayed by Bury (1982) and Charmaz (1991) and whilst for some this is temporary, for the majority of participants in this study are experienced well into the first year post SCT. Most survivors have been found to experience symptoms such as fatigue (Jacob's et al 2007, Lee et al 2001, McQuellon et al 1998) and up to two-thirds of patients undergoing allogeneic SCT develop chronic conditions including chronic GVHD (cGVHD), heart problems, endocrine and musculoskeletal disorders, neurocognitive impairment and secondary malignancies (Sun et al 2010). Perhaps the concept of chronic suffering more fittingly reflects how the individual experiences and lives with illness of an enduring nature.

Whilst testifying to the insights of Strauss (1975) in drawing attention to those with chronic illness being forced to withdraw from the field of social interaction, Bury (1982) identifies a pressing need to consider the deeper implications of this phenomenon. The participants in this study are required to make adaptations to accommodate fatigue and infection avoidance and their social pursuits are therefore constrained. The implications are primarily associated with the person's self-concept and identity as they endeavour to resume former roles and relationships both within and external to the family. Beech at al (2011) found that restoring a sense of wellness following surgery for colorectal cancer involves participants assessing and accepting physical limitations and that personal identity is recovered by achieving control over bodily functions. Participants in the current study similarly strive to achieve small goals with a belief that that there will come a time when they can more effectively predict stages of recovery, albeit different to how they were before the illness, whilst living with enduring uncertainty in the first year post SCT.
5.4 Physical aspects of recovery

In relation to the severe physical disruption and fatigue during the first three months and one year post SCT knowing how much to ‘push themselves’ and how long symptoms will prevail are two of the most significant issues described by participants. Similarly, in a study exploring the caregivers perspective of QoL post SCT (Jim et al 2014 ) they reported feeling unprepared for the severity and duration of emotional and physical changes in the patient and expressed difficulty determining how much they should ‘push patients to engage in activities’. In a matched control study (n=376), Kirsch et al (2014) compared the health behaviours between recipients of haematopoietic SCT and the general population. Evidence showed that twice as many patients in the former group were inactive leading to a hypothesis that the late effects of treatment and cGVHD potentially limited their physical performance. Whilst survivor’s fatigue can be a barrier to exercise, it can be reduced by regular physical activity (Persoon et al 2013). Furthermore, recent research suggests that in addition to regular activity reducing fatigue, the risk of developing diabetes and cardiovascular conditions, including hypertension following SCT may similarly be mitigated (Armenian & Chow 2014, Chow et al 2014). Accordingly, participants in the current study faced tiredness and fatigue, inhibiting their activity initially but all were keen to resume their former physical pursuits and endeavour to do so. Only one gentleman mentioned attending a physiotherapy class at the specialist treatment centre and due to geographical location, it may have been difficult for others to attend. Findings suggest that information regarding exercise would be well received by the participants.

5.5 Coping

An integrative literature review of haematopoietic SCT for haematological malignancies (Adelstein et al 2014) illustrates contradictory evidence as to whether physical, psychosocial, or spiritual challenges are the more distressing concerns for patients, although these issues are closely related. However, coping style appears to be a significant variable
in patient adjustment to HSCT related to the level of distress associated with these factors. Meaning-making was cited by participants as having an important relationship to effective coping, regardless of their individual coping style and those able to find meaning in their HSCT experience were found to manage physical symptoms more effectively. They were also less likely to report pathologic depression, anxiety, and PTSD symptoms after transplantation than those who struggled to find meaning (Adelstein 2014). As previously cited, Coolbrandt and Grypdonck (2010) suggested ‘keeping courage’ through the creation of a positive story was an active coping strategy for their participants. Farsi et al (2010) determined that finding meaning in their SCT experience formed the essence of effective coping for participants in their study. As evidenced in the findings, participants in the current study displayed a number of coping strategies including keeping occupied, being positive and determined and counting their blessings evidenced by their reference to being lucky. They also employed strategies such as comparison of their own situation to others who were worse off and avoidance of certain information specifically related to survival. Whilst endeavouring to maintain a positive attitude concurs with the findings of Schoulte et al (2011), who defined positivity as emotion focussed coping there is variance with the other two forms of coping styles they identified. Instrumental coping (characterised by information gathering) was found by Schoulte et al (2011) to be an adaptive coping style employed to manage a variety of physical symptoms associated with SCT. As evidenced in the findings, participants in this study have two distinct attitudes towards information; feeling more in control with it and feeling threatened with too much. Avoidant coping, when patients deny the existence of a situation is considered maladaptive by Schoulte et al (2011) and may lead to behaviours such as alcohol abuse. However, in the current study, it can be argued that participants adopted this strategy as an act of self protection to reduce inherent fear and anxiety. Since striving to be positive and determined is important to many participants in this study, attention will now focus on a discussion of this finding.
5.6 Being positive and determined

The meaning of positive thinking can be obscure, open to semantic ambiguities and its interpretation variable depending on people and circumstance (McGrath et al 2005). Furthermore, operational definitions can also vary considerably, evidenced by coding irregularities pertaining to the concept of positivity in qualitative studies as highlighted by Wilkinson & Kitzinger (2000). A recent Australian study compared patients and nurses understanding of positive thinking and found significant disparities between the two groups (O’Baugh et al 2003). Whilst patients frequently defined being positive as living as normally as possible, nurses made a greater association between being positive and personal attributes such as adopting a fighting spirit, maintaining optimism and hope. As in Wilkinson & Kitzinger’s (2000) study of 77 women’s experience of breast cancer, participants in the current study were not directly asked about positive thinking but similar discourse about the benefits of being positive prevailed in several narratives. In fact, the significant number of references to ‘thinking positive talk’ (Wilkinson & Kitzinger 2000) led to their analytic focus on how women with breast cancer talk about the role of positive thinking in their own lives. This approach prompted the researcher to note the number of references to positive thinking evidenced in the data in this current study and to reflect on the meaning and context in which such statements were made. Thirty seven references to being positive with direct use of this word were found with the highest proportion of these evident in three of the narratives (P7, P3, and P8). The highest number was thirteen, then eight, five, three and two. Six participants mentioned it once whilst four did not use the word at all. Those who did not use the specific word made statements such as needing to “try and get myself back up there again” (P1) which in the context in which it was said suggests the considerable personal mental effort required to make the transition from a very vulnerable state to one of relative normality. Extracts from another participant's narrative whose recovery is marred by significant challenges also encapsulate the notion of the personal struggle and hope required to carry on such as:
“at least you’ve given it your best shot and tried everything possible...I’ll never give up, never ever give up until I get success one way or the other” and “I think the consultant’s got a few more things up his sleeve that can eliminate this so I’m still thinking it will work in the end and I think that’s what you’ve got to hang onto ‘cos if you don’t then you’ll just go and lay in a corner and just ...curl up” (P10).

This gentleman’s words suggest a dual responsibility for a successful outcome; his consultant’s expertise and the capability of modern medicine, and his personal unrelenting determination.

Whether applied to ill health or more generally, thinking positive has become a socially accepted and widely propagated phenomena of modern life. The notion that mind over matter can result in positive outcomes is an attractive one, particularly when this signifies gaining control over an otherwise uncertain situation. Two broad benefits are claimed for positive thinking in relation to disease (McGrath et al 2006), one being that a positive attitude will enable the ill person to cope more effectively with the experience of illness and the other that it will increase the likelihood of a good outcome. Whilst there is evidence that maintaining a positive attitude can influence a person’s ability to cope with treatment and adapt to life after treatment for cancer (Taylor et al 2000, Taylor 1983) critics suggest otherwise (Oakley 2010, Ehrenreich 2009). Given the high value placed on certain interpretations of positive thinking, it is argued that this has the potential to place an unnecessary burden on a patient at a time when they are already facing considerable trauma (Holland 2000). Furthermore, in their study exploring the role of positive thinking in perceptions of cancer outcomes Ruthig et al (2012) suggest that exposure to the notion of positive thinking could lead to cancer patients being perceived as culpable for a poor outcome. Whilst participants in the current study do not articulate self blame, they do however feel an obligation to play their part, best illustrated by one gentleman (P7). He acknowledges that the medical teams are doing their “darnedest” for you and therefore “it’s
up to you to actually do your bit to make sure that you also do the same thing”. In terms of improving survival, Petticrew et al (2002) and Dyer (2012) challenge claims that positive thinking can improve outcomes in cancer. They also refute the suggestion that interventions that enhance benefit finding improve the prognosis of cancer patients by strengthening the immune system. Ruthig et al (2012) however, distinguish positive thinking from other theoretical perspectives and constructs applied to understanding positive adjustment to health and illness. The definition proposed in their study (Ruthig et al 2012) is that ‘positive thinking’ involves intentional cognitive strategies in order to experience and express positive thoughts and to actively suppress negative ones, whilst ‘benefit finding’ suggests that something positive can be gained from adverse events (Helgeson et al 2006, Tomich & Helgeson 2004). In the current study, P1 employed cognitive strategies by reviewing his University projects in an effort to reduce his anxiety, reclaim his identity and to realise future possibilities. Wilkinson and Kitzinger (2000) point to the way in which formulaic expressions such as ‘think positive’ can be used to summarise and underplay the seriousness of a situation in order to move a conversation on from a painful topic. As previously mentioned, health care professionals are also responsible for using such strategies as exemplified by the nurse advising one of the participants (P4) that it was important to be positive and doctors emphasising the notion of hope, “cure” and a “lovely new life”. Advising P4 to be positive when she was struggling to cope with members of her family who were unwell, financial worries and her own existential fears may not have been the most sensitive advice. This participant would have valued someone with whom to share her concerns but had limited social support at this time.

In a study carried out by Coolbrandt & Grypdonck (2010), interviews with patients undergoing SCT demonstrated that an optimistic attitude on the part of doctors has an undeniable influence on the ability of patients to face arduous treatment regimens. However, the nurses who were also interviewed questioned the honesty of the doctors’ approach and felt uneasy in the painting of an overly optimistic picture of treatment outcomes. In their
review of this study Dierckx de Casterle et al (2011 p238) argue that 'laying bare the function that optimism fulfils for patients' allows a more contextualized and differentiated discussion of the ethical issues raised in these situations. In a study involving nurses caring for patients with haematological malignancy, Leung et al (2011) found that nurses experience internal conflict related to their simultaneous need to help patients fight their disease and to prepare them for the possibility of letting go. The authors (Leung et al 2011 p 2175) used the terms 'letting go', not to reflect nurses' intents to abandon life but to release patients from perceived norms of the 'curative culture'. They suggest enhancing nurses' capacity to manage this dilemma and highlight the need for more research into educating and supporting nurses in work with patients who experience existential distress.

Participants in this study who used the actual term 'positive person' and 'positive attitude' the most will now be considered in light of the discussions above. The young female teacher (P3) who described herself as a positive person, expressed it in terms of her identity before her SCT and how this positivity was operationalised: “I'm a naturally positive person... I've always looked at the positives to anything, erm I always think well, what's the worst case scenario, can I deal with it, yes ok and let's get on with it.” Her interpretation of being positive in this and other examples serves to illustrate her approach to problems or difficult situations which she would endeavour to find a solution to. As evidenced in the findings, she also looked for the positive angle of being in hospital by making good use of her time and writing lesson plans when she felt well enough and also alluding to time saving by not having to wash her hair, the regrowth of which was delayed due to the effects of GVHD. These examples are more consistent with Helgeson’s (2006) notion of benefit finding as opposed to positive thinking per se. She also referred to focussing on something more positive by aiming to raise ten thousand pounds for leukaemia research.

In a study of media reports relating to 'cancer heroics' Seale (2002 p121) similarly found examples of men and women exemplifying considerable power over their reactions to illness including acts of bravery and physical and emotional challenge. One such lady began
climbing mountains ‘to symbolise to herself and others the personal mountain she was climbing’ whilst raising money for cancer research. The older gentleman (P7) who repeatedly made reference to the benefits of a positive attitude said it almost exclusively in relation to survival:

“It helped me just to sort of be positive about what the outcome was going to be, erm, you picture yourself being well again (laughs) and you’re going to be well again, that’s the theory at least isn’t it?”

Using positive imagery concurs with Ruthig et al’s (2012 p1245) definition of positive thinking where positive thoughts can include ‘positive expectations, positive healing imagery, and a positive attitude’. Whilst this participant acknowledges “the theory” behind a positive attitude he does appear to believe it with some conviction: “if you can keep a positive attitude, it does help tremendously. I, I believe so, anyway”. However, he does admit that he is making a conscious effort to maintain his positivity after feeling very down due to facing numerous setbacks in the first year following SCT. Whilst at one point he infers that a positive attitude and the right expertise may help to prolong life, he is careful to distinguish this from cases where neither of these attributes would be capable of affecting a poor outcome. Similarly in describing her initial and on-going reaction to her illness another participant (P8) advocates the adoption of a positive attitude whilst acknowledging that this must be self-motivated and not necessarily appropriate for everyone. A fourth participant (P2) who mentioned the word positive several times used it to reflect the attitude of others in addition to herself. In relation to her husband, it was his positive outlook and “doing so much” to help that was of benefit particularly when she returned home and was too fatigued to resume her normal domestic activities. The focus of her consultant’s positive approach was in direct relation to her blood results which she found very encouraging and made her appreciate the progress she was making biologically. Interestingly, this lady mentioned her general practitioner calling “not to offer anything positive, just, just support really”. Her own
positive feelings were linked with being able to eat normally again without the restrictions imposed when on anti-rejection therapy and also the passage of time post SCT.

5.7 The down side of positive thinking

Such is the often unquestioning and widespread acceptance of the value of being positive that patients may feel a social and moral obligation to suppress negative feelings of anxiety and uncertainty (Arman et al 2002, O’Baugh et al 2003). In her study of survivor loneliness in women following breast cancer, Rosedale (2009) found that the participants used various strategies including self-censorship to ensure they projected an image that met social expectations to be positive. These sometimes involved a deliberate attempt to withhold the truth about their feelings from fellow survivors for fear of projecting ‘an insufficiency of fighting spirit’ (Rosedale 2009). The distress felt by the women as a result of concealing their fears (Rosedale 2009) is indicative of the notion of ‘communication alienation’ described by Little et al (1998) arising as a result of cancer sufferers being unable to relate to those who have not been through a similar experience themselves or the social expectations placed on them to get ‘back to normal’ following treatment. The only difference appears to be the added pressure on survivors to aspire to media induced heroic status (Seale 2001). In the context of significant physical, psychological, social and emotional challenges faced by cancer patients (Taylor et al 2000, Doyle 2008) and specifically those living through and following SCT for haematological malignancy (Williams 2012, Jones & Chapman 2000, Cohen & Ley 2000) attempts to control negative thoughts by themselves or by others may compound their feelings of alienation and isolation.

In this study, participants articulated concerns for their families, knowing how stressful the situation was and in many cases continues to be for them. Participant’s wives present at the interview described the degree of psychological impact treatments and hospitalisation had on their husbands, their "paranoia" on first returning home and for some, the continued burden of disease and treatment complications. In addition, challenges such as changes in
self-concept, social role and financial strain are experienced and it is therefore not surprising that participants may feel a compelling obligation to put on a brave face. Given that participants said they found it difficult to interpret their bodies post SCT but showed evidence of utmost vigilance regarding their physical condition, it could be argued that what may be perceived as a negative attitude or “paranoia” is actually an act of self-preservation. This view concords with that of Ehrenreich (2009) who proposes that uncertainty and vigilance are important survival mechanisms more in keeping with realism than the ideology of positive thinking.

Condemning what he terms ‘the present day tyranny of positive thinking’ Holland & Lewis (1995) encourage people to use the coping styles most natural to them and for others to respect and support them. He argues that attitudes towards the mind-body-cancer connection has more to do with a person’s belief system and are therefore more aligned to religion than influenced by scientific evidence. In this study, as some participants begin to make a gradual recovery and in some cases face considerable on-going challenges to their physical functioning and general well-being the issue of how to live their lives becomes central to their existence. As suggested by Campbell & Swift (2002) chronically ill people face enduring physical and mental burdens forcing them to draw upon personal and moral resources in the face of continuing adversity. Findings from their study (Campbell & Swift 2002) investigating patient’s perspectives on the role of character in illness suggest that patients valued qualities such as courage, realism, self-respect, a sense of humour, hope and the ability to maintain good relationships with others.

5.8 Medical Talk

An important aspect of all of the participant’s experiences related to medical talk. In the main, these were positive, with an appreciation of expertise, being in safe hands, being listened to and the inherent optimism articulated to them regarding SCT. Conversely, a number of participants related experiences where they felt that communication had been
particularly blunt and insensitive. As reported in the findings, one gentleman had expressly requested not to be given details of his survival chances and articulated his distress when this occurred. This raises an interesting ethical debate regarding how much or how little prognostic information should be discussed and whether a patient’s requirement regarding the volume and nature of information discussed should be established prior to the commencement of treatment. Ernst et al (2013) found that haematology patients were often overwhelmed by the complexity of the illness and the therapy and did not want to assume any responsibility in medical decision-making. Participants in their study (Ernst et al 2013) reported a great deal of distress and very traditional paternalistic role expectations with regards to their health care providers, which limited their ability to partake in the decision-making process. Since scientific knowledge and medical know-how regarding stem cell transplantation (SCT) for haematological malignancy is an experimental, highly technical and developing field it is unsurprising that patients are not always involved in treatment choices. Whilst the aim of the current study did not set out specifically to investigate communication and information giving, they constituted significant findings. A number of participants were on trial chemotherapies and others noted the experimental nature of their treatments which changed course according to disease response. Although there was limited evidence of contributions to medical decisions about chemotherapy and stem cell transplantation per se one participant reported arguing his case to be treated following a brain seizure. There was also evidence that participants contributed to other medical decisions such as the example of one gentleman negotiating the discontinuation of his nausea inducing anti-rejection drug in favour of an alternative and the younger man wanting a scan to reassure himself and his clinicians that his disease had not relapsed. Other aspects of care when participants influenced decision making include those concerning admission to and discharge from hospital, declining the insertion of a naso-gastric tube for feeding purposes and a disinclination to discuss wig options because the timing did not feel right. These findings contrast with those of Seale and Charteris-Black (2008) as the
examples above involved a cross section of participants being involved in decision making irrespective of age and gender as opposed to a predominance of older men.

5.9 Information

Participants in this study and their care givers had differing attitudes towards their requirement for information. It appears that those wanting to know as much as possible gained an increased sense of control and independence with greater knowledge. This was particularly evident in critical situations when loss of control was felt more acutely, for example the two participants who related their experiences of the intensive care environment (P7, P8) as also found in Parker’s (in Claidin & Connelly 1999) study of patients’ recollections of their intensive care experience. In direct contrast a number of male participants held a diametrically opposite view with regard to receiving or actively seeking information. As previously highlighted, explanations for adopting this latter stance varied. The rejection of certain web based information was linked to a fear of taking information out of context and subsequently increasing anxiety through misunderstanding or misinterpretation. This applied to both pre and post transplant situations with the prime concern post SCT relating to the interpretation of physical changes and signs of disease relapse (P1, P6, P11). However, some participants (P6, P10, P16) were happy for their partners to take on the role of information gathering so long as these were from established and reliable sources.

As mentioned in the findings, P11 established his own blog in response to web-based questions from fellow sufferers on a disease specific website dedicated to practical advice for those undergoing SCT. Unfortunately, despite numerous efforts to access the blog, it was not found and therefore not possible to assess the nature of ‘conversations’ though from what he described they involved useful tips rather than emotional issues. Sharing of personal stories and dilemmas regarding treatment modalities for ovarian cancer (Kenen et al 2007) was found to be of considerable support to a group of women. Data was collected
from a website dedicated to women at risk of hereditary breast and ovarian cancers. Contradictory media information and medical uncertainty regarding the long term consequences of hormone replacement therapy led the women to seek additional resources. These included emotional support and specific experiential knowledge from one another engendering a unique sense of community and a high level of trust (Kenen et al 2007). Exploring the communications between Norwegian women with breast cancer as self-selected members of an on-line self-help group, Sandaunet (2008) identified the benefits of sharing both positive and negative aspects of their experiences. Whilst she found that fears were shared to a degree, these were almost exclusively after the event when the women felt more in control and able to participate in ‘socially desirable exchanges about cancer’ (Sandaunet 2008 p 1638). Furthermore, the group were bound by an ‘obligation to be considerate’ to each other which did not deny mention of difficulties but rather emphasised effective management of them. She therefore suggests that creation of an online potential ‘space for suffering’ was one which was underutilised for this purpose perpetuating the expectation of stoicism in facing cancer (Sandaunet 2008). One woman who did admit to feeling depressed noted the limitations of the group in responding to her, a view endorsed by Ehrenreich (2009) who received indignation from fellow sufferers when she tried to express anger about her own experience of breast cancer. Conversely, informants in Dickerson et al’s study (2006 E14) shared anxieties and frustrations ‘if we feel like whining...or complaining...we will just whine to each other’.

5.10 Emotional response to information

The time when several participants expressed a more emotional response to unwanted information was during the treatment phase of their illness when they felt most unwell and their survival was uncertain. In her paper exploring aspects of living with uncertainty Penrod (2007) found that an individual’s sense of confidence and sense of control are primary essences in determining the nature of the experience of uncertainty. When participants in
the current study faced issues of their own mortality, it makes sense to assume that their confidence and control were adversely affected, thereby increasing feelings of uncertainty and discomfort. In a study exploring the experiences of patients using the Internet for information and support to manage the self-care aspects of illness and treatment, including symptom management, Dickerson et al (2006) similarly found some participants who at times rejected certain information. One informant who had a bone marrow transplant for leukaemia preferred information one step at a time so she could adequately process it and was ‘scared away’ by statistical information whilst others found it useful to weigh up treatment options (Dickerson et al 2006 E12). In a study exploring the patient’s perspective of information needs regarding autologous bone marrow transplant (ABMT) Tarzien et al (1999) highlighted the complexities associated with this area of care. As one of the participants in their study (Tarzien et al 1999) affirmed, judging the right amount of ABMT information and the correct timing for giving it is "a real fine balance." Individual coping styles, the complex nature of the transplant process and the fact that it can pose significant risk to the patient whilst also providing a chance of survival are all factors for consideration (Tarzien et al 1999) as ‘patients themselves vacillate between wanting information about side effects and survival and simply wanting messages of hope and motivation’. An important finding in Tarzien et al’s (1999) study was that conversations between pre ABMT and recovered ABMT patients provided an opportunity to discuss and validate feelings experienced throughout the process. In the current study, participants highlighted limited possibilities to enter into conversations with other patients due to being in protective isolation facilities. The waiting areas for follow up consultations post SCT which were observed by the researcher were not necessarily conducive to social interaction. However, on the few occasions that interaction was possible, for example attendance at a support group and one occasion reported by a participant that took place in the waiting room, participants felt they gained much from sharing experiences.
Whilst for many, living through uncertainty has the potential for personal growth and a changed outlook on life, for others past experiences of uncertainty accentuate threats to confidence and controlling current situations (Penrod 2001). Illustrations of both these reactions are evident amongst the participants in this study and for one young gentleman in particular, both responses are apparent in his narrative. On the one hand he describes very eloquently his feelings of psychological distress in relation to disease relapse, challenging treatments and the momentous occasion of being told that he could go home. However, later in his account he acknowledges the life changing qualities of his experiences as evidenced in the previous chapter.

For the two participants (P7 and P8) who described their experiences of being on life support in an intensive care unit, references are made to ‘flashbacks’ suggesting a high level of existential distress associated with these events. Similarly, in a study reviewing the literature pertaining to emotional outcomes after intensive care Rattray et al (2008) found that being in intensive care can result in on-going significant emotional and psychological problems for a number of patients. Those who were less aware of their surroundings or who had frightening experiences had more post traumatic stress disorder (PTSD) symptoms after discharge than did other patients (Rattray et al 2008). Post traumatic stress is often associated with combat, violence, abuse, or natural disaster and according to American Psychiatric Association (APA 2000) is a stress related anxiety disorder comprised of exposure to a traumatic stressor, intrusive thoughts, avoidance, arousal or reactivity symptoms and negative mood and cognitions. Both participants in the current study retain vivid memories of being in an intensive care unit and indicate that this was one of the worst experiences for them. Individuals with PTSD normally avoid any stimulus that can be associated with the trauma, such as feelings and places (APA 2000). Whilst one participant (P8) suffered “panic attacks” when she had to have a naso-gastric tube for feeding purposes because it reminded her of feeling constricted by tubes during her intensive care experience, the comfort provided by the nurses who sat with her in the night alongside what she
expressed as applying her own logic alleviated her fright. As opposed to avoiding the place associated with his trauma, the gentleman (P7) pro-actively returned to the intensive care unit to proffer his thanks for the care he received. Nonetheless, there is no doubt that these events coupled with their overall illness experience have the potential to contribute to ongoing distress.

5.11 Recovery and liminality

In what he terms the remission society, Frank (1995) describes the position where people with diseases such as cancer and others of a more chronic nature are unable to resume what were once their normal obligations. Had the current study allowed for longitudinal data to be collected it would have been possible to assess what this meant for the participants further into their recovery. Frank’s (1995) use of the term remission society is exemplified by Sontag’s (1978) metaphor of illness as travel. She argues that people are citizens of two kingdoms; that of the well and that of the sick and whilst our preference is to reside in the former, we will all find ourselves citizens of the less desired place at some stage and perhaps for an undetermined time. For participants in this study, transition between states of feeling ill and feeling better not only fluctuate according to their disease status but also concern their physiological response to treatments and their undesired side effects. They use metaphors such as being “in limbo”, experiencing a “non linear” recovery and having “no reference points” to describe how this feels. Accordingly, as Andrykowski (2005) postulates, because HSCT survivors evidence deficits across a spectrum of physical, psychological, and social outcomes, it cannot be claimed that they will achieve a full restoration of health. This continued period of transition has resonance with the concept of liminality as described by anthropologist van Gennep (1960) who suggested that ‘the life of an individual in any society is a series of passages from one age to another and from one occupation to another’. Typically these rites refer to such life events as birth, marriage and death (van Gennep 1960 p3) where the rite of passage is characterised by ‘severing connection’ with an existing social state or position and re-entering or being born into a new social role.
The period between these two states is an ambiguous one, a liminal state, where an individual’s identity can be viewed as being temporarily suspended. Whilst participants in this study have experienced the life giving qualities of SCT it is evident that they have entered unknown territory in terms of understanding the extent or duration of their recovery. As slow recovery ensues, however, their new identity appears to be one that integrates their illness experience (Zebrach 2000) in order to accept a lower level of physical functioning and in some cases coming to terms with enduring uncertainty and coping with existential distress. In McKenzie and Crouch’s (2004 p140) research, an abiding aspect of liminality is ‘chronic suffering, a protracted condition of existence that commences abruptly with the cancer diagnosis’. In a later paper, Crouch and McKenzie’s (2006) analysis of three of their own studies drawing on the concept of liminality led them to the view that: ‘Confined to a borderline condition between well and unwell, surviving and being threatened, cancer survivors must endure the indeterminacy of both their lives and their social personae’.

Little at al (1998 p.1492) suggest that liminality is experienced in two phases: ‘acute’ and ‘sustained’. The acute phase occurs at diagnosis, characterised by disorientation, loss of control and uncertainty whilst sustained liminality refers to the adaptive phase involving reflection on life’s meaning and one’s own identity. For the participants in the current study there appears to be a protracted phase of ambiguity when the state of remission is not guaranteed and the possibility of life threatening infection or chronic GVHD pose on-going threats to health and recovery. Success or otherwise of SCT will determine their survival and subsequent experience of the adaptive phase (Little et al 1998). Whilst sustained liminality is not guaranteed for other patients undergoing treatment for non haematological cancer to an extent, they are not dependent on the receipt of donated cells for survival in addition to surgical, chemotherapeutic or radiotherapeutic treatments. Indeed, a unique position for the participants in this study is the adoption of a new biological identity by virtue of their stem cell donor. How this was experienced by a number of the participants varied with one lady blaming her short-temperedness on her donor “it’s not me, it’s her”, another questioned if
she should feel like a twenty three year old (the age of her donor) and in the case of the gentleman receiving cord cell transplants from two separate donors which genetic make-up would be adopted proving the efficacy and prowess of one nationality above another.

5.12 Support Groups

Patient support groups were available to patients and their families at both specialist treatment centres. Those who spoke about attending these sessions felt reassured by sharing experiences and one lady commented particularly on how encouraged she felt to meet longer term survivors. However, because participants lived some distance away and were attending out-patient appointments frequently it was difficult to build this in from a geographical and time perspective and also due to fatigue. The wife of one participant commented that the support group occurred at the same time as the follow up clinic and she felt it of greater importance to attend the consultation with her husband. Sherman et al (2005) reported on the themes generated within a support group for patients following SCT for haematological malignancy in existence for three and a half years. The group was borne out of an unmet need expressed by many patients to be educated and supported in their challenges post transplant. The findings were categorised into three major themes: physical, psychological and social many of which were similar to the experiences of participants in this study. Furthermore, Sherman et al’s (2005) study highlighted a similar finding in that participants articulated the incongruence of post transplant expectations. Not only did they report feeling unprepared for the life-long changes they were facing but they did not remember realistic discussions regarding post transplant life. This finding accords with a number of participants in this study who similarly had no recollection of conversations about the transplant experience and the post transplant experience or if they did, it did not adequately prepare them for what was to come. As discussed in the findings chapter, the sense of feeling inadequately prepared experienced by several participants centred on two aspects. In some cases they were overwhelmed with the volume and complexity of information including discussions about survival outcomes. Others acknowledged a
deliberate strategy of avoidance in seeking detailed information in an effort to reduce stress prior to treatment. Informants in Dickerson et al’s study (2006) highlighted the benefit of being able to discuss symptoms that their doctors did not have time to explain with others on a web-site. Symptoms such as difficulty sleeping and tingling or numb fingers were discussed and were similarly reported by participants in the current study. However, these symptoms seemed to be overlooked on occasions either because they were simply forgotten, not considered important enough to raise or because it was felt that the appointment time did not allow for much more than the blood test results to be discussed.

5.13 Survival

Novel treatments for haematological malignancies have been developing at a rapid pace offering greater chances of survival to those who previously faced an extremely poor prognosis. As evidenced in the findings, several participants make direct reference to being given prognostic information regarding their disease at the diagnostic and initiation of treatment stage but more specifically in relation to the SCT. In some instances, the way in which prognoses were communicated compared the percentage chance of achieving disease remission with chemotherapy and radiotherapy with that of undergoing conditioning therapy and stem cell transplantation. The possibility of developing a secondary cancer as a result of chemotherapy was also reported as being discussed. However, the gentleman (P7) reporting this particular aspect of treatment complication readily dismissed any anxiety related to it due to the length of time post-transplant that it was predicted, “I’m sixty seven now so in twenty or thirty year’s time, I don’t think I’m going to be so very worried about it”.

In view of the uncertainty experienced by all the participants in relation to survival whether acutely during treatment and associated with critical life threatening events or in a more enduring sense over the year following SCT, communication regarding prognosis is worthy of further discussion. In his thesis, Rich (2002) charts the progression of medical advancements in parallel with the relative decline in clinical prediction. Historically, the three
core elements of medicine involved diagnosis, prognosis and treatment (Hutchison 1934). In earlier times, diagnosis and prognosis were the more prominent until the advent of modern medicine between the 1930’s and 1980’s marking the evolution of the biomedical model and disease directed therapies. Significant curative advancement during this era included the considerable contribution associated with antibiotic therapies. Such was the effect of these on diseases such as pneumonia, that decreasing attention was given to prognosis in leading medical texts in favour of a focus on curative therapies (Christakis 1997). Prognostication, as described by Rich (2002) encapsulates the formulation of a patient’s prognosis by the physician and its effective communication to the patient or appropriate surrogate if required. His argument that the medical profession demonstrate a reluctance to carry out the latter is centred on the basis of doctors not wishing to acknowledge the limitations of medicine and their aversion to seemingly fail a patient by their inability to offer a cure. Furthermore that they may risk harm to the patient by sharing information they may not be able to understand or by removing any remaining hope that they have. The requirement for informed consent for experimental therapies led to a step change in practice regarding communication with patients including the disclosure of its potential risks and benefits. Consequently, the continuing development of anti-cancer interventions over recent years is thought to be a major influence. Not only was comprehensive explanation and consent a legal requirement for new treatments but their introduction a promise of improved outcomes. As a direct consequence, it is postulated by Rich (2002) that physicians felt more able to disclose a cancer diagnosis.

The relevance of the above arguments and analysis to the current study concern the nature of medical communication regarding treatment options reported by the participants. As noted by Rich (2002) it is likely that conversations regarding prognosis were instigated as part of the consent process and based on his argument that the ability to offer some hope of remission made these discussions less daunting probably contributed to their occurrence. Unfortunately, whilst progress has been made with new chemotherapy agents, remission
can still be relatively short-lived, particularly in cases of aggressive and diffuse disease leading to SCT being the remaining treatment option available. It is perhaps more understandable still in these circumstances that this highly technical and complex procedure is given such a high status in scientific medicine. Building on Rich’s (2002) argument that the act of consent and hope drives discussions about prognosis, it is perhaps unsurprising that participants report such phrases being used as “well, the bad news is you’ve got leukaemia, the good news is we’ve got the cure” and “you’ve got to think it’s a new life”, since the only other option would be to discuss the possibility of death and the role of palliative care. As highlighted by Kelly (2000) the experience of those who fail to respond to aggressive treatments or those who face death as a result of treatment-induced complications has been relatively under-researched. As one participant (P7) stated, “I mean I went into this knowing, I mean the very sobering thought that up to thirty per cent of people will be dead in the first three months”.

In a study examining the influence of evidence based medicine in shaping the nature and direction of biomedical practice and organisational culture, Broom et al (2009 p 198) found that haematologists had a greater tolerance for ‘poor’ evidence than their medical oncology counterparts. It is interesting to note the stance taken by five women diagnosed with breast cancer in Sinding et al’s (2010) study in relation to making treatment choices. Whilst acknowledging the importance of an evidence base for judging the efficacy of certain treatments, the women’s measure of their physician’s expertise was in their clinical application of such evidence in individual cases, as one lady stated ‘and so I’m wanting your best intuition and gut even though we don’t call it that because that’s not very medical, that’s not professional’ (Sinding at al 2010). Indeed critics of evidence based medicine argue that it undermines other forms of knowledge and risks replacing professional acumen and decision-making with ‘formulaic’ practice (Trinder cited in Trinder & Reynolds 2000). One clinician in Broom et al’s (2009) study suggested that a different philosophy exists within haematology whereby patients are potentially over-treated in an effort to cure or at least
prolong life. Oncologists on the other hand were seen to ‘view themselves as palliative care physicians’ (Broom et al 2009 p196) and therefore perhaps more accepting of the fact that many patients would have relatively poor prognoses. On entry to the haematology speciality, the researcher of this thesis recalls the words of a clinical nurse specialist who told her ‘in haematology it’s lift the lid of the coffin and try one last treatment.’ It should be reiterated here that whilst participants in the current study were grateful for a chance of survival with SCT, several gentlemen alluded to being pushed to their ultimate level of physical and psychological tolerance during treatment, that it was “too late to go back” or that if they had been older, they would not have wanted to go through it.

5.14 Unmet need

As previously mentioned, all participants in this study value the expertise of their specialist medical teams and the opportunity to undergo life-saving treatment. There are however, areas which became apparent where significant distress could potentially be reduced. The speed of diagnosis, initiation of treatment and lengthy hospital stay caused shock and confusion as their normal everyday activities were severely disrupted. Family members are similarly affected, whereby life becomes a continuous cycle of travelling often considerable distances to visit their loved ones whilst trying to care for children, maintain employment and maintain the home. As one participant observed, having one day of sickness necessitates significant arrangements to manage work and the family, let alone a year. Many participants made reference to financial hardship and whilst not established if they were eligible for a grant or other form of support, it appeared to be a considerable worry. Concerns ranged from meeting the high cost of travel, parking and subsistence when visiting or attendance of appointments to being unable to meet mortgage payments due to loss of salary. Advice regarding such issues would have been welcomed during hospitalisation for treatment and on return home. Supporting this finding, Meehan et al's (2006) study also highlighted the significant financial and time requirement on the part of caregivers of autologous SCT recipients during the period of hospitalisation. Similarly Hamilton et al (2014) suggest that
serious economic challenges can be viewed as chronic stressors capable of reducing survivors’ mental and physical well-being following SCT.

Discharge decisions are seemingly determined by satisfactory blood counts and a minimum level of functional ability. Whilst some participants report receiving information regarding diet, medication and infection avoidance, the responsibility for self-monitoring and symptom management felt overwhelming to some in the context of leaving the relative safety and care of the hospital environment. Although the participants looked forward leaving hospital it appears that an increased emphasis on the mental preparation required to make the transition could be of benefit. In their study of autologous BMT survivors Cohen and Ley (2000) similarly report that participants experience a fear of leaving the protective environment of the medical centre upon discharge home. A recent study (Cooke et al 2009) sought to develop an educational programme to support patients discharge from hospital following SCT based on topics identified by patients. The programme includes a pre-transplant teaching session and progresses throughout hospitalisation in preparation for discharge and subsequent follow up. The study's results showed that psychosocial issues were the most prevalent for transplantation recipients. Proponents of a survivorship care plan (Beavers & Lester 2010) suggest that advanced practice nurses in the ambulatory setting would be uniquely positioned to guide survivors from acute to short-term care, the sub-acute phase and successive long-term chronic phase of survivorship. Similarly Oguz, Akin & Durna (2014) highlight the need to provide patient-family education and psychosocial support for symptom management. Their study included only patients following autologous SCT and therefore the need for those following allogeneic SCT is likely to be greater.

Participants in this study are monitored closely at the specialist treatment centres and have access to telephone advice for emergencies but what appears to be lacking is a semblance of longer term support to address the practicalities of living with enduring fatigue, weight loss and the fear of disease recurrence and other psychosocial issues. Although much of their
narrative focus relates to the acute phase of illness, there is no doubt that participants are
endeavouring to gauge to what extent their previous life will be restored.

Current policy (Macmillan 2013) highlights a deficit in knowledge regarding the longer term
implications of cancer survival which is shared amongst health care providers and patients
alike. Elliot et al (2011) also suggest that whilst the profiles of individuals living with and
beyond cancer have marked similarities to those with chronic or long term conditions, there
is little progress in designing models of cancer follow up care to meet long term needs.

5.15 Storytelling as an ethical duty
As stated in the rational for choice of methodology, researching lived experience is
advocated by Dierckx de Casterle et al (2011) not only in its own right but for its significant
contribution for health care ethics. In earlier work, Frank (1995) suggested that the ethical
imperative of illness stories are located in issues of testimony and witness, and thus, in
‘wounded storytelling’ the physical act becomes the ethical act. He refers to a personal and
social responsibility to share illness stories, and in so doing, ‘recover the voices that illness
and its treatment often take away’ (Frank 1995 xii). Participants in this study appeared to be
endeavouring to make sense of their experiences. This was demonstrated by repetition,
faltering speech, questioning and on occasions appearing to reach an understanding or
realisation. Some of the narratives exhibited sticking points where a part of the story kept
recurring, perhaps because the tellers had failed to assimilate the experience. Caruth (1996)
suggests that unassimilated traumatic experiences are characterised through behaviour
such as unwitting repetition referred to as ‘repetitive reporting’ by Ben Ezer (1999:35) where
an event is recounted, usually in detail, several times during the story. Felman (1992)
suggests that when events are extraordinary and sudden they are difficult to assimilate and
fit into appropriate frames of reference even when reflective space is available to
accommodate this process. The participant’s readiness to contribute to this current research
was related to a desire to help others but could also be a desire to process their experiences
particularly as these involved such distress and trauma. Another reason for participant’s willingness to share their narratives with an ‘outsider’ could be associated with their reluctance to overburden loved ones who shared their suffering. Bartley et al (2013 p1) found that high levels of ‘holding back’ or withholding of discussing disease-related thoughts and emotions were significantly related to lower levels of social well-being. Reluctance to discuss emotive issues with his wife (P6) was described in the findings though this gentleman does admit that there could have been mutual benefit in doing so. His disinclination seemed to accord with Cordova et al’s (2001) suggestion that patients may limit discussions about their concerns for fear that dwelling on cancer-related thoughts may increase their personal distress. It is apparent from analysis of the interview with P8 that her husband is experiencing acute anxiety about her condition and that she does all she can to reassure him. This evidence is supported by field notes and the pen portrait recorded at the time of data collection and concords with Gotcher’s (1995) findings that patients may hold back from discussing health concerns to avoid upsetting the caregiver.

A number of authors suggest that storytelling may be an effective intervention for patients who are critically ill because it allows for positive reappraisal and regaining a sense of control in an out-of-control situation (Pennebaker, 2000; Polkinghorne, 1996; Sakalys, 2003; Sandelowski, 1994). Similarly, Hubbard & Forbat (2012) postulate that oral narratives can help to alleviate the distress associated with uncertainty and a disrupted biography. As a consequence of their integrative literature review, Adelstein et al (2014) recommend the development of a structured narrative intervention designed to promote meaning-making amongst survivors of SCT. This view accords with Frank’s (1995) recognition that many illness stories allude to a sense of being shipwrecked by the storm of disease and that metaphorically speaking, storytelling assists in repairing the wreck.
5.16 Summary of chapter

This chapter has discussed key findings of this study with reference to themes emanating from the data analysis and in relation to the wider literature. The findings suggest that the experience of treatment with allogeneic SCT and the recovery journey within the first year post SCT is an uncertain one. The immediacy of illness and existential crisis and recovery journey have conceptual links to existing knowledge of chronic illness as biographical disruption (Bury 1982), liminality (Little 1998)) and consideration of haematological malignancy as a chronic illness. Participants coping strategies, including being positive and determined and communication and informational matters, have been discussed and unmet psychosocial and emotional needs highlighted.
CHAPTER 6

Conclusion

This chapter concludes the thesis and presents a summary of the study findings. The study adopted an interpretive phenomenological methodology to explore individual's experiences of returning home following allogeneic stem cell transplantation. Whilst participants in this study were treated at two specialist treatment centres in the United Kingdom, key themes and implications for practice may be relevant to patients treated elsewhere. This chapter will also present the strengths and limitations of the study and propose suggestions for further research.

6.1 Summary of existing knowledge

Quality of life studies have highlighted physical, psychosocial and emotional domains which present challenges to patients following allogeneic stem cell transplantation. As discussed in the literature review, however, patients QoL scores often belie the overall effect that treatments and on-going complications can have on an individual's ability to resume their previous life activities and commitments. Over recent years studies of patient experience have begun to highlight the challenges faced, not least to make sense of the traumatic events leading up to and during treatment. Less attention has focussed specifically on patient's experiences of returning home following allogeneic SCT. Close monitoring and interpretation of the participant’s blood profile occurs frequently in the immediate post-transplant period and continues regularly depending on recovery of ‘normal counts’ and the adoption of their donor’s blood group indicating successful engraftment of the donors stem cells in the recipient's bone marrow. Participants also have access to their specialist teams for consultations and advice in emergencies. However, there is a dominant biomedical focus to these interactions and whilst reassuring to know that ‘blood counts are good’ this emphasis ignores or at least underestimates the biographical disruption that people struggle
with. Once patients return home research suggests that individuals and their caregivers
endeavour to manage recovery in the face of enduring uncertainty and a significant
alteration of previously held family roles and responsibilities. Whilst hospital follow ups are
frequent, they do not or cannot always address relevant health and psychosocial needs
leaving people feeling vulnerable and without adequate support.

6.2 Summary of the findings of this study
The two overarching concepts emanating from the experiences of individual’s returning
home following allogeneic stem cell transplant are the immediacy of illness and existential
crisis and the recovery journey. These two concepts are inextricably linked as patients
endeavour to come to terms with an acute disruption to their bodily and biographical status.
In the first year of returning home, participants face considerable uncertainty about their
future in terms of survival and resuming a sense of normality. Whilst participants
acknowledge that “everybody is different” they articulate a need to understand more about
what their recovery would look like in the future, how long it would take and how much to
expect in terms of returning to their previous sense of normal. From a physical point of view,
treatment side effects such as fatigue, the constant threat of viral and bacterial infections
and cGVHD hamper recovery and render the participants in a state of sustained liminality. It
is interesting to note however, that it is sometimes the less immediately life threatening side
effects that cause most concern such as recovering taste after radiotherapy. As the
participant who experienced enduring loss of taste and significant weight loss explained, at
least infections could be treated quickly and effectively with antibiotics (such had been his
experience to date). From a social perspective, whilst one participant made the decision to
retire, others had no idea what their future held in respect of returning to paid work, or in the
case of the youngest participants, if and when they would be able to pursue their chosen
careers. Support from family members was highlighted as being crucial at the time of
discharge from hospital and participants felt both surprised and guilty at the length of time
they continued to depend on them. Household tasks and contributing to childcare were the
two main concerns but participants were also conscious of the effect their situation had on their family’s social pursuits. Even going out for a meal was difficult due to dietary restrictions in the first 3-6 months post SCT.

For those with less family involvement, participants felt alone and isolated with their worries and lacked support even in having someone with whom to talk. Nonetheless participants set themselves small goals to achieve such as being able to pull the starter motor on the lawn mower in one case and being able to help with cooking, shopping, other activities around the home and resuming gentle exercise in others. One participant, a keen sportswoman felt comfortable with pacing herself and found herself alternative forms of activity such as cycling instead of touch rugby. However, others would have appreciated direction as to how much to ‘push themselves’. In spite of these challenges, participants believe that being positive and determined in the face of adversity can help them to remain focussed on recovery, though caution is advised regarding health care professionals prescription of it.

6.3 What this study adds to existing knowledge
This study highlights the need for increased attention to the physical, psychosocial and emotional effects of haematological malignancy. The social needs of the participants are evident at disease onset as they endeavour to organise their life situation to accommodate the severe disruption caused by their illness. As arduous treatment regimens commence the participant’s concerns for their loved ones run in parallel with fears for their own survival. Consideration of the concepts of biographical disruption and liminality have assisted exploration of the participant’s experiences of returning home following allogeneic stem cell transplantation from a sociological perspective. There is some evidence that having an opportunity to assimilate traumatic events could be of benefit and enable participants to transcend the physical, psychological and social losses experienced through illness and to
redefine themselves. Exploration of the participants coping strategies has raised interesting arguments both for and against the virtue of positivity.

Evidence of financial hardship and the stresses associated with loss of earnings and navigating the benefit system concur with other research. Whilst policy (NCSI 2013, MacMillan 2013) aims to mitigate against such difficulties it is evident that there is a need to improve processes and access to relevant agencies.

6.4 Researcher lessons learned

A favourable ethical opinion was obtained through a National Research Ethics Service (NRES) committee in London following minor changes to the participation information sheet and data storage arrangements. The Research and Development (R & D) approval process at the specialist centres was perhaps one of the most challenging areas to achieve and impacted on timescales envisaged for the project. There were two elements of significance; one concerning the requirements for approval in addition to it being my first experience of R & D since 2001 and the other concerned severe staffing issues within the R & D departments at both specialist centres. Provision of a comprehensive list of the information required by the R & D committee would have been helpful and this will be suggested to departments at both centres. The research ethics review procedure proved straightforward, once all required documents were submitted though the process did take eight months to complete. Honorary contracts were obtained at both centres and involved very thorough processes including occupational health checks and assessment of infection risk. I was particularly impressed with this level of surveillance since I was interviewing participants who were still immune-compromised. However, the checks all took valuable time to complete. Defining a research question earlier in the programme and subsequent development of a study proposal could have helped to mitigate against R & D delays allowing collection of data to commence earlier. However, the time taken to thoroughly review the literature and to identify a gap in knowledge was time well spent.
Undertaking the Doctorate in Clinical Practice has allowed me to combine a clinical and managerial role in acute care with an unparalleled opportunity to extend my knowledge base and to conduct research in a highly specialised area. The modules undertaken served as a basis for the research and also influenced the way in which I have developed as a practitioner. Having a greater political awareness and the ability to source and appraise evidence effectively has led to successful practice change within the haematology speciality. Similarly, my experience as a practitioner and manager undoubtedly served as a sound basis on which to further develop my interviewing skills and to organise and structure my thesis. Having a wide network of colleagues both within and external to my place of work was paramount in achieving access to patients and of significant value in planning and completing the project. Some of the most challenging times faced on this journey as I have strived to achieve the required level of academic work have been the most developmental and of significant personal gain. I feel that I have developed the ability to manage more complex tasks than previously and a greater resilience to face the inevitable self-doubt associated with research and operating outside of one’s own usual ‘comfort zone’. (see Research Log and Overview of the Integration of Knowledge, Research and Practice for more detail).

6.5 Strengths and limitations of the study

The small sample of participants in this study were recruited from two specialist treatment centres in the United Kingdom and therefore reflect the experiences of these specific populations. It is feasible that experiences could be different for those treated in alternative treatment centres in other geographical locations and cultural contexts. However, recruitment from two centres guaranteed sufficient participants for the study and as stated previously, having a community of practice assisted with access to patients and collegiate support for the study. It is conceivable that the findings in this study could be transferable to other settings and may have resonance for other patient groups facing a protracted and uncertain course of recovery from illness. Had the current study allowed for longitudinal data
to be collected it would have been possible to assess what this meant for the participants further into their recovery.

One of the major strengths of the study was the willingness of the participants to share their stories and because of the qualitative nature of the study, the rich source of data gained. Whilst some of the findings concurred with data from quantitative quality of life studies, such as the participant’s fatigue and other physical and psychological manifestations of treatment, a deeper understanding of how these experiences effect the life worlds of the participants has been possible through their narratives. Although the number of participants was only fifteen, the volume of rich data obtained from their narratives was substantial. Any more data would have been overwhelming and any less would not have captured the spectrum of participants from the point of view of age, disease, symptoms, contextual factors and experience.

6.6 Table 9. Recommendations for practice

<table>
<thead>
<tr>
<th>Issue</th>
<th>Recommendation</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of preparation to return home</td>
<td>Specialist treatment centres to offer a structured but individualised education programme for patients pre and post SCT.</td>
<td>Develop an educational programme and support programme for patients which commences at the beginning of their stem cell transplant experience.</td>
</tr>
<tr>
<td>Lack of support at home</td>
<td>Provide on-going support for patient’s physical, psychological and social needs on discharge home. Include proactive telephone contact and home visits to monitor and assess including late effects of treatments such as GVHD post SCT. Promotion of interventions to prevent unplanned hospital admissions. Consideration of telemedicine.</td>
<td>Develop a business case to support a community based Advanced Nurse Practitioner role. Seek charitable funding to set up the post and evaluate after six months.</td>
</tr>
<tr>
<td>Financial hardship</td>
<td>To provide patients with information regarding financial support early in their diagnosis and treatment period. To provide information for patients and employers regarding preparation and options for returning to work.</td>
<td>Develop comprehensive patient information of benefits and charitable organisations. Consider the role of occupational health to support vocational rehabilitation.</td>
</tr>
<tr>
<td>Isolation due to immune-suppression and geographical distance from specialist treatment centre</td>
<td>To provide a means for patients to keep in contact with each other for support. To provide an additional forum to enable patients to process critical events and the on-going uncertainty that they experience.</td>
<td>Investigate ways to enable patients to share their experiences with each other. e.g. creation of a website linked to the specialist centre.</td>
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</tbody>
</table>
### Table 10. Recommendations for Education

<table>
<thead>
<tr>
<th>Issue</th>
<th>Recommendation</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical focus during and post</td>
<td>To raise awareness amongst staff to provide psychological and social support</td>
<td>Effective use of the Holistic Needs Assessment (HNA) document as</td>
</tr>
<tr>
<td>treatment</td>
<td>by signposting patients to appropriate services when required</td>
<td>promoted by the Cancer Alliance</td>
</tr>
<tr>
<td>Dissemination of study findings</td>
<td>To provide a forum for patients to meet and explore some of the themes raised</td>
<td>To continue the collaboration between the Arts &amp; Music and Health &amp;</td>
</tr>
<tr>
<td></td>
<td>in the study and through their individual experiences. To explore possibilities</td>
<td>Social Science Faculties instigated at through the viva process by</td>
</tr>
<tr>
<td></td>
<td>that the arts could have on patient experience and recovery.</td>
<td>arranging an event for patients, academic and clinical staff at the</td>
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<tr>
<td></td>
<td></td>
<td>University of Surrey in 2015</td>
</tr>
<tr>
<td></td>
<td>To pursue the opportunity to present the findings at the European Cancer</td>
<td>Submit abstract by April 2015</td>
</tr>
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<td></td>
<td>Congress</td>
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### 6.8 Implications for further research

Whilst the aim of this study was to understand the experiences of patients returning home in the first three months to a year post SCT a qualitative longitudinal study examining patient’s recovery and on-going health and social needs warrants further attention. Further exploration of the uncertainty, coping strategies and information themes from the health care professionals and care giver perspective would be of benefit.

In summary future studies could consider:

- implementation and evaluation of an education programme pre SCT during the treatment phase and post SCT to better prepare individual’s for the experience from a medical and social perspective
- a longitudinal study to explore patient experience 1-5 years post SCT
- exploration of the provision of an advanced practice nurse in the community to support transition home following allogeneic SCT and future monitoring of treatment complications
• the introduction of telemedicine and locally supported follow up to reduce fatigue and infection risks to patients when attending follow up appointments a long way from home
• introduction and evaluation of locally provided exercise programmes
• an ethnographic study to explore the discourse between patients and health care professionals in the in-patient, out-patient and haematology day unit settings

6.9 Recommendations for clinical practice
Advising and educating health care professionals about how they can most effectively address the pressing psychosocial needs of patients and their families whilst also providing highly specialised and technical medical care could have a positive impact on their overall experience. As suggested by authors of recent research and in accordance with findings in the current study, interventions such as an educational programme commencing prior to SCT organised in a quality of life framework, that is: physical, psychological and social domains including spiritual and survivorship aspects would be of assistance to both patients and caregivers. Given the issues relating to fatigue and an excess of medical appointments the use of social media such as skype could be employed to access educational sessions in real time and enhance patients’ ability to support each other. Early intervention to prepare patients for life beyond treatment for cancer is supported by recent policy and aligns with the notion of ‘prehabilitation’ (NCSI 2013). There are also implications for managing both the immediate and longer term effects of treatment including support of those with disease relapse and consideration of palliative care.

Employment of an advanced level practitioner to support patients in their transition home following allogeneic SCT and on-going management of acute and chronic symptoms could provide significant reassurance to patients and their families. This degree of surveillance alongside the provision of specialist blood testing locally could also reduce the number of hospital attendances required for follow up. Administration of intravenous antibiotics at home
could be considered in some cases reducing the need for readmission to hospital though this may be judged too high a risk for some patients.

Survivors of allogeneic stem cell transplant are likely to have a requirement for supportive care for some months or possibly years after treatment as they exist in a state of sustained liminality, between illness and wellness, facing complications of an acute and chronic nature. Post treatment threat of disease recurrence and the associated uncertainty is a key feature of the liminal life (Little 1998). Nurses and health care professionals can provide support for patients by having an understanding of liminality, listening to patient anxieties and providing information and symptom control as required. For those who cannot return to their former employment or educational pathway there is a requirement for vocational rehabilitation and a robust system for welfare advice and guidance.

6.10 Dissemination of findings
The aim of undertaking the Doctorate Study was to combine considerable experience of clinical practice with an academic programme capable of furnishing me with the skills to undertake research of a sufficiently high quality to contribute to a growing body of knowledge in health care. In the event, since blood cancers and their treatment was not my area of expertise this thesis has enabled me to learn an enormous amount in this specialised field. A summary of this research has been submitted to a national peer reviewed academic nursing journal and has recently been presented at the British Sociological Association conference. It will be shared amongst health care professionals working in cancer care and more specifically those working in stem cell transplant centres through presentation at a European Bone Marrow Transplant conference (as agreed on receipt of a travel scholarship to attend the 2011 conference at the start of this research journey). Findings will also be shared with patients undergoing SCT, possibly through involvement in patient support groups.
My aim is to influence others to consider the social implications of ill health as I have been influenced through observations in clinical practice and a considerable number of inspirational scholars, academics, researchers, sociologists, anthropologists, clinicians and patients themselves.

6.11 Summary of chapter

This chapter has presented a summary of the study findings. Implications for clinical practice have been suggested which could have a positive impact on supporting patients transition home following treatment for haematological malignancy. The limitations of the study have been discussed and recommendations for future research proposed. The original aim of the study was to explore the experiences of individuals returning home in the first year post-allogeneic stem cell transplantation. The themes which emerged lead to consideration of haematological malignancy and its associated treatment side effects as a chronic illness and participant needs equivalent to with those who face other long term conditions.
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PARTICIPANTS INFORMATION SHEET

Research Study: To explore the patients’ experience of returning home following allogeneic stem cell transplantation.

You are invited to take part in a research study relating to your recent experience of returning home after treatment. I am a nurse and researcher and this project is part of my doctoral, higher degree studies. Please read this sheet before deciding whether or not to take part in the study.

What is this research study about?

I am trying to find out about your experience after your return home following your stem cell transplant. I am interested to find out how you are managing at home, and what kind of support you are getting.

Why have I been invited to take part?

Because you have returned home following a stem cell transplantation within the last three months to one year.

Do I have to take part?

No, you do not have to take part. If you agree to take part, you can keep this information sheet. We will also ask you to sign a consent form. You can change your mind at any time, and you will not be asked for a reason. If you do not wish to take part, or change your mind later, it will not affect your treatment or care in any way.

What would I have to do?

If you agree to participate you will be invited to talk to me about your experiences. You will be asked to speak about anything you think is important about having a stem cell transplant, returning home, any follow up care and support you receive and the challenges you face. The interview will last between 45 minutes and 1 hour and the conversation will be recorded. The researcher will be happy to come to your home, or meet you at your hospital, or anywhere else convenient. If you decide to travel, your expenses will be paid. You may be contacted after the interview to check that the researcher has understood what you have said and to ask further questions if required. The researcher will ask for your permission to obtain clinical details from your medical team and if necessary from your medical record. This will provide valuable information regarding your treatment. The researcher will also ask your permission to inform your GP that you have agreed to take part in this study.
What are the possible benefits of taking part?

It is unlikely that taking part in the study will help you directly, however, some people find that talking about their situation can make it easier to deal with. It is hoped that the information gained will contribute to research that may help those undergoing stem cell transplantation in the future. I will provide you with a summary of the findings of the research study if you would like one.

What are the risks?

It is not anticipated that there will be risks to your well-being by taking part in the research. However, if you felt distressed at any time when relating your experiences, the interview would be stopped and immediate support offered. It would be your decision as to whether you wished to continue. If you felt that you would like to contact your clinical team or be referred for professional support, the researcher can arrange this for you with your permission.

Will my information remain confidential?

Anything you say will not be linked to your name or personal details. The recording and any written material will be stored and destroyed in accordance with the Data Protection Act 1998. The only exception to this confidentiality would occur if anything came to light which was linked with unethical practice. In such a case the researcher would have a duty to disclose this information but would discuss this with you.

What if there is a problem?

If you felt there was a problem or have a complaint about any part of the research process or the researcher please contact the researcher’s supervisors at Surrey University:

Dr Anne Arber or Dr Ann Gallagher
Duke of Kent Building
Surrey University
Guildford
Surrey

Dr Anne Arber Tel: 01483 686768
Dr Ann Gallagher Tel: 01483 686711

Contact Details

If you would like to discuss any of the information provided here, please feel free to contact the researcher, Liz Dunn at Guys & St Thomas’ Hospital on 0207 188 2792 or 0207 188 7188 and ask for bleep 0813. Alternatively please speak to your Clinical Nurse Specialist or Consultant Haematologist.
Taking Part in the Research

If you would like to take part in this research, please fill in your details below and give the tear-off part of this information sheet to your Clinical Nurse Specialist or Medical Consultant. Alternatively, please send directly to Liz Dunn in the pre-addressed and stamped envelope provided:

Liz Dunn
c/o Haemophilia Reference Centre
1st floor North Wing
St Thomas’ Hospital
Westminster Bridge Road
London
SE1 7EH

Liz Dunn, researcher from the University of Surrey will then contact you to answer any queries and if you are happy to proceed, arrange a suitable time for the interview to take place.

Name:  -------------------------------------------------------------------------------------
Tel:  -------------------------------------------------------------------------------------
Mobile:  --------------------------------------------------------------------------------------
Email:  -------------------------------------------------------------------------------------
Address: -------------------------------------------------------------------------------------

Please * your preferred method of contact.

Signature  ----------------------------------------------------------

Signature of Referring Clinical Specialist Nurse/and Medical Consultant

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The study has been reviewed by the National Research Ethics Service Committee – London Queen Square.

Thank you for taking the time to read this Information Sheet
Appendix II: Pen Portraits

Participant 1
Participant 1 was extremely keen to participate in the study from the outset of meeting him with his mother at the post-transplant clinic. He said he felt he had so much to say that he wanted to tell me there and then. When I rang a week later, he was making notes in preparation. On the day of the interview he was not feeling great – nauseous and on high dose steroids due to diarrhoea over the past week. However, he was determined to go ahead. The overall sense of his story is that the transplant experience is one of great magnitude referring to it as ‘a big thing’, ‘a huge thing’ and one that has had a profound effect on his life and also on his work.

The massive step of leaving 'your cocoon' and beginning to build up your life again brings with it the overwhelming responsibility of suddenly having to 'take charge' again when you are feeling at your most physically and mentally vulnerable. You are weak, there’s so much to be ‘on top’ of and you need your wits about you.

In spite of this however, he feels that his experience has enabled him to share a different view of cancer, opening his mind and others through his artistic work and expression. ‘You can’t express your feelings, you need objects’. Positive aspects of his experience include age appropriate care, support and respect for his concerns from his mother and the health carers, the ability to express feelings through art and an opportunity to pursue a life’s ambition.

Aged 22 years. Art school studies interrupted due to Hodgkin’s Lymphoma.

Participant 2
Participant 2 described her treatment experience for.... as being fairly straightforward and wondered if she had enough to say that would be useful to others. She mentions on many occasions throughout the interview the extreme tiredness she has felt and that she had never expected it to continue for this long. She also mentions several times that advice about how far to push herself would be useful and also to have a point of reference, including meeting someone else in a similar position.

She concentrated predominantly on the physical aspects of her experience but on gentle enquiry does mention how emotionally tough it was to be isolated from her new Grandson at the time of her treatment and early recovery. She appears to have a very stoical attitude towards her illness and suffering and repeatedly acknowledges the enormous support she has received from her husband – in fact that she could not have got through it without him particularly in relation to the domestic chores. She also acknowledges the support of her friends and wider family and the importance of receiving encouraging words from the consultant.

Aged 67 years, married and retired.

Participant 3
The main feature of Participant 3’s narrative was her motivation and determination to make the best of her experiences, resume her previous life with some adjustments and take on new pursuits i.e. fund raising to ‘give something back’ marking her thirtieth year - one which at diagnosis she was not guaranteed to survive. She describes her diagnosis and treatment as fairly straightforward though there were potentially devastating consequences during this journey, for example the speed of treatment required and subsequent effect on reproduction, an extreme reaction to a trial drug and on-going infection risks. As a teacher, she spent time in hospital preparing lessons in an effort to retain some normality in her life.
She describes positive aspects regarding relationships – wonderful support from her parents, a new partner who ‘stuck with it’ and a friend who ‘came back’ after a major fall out. At the time of the interview she was approaching the anniversary of her stem cell transplant. She had returned to work quickly and successfully, maintaining a reduced timetable but engaging in extra-curricular activities such as the school play, sporting activities, applying for promotion and similarly resuming personal exercise and travel pursuits.

She described full confidence in her medical teams both locally and at the specialist centre and had full confidence in their knowledge whoever she asked for information. Throughout her narrative, this participant displayed incredible strength and resolve which she attributes to her inherent optimism:

‘I’ve always looked at the positives to anything. I always think well, what’s the worst case scenario, can I deal with it, yes ok and let’s get on with it.’

Aged 29 years teacher – had returned to work.

**Participant 4**

Participant 4 described her experience of returning home as a little extreme since her situation was complicated by her mother suffering from dementia and her son from a long-standing depressive illness. Both members of her family depended on her a great deal so she was extremely anxious about them whilst in hospital. She describes the hospital as providing a safe cocoon from the outside world which was both a relief and frustrating since she was not able to care for them. She had arranged respite care for her mother though due to her own uncertain prognosis she was advised to consider this as a permanent arrangement.

She describes a strengthened relationship between herself and her sister developed as a result of her being the donor of her stem cells. Unfortunately her sister’s husband was diagnosed with cancer and her niece’s husband died suddenly preventing further support on her return home.

Participant 4 states how grateful she is for the treatment she has received and appears to be reconciling herself to living with a degree of uncertainty regarding her future. She has been told that if the disease relapses, there are no further treatment options available to her.

Her prevailing worry is for her son as she feels unable to provide security and psychological support for him since due to the uncertainty of her treatment outcome it was necessary to take early ill-health retirement. She is struggling financially and the future of her home is at risk due to her inability to meet mortgage payments.

She comments on the care she has received and the encouragement she receives from her consultant. She does however mention how beneficial it would be to share experiences with others but has not been able to source a relevant support group or to receive psychological assistance from MacMillan.

**Participant 5**

Participant 5’s mother was present at this interview and at certain points the narrative is largely dominated by her. This did not appear to be a problem for her and when she wanted to make a point or to disagree, she did so and made her point very clearly. Participant 5 was a pastry chef and her apprenticeship in patisserie and confectionery was brought to an abrupt halt when she was diagnosed with aplastic anaemia. Suffering numerous episodes of critical illness she remained in hospital for many weeks waiting for her condition to be stable enough to receive chemotherapy conditioning prior to transplant. She felt cheated of an ever diminishing opportunity to return home for a brief period prior to the transplant itself.

She relates her observations of good and bad care practice throughout her hospital stays highlighting the positive effect of genuine caring received. Her debilitating illness results in
her being dependent on a wheelchair for outings and she comments on the poor attitudes and stigma displayed by certain people in relation to her disability. Both she and her mother have a heightened awareness of the benefit of bone marrow donation and are campaigning for more Afro-Caribbean donors.

Aged 23 years, single, pastry chef

**Participant 6**
Participant 6 describes his journey as relatively straightforward though does refer to various ups and downs and a non-linear disease and treatment experience. He states his reluctance to receive too much information whilst acknowledging that he and his wife have ‘Venus and Mars’ attitudes toward discussing the implications of his illness. He seemed a little uncomfortable to talk about his feelings but when asked what he would tell others about the experience he described his emotional response of ‘shutting down’ and assuming a vegetative state as the intensity of his chemotherapy and radiotherapy treatments progressed. He states that his wife would have appreciated him being prepared to discuss his feelings more openly and admits that this may have been beneficial for him too. At the end of the interview he mentions the difficulty of knowing how much information to share with his children opting for honesty and a focus on positive aspects. After the interview, he said he attended an exercise programme run by physiotherapists in the gym where strengthening exercises were performed. This was run 6 weekly and he mentioned that the attendance did not seem to match the number of patients undergoing transplant.

Aged 63 years married and retired.

**Participant 7**
Hope and a positive attitude were the prevailing themes of this interview. Participant 7 felt that keeping busy, having knowledge and feeling in control were his ways of coping. He had prepared for his hospital stay by taking model kits which he made and gave to staff for their children. He played down the critical points throughout his journey including his life-threatening chest infection, a hernia operation and an episode of shingles. He did admit to feeling anxious when in the Intensive Care Unit as he did not remember going there and did not understand where he was and why. He also mentions on-going visual problems related to the shingles that sometimes cause him to feel down and as if there is no end to the complications. He maintains that being positive and keeping occupied have a positive effect on recovery and this is enhanced by the encouragement and expertise of the medical team.

Aged 68 years married with two daughters and retired.

**Participant 8**
Participant 8 was interviewed with her husband present. She repeatedly acknowledges her gratitude for the treatment she has received. Despite a difficult time including critical episodes threatening her survival during her treatment she remains largely positive. She states how ill she was on her return home and that she remained upstairs for some while, unable to manage the stairs. She is indebted to her husband and admits that she could not have coped without his help.

She had experienced a critical point during her treatment when she bled into her lungs and this necessitated Intensive Care. She states that her husband was warned on several occasions that she may not pull through.

Her husband reports a change in her temperament where she displays an uncharacteristic impatience and irritability in certain situations. Participant 8 jokes that she blames this on the
character of her donor but admits that in reality, it is a response to her stress. Despite being
told to be extremely careful about picking up an infection, the out-patients waiting area is
cramped and she feels surrounded by people coughing and sneezing.

Her major concerns are for her family and loved ones whose lives are affected by her illness
and her husband feels that he can never relax for fear of disease relapse or another
complication. He is aware of how life threatening infection can be and is constantly on his
guard and ready to react as appropriate.

Aged 63 years, married and retired.

**Participant 9**
Participant 9 described her fortune of surviving leukaemia against all the odds. She had
been told that there were no further treatment options following the final chemotherapy and
stem cell transplant. She acknowledges difficulties arising within the relationship with her
son. This is a recurrent theme within her narrative along with the loss of her husband and
the challenge of coping alone on her return home. She alludes to arduous journeys to and
from the hospital post-transplant and feels that this contributed to her contracting pneumonia
and being re-admitted to hospital.

A strong sense of identity is portrayed in the narrative where independence, bravery and a
fighting spirit are depicted whilst also acknowledging her difficulties and worries in relation to
her disease and her adult children. She tells a number of stories within the main story which
gives voice to her life as a whole including past, present and future possibilities.

**Participant 10**
Having felt well up to 100 days after his treatment this gentleman had reached a particularly
low point during his post-transplant experience. He was showing signs of stem cell rejection
and was facing numerous complications including severe weight loss recurrent infections
requiring hospitalisation, fatigue and debilitation. He admitted to having a terrible week
exacerbated by poor planning by the hospitals whereby an investigation was delayed twice
due to lack of platelets which he required in order to undergo it. His physical state was so
severe that his wife had obtained a wheelchair for him. Despite feeling poorly, he insisted
that he was still willing to take part.

He did not make eye contact a great deal during the interview and is visibly upset when
talking about the effect his illness has on his wife. He notes the physical, psychological and
social impact his illness has had on both of them highlighting simple pleasures such as
going out for a meal that have had to be abandoned due to his inability to eat without
retching.

He talked about the financial burden caused through his illness. His wife had increased the
days she worked to accommodate an early finish in order to come home and care for him
and he said they received no benefits due to her working. The Masonic group had helped
with transport which reduced the financial burden incurred attending appointments at his
local hospital and the specialist treatment centre.

Towards the end of the interview he reflects on his illness experience and his current
position. He is able to put the recent challenges into a perspective whereby he finds strength
to carry on:
‘when you’ve gone as far as I’ve gone, there is no going back, so therefore I'll keep going.’

Aged 62 years, married, employed part time but not currently working.

**Participant 11**
Participant 11 explained that since being diagnosed in 2008, he was aware that due to the
nature of his disease he would eventually become blood transfusion dependent. He knew
that at this point a stem cell transplant would be performed and acknowledges that this had been his major focus without looking beyond it. He states that he though he may have been told about what it entailed, he had not prepared himself for the arduous journey to come. He developed GVHD and became very ill two weeks following the transplant suffering skin and hair loss, an inability to eat, infection and difficulty sleeping. Once these symptoms were under control, his return home was delayed by an infection, the source of which was difficult to identify.

At home, his weight continued to drop and he felt extremely debilitated, sleeping sixteen to seventeen hours a day.

'It's when you leave hospital and return home, that the personal work has to start, and I had to go through a period of sort of wallowing in it and feeling very, very down and very, very tired and erm, you know, a bit of a ghost until.. I, I, I don't know exactly what it was but I had some kind of internal re-set happened.'

He reports reaching a point where he started to feel frustrated with his on-going fatigue and seemed to make a conscious effort to overcome it. Once he was feeling slightly stronger he started to make progress with resuming his role of ‘house husband’ which he had adopted following his diagnosis. He reported having no financial worries due to retirement on medical grounds and his wife being the major wage earner. He stated that he had time to re-evaluate the important things in life and was pleased to be out of the rat race and able to consider more interesting job prospects closer to home.

His ambition is to continue to recover physically in order to contribute fully to managing the home and also to resume his activities in the gym. He had endeavoured to keep as fit as possible throughout his illness and especially pre-transplant and stated that he would return with realistic expectations for his future fitness.

Whilst in hospital he set up a blog offering practical advice as to how to cope with various aspects of the treatment which had proved extremely popular.

Aged 50 years, married with one son, employed but not currently working.

**Participant 12**
Participant 12 explained that when he was initially diagnosed with an aggressive form of T cell Lymphoma, he was forced to face his own mortality. The serious nature of his disease was compounded with numerous life-threatening complications including involvement of his central nervous system and a perforated bowel. However, having survived this he felt that this experience served as training, preparing him to cope with what was to come.

In hospital he appeared to prepare his entertainment and be relatively self-sufficient, particularly following his previous experience within an isolation facility.

On returning home he relished the change of environment and independence, choosing when and what to eat and commencing the slow journey of recovery. His goals were to spend time doing ‘normal’ things like playing with his children and mowing the lawn.

He felt that providing care for his father, recently diagnosed with prostate cancer had offered a different focus and it felt good to be able to share his own knowledge and lend practical support.

Aged 28/38, married with two young children and employed as an accountant but not currently working.
Participant 14
Participant 14 was interviewed with his wife present and she provided some insight which was helpful in portraying the impact of the chemotherapy and stem cell transplant on her husband. He feels she will remember things to say where he may forget.

He begins by relating events leading up to his transplant and felt ‘in quite a state’ after the chemotherapy. He lost a lot of weight and found taking the medications difficult. He was extremely grateful that a doctor listened to him when he managed to elicit the tablet responsible for his vomiting.

His wife explained that when he felt unwell after his return home, he had a tendency to panic and to feel very unsafe. She felt that it was usually for a good reason and they telephoned for advice on numerous occasions. She also commented on the fact that he was depressed and reluctant for his friends to see him looking very underweight and ill. He describes his emotional state as frustrated rather than depressed and whereas his wife feels he has changed, he feels that he has just changed his outlook as a result of his experience.

He makes reference to the fact that he cannot remember being told what the treatment would be like though his wife points out that they received a full explanation and felt that he focussed on the transplant as a cure and therefore ignored the warnings: 'our son was with us as well and he’d got this huge list of questions and he (the doctor) was so patient and he answered every one of them and he told you it was going to be no walk in the park.'

Participant 14 returned to work part time with his brother and nephew working alongside him ensuring he did not overdo things. Both he and his wife alluded to the financial burden and stated that their hospital insurance policy was halved due to his being over sixty-five. He jokes that his wife will allow him to ‘down tools’ when he’s ninety-five. He mentions several times that he feels he is over the worst of it now.

Aged 67 years, married with three adult children, working part time as a plumber with his brother and nephew.

Participant 15
The interview with participant 15 was conducted in a public area in his business property. His wife worked there too and arrived back from taking the children to nursery. She carried on with her work and joined in later to comment on the difficulties they faced regarding finances and benefits and particularly the lack of information available.

He described his experience of being in isolation as feeling like a ‘caged animal’ particularly when feeling mentally and physically reasonable and he kept a calendar to cross off the days. He referred to receiving information about the treatment effects and actually experiencing it as being like reading a textbook compared to going on a field trip. He felt unprepared for the reality of the post-transplant journey and stated that he often felt more ill at home than he had done in hospital.

A critical time for him was when his disease spread to his optic nerve whilst receiving chemotherapy. This was extremely rare and the prospect of losing his sight on top of all the existing challenges was too much to bear.

After the recorder was switched off he said the following. Everyone is focussed on depression and feeling sorry for you because you have cancer. They offer you counselling, massage and diversion therapy but what you really need is advice re benefits and financial aid in the very first part while you are adjusting to months of treatment. His wife said that there were weekly support groups for spouses but these ran when clinics took place and she wanted to be with her husband to hear what was being said by the doctor.
The financial difficulties experienced were a major theme for this couple. Newly married when the disease struck with two young children to support plus a new business of their own to run caused enormous anxiety and both were disappointed in the information available to help them. Without financial help from their parents and friends who raised money for them they feel they would have lost their home and business. As a result of this he had set up a charity to help others in a similar situation.

Aged 33 years, married with two young children, self-employed as an estate agent.

**Participant 16**

Participant 16 stated that he was very willing to participate in the research study as he wanted to give something back, also reinforced by his wife. She said she did not mind being in or out of the room but her husband said she may remember something he did not and in a similar way to other spouses she added certain details, particularly about him being down and not wanting to know or discuss details of the illness or treatments.

He relates how severely the conditioning chemotherapy affected him prior to the transplant including infection which almost put him into Intensive Care. Regarding his return home, he repeats several times how vulnerable he felt out of the relatively safe environment of the hospital. His wife agrees stating how terrified he was of doing anything that may necessitate returning to hospital. She actively encouraged him to get out a bit more and their love of the countryside meant this was an activity that they could do whilst avoiding crowded places as advised by the medical staff.

His wife referred to the strain she felt visiting and making long journeys to the hospital. She stated that she was exasperated that her husband did not want to receive detailed information about his treatments and the possible effects, nor discuss this with herself and her daughter. Whilst they craved information, his rationale for not wanting it was that he was afraid he would dwell on it and therefore not cope as well.

He did get tearful when talking about the worst times which he stated were birthdays and significant anniversaries or festivals such as Christmas. His wife stated how important their Grandchildren were to them and that she reminded him often of how he must get better for their sakes. He acknowledged how small gestures made a big difference such as the nurses bringing him a Birthday cake when he had been devastated at the news of not being able to go home as planned.

At the time of the interview he felt that he had made good progress and although he may never resume his former state of fitness, he could manage most things as long as he rested adequately. Prior to his illness both he and his wife were going to retire, sell the house and go touring so their plans had to be abandoned. He was in a demanding job and despite an offer to return part time, he decided to retire which his wife feels has helped to reduce his work related stress and improve the quality of both their lives.

Aged 62 years, married with two adult children, retired as a result of illness.
### Appendix III

**Interview Topic Guide**

<table>
<thead>
<tr>
<th>Opening question:</th>
<th>Can you tell me about your experience of being treated with allogeneic stem cell transplant for x (blood disorder if known) and what it's been like trying to resume a normal life at home?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probing questions:</td>
<td>What has gone well?</td>
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<tr>
<td></td>
<td>What has gone not so well?</td>
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<td></td>
<td>Why do you think that is?</td>
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<td></td>
<td>Have you had any help from family, friends or others?</td>
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<td></td>
<td>What has had the biggest impact on you being able to get through this experience?</td>
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<tr>
<td></td>
<td>Is there anything you would have appreciated to help you get by? In hospital? At home?</td>
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<tr>
<td></td>
<td>How do you cope as a person?</td>
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<tr>
<td></td>
<td>What is the most important thing to you now?</td>
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<td></td>
<td>How are you feeling?</td>
</tr>
</tbody>
</table>
Appendix IV

Dear Doctor

Re patient:

I am currently carrying out a study to investigate patient’s experiences within the first year of returning home following stem cell transplantation for haematological malignancy. This will involve interviewing patients treated at Hospital A, and Hospital B. The study forms part of a Doctorate of Clinical Practice which I am undertaking at the University of Surrey and has been approved by the National Research Ethics Committee and the relevant Research and Development committees.

I have provided the patient named above with an information sheet and they have consented to participate and for me to contact you regarding the study. If you have any concerns about this individual participating, or questions in relation to the study I would be grateful if you would contact me by telephone or letter by …

Liz Dunn, Matron Haemostasis & Thrombosis
Haemophilia Reference Centre
1st floor North Wing
St Thomas’ Hospital
Westminster Bridge Road
London
SE1 7EH

Yours Sincerely

Liz Dunn
Appendix V

CONSENT FORM FOR INTERVIEWS WITH PATIENTS

Project title: Patient’s experience of returning home following allogeneic stem cell transplantation

Names of researchers: Liz Dunn (Guys and St Thomas’ Hospital), Dr Anne Arber and Dr Ann Gallagher, University of Surrey

Name of local Principal Investigator: Liz Dunn

Description of research project:

1. Participants are being asked to take part in an interview which will last between 45 minutes and one hour. This interview will be recorded and transcribed.

2. The transcriptions of the interview will be coded and kept at the work place or home of Liz Dunn where only she will have access to them. They will be stored and destroyed in accordance with the Data Protection Act 1998.

3. Only the Research team on this project will have access to this material.

I have been given information about the research project and the way in which my contribution to the project will be used.

Please tick the boxes below.

☐ I confirm that I have read Information Sheet for the above study, I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

☐ I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without my employment or legal rights being affected.

☐ I understand that the information I provide during my interview will be looked at by responsible individuals within the Research team named at the top of this form. I give permission for these persons to have access to the information I have given today.

☐ I give permission for the researcher to speak to my medical team about my clinical condition and treatment and if necessary to access my clinical record.

☐ I give my permission for my GP to be informed that I am taking part in the study.

☐ I agree to take part in the above study

☐ I give my permission for the information I am about to give/have given to be used anonymously for research purposes only (including research publications and reports)

I hereby assign the copyright in my contribution to the researchers for research purposes only.
Signed Participant

_____________________________________ Date _______________

Signed Researcher

_____________________________________ Date _______________

This information will be retained separately and securely from the information given during the process of the research.
## Appendix VI

### Sample of participant interview transcript line by line analysis

**Narrative processes, Participant 12, 18.06.2013**

<table>
<thead>
<tr>
<th>Initial interpretations</th>
<th>Clarification of the research question.</th>
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<tbody>
<tr>
<td>I Right, er, P12, I’ve just switched the tape on now and thanks so much for being part of the research, (ok) I really appreciate it, particularly you just seeing a flyer and ringing me, it was really good of you. Erm, so what I’m really interested today is to hear about your experiences of returning home after your stem cell transplant (mm mm) anything that you think’s important. I just want to check you’ve had the information sheet so you’ve read through that (yep), you know that you can withdraw from the study any time (I do) without giving a reason (yep) and that’s absolutely fine, erm, I asked you if I can contact you afterwards if there’s anything that’s not clear (yep, that’s fine) or just to give you a summary as I understand it and erm, you’ve also signed the consent form today</td>
<td></td>
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<tr>
<td>P12 Yep, all fine yea.</td>
<td></td>
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<tr>
<td>I Ok (that’s fine) so over to you.</td>
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<tr>
<td>P12 Over to me, ok, so er, yes, I had a er, stem cell transplant from my brother on the 15th March, erm, because I’ve got peripheral T cell lymphoma and there was a suspected CNS involvement ‘cos I’d had a <em>seizure</em> on New Year’s Day, erm, a one off, (mmm) then erm I had pretty strong conditioning beforehand so I had cranial radiotherapy, I had er TBI and I also had erm one er high dose of atoposide as well, chemo, as well as all the usual Chem Path and stuff like that.</td>
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<td>So, I think alot of my experiences after I’ve left hospital have actually been informed by the degree of conditioning I had. Initially I was planned to come in for a transplant and it would have been maybe a chemo course or a lighter radiotherapy course beforehand but because I had the TBI, I think that’s impacted alot on how I’ve felt since. Erm, so essentially er, getting out was good. After a few weeks in hospital it’s nice to get out.</td>
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<tr>
<td>I’d kept myself in isolation. I told my wife not to come in, I’ve got two little kids so I deliberately kept myself in isolation here, because I knew it was a sort of one off and there was no point having a cold or anything, it was only going to be dreadful and previously I’d been hospitalised for like seven weeks in Brighton, so five weeks was doable, you know, I could do it in my head so it was fine (yea).</td>
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</table>

Orientation: temporal in terms of diagnosis and transplant date followed by treatment regime for lymphoma. Intensive due to CNS involvement. Demonstrates good understanding.

The conditioning was strong including cranial radiotherapy and TBI due to severity of the disease. Good to get out of hospital.

He comments on the fact that it was good to be out of hospital after a few weeks. His description of the hospital stay suggests that he had planned quite meticulously and had prepared himself mentally to cope. He knew the infection risk and therefore decided it was best to isolate himself from his 2 small children to protect himself. He suggests that previous experience involving a 7 week stay made him know it was ‘doable’.
(Intake of breath), er, when I got home, erm, I guess the first thing is just relief to be at home, not to be eating meals at half past five which they make you do here, you feel like you’re being fattened up for Christmas in the middle of the day and then they leave you from half five until half eight the next day you know,(I laughs) so it’s er, it can be a bit frustrating there, so, erm, got home and felt good to be out ‘cos I was out, you know, I could see the kids, see the wife, just in comfortable surroundings. I can make myself a cup of tea when I wanted to and things like, just those little things that’s what counts, just being able to walk upstairs or downstairs or whatever you know (yea) or sit on the sofa, just a change of scenery, that was vital,

erm, but pretty soon, I can’t remember exactly when but I did feel very tired and I guess for the majority of the three months post-transplant fatigue has been what er, characterised my experience (mm) if you like, and I’ve heard that everyone, everyone that I’ve spoken to who has had various forms of cancer always go, oh yea, you’ll be tired and I was yea, ok, but I, I actually wasn’t quite prepared for the degree of tiredness.

I did a jigsaw the other week and I had to go for a sleep afterwards you know, (ahh) that’s the kind of level of tiredness we’re talking about (yea), erm and that’s taken quite a long time to er, to shift and I wouldn’t say it’s shifted yet but the last couple of weeks, yea, I wouldn’t say I feel as though I’ve turned a corner but maybe the corner’s appeared on my satnav and I can sort of, (I laughs) anticipating it coming up ahead, you know. Definitely the past couple of weeks have felt different to the previous er, three months.

Erm, the other thing that’s characterised it beyond the fatigue, and probably that’s been more frustrating for me because actually during the day the kids are at nursery or my wife might be at work, so actually I’ve got time to sleep and do whatever but erm, er is changes in my mouth. Again another thing lots of people had warned me about but I actually never fully appreciated er how bad it would be, I had a degree of mucositis when I was in hospital but it actually didn’t last very long, it only lasted for a couple of days I was NG fed and stuff like that but it wasn’t, it was nowhere near as bad as I was expecting. However, since coming out, then I’ve ended up with eer, er, sweet things were hypersweet, so my tea which had like half a sugar in was just like ugh, strawberries even now still taste alot sweeter (oh gosh) than they did. I’m a massive fan of snacks, chocolates, crisps biscuits and they were all off the agenda. Chocolate just tasted and still generally does taste pretty bad, erm, biscuits, well usually they’ve got chocolate in so they taste bad because of that but also anything starchy, so biscuits, pasta erm, like monster munch corn snacks, anything like that, er, just would absorb all the moisture in my mouth and become really, really hard to eat (oh right) and like bread as well, anything that was like carbohydrate based is just very, very difficult. So erm, and

Independence, choice and control over what and when to do things e.g. mealtimes. Also environment was important. Relief to be home. Re-establish family life and relationships. Themes: Independence, choice, control, family relationships and environmental factors.

He says that fatigue has characterised his experience during the first 3 months post-transplant. Speaks of his unpreparedness for the level and duration of tiredness despite expecting it e.g. needed to sleep after a jigsaw. Theme: extent and duration of post-transplant physical effects.

The last 2 weeks have been different from the previous 3 months ‘the corner’s appeared on my satnav’ says it with caution. Again, the recovery journey is an unknown quantity. Theme: uncertainty. This could be due to the number of setbacks or side effects which characterise the recovery period resulting in an uncertain course of rehabilitation.

Oral changes have been more frustrating than tiredness. The taste is exaggerated and textures difficult due to a dry mouth. He feels mentally willing to eat anything that will help re-gain severe weight loss but finds it difficult. His expectations re eating were that it would be bad initially. However, it was cope-able with in hospital even though he had to have NG feeding, it is more the longer term effects. Theme: late effects, enduring effects.
still now I do still find that, er I’m just starting to get back and everyone’s saying to me ‘cos I lost alot of weight, I lost, I’m two and a half stone lighter than I want to be, than I was before the disease, although pre-transplant I wasn’t at that weight but erm, you know, everyone’s imploring me to eat rubbish and I really want to eat rubbish and generally speaking I’m pretty good at eating rubbish (I laughs) but I er, it’s been a struggle.

I Just not the same?

P12 Mm, there’s a funny taste in my mouth, my tongue is er coated, you know I, they were talking about whether or not it was like a thrushy type of thing. I mean I’ve been er taking itraconazole, fluconazole, nystatin, you know, it doesn’t, nothing’s shifting it really, but again and I’m sure this is allied to the fact that I don’t feel so fatigued in the last couple of weeks it has been easier for me to even force things down. Like before everyone was saying just force it down you, just get it down you, you know, it’s like I really want to don’t think I’m not hungry ‘cos I’m absolutely starving, I physically can’t manage this, you know, chewing, I’d chew a piece of meat for like you know a hundred times before it goes down, you know, just, it’s that kind of thing but more recently I have actually been able to just force things down, I was, I’ve always been very conscious of the importance of nutrition in all of this, in the whole health (mm) part anyway and particularly in this recovery but, and I’ve always tried to keep to eating three meals but it might have been that in the early days I would be eating at dinner time, it would be like rice crispies and a yoghurt, just because, you know, the yoghurt’s soft, smooth, easy to eat, rice crispies are light, they come with milk so it’s very moist, you know, I’d have to rely on those things that are giving me, you know, very low nutritional content, or certainly a low fat content (mm) erm, but it was just to keep it ticking over but I really, you know I’d loved to have just sat there and eaten a fillet steak or something but it just wasn’t, it wasn’t going to happen. 

Soooo, yea, that’s kinda been the d ... and I think that’s probably been the difficult bit I’ve never felt er, downbeat or depressed or anything like that in terms of my experience with it, erm, I feel quite lucky ‘cos you know, on the 1st January the doctors in Brighton essentially said game over, you know, you’ve, you’ve had this seizure so if it’s in your spine or central nervous system you’re, it’s, nothing’s going to happen, we won’t be doing the transplant.

Managed to get them to give me some methatrexate and that seemed to get me into a decent enough position to attempt a transplant, so I, you know, I’ve actually felt very lucky to be … there’s been plenty of times when I’ve wondered if I’ll see the end of the football season you know, that kind of thing erm, you know and we’ve had to do all the usual you know, making wills and all those kind of bits that you try and, not to think about (mmm mm) so post transplant I feel very lucky to have had the transplant and to be in the position I’m in so I’ve never felt down.
but the only thing, the thing that has made me least happy has been just, you know, not being able to eat, if you like, eat what I want, when I want, (mm) er, and, and because also with erm, er, previous chemo cycles that I’d had in Brighton would be ok once you’ve had it once you get used to the routine, so I’d be in for a few days, I’ll probably feel alright while I’m actually having the chemo when I come out I feel alright for a week, I feel rubbish for a week when I go into neutropoenia and then I’ll be fine again a week later and then we’ll go through the cycle again so you know what’s happening but I think with this, it’s, it’s interminable, there’s no obvious er, point at which dips are going to be, you’re going to come out of dips

P12  Exactly, if somebody could say it’s going to be rubbish but on June the 6th you’ll start feeling better (you can eat a Mars bar) and on July the 2nd yea, exactly, exactly, you can do it and you speak to the doctors and they’re, I couldn’t expect, I want them to be but I can’t expect any more of them, they’re very vague, you know, I mean everyone’s different, er, you know, and they’re treating people over a huge range of physicalities, age range, you know gender (mm), ethnicity, so all these different factors that apply, underlying histories, er, er, you know so yea, it could be six months, it could be you know, no one can ever say, they all go yea that’s terrible but it doesn’t help actual with the practical day to day dealing with it and so probably after two months or something you just start thinking, is this gonna end. I mean I know, I know in the back of my head I know it is going to end and I know I will be able to eat these things and they will give me the pleasure that they used to, do you know what I mean and I will be able to mow the lawn or take the kids out or whatever you know, or go swimming with the kids all those kind of things but, you just can’t see when that’s going to be and no one can help you when you come into clinic for five minutes no one can help you see when those flags are when they, (yea) when they’re likely to be so, is that waffling enough for you would you say?

I  Yea, you think good I’ve only got to get till June or July.

Reiterates eating problem. He highlights the benefit of being able to anticipate the ups and downs e.g. with chemotherapy at initial diagnosis. At least you know how you’ll feel. Themes: Choice, independence and ability.

Appreciates the difficulty of being specific about degree and duration of symptoms but feels it would be easier to cope with if you knew. Demonstrates this by comparing the uncertainty of resuming normal eating habits with the chemotherapy where at least you have an expectation and lived experience of what will happen. Theme coping with uncertainty in relation to recovery/eating. You never know when a ‘dip’ will occur. This sounds more general than just eating, though eating is a major issue for him. Acknowledgement that it is difficult for doctors to predict recovery points on an individual basis but that a timescale would help. If you know how long something will last it’s easier to deal with. Theme: severity and duration; uncertainty. A “road map” of physical recovery would help e.g. resuming normal activities such as mowing the lawn and taking the kids out. No-one can “help you see when those flags are”. 5 mins in an appointment v dealing with the practicalities. Still, despite the difficulties he maintains hope and tells himself there will be improvement “I know in the back of my head I know it is going to end”.

Theme: Choice, independence and ability.
I That’s, that’s great. I wanted to ask you a bit more about, when you said, so that was fine I knew it was going to x number of weeks in hospital and you got yourself (yep) mentally satnaved to (yea, yea) get through it, how have you gained, ... how have you got that attitude, do you think it’s something that you’ve approached that way anyway whatever comes or ... sounds like a very brave…?

P12 I dunno, I think (attitude) a little bit of it, yea (sounds contemplative), I suppose I’m a bit of, not really an island, I don’t want to sound like some sort of emotional retard (slight laugh) or something but you know, I suppose I can be quite content within myself so long as I’ve got enough DVD box sets (mm) you know, essentially erm, so that doesn’t bother me. As I said I felt quite, I probably had more of a positive attitude because I felt lucky to be having the transplant and I could, as I sort of mentioned about the eating thing, if someone could say to me listen, you’re going to feel rubbish for five weeks but then it’s alright, I can cope with that (yes) and probably because I’d been in, as I say, Brighton for seven weeks at the start, then I knew that however long I was in here was for less time than that, so it was doable, I know that I’d done worse do you know what I mean, it was almost like training.

I But that had been unrelated?

P12 No, no, no, that was when I was initially diagnosed and was going through my first series of CHOP chemotherapy (ah ok) but what happened is, I ended up with a couple of, so there was a whole period where there was the diagnosis ‘cos it takes a while, er, and then there was er, further complications in so far as erm, the very first dose of CHOP, erm, perforated my bowel, I think, ‘cos I’d had previously I’d had ulcerative colitis in the past and I think there was a weakened part of the bowel where the er, nodule had detached itself and then when they gave me the steroids and it had shrunk it, it just tore basically and so then I ended up having bowel taken out as well and that again was like one of these ones whereby I had raging lymphoma and they were doing like a fairly major operation erm, and you know within a couple of days of doing, and when it happened I was neutropoenic so they had to wait and when, once they’d done it then the er, the lymphoma came back very quickly so there was this battle about so well we want to give him treatment, we want to give him steroids and healing bowel is not a good combination.

(no) basically, so I’d been through alot of rubbish before and again it was like well you know, ok so we’ve got through that then five week isn’t (iron man) is kinda well it’s, it’s a bit like training for a hundred metres by doing two hundred metres all the time or something you know, er, I dunno, you, you kind of over train and so I just feel as though we’d just sort of gone through enough then that it was, it was doable.

He feels that being content with his own company and ability to entertain himself coupled with a positive attitude at being treated at all in the face of a life threatening illness. He restates how much easier things are when you know what you need to cope with and for how long. He feels his previous hospital stay at diagnosis was ‘training’ and he was therefore able to plan and control. Theme: prior knowledge/experience.

I Had faced life threatening disease in view of aggressive lymphoma plus the severe complication of a perforated bowel. It was therefore necessary to weigh up the priorities of treatment.

Repets that this was easier due to previous experience and helped him to cope particularly as it had been so serious: “it’s a bit like training for a hundred metres by doing two hundred metres all the time or something you know, er, I dunno, you, you kind of over train and so I just feel as though we’d just sort of gone through enough then that it was, it was doable”.

Theme: previous experience of severe illness. Mental and physical tolerance had been tested in the face of uncertainty re survival.
and you know in this day and age we’ve got erm, you know, skype or whatever and I could still see the kids, in fact I saw the kids more than whenever, you know I was also very conscious, we’ve got a two year old and a three year old, for my wife to come up it’s a long trip, she’s got to worry about the erm nursery and stuff like that, doesn’t want to bring up the kids because they’re just riddled with infection all the time at that age so actually, it was a nice way to do it, you know, I made sure I had enough things to entertain me, I was in touch with enough people, you know, I’ve got an iPad so Facebook, I can watch videos, I can watch (mm) speak to people, you know so I didn’t feel isolated, listen, if I was doing this five, five years ago I’m sure it would be a completely (wouldn’t it) kettle of fish I think you know because then that would be much harder to cope with ... you know.

Technology helps. He is conscious of the potential strain on his wife in terms of distance to travel and childcare responsibilities.

Understands the infection risks so is prepared to be parted from family. He comments on the potential strain on his wife re distance to travel and practical aspects of child care.

Technical advances have made a big difference e.g. Skype so isolation tolerable. Theme: virtual social interaction.

I Yea, you’re still in the world now aren’t you?

P12 Exactly, I can still, I can actually see my kids and they can see me and you know, wave and stuff like that so it’s, it’s much easier to cope for, I mean obviously, I’m quite lucky in that somebody gave me an iPad but alot of people coming in here don’t necessarily have that you know but at least there are DVD players and stuff here and things like that to get through.

Theme: maintaining visual contact. Lucky to have iPad.

I But you literally decided you were going to have no visitors at all?

P12 No I got one person to come in and bring me, I had to have a mercy visit for erm, for drinks, there was a guy who lives not that far away like Ashstead or whatever and it was just, listen can you please, I, I’m getting bored of water or whatever, you know, can you just get me some iced teas and some you know, these vitamin water kinda drinks, just something different to stock up my fridge, even if I don’t drink them, just so that psychologically I know there’s an alternative (you’ve got a bit of variety) over that, you know? As I say alot of the food was, I wasn’t doing alot with food then or, or you now, it’d be pretty bland food (mm) and stuff like that but, the drinks were the only thing I could go for so you know, I wasn’t really eating biscuits or anything like that so, yea, so I think it helped that I’d had a ? before

Variety important especially when food and drink options are limited. Theme: choice, independence and control

Language e.g. “even if I don’t drink them, just so that psychologically I know there’s an alternative”.

and I think it helped that I’m lucky enough to being in contact with plenty of people, of an age to be in contact with plenty of people on the internet as well as having like access to Skype and stuff like that and I think er, er, it helped actually to get in just a few things of what I like, like the drinks but I didn’t really do that at the start so you know, well I did do at the start but then half way through I had to get somebody to replenish supplies (yea) so, so I think that was just the way, to er, to get round it actually.

Important to have social contact with others via internet etc. Ability to have someone bring in drinks seems to contribute to feeling of control in addition to providing choice. It may be that this became more important as his confinement continued (like a prisoner – limited access to anything other than what is supplied and limited belongings). Could be related to identity.
And in terms of now (yep) you said a couple of weeks ago (yep) you feel as if you’re just steadily getting there (yea) do you have a vision for yourself about the goals, difficult though it is to see end points of things?

P12  Yep.  Erm, I have alot of things I’d like to do.  I don’t think this is going to inspire me to like climb Mount Everest or swim the channel or anything like that but erm, there maybe more er ..., er, maybe more modest goals, you know, going away on holiday somewhere, abroad is you know, just to be out on a sun lounger, somewhere, you know (mm) Majorca or so ..., I dunno wherever it is you know is, that’s the kind of thing, it’s a bit like torture really because actually I know it won’t happen for a little while but that’s the kind of thing I want to get to.  And more of these things in terms of I’ve not been able to do alot with my kids just because I get tired you know, get to Friday evening it’s like oh my God we’ve got the kids for the weekend and I mean it’s completely the wrong way around or completely different to how it was before so erm, er, there maybe more er ..., er, maybe more modest goals, you know, going away on holiday somewhere, abroad is you know, just to be out on a sun lounger, somewhere, you know (mm) Majorca or so ..., I dunno wherever it is you know is, that’s the kind of thing, it’s a bit like torture really because actually I know it won’t happen for a little while but that’s the kind of thing I want to get to.  And more of these things in terms of I’ve not been able to do alot with my kids just because I get tired you know, get to Friday evening it’s like oh my God we’ve got the kids for the weekend and I mean it’s completely the wrong way around or completely different to how it was before so erm, er, we’ve been very lucky to have alot of support from my wife’s parents who’ve come down and stayed with us alot and have er, you know helped with the kids and taken them out and entertaining them and stuff like that, erm, this was the first weekend when we didn’t have anything like that, no friends or family around or down so had to do it all and had to be involved the whole time and actually it was ..., fine, so you know, that gives me hope, I mean, yes as I said earlier, I’m sort of flagging a bit now but I, that gives me hope, ok look I’ve done it, I’ve got through this weekend so hopefully we’ll keep building them up but it’s, it’s things like, I just wanna take them swimming and stuff like that you know, just, it’s very little things that I’m very conscious that I haven’t been able to do, you know er, with them at their age and at my time of life you know, so.  Yea, I think those are the kinda things we think about, going away and yea, just actually be enjoying the kids as opposed to feeling as though it’s, it’s a burden, which I’m sure it does to anyone at various points you know (yes) they’re not easy, but erm, you know, just to do things with them (when your energy’s sapped as well) exactly, exactly it’s very frustrating you know and they and they do not understand, they’re not of an age where they could understand what’s going on.

They um, they know that I, I’m in bed sometimes, you know (mm) or that I’ve been in hospital and stuff.  If ever they see a picture of somebody in a hospital bed they go oh Daddy, you know (oh how sweet) which is awful if that’s how they er, think of me, but erm, yes, it’s just doing, doing stuff with them, but as, as I say the last couple of weekends, we’ve been able to do more and it’s made quite alot of difference, gives you, it, it’s starting to become more of a virtual circle whereas er, I think in the first couple of months there was a danger of it being a viscous circle, you know, don’t eat, get fatigued, you can’t spend time with your kids, feel guilty, you know, never, just never quite feel up for it and I can’t specifically say what might have made it better although I have, possibly coming off medication so I have been having cyclosporin and stuff like that and I think that’s come off.  I had er, quite an upset stomach as well for alot of this period, now I haven’t since I came off the cyclosporine erm, oh great and that’s the thing, you’ve had radiotherapy, you’ve had chemotherapy, you’ve had a bone marrow transplant, so you’ve got somebody else’s stuff inside you anyway, you’re on eight different pills, all of which have got you know, double A4 sheets of er, side

He maybe thought I meant life changing goals in view of his illness but states that he has modest goals in terms of recovery e.g. going on holiday and doing things with the kids.

Having coped on their own with the kids for a weekend has given him hope.  Phenomenon: the importance of incremental goals.

His children have recognised that he is unwell i.e. associate him with hospital.  Articulates the vicious circle of not eating, fatigue and consequent feelings of guilt re his children.

There are so many potential causes of side effects and symptoms that you never really know which it is.
effects, *potential* side effects. That's the other thing if anything happens, you can't go well specifically, oh that's the radiotherapy or that's the cyclosporine, but it's only as you start coming off things you realise (mm) that maybe, that was you know, contributing to it, but I'm *sure* that having stepped down my intake of pills has helped (must make a difference mustn't it). Yea, yea completely, and also you're on, I think I'm permanently on antibiotics and they, they cause enough upsets as well.

| P12 | They do and appetite (mm) doesn't it. When you mentioned about the, the erm, feeling like you've got something, you know, you've got somebody else's blood (yea, yea, yea) or whatever inside you, how does that make you *feel*, does, does it have any effect at all or do you largely just think oh ... |
| I | Whilst blood tests have been ok he has a diverse range of side effects to deal with. |

| P12 | No not at all, you know what I don’t give it any, I should, it’s a miraculous thing and a generous donation from my brother and I, I, 'cos we’re not a particularly close family you know so for him to do it, not that I’d expect him to say no but you know, he was utterly accommodating and great, but I *really* don’t think about it at all (no) it doesn't, I don't go thinking ooh I’m like the bionic man or I’m half me and half my brother or something like that you know I, er, it, it doesn’t , doesn’t occur to me really, I, I don’t think about it. |
| I | And in your blood tests have you has he, he has taken over has he? |

| P12 | Yea, yea it appears to be, all my blood tests have been fine the whole time so I mean, actually since I’ve come out I have a little list of things that make me sound like Dot Cotton when I reel them off to the doctor, you know, I go ooooh my *feet* hurt, you know or my skin, like I had *bad* peeling on the soles of my feet (did you) and stuff like that erm, and what feels like erm, er, what do you call it er, when you lose the erm, feeling in your ... er, neuropathy (yes) in my feet as well erm you know, and as I say and a bit of an upset stomach and that kind of thing but *actually* my blood have always been really good. I got let out pretty *quickly* after my transplant erm, I would have got out even quicker if it hadn’t have been like a Bank Holiday then as well so you know that was … |
| I | Did you make it in the five weeks then? |

| P12 | Yea, yea, yea, yea it was, it was, it was, as I say I was hoping to get out earlier but then it got to like a Friday and you know once it gets (I do, I understand) to the weekend you don’t want to get out at a weekend so it didn’t bother me that was the hardest bit probably the last three days when you’re just hanging around (I was going to say we don’t like you to) exactly (we think we know best) no and I don’t want to be at home thinking ooh I’ve got a twinge, got a twinge erm so eeeer, yea, what was I wibbling on about erm, completely. |
| I | You were saying about you go in with a whole list of things you feel a bit. |

| P12 | Oh yea, yea, yea, exactly, exactly *but* actually I think I’ve got off pretty lightly in that, you know, I think in the great scheme of things, I, I haven’t, touch wood, I haven’t had any erm, complications or anything. |
| | By complications, I think he means relapse of disease or rejection rather than other side effects as above. |
My scans came back from a few weeks ago that were, appeared to be clear although I’m having another one today so erm you know, that is that seems to be pretty good (mm mm), hopefully, we’ll see,

but what you don’t get, well I suppose it’s with alot of the things, I imagine it’s the same as when you’ve had a heart attack or anything is, is I don’t have the luxury to have twinges or aches and pains ... if I feel something in my head I think ooh is it coming back in my head do you know what I mean (yea) if I feel a twinge in my stomach I don’t just think I might have had a dodgy prawn sandwich or something you know it’s it’s you think (you relate it) ooh is this you know lymphoma or something like that

but I haven’t had any of the big signs that I had initially which is like night sweats and fevers and that kind of thing, so, er, it isn’t but it’s hard to er, it’s, it’s only time actually heals that er, I’m a great believer you know. The first couple of weeks after my seizure, anything I was just like ooooh, is it another one coming, you know (yea, yea) but you know it’s been six months (very understandable) and now, now I’m just thinking, oh, why can’t I drive you know. I’ve got to see the neurologist so I can get my driving licence back and stuff like that you know.

I Oh do you, how long is it?

P12 Well, there’s no set time limit, they just need the neurologist to, they need a doctor’s opinion to say you’re fine to drive but then obviously everything’s been side-tracked by coming here and then recovering from this and it’s kind of like one, one step at a time, so, er, those are the kind of things that er, er can be very irritating as well, it’s just, you know, I can’t just drive out to get a sandwich or pick something up that I’ve forgotten to pick up or, not that I’ve got any dry cleaning but dropping dry cleaning, you know, anything like that even going to the dentist, it’s just everything becomes that much more of a pain (mm) if my wife isn’t around to ferry me round, and I can’t take the kids into nursery or pick them up there’s no option (no) it’s all on her you know, so erm it’s those kind of, those kind of practicalities I think.

I When you very first got diagnosed (yep) did you erm, were you somebody that wanted to know as much as you could know about the whole thing? Were you warned about a transplant straight away?

P12 Er no, no, didn’t mention a transplant and also whenever a transplant has been mentioned it’s never been erm and this might just be semantics in terms of a warning but it’s always been a positive thing (yes) it’s always been sold to me as a positive thing (yes)

erm, but er when I was first diagnosed (sounds thoughtful) no, it’s not really head in the sand but I don’t you know, there’s people like my brother will just get onto doctor google and start looking, all I’ll do is I’ll see every, well, 95% of the stuff I won’t be able to understand ‘cos it’ll be abstracts of medical papers and the rest of the stuff will be people who have either had some miraculous cure or some horrific experience you know, it’s just not representative, it’s, it’s a self-selective group of people (mm) that post there so I wasn’t really erm, that interested you know, and there was quite alot of literature around, I suppose the Macmillan are quite good with their (yea, aren’t they) guides and stuff but I can’t say I really read it, what I really wanted was somebody else to read it and sort of digest it and then

He describes himself as not ‘head in the sand’ but he sounds discerning in relation to what information will be useful. He does however refer to the wish for someone else to take charge of the information and to sift it for him informing him of the ‘salient points’. This phenomenon is mentioned by others: P4 wanting others to take charge of the information whilst they get Time without recurrence increases confidence.

Phenomenon: living with uncertainty.

You are always on your guard for things "I don’t have the luxury to have twinges or aches and pains".

Transplant was always sold as a positive thing.

The seizure resulted in not being able to drive, complicated by his treatment. Phenomenon: lack of independence.
pass it on to me, do you know what I mean (yea) so let me know the salient points, not, I don’t you know as I say if you read it you end up thinking I’ve got everything and it could go this way it could go that way, you want somebody else actually to read it and then give you their version of it if you like. Quite lucky in so far as I know quite a few doctors and medics and consultants anyway just friends from Uni (mm) so I had quite a base of people to speak to about it now none of them are oncologists and none of them specialise in it but they all have a grounding or they, they knew other people (yes) who you know, someone was involved in lymphoma research in the US, that kind of thing

and was able to say, 'cos you know we were saying at the start I felt as if I wasn't doing that much I felt like I should be like Lorenzo's oil and I should be out looking for a solution for it myself and finding out if there are erm, er you know, studies and research projects going on, but erm, you know, at least with these I was able to get kind of third party (yea) advice if you like, again I was quite fortunate in a way I’m quite fortunate in being able to call on those and they were all able to help with, well you can do this, that and that, this is why they’re doing it and they could interpret these things for me into layman’s terms, you know. And whether or not it was right or wrong or whether I was being fobbed off or anything like that, so I got quite alot of comfort from there (mm mm)

Helpful to have friends to interpret information for him. Interesting that he refers to the possibility of being 'fobbed off'.

Erm, er, it was a bit of a shock, I wasn’t expecting it at all. I’d gone in and I’d had trouble breathing, sweats, stuff like that and it, it was like four visits to the GP before anyone even sent me for a blood test and a chest x-ray er, and then they called me next day and I thought right, well that’s not good and I thought it was because of the chest x-ray, probably because of the wheezing, I couldn’t properly inflate my lungs I was thinking this is like lung cancer or something like that was kind of what I was expecting, but then, 'cos initially I was thinking this is some kind of virus or, you know, erm, but then they took me away to the quiet room as they do and sort of mentioned it but it was kind of like a whole new world it’s not something I was, blood cancers isn’t anything I know anything about (no no) you know at all so er probably for me it probably again was harder for my wife because she was having to deal with it. I was actually in too much pain on morphine to do, actually be thinking about the practicalities of it, you know, it was more about this is, I feel rubbish you know, erm (yes yea)so, so even now I haven’t really probably read all, I’ve sort of over the course of a year probably out of boredom ended up reading most of the brochures I’ve been given but I didn’t really do it at the time and I didn’t necessarily seek it out I thought the er, oncologists were pretty good in explaining stuff to me and as I say I was lucky to be able to just have informal chats with friends who could (mm) actually kinda give me the lowdown.

I Was that oncologists at Brighton?

P12 At Brighton, the haemonc team at Brighton. I mean I was with them all the way until the very end of February when I came here so they’ve been completely looking after me for the first eight months or so.

I And when you said if you get erm, if you get twinges now you’re sort of on the alert a bit (yea) if you were worried about something who would you contact, would it be GP or here or Brighton?

P12 It wouldn’t be the GP ‘cos after, although they’re very attuned to me
now but after four failed attempts to get anything out of them er I don’t think they’re necessarily the best place. Erm, my tendency would be, really now it would be, is actually to speak to here (yea) but I’ve spent so much more time at Brighton as an in-patient (mm), it’s a much smaller Unit, there’s I don’t know, maybe a dozen beds tops, erm that I know those people so well

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<td><strong>P12</strong></td>
<td>It’s a haematology oncology unit so it’s only leukaemia, lymphoma and myeloma erm, they’re, that’s where I would want to go to but transplant isn’t their thing so I, I would come here and I, I feel alot more anonymous here even though again it’s relatively small unit (yea) I guess relative to the size of the hospital, it’s so oversubscribed up there, you know, you go up to clinical appointments it’s just like so packed that you just feel like er, a bit more of a number here than as a, than as a, than as a person I’d say, and, and as I say, you spend less time with it and the whole time I was there I was in isolation, only ever saw people with masks on I didn’t recognise any of the nurses if they’re not wearing masks (yes yes like when you’re in theatres) yea, you have to look at people like that and it’s oh yea ok so! So yea.</td>
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<td>Feels treatment is more personal in local hospital.</td>
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| I | I wasn’t sure then, when you said you’re a bit more anonymous here whether you felt that was a good thing or a bad thing. |
| P12 | No, no, no I think it’s a bad thing. I like the relationship I have with the guys in Brighton (mm) they’re really good, it was really informal, they’re really er, er, don’t get me wrong I think they’ve made a few mistakes during my treatment on the doctor side but the nurses are fantastic, you know, and it just feels more like er, er, I dunno, it just feels more kind of familial, it sounds weird I sort of look forward to going back there. I feel quite disappointed that I, I’m not under them anymore, do you know what I mean? I don’t get to see them anymore. |
|  | Relationships with staff are important and because of that you can allow a few mistakes. |

| I | I wondered whether you had, ’cos some people have blood tests at the centre where they’ve had the transplant (yea) and some of their blood tests locally. |
| **P12** | Yea, that might happen in future, I've been on a sort of weekly regime up here and it might be that in future. |

| I | Yea, you’re still early days aren’t you, they’ll…? |
| **P12** | Yea, yea, yea, exactly I always think bloody hell I must be at the end of this now and they go oh, it’s only been thirteen weeks since your transplant, you know I think ... early days, early days ... |

| I | Yea, they’ve still got their ... you’re still in their claws aren’t you? |
| **P12** | So maybe as things go on, I’ve still got a line in but that’s supposed to come out next week so there’s less need for just line care and basics like that (yea) and if it becomes, listen you need to have bloods every couple of months, or you know, every couple of weeks it could possibly be |
at Brighton, yea.

I It'll be nice ‘cos they’ll be thrilled to see you back there after you’ve ...

| P12 | No, no, no it would be good to, it would be good to er, it would be good to go back, still here, still here gov haven’t shifted me yet! (I laughs) so er so yea, no, no so yea, it’s kinda weird I’ve got a strange attachment to them, you spend alot of time with them, do you know what I mean, you go through some big things with them so(yea definitely) yea. | A closeness develops from going through big things. |

| P12 | Erm, I’m trying to think what else has happened since I’ve come back (speaks slowly as if thinking), Er, I think we covered most stuff really, erm, as I say, yea, fatigue, upset stomachs and stuff, poor appetite they’re, they’re kind of the key ones. | Reviews the information he’s told me so far in terms of side effects. |

| P12 | I personally haven’t felt depression or down particularly about it. I can imagine alot of other people that have been through the same have, and I’m not saying that’s ‘cos I’m brilliant or great but I can imagine depending on other things that happen, I’ve got away quite lightly as I said, I can imagine other people have got away less lightly or they’re older or it would take, you know this is the only place I come to and people go, you’ve got youth on your side, no-one’s said that to me for about fifteen years, so you know, it’s kinda good to hear it once in a while, but you know alot of people being treated have got thirty years on me, you know? So it’s, I can imagine it taking its toll (mm) er, more so on them and recovery times being longer and stuff like that. | Feels his experience has been better than others due to age possibly. |

| P12 | Had we had this conversation (pauses) three or four weeks ago, I think it would be quite it could be quite different to how it was now because I, I still couldn’t see (speaks thoughtfully) that ... where it was going to start changing but I think now, especially after this last weekend, this last few days I can see. | Repeats that he has more hope as he improves physically and achieves small goals in terms of resumed his responsibilities as a father and husband. |

| I | You described it as being that corner in sight. |

| P12 | I can see it coming, I can see it coming, yea, I can see it coming and that gives me more hope and as I say, hopefully we’re moving from a viscous to a more virtual circle. |

| I | Just my last couple of things … |

| P12 | Yea yea. |

| I | Just picking up on that, what do you think pulled you through when those time were pretty bleak, when you said if you’d interviewed me a few weeks ago I wouldn’t have felt like that (mm) would you have been saying then, I didn’t really, I haven’t really felt depressed or do you think at that stage you were feeling oh, when am I ever going to get to the end of this? | Reduction in medication has made a difference. Admits to being concerned about the brain scan. Theme of uncertainty. |

| P12 | Er, maybe, I’m not sure quite what happened, as I say the reduction in the pills has probably helped, I think the cyclosporine was doing all sorts and er I think that (speaks slowly and deliberately) having had the scan, not that I was worried about the scans like everyone was going oh the scans, good luck, you know, and I didn’t , like consciously think of them as being like that but actually when it comes back it’s, feels (nice for you) better and you know although I’m slightly suspicious about why I’m having |
this scan today, I did know deep down I’m having a scan on my brain because neither a standard PET or MRI gives them the er kind of comfort that they want over what's going on in my brain, neither of them are quite clear enough. This particular type of choline PET scan gives them better clarity. I know that. Then you’re sort of thinking have they seen a shadow on a previous scan or something, you know, you can talk yourself into it (yes) so I’m sure when I see them next week and if they say yes, your scan came back and it was fine I’ll feel (it'll be one more thing) yea it’ll just be, I’ll just think ooh, I'll just walk along a bit taller, do you know what I mean (I do).

erm, er, and, what else, I think, I always try and make it very clear to my long suffering wife who does understand but for her, I, especially after a year it can get quite, it’s very wearing for her and if she’s having to wrangle two toddlers while I’m sat there watching Pointless or something, do you know what I mean it can really, I’m sure it really grates, but just saying to her, look, you know, if I can help I will ‘cos I do want to but if I can’t, I can’t and I won’t. I can’t break that, you know. If I need to go and lie down, I’ve gotta listen to what my body’s (yea) telling me, so and you just want everything to be normal,

you want to be doing stuff because its normal, you want to do stupid things like mow the lawn, not because I’m particularly proud of my lawn but just because it’s normality (yes) it’s what people do (yea), it’s what I should be doing er, and I just want to be doing that kind of thing. I want to carry my kids round ‘cos that’s what people do, they carry kids round, but actually I get pretty tired even though they’re not that big or they like sit on my Hickman line and like pull it down, you know, it’s just like not what I should be doing, but you just want to do things to, just to regain (mainstream) some sense of normality. Yea, but as I say I think it was just physiologically, I only really felt particularly down closest to when actually I'd just finished coming off the cy, and they actually started taking my cyclosporine down pretty quickly and that was a bit of a fillip in itself 'cos you just thought right I'm going to be off this in a couple of weeks (mm) you know and I’ sure that all helps as well as the fact that physiologically it’s not mucking up my body as it was (yes) before (yea) so er, yea I think it’s those sort of elements help.

I And if you were to give anyone advice who was going to go through it, (yep) what would you say to them was the main …

P12 Er, so (appears thinking, as speaks slowly) I think in terms of actually having the transplant it’s just preparation, mental preparation in terms of knowing that you’re going to be in for a while, preparation in terms of making sure you can keep yourself entertained erm, and realistically don’t be thinking, don’t take in War and Peace thinking you’re going to read it ‘cos you read like a page or something, but you know take in DVD’s and things that are sort of mindless or whatever but don’t make you feel crazy like watching TV and take in things that are as close as you can get to luxuries if you like, as I say, with the eating itself then crisps and chocolate actually don’t do much good because you just don’t want them but flavoured drinks, something that stimulates the senses in some way (mm) is it. For afterwards, I think it’s about having support as I say, I've been very lucky in terms of my, my wife’s family, not my family, my wife’s family coming down alot and you know, we have specific circumstances as everyone does. We’ve got two little kids you know, so it's, that needs

Strain on his wife having to do everything but has to listen to his body and rest when necessary despite a wish to be normal.

Reflecting on what normality means: ‘I just want to be doing that kind of thing’. Many other participants say this. Hickman line restrictive. He admits to feeling down whereas he has denied this previously in relation to the treatment. Reduction of cyclosporine was significant and he felt physically and therefore mentally different “that was a bit of a fillip in itself”.

Advice to others would involve: being mentally prepared for isolation; entertainment with limits i.e. not ‘war and peace’; luxuries such as flavoured drinks; family support; work/financial support both for him and his wife; don’t worry because it does get better though knowing it is different from living it. Theme: attend to the practicalities and be mentally prepared.
managing and they've really er, helped with that, erm, I've had very understanding work in terms of, you know, letting me off work and er, and still having er salary or you know like I work for a big enough company that has that in place and also my wife has been given quite alot of time off work that's paid that I wouldn't have expected that at all, so again we were quite lucky from that point of view (mm) erm, er, and I would say don't worry 'cos I think it does get better but as I've said to you there's a difference between knowing that and living it and (yea, yes of course) I think that's a circle that can never be squared or whatever, you know. I think. Yea?

I  Yes absolutely I think that feels like a natural end, do you (yea) unless there's anything else?

P12  Yea, no I can't, I can't, I think I've chunted on enough. I think I've covered all the bits that are kind of happening, I mean the reality is that the day to day is, it's very boring actually you know, it really is. It is groundhog day and er and sometimes you can struggle to remember where things happened because you don't have specific reference points, you don't have oh yes that was the week before Jonny's wedding or something 'cos I don't have any of that, it's just, you know I have countdown which is essentially the same every single day, you know, so you have no reference points and things can get a little bit bland, it just sort of rolls on interminably and when I come here, it's just it's just early days or it's only been three months and I think it just seems so much more but obviously it's on the back of another eight months before it (yes, yea) or nine months before it but it still erm, never ceases to amaze me er, and, and I can't imagine certain things. I can't imagine going back to work, that'll be really weird. I want to go back to work but I just, I don't think I knew what I was doing when I was there last time so after like a year and a however long out, then er …

I  So you went back in between?

P12  No, no, no, no, er, before I got ill (yea) you know I was, but, but er now if I've taken a year plus out it'll just be very strange going back but I, again it's normality, it's something that I sort of relish, you know erm, in terms of doing it. Hopefully I'll get the er the work life balance back but I'm sure I will but er, er, yea, erm but no I think there's yea, yea, yea just can be very boring. Jigsaws, that's another good thing to take in. I never thought I'd say it but they're very good to focus on, I never, yea.

I  As long as you've got a bed to lie down on afterwards.

P12  Exactly, exactly, exactly.

I  Particularly if it's a thousand pieces.

P12  Exactly and a big enough space to put them on, it completely threw me I tell you, it was a nightmare finding a board to put it on, (with two little kids) yea, they just say what's that buff! Oh no! Yea (ah). Well, if there's anything else that you think of or if there's anything else I think of you know, let me know and likewise I'll let (we've got the numbers) yea, yea, yea, completely, yea.
| I | So, I’ll type this up and July and August I’ll be getting deep into it, analysing it and all the rest of it so I might just send you a sheet of paper then just to say have I got the flavour of it. | Establishing permission to verify data analysis. |
| P12 | Yea, yea, yea, yea, yea fine. | |
| I | And hopefully you’ll be round that corner by then. | |
| P12 | Yea, definitely, definitely. | |
| I | Great, thank you very much P12. | |
| P12 | No problem. | |
| Tape off. | |
| I | I’m putting the tape back on ‘cos P12 has just (he laughs) remembered something that he wants to say. | |
| P12 | Well it’s very, again it’s very much down to individual, personal circumstances but possibly another thing (says the last two words slowly as if deliberating) and this might sound counterintuitive erm, that has helped in a way is that my Dad has become ill with prostate cancer and he’s quite ... he lives on his own and er, and is showing early signs of dementia, so I’ve had to get very involved in ... helping him with, you can imagine the protocols, and the things that come through, it’s a bombardment of information you know and if it’s not something you’re used to anyway it can be a bit whatever, but if you’re not completely with it as well, it can just be too much. | Father’s illness has provided a focus. Volume of information overwhelming for both (?) for different reasons. |
| | We were getting to the stage whereby we would be, I have a couple of brothers and we’re all spread out (laughs) we would be er, we’d speak to him but you could never understand quite what was going on because he had, he couldn’t really say, oh yes I’ve got to go to the doctors here or I’m doing this or I’m doing that, erm, he would just sort of turn up where he was told to but didn’t really understand what was underlying it (yea). I’ve been involved quite alot. I had to take him up to the Churchill in Oxford last week for his planning meetings and speaking to GP’s and sisters and stuff and I’m going up to see him again tomorrow, so, actually, kind of bizarrely, having a different focus has, there’s always someone else for me to care about, ‘cos this, I have some experience I suppose of radiotherapy, has also in some way possibly helped. | His experience has helped him understand his father’s situation and lending support has diverted his attention and given him another focus. |
| | And the only reason why I mention it is the driver in the car was saying that exactly the same thing had happened with his brother who’s got myeloma but was doing alot of caring for his sister(yea) who’s got dementia and actually it was just giving him another focus to er, to to concentrate a bit on. I’m not suggesting that everyone should go and (have an ill relative) (both laugh) have an ill relative in order to do it but I think it’s another sort of contributory factor whereby, you know, not that I was particularly focussed on it but if, it just gives, it’s another thing that keeps you focussed on something else. | Importance of having a focus. |
| | And maybe it’s, we’re new to the area where we live, so I don’t have, it’s | Because of moving prior to diagnosis he has no local |
not like I have a *football* group, all my friends are still back in London and stuff like that you know, or I wasn’t part of a *clock* repairing society or something, but if you had a hobby or, *that’s* the kind of thing that you need that kind of distraction I think, that *other* focus which I think would help. It’s been lacking for me, just again because of personal circumstances. We moved to Burgess Hill, I got ill within a month. So we just didn’t know anyone. There was none of that down there, we weren’t doing anything, we weren’t plugged into the community in any way, shape or form. But for other people, if they *are* doing things, if they’re going to the University of the third age or whatever it is that, *(mm)* that interests them then I think those kind of distractions, diversions are possibly another good way of just helping you through it you know *(mm mm).*

<table>
<thead>
<tr>
<th><strong>I</strong></th>
<th>Well you’re doing children of the first age aren’t you. <em>(Exactly)</em> That’s your focus.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P12</strong></td>
<td>I used to like going back in for chemo ’cos I knew I’d have four days without even feeling guilty about it, do you know what I mean. I’d just be in bed and that was it. People would bring me my meals and I wouldn’t have people clawing at me or going, can you not just look after them for five minutes? <em>(Oh P12 we won’t be playing this to them. Can I just assure you that at the end of all this I destroy the tapes, it will <em>not</em> be available to your children.)</em></td>
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<tr>
<td><strong>P12</strong></td>
<td>Okay, fine. Good, good, good!</td>
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<tr>
<td><strong>I</strong></td>
<td>Thank you for that, I think that’s a really important point actually.</td>
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</table>

Attending for chemotherapy was a legitimate reason for not playing your role in the family so relieved guilt. The pressure was relieved and you were cared for. Theme: guilt, legitimacy.

Social network. He highlights the importance of this as a focus. Also, diversions such as learning new things.
## Appendix VII

### Sample of preliminary interpretations for each participant

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<th>P4</th>
<th>P5</th>
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<tbody>
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<td>Big thing, isolation, prison, cocoon</td>
<td>Gender</td>
<td>Nervous</td>
<td>Dependents</td>
<td>Scary</td>
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<tr>
<td>Support</td>
<td>Fatigue</td>
<td>Limited strength/pacing</td>
<td>Big transition</td>
<td>Side effects</td>
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<tr>
<td>Survival/recurrence appointments</td>
<td>Appetite/weight loss</td>
<td>Distraction - writing</td>
<td>Protected/cocoon/bubble</td>
<td>Previous treatment experience</td>
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<tr>
<td>Anxious re coping feelings</td>
<td>Normality/activity/social</td>
<td>lessons</td>
<td>Psychological strain</td>
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<tr>
<td>Being believed not labelled</td>
<td>Support</td>
<td>Making most of time/interruption</td>
<td>Macmillan and rare disease ALL</td>
<td>Diet</td>
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<tr>
<td>Knowledge and information</td>
<td>Information/advice re activity</td>
<td>Goals – work; exercise; travel</td>
<td>Confidence/worry re blood results</td>
<td>Infection/sepsis</td>
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<tr>
<td>Age appropriate care/exclusion</td>
<td>Infection risk</td>
<td>Hair</td>
<td>The actual transplant - +ve Side effects</td>
<td>Profession</td>
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<tr>
<td>Identity appearance</td>
<td>Role as Grandma</td>
<td>Support from family and friends/students</td>
<td>Age &amp; survival</td>
<td>Pain</td>
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<tr>
<td>Hair</td>
<td>Experts/lack of confidence/GP</td>
<td>Resuming activities</td>
<td>Body wonderful and forget pain</td>
<td>Isolation/confinement/embarrassment</td>
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<tr>
<td>Normality</td>
<td>Time to recover</td>
<td>Dr's encouragement</td>
<td>Family</td>
<td>Panic attacks/confidence</td>
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<tr>
<td>Future goals</td>
<td>Resuming activities</td>
<td>Donor – grateful/process</td>
<td>relationship</td>
<td>Re-socialisation</td>
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<tr>
<td>Work/passion</td>
<td>Goals – work</td>
<td>Technology/isolation</td>
<td>Delay for donor</td>
<td>Visible difference/stigma</td>
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<tr>
<td>Expertise v lack of confidence</td>
<td>Effect on new relationship</td>
<td>Carer burden/well-being</td>
<td>Experts/lack of confidence</td>
<td>Give something back</td>
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<td>+ve &amp; -ve aspects of cancer</td>
<td>Reflection</td>
<td>Technology/ isolation</td>
<td>Expertise</td>
<td>Physical impairment</td>
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<td>Strain on others</td>
<td>Regaining self/turning points</td>
<td>Carer burden/well-being</td>
<td>specialist/local/info</td>
<td>Support/counselling</td>
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<td>Sleep</td>
<td>Hair</td>
<td>Food choices/facilities</td>
<td>Hair loss</td>
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<td>Hair &amp; wig/turban</td>
<td>Support</td>
<td>Re-evaluation of relationships</td>
<td>Parental support groups</td>
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<td>Technology for keeping in touch</td>
<td>counselling</td>
<td>Trial drug</td>
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<td>Lucky/safe/determination</td>
<td>Staff knowledge/confidence or not</td>
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<td>Physical effect GVHD</td>
<td>Access</td>
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<td>Giving something back</td>
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<td>Magnitude of it all</td>
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<td>+ve attitude of self</td>
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<td>Keep busy</td>
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<td>Partnership – you do your bit</td>
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<td>Balance of medicine doses</td>
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<td>Monitoring by husband</td>
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<td>Anxiety &amp; concern for others</td>
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<th>Being alone</th>
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<td>Inexperienced clinicians</td>
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<td>Support from son</td>
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<td></td>
<td>Burden of hospital appointments</td>
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<td>Grateful for hospital transport as long distance from specialist centre but very early and results in fatigue and illness</td>
</tr>
<tr>
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<td>Resistance to re-hospitalisation plus OPD is like another world</td>
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<td>p14</td>
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<td>Survival/mortality</td>
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<td>Loss of husband</td>
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<td>Rejection of donor cells/GVHD</td>
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<td>Determination</td>
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<td>Physical impact</td>
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<td>Lack of understanding from son</td>
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<td>Relationship thread running throughout</td>
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<td>Feels abandoned by both her children</td>
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<td>Independent</td>
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<td>Decrease in confidence (potential of loss of husband and illness)</td>
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<td>Testing herself/pride in achievement and own strength</td>
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<td>Product of her donor</td>
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<td>Desire to help others research – bloods and this</td>
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<td>Hair</td>
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<tr>
<th>P10</th>
<th>All ok till day 100</th>
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<td>Technical detail re engraftment</td>
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<tr>
<td></td>
<td>Information booklet – all experienced – fatigue, weight loss, appetite decrease, infection</td>
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<td>Transfusions</td>
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<td>Top up transplant transfusion</td>
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<td>He’s gone from good to poor – needs sleep+++; wheelchair, has diarrhoea, GVHD, medications are a problem</td>
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<td>Felt like giving up recently – one thing after another</td>
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<td>Huge resistance to returning to hospital despite potentially life threatening infection</td>
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<td>Experience of incompetent staff and lack of organisation</td>
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<td>Fluid retention</td>
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<td>Colonoscopy and platelet issue</td>
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<td>Anticlimax of actual stem cell transplant</td>
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<td></td>
<td>Worth it for the cure</td>
</tr>
<tr>
<td></td>
<td>His condition was very painful</td>
</tr>
<tr>
<td></td>
<td>Work and hopes to return</td>
</tr>
<tr>
<td></td>
<td>Has had counselling – helpful. Physical manifestations of transplant make you score high on depression scale</td>
</tr>
<tr>
<td></td>
<td>Wife and family support</td>
</tr>
<tr>
<td></td>
<td>Wife altered work pattern</td>
</tr>
<tr>
<td></td>
<td>Distance from specialist centre</td>
</tr>
<tr>
<td></td>
<td>Financial burden</td>
</tr>
<tr>
<td></td>
<td>Some local care possible &amp; preferable</td>
</tr>
<tr>
<td></td>
<td>OPD all day event</td>
</tr>
<tr>
<td>P11</td>
<td>Biggest memory of SCT is anti-climax Holding treatments for 4 years No mental road map post transplant Information given maybe but not absorbed Chemo – from doddle to bad side effects Medications++ Hair loss Sleep affected and seeping tablet addiction Water retention</td>
</tr>
<tr>
<td>Mucositis</td>
<td>Infection</td>
</tr>
<tr>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td>The high of returning home</td>
<td>Sleeping alot</td>
</tr>
<tr>
<td>Resuming previous roles</td>
<td>Support from friends re child care</td>
</tr>
<tr>
<td>– became more realistic</td>
<td>Painful limbs</td>
</tr>
<tr>
<td>Rethink re future work</td>
<td>Changed view on work</td>
</tr>
<tr>
<td>Strain on wife re work and child care etc</td>
<td>Recovering and less OPA’s</td>
</tr>
<tr>
<td>Wife plays part in mentioning issues at OPA as he is ‘man’ about it</td>
<td>thought it was Hair curly and different colour</td>
</tr>
<tr>
<td>Self-sufficient/keep occupied</td>
<td>Losing battle re food</td>
</tr>
<tr>
<td>Had a practice run with previous illness experience/mental preparation</td>
<td>Transplant and age</td>
</tr>
<tr>
<td>Initial diagnosis</td>
<td>Experience hard but no alternative</td>
</tr>
<tr>
<td>Serious complications - treatment v side effects</td>
<td>Metaphors ‘battle’/‘raging’</td>
</tr>
<tr>
<td>Technology – keeping in touch</td>
<td>‘battle’/‘raging’ Technology</td>
</tr>
<tr>
<td>Concern for family</td>
<td>One visitor – a mercy visit for drinks</td>
</tr>
<tr>
<td>Needed variety of the only thing he could have orally modest goals</td>
<td>Holiday</td>
</tr>
<tr>
<td>When ‘line’ out possibility of local care</td>
<td>Backward step and effect expertise available</td>
</tr>
<tr>
<td>Being young as a positive of getting through it</td>
<td>Feels a turning point - maybe aided by reflection on the story and talking about experiences</td>
</tr>
<tr>
<td>‘It was never really explained’ Maybe forgot detail when lifeline treatment identified</td>
<td>‘I didn’t want to think what I was going to go through’</td>
</tr>
<tr>
<td>Good explanation from Dr ‘no walk in the park’ Access to experts good – good to be known and response reliable</td>
<td>Acknowledgement of being listened to</td>
</tr>
<tr>
<td>Long IP stay</td>
<td>Access to experts good – good to be known and response reliable</td>
</tr>
<tr>
<td>Need for someone to address how this impacts on your life</td>
<td>Need a road map of info re entitlements/benefits/tax credits etc</td>
</tr>
<tr>
<td>Feel better than warned then it hits and hits hard</td>
<td>TBI</td>
</tr>
<tr>
<td>Bad headache</td>
<td>Relapse on treatment</td>
</tr>
<tr>
<td>Effect of this and feelings re children</td>
<td>Transplant hastened</td>
</tr>
<tr>
<td>He views infections as something easily treatable v weight loss and appetite</td>
<td>Suggestion of tube feed led to angry response as all frustrations come out bored, no eyebrows, no eyelashes</td>
</tr>
<tr>
<td>Bargaining re weight gain/no tube</td>
<td>Visible difference and kids</td>
</tr>
<tr>
<td>Texture and consistency important</td>
<td>Dietition lowered standard of nutrition</td>
</tr>
<tr>
<td>First six months are a nightmare</td>
<td>Financial worries/children/work</td>
</tr>
<tr>
<td>Need for someone to address how this impacts on your life</td>
<td>Need a road map of info re entitlements/benefits/tax credits etc</td>
</tr>
</tbody>
</table>
| Wife highlights irony of being told to relax when stresses are
<table>
<thead>
<tr>
<th>Support group – Macmillan group meets and disease specific e-contact plus own blog</th>
</tr>
</thead>
<tbody>
<tr>
<td>Danger of intranet info</td>
</tr>
<tr>
<td>Tips e.g. lip salve</td>
</tr>
<tr>
<td>Isolation hard</td>
</tr>
<tr>
<td>Access to treatment/age</td>
</tr>
<tr>
<td>Living a day at a time and looking forward to being able to plan</td>
</tr>
<tr>
<td>Rehab hard e.g. driving, shopping</td>
</tr>
<tr>
<td>Feels better when others have similar issues</td>
</tr>
</tbody>
</table>

| waiting |
| Recent scans and trying not to worry |
| I don’t have the luxury to have twinges or aches and pains/fear of return |
| Seizure – driving ban results in lack of freedom/independence |
| Information – objective view re internet |
| Medical friends for info – wanted someone else in charge of knowledge though thought he should be doing more returns to diagnosis and shock of it/rare |
| Limited faith in GP |
| Expertise of specialist centre but personalised care at local hospital |
| Whole experience feels an age but medics say early days |
| Subconscious anxiety re scan |
| Need for others to understand his tiredness is genuine |
| Striving for normality |
| Preparation/boredom/luxuries/family support/financial support through work |
| Surviving rather than living at the moment ‘groundhog day’, no ‘specific reference points’, ‘things can get a little bit bland’ |
| Surprises himself with things to keep him occupied. Distraction of father’s illness has helped in a way |
| Adopting carer role |
| Moved recently so no immediate social group |

| Small steps raise the spirits |
| Psych v physical pain |
| Resuming normality curry on a Friday |
| Social life affected |
| Alcohol tolerance |
| Worst is behind – focus on future |
| It’s in the background but reminded just how ill you’ve been |
| Sick role v carer role comments |
| Uncertainty ‘element of doubt’, ‘there’s always a but isn’t there’ |
| Trying to understand technical detail re transplant and blood results |
| Top up maybe |
| Lost bone marrow aspirate |
| Technological advances re BMA’s |
| Diagnosis and what led up to it |
| The very beginning of illness/reluctance to visit GP |
| Can’t fault NHS – confidence re speed and treatment |
| Wants to contribute |
| Financial hardship |
| Raison d’etre re family |
| Infection risk |
| Internet info and technology – skype to keep in touch/hospital website info good |
| Reduction in medication a sign of getting better |
| Vaccinations |

| medical/physically/socially |
| Self-employment a particular concern |
| Charity – others for him and him for others |
| Strain on wife and family |
| Expense of travel |
| 3-5 OPA’s a week |
| Wife felt health most important but knew his business was of great importance for him |
| Financial stress major issue |
| His business/finances worse than illness |
| Married just prior to illness |
| You’re not depressed so much by cancer but all that it brings. Financial advice not good; need realistic advice particularly as recovery time uncertain. |
| Need for someone to spell it out |
| Care is the up side like a hotel |
| Consistency of care highlighted |
| Really looked after as an individual |
| Medical/nursing care great but home circs neglected |
| Perceives minimal impact for older people |
| Family strain - it would be ok if you could just get on with it |
| It’s the speed of the crash and long interruption to normality |
| Almost enjoyed chemo as a rest and no-one had expectations | Donor cells – an alien in your body  
Importance of having questions written down 'I think you’re so relieved because your counts are good  
Effect on fingernails  
'there's no hard and fast rules with what's happened to me is there?'
## Appendix VIII

### Cross cutting themes

<table>
<thead>
<tr>
<th>Biographical Disruption</th>
<th>Information</th>
<th>Fatigue and physical changes</th>
<th>Uncertainty</th>
<th>Identity</th>
<th>Coping</th>
<th>Importance of relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Groundhog day</td>
<td>I've learned alot I didn't want to know</td>
<td>Hair, Nails, Posture, Pain</td>
<td>Diagnosis</td>
<td>Stigma</td>
<td>Keeping positive and occupied (don't dwell on things)</td>
<td>Relationships (re-negotiation, re-establishment of existing or lapsed relationships)</td>
</tr>
<tr>
<td>Turning a corner</td>
<td>Information, blogs, websites and hospital 'huge step' to go home</td>
<td>Physical limitations, debilitation, frustration</td>
<td>Treatment 'in limbo, shut down; vegetative state</td>
<td>Hair loss</td>
<td>Goal setting</td>
<td>Family/Others</td>
</tr>
<tr>
<td>Work</td>
<td>Support groups E-information and websites re disease info</td>
<td>Muscle wasting, Numbness (peripheral neuropathy)</td>
<td>Critical illness e.g. infection/drug reaction (3 &amp; 8), heart failure (6 &amp; 8), fluid overload (12) during chemotherapy/SCT</td>
<td>Nails, skin</td>
<td>Being lucky</td>
<td>Medical staff</td>
</tr>
<tr>
<td>Relationships</td>
<td>GP Access to experts post SCT</td>
<td>Unable to do 'normal' things e.g. drive the car, mow the lawn, carry the kids</td>
<td>Complications e.g. seizure (12), headache &amp; blindness (15)</td>
<td>Physical manifestations</td>
<td>Hope</td>
<td>Nursing staff</td>
</tr>
<tr>
<td>Reproduction</td>
<td>Limits social activities</td>
<td>Overall 'big bang to your body ' (1) Survival</td>
<td>Loss of macho image</td>
<td>Eating</td>
<td>Optimism</td>
<td>Psychologists</td>
</tr>
<tr>
<td>Social aspects</td>
<td>Regaining independence</td>
<td>No more treatment options Relapse</td>
<td>Normality</td>
<td>Fatigue</td>
<td>Bargaining and partnership with medics re decision-making, 'journeying with the team'</td>
<td>Group support (or not)</td>
</tr>
<tr>
<td>Liminality</td>
<td>Frequency of follow up appointments</td>
<td>Interpretation of blood results Recurrence</td>
<td>Sleep issues</td>
<td>Fatigue</td>
<td>Positive attitude of doctors</td>
<td>Care shown by nurses made a real difference (conversely examples when it did not)</td>
</tr>
<tr>
<td>Re-evaluation of relationships</td>
<td></td>
<td></td>
<td>Importance of special occasions</td>
<td>Importance of special occasions</td>
<td>Growth through experience</td>
<td>Participant's worry for their families</td>
</tr>
<tr>
<td>Distance from specialist centre</td>
<td></td>
<td></td>
<td>Regaining independence</td>
<td>Regaining independence</td>
<td>Desire to help others; encourage donors; money raising; participation in research</td>
<td></td>
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<tr>
<td>Financial burden</td>
<td></td>
<td></td>
<td>Re-establishing their position e.g. as parent, Grandma, wife, husband etc</td>
<td>Re-establishing their position e.g. as parent, Grandma, wife, husband etc</td>
<td>Money raising; participation in research</td>
<td></td>
</tr>
<tr>
<td>Re-evaluation of life ambition, work etc</td>
<td></td>
<td></td>
<td>Importance of age appropriate care.</td>
<td>Importance of age appropriate care.</td>
<td>Participating in research</td>
<td></td>
</tr>
<tr>
<td>Critical illness events – trauma narratives</td>
<td></td>
<td></td>
<td>Difficulty in expressing emotion or discussing emotive issues leading to feelings of isolation.</td>
<td>Difficulty in expressing emotion or discussing emotive issues leading to feelings of isolation.</td>
<td>Humour</td>
<td></td>
</tr>
<tr>
<td>Road map, viscous circle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reducing risk and taking care</td>
<td></td>
</tr>
<tr>
<td>Not the doddle I thought etc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Vigilance re health status and monitoring</td>
<td></td>
</tr>
</tbody>
</table>

- **Diagnosis**
- **Treatment**
- **Vegetative state**
- **Critical illness**
- **Infection/drug reaction**
- **Heart failure**
- **Fluid overload**
- **Complications**
- **Seizure**
- **Headache**
- **Blindness**
- **Macho image**
- **Eating**
- **Normality**
- **Sleep issues**
- **Fatigue**
- **Importance of special occasions**
- **Regaining independence**
- **Re-establishing their position**
- **Dad**
- **Mother**
- **Wife**
- **Husband**
- **Participating in research**
- **Humour**
- **Reducing risk**
- **Vigilance**
Appendix IX

Sample of meaningful statements, participant 1

<table>
<thead>
<tr>
<th>Participant 1</th>
<th>Initial interpretations</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think the first thing is when they tell you</td>
<td>Communication and information</td>
</tr>
<tr>
<td>to er, being told that your counts are starting to go up</td>
<td>Biomedical focus</td>
</tr>
<tr>
<td>and you almost feel that enormous sense of relief that it’s time to go back home but after going through such a big transformation during transplant that you almost feel where do I start. Telling me to go home is just such a huge step and there isn’t that much of a guidance that they tell you that you need to. (stops and is visibly moved at this point)</td>
<td>Safety of the hospital (safe in the bubble), lack of information</td>
</tr>
<tr>
<td>So definitely with the first thing when they tell you to go, that you’re ready to go home you need that psychological support, erm, as soon as they said that your counts have gone up and they tell you that you’re ready to go you get that almost that, that overwhelming feeling inside that you can’t wait to leave the hospital and you almost wonder whether it’s staying in one place all the time that makes you feel weak or if it’s still the treatment that’s kicking in, you’re still not sure, as soon as they tell you you can go home where do I start from there.</td>
<td>Left to stand on your own two feet</td>
</tr>
<tr>
<td>That’s, that’s a huge, huge thing and being by yourself and being told that, sometimes you can take those things for granted and what I mean by that is I think that many people think that as soon as the doctors tell you you are fit to leave, you take this for granted that you’re being given a key that unlocks certain doors back to your normal life but not fully understanding the consequences of being left to stand on your own two feet after such a journey.</td>
<td>Possibility of facing one’s own mortality</td>
</tr>
<tr>
<td>You’re put into a very light room from being in such a very dark room. You get worried, you wonder how you might feel will I be fine, will be enough, will that ease my worry. Will I be fit enough to call, will I, what will I come across during that time. And the main worry for me at that time when they told me was, am I going to survive, how am I going to make sure that everything will be fine with me.</td>
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<tr>
<td>It’s ok to take the medication but you need someone there with you, behind you, I don’t think you can do that by yourself, at all. Yes, the nurses are there to and there’s only so much they can do, but you need that push not just from yourself but from other people as well and my push was my Mum. That’s what pulled me through this journey. It’s almost like being given the green light. You haven’t got to go through any more pain, now it’s just the recovery from it (right) and you’re not trapped into this room, all this time, you are set loose. You feel almost human again.</td>
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</table>
Yes, but even that has its consequences because when you’re being told that you’re free to go, you don’t know really where to start to get your, you have to build up again and you’re not at your optimum strength so you’re thinking with also with a weak mind as well which is dangerous I think. Erm, the nurses and the doctors are there to tell you that everything will be fine and you will be monitored but that psychological part is something they can’t give to you, you have to give to yourself I if you haven’t got that in a way that you feel you’re ready to go. It’s just a difficult time

| Not knowing where to start and being left to stand on your own two feet |

I remember when I was given all the medication and not even, you need to understand alot you need to take in a lot, it’s not that they just tell you to leave, there’s alot of things that you need to remember and without having someone behind you, I’m not saying you know you’re in this world alone but going through cancer you need someone to be with you. The saying is that you shouldn’t go through cancer alone (yea) and that’s the main priority, to have someone with you because you can deteriorate, you can go in, they tell you that you can leave the hospital but if you don’t take care of yourself you go straight back in. *And that’s the worst part* (quietly and meaningfully stated).

| So much to remember in terms of self-management and monitoring. Importance of having someone to support you through the cancer journey. It is a difficult time |

Then there’s the whole idea of nutrition, dieticians, that needs to be taken care of and with my diet that I had as well being intolerant to many foods, I had to take another big leap with that as well. I wasn’t really told what I should and shouldn’t eat, just it’s been rather difficult. You’ve already got one problem and I’ve been given another problem.

| So much to worry about and will I survive? |

Trying to recuperate from all the chemotherapy that you’ve had a huge bang to your body you need to be on top of that and if you’re not on top of that you can deteriorate as well and then that makes you wonder am I going to survive, am I going to recover the way I should recover, am I going to get side effects if I’m not taking care of myself. *It’s a big, big thing for me.*

| Complications associated with allogeneic SCT e.g. GVHD. Increased vigilance required |

There was no way I could do this by myself. And I keep on saying that. It sounds like I’m really relying on my Mum but she was the only one there to really support me during that time. So my Mum and I, we had to rent a place near the hospital to make sure, because you have to come in about five or six times a week almost like a week every week. And to travel back and forth being nauseous, not being able to eat, feeling weak, hating the idea of travelling to be five minutes away for anything because there are more complications with a donor transplant than with a normal one because your counts just go back to normal. You can get complications of GVHD, many, many other things, and that was, you had to be on top of that as well. There were sometimes I could not walk, I needed to travel and my Mum had to take me, er, every day to the hospital. I felt … *a baby* again. It’s not that you’re, it’s like you’ve been stripped down from your whole, your whole body’s been stripped down and you feel weak and you can’t help to feel almost like in a little cocoon and then they tell you to, to get out and try and do things, and you can’t. The first few stages you’re too weak to even think about that. You just want to go into the hospital, make it as quick as possible and go out.
I found the place myself. They did offer but sometimes you don’t want to be in hospital all the time. It’s enough to only go through a transplant being twenty-two and being in a hospital, it’s, among other unwell, I’m not saying that a hospital is a place where everything is beautiful, it’s amazing but you don’t want to be there, it’s not where you should be. You should be out there, I’m only twenty-two I should be able to do things, to get out there.

It’s almost you need to feel that little bit, a sense of normality as well during your transplant. It’s not just about being in hospital, because, that would be the biggest thing, the biggest worry that you spend all this time, you spend six months in hospital for example and if I didn’t find my own place and then they tell you to, that you’re free you’d be feel even more lost than before.

<table>
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<tr>
<th>Loss of identity</th>
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I made sure that I was kept busy during this time and to avoid getting into too much detail with certain things after transplant avoiding going onto the internet to make yourself feel worse. After transplant you’re very vulnerable and you want to try and find an answer even after transplant, and especially when you haven’t had a PET scan you want to know what’s going to happen to me, find out other people’s stories and that's a really, really bad thing to do. If I didn’t have a previous transplant before this one, I’d probably have done that again, I wouldn’t have learnt from my mistakes. I would have made myself even worse. And with time your brain becomes a little bit more stable.

<table>
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<tr>
<th>Keeping occupied</th>
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You realise that everybody is different and that things will get better. But during the first three months that is definitely not the case. Definitely not the case. I know I keep on saying, going back to my previous transplant, because I’ve gone through the whole works. I mean I’ve tried everything, I even tried counselling, I tried to have counselling before and after treatment but there is only so much you can say, and you need to find in your own stride try and keep yourself busy, and try and do things to make you not think too much. And it’s very hard to put your head around that. Very, very hard. There’s only so much nurses can do. And I had to dig up old projects that I did from University and try and get myself back up there again. Whether it’s just five minutes, ten minutes, it was something. I needed to feel normal. I had to…, and I don’t think the nurses could do anything to (pause) to make me feel that way. I needed to do it myself.

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<thead>
<tr>
<th>Fear of disease recurrence</th>
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</table>

That’s also another thing that helped for young adults. It makes you look forward to something. It doesn’t make you think oh I’m going back into hospital again. That was a huge huge thing, and I rejected that many, many times. Then it came to a point when I thought, do you know what, I’m going to do it this time because life is too short and they really put a smile on my face and made me think less about the whole transplant.

<table>
<thead>
<tr>
<th>Distraction to avoid undue worry</th>
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</table>

But I keep on, I keep on saying this, the first three months, there’s no way you that can think all of this with a straight mind.

<table>
<thead>
<tr>
<th>So much to concern yourself with in the first 3 months post SCT</th>
</tr>
</thead>
</table>
I think it was things these visions that things that I've seen before on the news, patients, young patients who have gone through cancer and I thought ‘the wish’ was just based on... because they’re dying. Not based on their moving on with their life. The media doesn’t help. The media always talks about kids who’ve had cancer and they’ve gone. Maybe that’s the only things I’ve absorbed and they’re the only things I’ve been seeing. And I thought the Willow Foundation was that, the Willow Foundation is your only opportunity to do something really great before you go.

And once you’ve been hit too many times, you don’t care, you really don’t. I’m going to do it and I did do it. And in seven weeks' time I’ll be going to do something I've always dreamed of which is great, really great. I’ll be meeting the designers of Alexander McQueen, er he’s my greatest, greatest fashion designer. I absolutely love him and they invited me to go to the men’s catwalk in seven weeks to see the show. But those type of things are great to get back on track after transplant and you need that, and especially for someone who’s very young. You definitely need that. I can’t stress that enough. And I was, maybe it wasn’t time for me to go and say yes. Maybe it was time to say yes now. I don’t know.

You can still do it, you’re not ... you’re going to the other end of the world. And these events that he creates to go out for like a pizza or a movie. It’s a nice thing to have because you meet other people who’ve gone through the same thing of your age. Going through transplant and seeing people who are about fifty or sixty years older than you or forty years older than you, it’s not nice, it’s not nice. You almost feel like the odd one out, you’re not at their level and it’s not nice at all. But being with people familiar to you, the same age, it doesn’t exclude you and another great thing about after transplant this time was to be with the young adults. That’s a huge thing, to, to talk to other people your age.

It wasn’t nice, I felt captivated

When you are feeling better, you can go into this lovely room where you’re with other people your own age, you can play games, you can socialise, you can watch TV. Your own, your own little fun house and the food’s different as well. They offer you snacks, they stimulate your appetite which is a nice thing and the nurses are lovely, they’re all young, they’re all very very young, experienced and so grown up, soo on the ball. Also they allow you to bring your parents along, they can sleep next to you, they er, there’s a bed specially there for, for the parents which is a lovely thing because the last thing you want is to be by yourself and you can have your Mum, your Dad, your partner, whoever next to you during this difficult time. Sometimes you don’t even want to get up. You wrap yourself too much, because you are already in, you wrap yourself up too much in your own mind, thinking what’s going on, what’s happening, more medication, more lines, more this, more that and you just need someone

| Needing distraction “something to live for” | Doing ‘normal’ things and sharing experience with others of the same age | Feeling captivated due to being in an isolation facility | Distraction is important. Teenage and Young Adult facility was appreciated. Support of loved ones |
whose there with you, like a, your family or someone who will look after you other than the nurses to give you that stability.

<table>
<thead>
<tr>
<th>Loss of identity due to altered physical appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your body is so agitated because it’s going through so many changes once again internally, externally, visually, you know...(this is about...about rest). You don’t even want to watch TV because you compare yourself with the people who are well and you think look at me, I’m blown up and I’ve got no hair and I’m not the way I should be.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>You feel different because of what you have experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some emotions you can’t even describe to someone who hasn’t gone through it. There has to be almost like a connection to someone else who has had cancer and would understand. There’s certain things that, no matter how much you describe them it will never be how you feel inside. It’s something that you can’t describe if that makes sense?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling of abandonment and uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s a heavy journey. A heavy, heavy journey. And almost after six months, it hasn’t quite been six months yet for me, once your brain starts to go back to that normality and you see the Doctor less, your head almost for me it’s expecting too much. Sometimes I almost forget that I’ve had a transplant and because you’re picking up on your own two feet after being protected for so long before transplant and then they tell you to leave and you’re not seeing the Doctors anymore, you demand too much of yourself because you’re thinking ok and you start to become something, someone, before it all goes again. That’s my problem now. I see it as a huge, huge problem,</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Loss of identity and feeling different from those who have not experienced cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>when you’re putting your life in their hands and they don’t know what disease you have. Don’t treat me, you know I want to be somewhere where with open arms they know that they are doing. They took quite a long time to try and find me a donor when there weren’t any donors there.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Disruption to life plans due to disease recurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’m still not happy with the way I am. I don’t know whether this a long term thing that I’ve had or if it’s to do with transplant and being hit too many times, but I’m also trying to compare myself to too many people, to people who haven’t gone through anything. You forget that because you’re on your two feet again. Does that make sense Liz? It’s just that it’s almost you’re, you’re being told to go, being told to find your life again and you’re already a rare case at a young age to be diagnosed with cancer and you see all these other students. Obviously, I don’t know their history but they haven’t been through anything. You’re comparing yourself with them and they haven’t actually gone through any of that.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disruption to life plans due to disease recurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>The first time I got diagnosed was 2009, and I had just managed to start the foundation course, erm, sorry, this is rather upsetting. I got diagnosed with Hodgkins and had six months treatment, unfortunately the scar tissue I had in my body was not scar tissue it was relapse of disease. The disease was still there. So I had to go through a transplant and deferred my foundation for a year. Eerrrrm, going through that decided to go back to study, finish off the foundation. You can’t start in between years you have to start all over again.</td>
</tr>
</tbody>
</table>
Got into BA course at the same University, did my exhibition and unfortunately got unwell again. So now if everything 
would have been fine and it didn’t come back I would have been studying for my three year course and finish in 
January. But that’s been on hold and now hopefully getting back to normality again.

| Loss of identity and feeling different from those who have not experienced cancer |

This is what has inspired me, because these things they don’t happen to everyone (animated)

| Experiencing cancer has had an effect on his creative work |

I’ve noticed that my work has changed alot compared to other students.

| The importance of hair as part of your identity |

It’s almost I have a different view on things and most of my pieces have dealt with hair. Hair has been a huge 
importance. Even before I was diagnosed hair was the main thing I was interested in, I always very much liked, very, 
very vain, very much liked doing my hair and styling it. You know as a, as a teenager, (yea, yea) but having lost it 
many times you understand the importance of, how important hair is and with jewellery, jewellery is something that 
you are bound to a, like hair is to you. It’s what makes you beautiful, personalises you. I just find hair so powerful. 
After having just gone through these transplants, I find that hair is just so important as er. Because you don’t have 
any hair. When people want to feel beautiful they do up their hair. They want to have something that makes them 
feel. It’s what makes them them.

| Thinking differently about life as a result of the cancer experience |

It opens other people’s minds as well, especially the students, I mean it opens their minds. They are shocked when 
they hear the word cancer like anyone does and if you can make that cancer look something beautiful in a piece 
using hair and not judging hair as something dead. You almost like making the hair look alive again. It’s, it’s very 
hard to explain (Pauses). Like giving a new meaning to cancer. It’s not all about death.

| Personal growth through the experience of cancer |

And you try to express that through your work because there’s alot of negativity in cancer and I try to do that as 
much as possible, and as much as I hate cancer, and I hate what I’ve gone through, it has made me rethink about 
many things, my work, the way I think, the way I communicate with people, the way I see life. It’s massive, it’s a 
huge thing. A huge, huge thing. And no-one can take that away from me.

| The use of art to express feelings about your experience when it is difficult to describe |

I’m very proud of that, very, very proud. No-one is ever going to take that away from me at all because it’s made me 
who I am now. It’s a growing process as much as cancer is the devil, yea, it’s the black hole but not really, it’s erm, 
it’s a whole new kind of escape, but it’s not nice to have.

| When you have cancer, sometimes you can’t express, like I was mentioning before, you can’t express your feelings, 
you need objects, you need that power, that charm, you need er, something on you to make you feel that, a bit more 
powerful because you feel so weak. |

When you have cancer, sometimes you can’t express, like I was mentioning before, you can’t express your feelings, 
you need objects, you need that power, that charm, you need er, something on you to make you feel that, a bit more 
powerful because you feel so weak.

| It’s the expression, I mean this power is like a soul, speaking, if you can’t speak, your soul will speak. I had to build 
this huge transparent piece which, because you can’t see the trachea inside here, coming out then it had, it came out 
and it was made out of plastic and it had wings. Then it had, you know like a jewellery box with the key and because 
you can’t speak, it is locked within the trachea, in the middle and there are all these sharp shard like broken glass |

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you can’t speak, it is locked within the trachea, in the middle and there are all these sharp shard like broken glass.
that you’re trying to fit all together again like life of cancer. You have all these pieces that you need to start building yourself back up again, picking up of this beautiful, powerful person…it did do really well and not because it’s my work but once again it opened many people’s eyes and it gave a new light on cancer and the other light of cancer is that I’m still here. Touch wood.

I went through the first three months and the scan was clear, thank God. Then I started to get symptoms about, sorry, I started to get symptoms about a month and a half after and I started to panic. I started to get worried and certain, certain diseases, they don’t show through the blood, especially Hodgkins, and the other signs would be sweating, lumps, itchiness, feelingitchy and there’s only so much that bloods can do and even the chimerism within the bloods to say how much is yours and how much is the donor. Err, it’s so good to be rest assured, and to have confidence in the patient that if something is not right at least to order an alternative scan or a CT scan or something or I don’t know. My disease had been acting very very funny and go and say oh you can’t be, you look well, you look fine. If I relied on that then there would be no need to have any scans would there? And I know they cost alot of money, for the NHS to go through all of this but ... I need to be rest assured for their sake as well because it’s easier, it’s good to have the disease under control and know what exactly what is happening with the disease rather than we don’t need one, you look fine, your bloods are fine.

He made sure that he was going to do one because he knows the prognosis of your disease and know how everything goes and it’s to rule out any complications, anything. And that is very very important. Very important. And he did do that and everything was fine and I couldn’t thank him enough because he I have trust in him and he listened to me, he didn’t ignore it and that’s also important the doctors do not ignore even the smallest of things, the small things can turn into something big.

Not all the time but to generalise someone and just say that it’s nothing without really just looking into it, going the extra mile to make sure that you’re fine. You need that. You definitely need that, because it’s one thing that oh you’re anxious, that you’re over thinking, you’re new this, it’s only been three months and you’re already thinking about this and getting too much into it. How about, how about if I’m not, getting too much into it, what about if there really is something there. And I know you can’t...you just need to find out.

The worst thing is especially when your mother is there and she’s worried because you know, having a child whose unwell and knowing the disease can come back, oh she’s anxious, she’s an anxious mother, you know, don’t listen to her. It’s not the case all the time. I don’t like that, I’ve absolutely hated the judgement of that. It makes me feel as if I’m almost paranoid, that I’m getting almost too much into it.

As long as you address it and do something about it. Not immediately, I’m not expecting miracles but at least they
don’t ignore it, and I keep on stressing that as long as they don’t ignore it and you look fine in two or three months and you find a lump somewhere. It’s not a good thing.
I mean you can get worked up within, thinking this could be the disease, this could not be the disease. It’s normal. But, to not act upon that, it’s not a good thing. It’s not a good thing. It’s definitely not a good thing.

That’s also very straining and draining coming in every day to make sure everything is fine. And then other things would be having your line checked. The line, that’s another thing that needs to be taken care of. There’s many, many, many things, and I don’t think. Some people don’t have a choice and have to do it by themselves but if you do have someone, if you do, yea, if you do have someone then that would be the biggest help, the biggest help, for anyone.

Obviously there are infections there are many things, it could be GVHD, could be infection, could be erm, you could have different variables, different types of medication that you need to go and take, whether you’re taking too much or whether your body’s not absorbing it, or if it’s how severe your GVHD is in your gut or on your skin, anything. There’s so many more things, so many more things insides and on top of that you need to worry about the disease as well

You can tell it’s a journey, it’s a big journey. And if someone says that it wasn’t, they’re lying. Laughs. They are lying. But for now the main points are: nutrition, psychological, erm having someone to contact, being reassured by the doctors, doctor being on top of things to make sure everything is fine, to keep busy and my big young adult people, you’ve got to ...you have. That’s the biggest one. I’m not sure about the rest because this is my story, but that is the main thing, so you don’t feel excluded because you’re already excluded enough to not go to university like stereotypically everybody else does.
Research Log

by

Liz Dunn

THESIS
Submitted for the degree of Doctor of Clinical Practice

PART ONE

Faculty of Health and Medical Sciences
Division of Health and Social Care

University of Surrey

September 2014

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9.0 Research Log

This research log presents the development of research skills and provides evidence of the research process including the rationale for decision making during the journey.

Developing research skills

I started the Doctorate programme with some personal research experience and having had the opportunity to attend conferences to learn about studies in a variety of areas of clinical practice. I completed my Masters in Science in 2001 when I carried out research to explore factors affecting the quality of life of ventilator dependent people living at home. A learning needs analysis was completed at the outset of this study highlighting areas for development (Table 1).

Table 1: Skills and knowledge to develop (Research Log 2009)

<table>
<thead>
<tr>
<th>Skills/ Knowledge</th>
<th>Areas to develop</th>
<th>Notes/ action plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge and Understanding</td>
<td>Advanced research methodologies; knowledge of relevant policy; knowledge of clinical speciality; health service changes</td>
<td>Modules within taught element. Breadth and depth of reading, regular review of new research</td>
</tr>
<tr>
<td>Cognitive skills</td>
<td>Critical reading &amp; analysis, systematic review, synthesis, report writing. Advanced conceptual and theoretical understanding</td>
<td>Library search skills; seminars; Introduction to Doctoral Studies module/ Advanced Research Methods</td>
</tr>
<tr>
<td>Presentation and writing skills</td>
<td>Strategies for dissemination</td>
<td>Writing skills; supervision process; wide reading. Submission to conferences; attend and present at post graduate seminars</td>
</tr>
</tbody>
</table>
Literature search strategies and literature management

Literature reviews were conducted to understand more about haematological malignancy and its treatment including stem cell transplantation and to identify areas that were undeveloped. Reviewing the literature suggested less research had been conducted which examined what these treatments were like for patients and how they coped on return home after prolonged periods in hospital. Literature searches were conducted with some initial help from the librarians at the University of Surrey library and the Royal College of Nursing library. I have also found it useful to visit the Kings Fund Library and obtain certain material from the British Library.

Supplementary information

A number of sources of supplementary information were obtained which are outlined below:

Official publications DoH

The policy review assignment provided me with the opportunity to examine the Cancer Reform Strategy (2007) stemming from the original NHS Cancer Plan (2000) which aimed to provide a comprehensive strategy to tackle cancer across the whole patient pathway. The Cancer Reform Strategy (2007) and subsequent policies have started to address issues relating to cancer survival and are therefore relevant to this study.

Websites

I joined the James Lind Alliance (JLA) on the advice of one of my former supervisors and have found it helpful to refer to. The JLA facilitates priority setting partnerships and their belief is that:

- addressing uncertainties about the effects of treatments should become accepted as a much more routine part of clinical practice
• patients, carers and clinicians should work together to agree which, among those uncertainties, matter most and thus deserve priority attention

This philosophy very much supported the approach I took in my research and therefore helped to justify my chosen methodology.

The European Bone Marrow Transplant (EBMT) website was also a source of information and current developments in the field. As mentioned in the overview of knowledge paper, this organisation awarded me the travel scholarship to attend one of the European conferences at the beginning of my study.

**Networks/communities of practice**

Having a network of colleagues in haematology was extremely helpful to gain support for the research and to discuss ideas and strategies. Having contacts also helped to identify the appropriate clinical nurse specialists, haematologists and research and development staff in the two specialist centres.

**Methodological considerations**

Because my interest arose from an interest of how patients experienced stem cell transplant and the challenging times post SCT a methodology used to explore lived experience was a logical choice. As I read more about interpretive phenomenology and a wide variety of studies using this methodology it appeared to be the most suited for gathering rich in depth data. From a practical point of view, carrying out a pilot interview was of great value. A colleague’s husband had recently had extensive oral and jaw surgery for cancer and volunteered to be interviewed after his hospital stay. He had significant medical needs such as gastro-endoscopic feeding and suffered from impaired speech caused by removal of part of his tongue. He talked a lot about his on-going needs following his return home and his reliance on his wife for much of his care. The interview served to raise my awareness of the
potential issues faced by those returning home after cancer treatment including fatigue and emotional responses relating to their experiences.

There are mixed views about returning to participants after the interview to discuss interpretations and this is something I deliberated about for some time. At the time of the interview I was eager to establish whether participants would mind if I contacted them subsequently if required to which all agreed without hesitation. However, on reflection, I made this provision to allow for further information to be elicited or clarified in case my interviewing technique was lacking in addition to the potential for interpretation checking. However, in the process of reading and analysing I found that I had sufficient rich data and whilst I recognised a number of lost opportunities to probe further in the interview transcripts, there were no major reasons to seek clarity. As I researched more about the merits and drawbacks of member checking I felt able to make the decision not to inconvenience participants further. Evidence is provided in the methods chapter.

**Sample**

Clinical staff were able to obtain details of all the patients who had undergone a SCT over the past year and fitted the inclusion criteria for the study. The initial strategy for recruiting patients was by using a flyer inviting participation in the study. The flyer was sent by post to all potential patients at Centre B. This was sent with information about a patient support group facilitated by the clinical nurse specialist for SCT. Subsequently both Centre A and B provided the flyers at the out-patient departments where patients attended regularly post SCT. I met with the consultants leading the SCT programme and specialist nurses to seek their support in patient recruitment at the clinics including provision of the participant information sheet. My rationale for this approach was twofold. Firstly, that patients would be reassured about the purpose and nature of the research if explained by familiar staff and also the authenticity of the researcher since I had worked with many people in the clinical teams or met them as the research proposal and approval for the study was developed.
Secondly, that patients would not feel pressured into participating as the study was being carried out by an external researcher as opposed to their clinicians. Endeavouring to protect potential participants in this way was concerned with their vulnerability following their illness and treatments and their continued debilitated state.

When this approach yielded no participants I sought permission to attend a series of clinics at both specialist centres and did not look back. Any concerns that patients would lack trust or feel pressured into participating were unfounded and I met with such willingness and enthusiasm it was both humbling and reassuring. Humbling because the participants’ engagement from the outset was remarkable considering what they had been through and reassuring in that they were so agreeable to share their stories.

**Ethical approval R & D**

A favourable ethical opinion was obtained at national level following minor changes to the participation information sheet and data storage arrangements. Research and Development (R & D) approval was perhaps one of the most challenging areas to achieve and impacted on timescales envisaged for the project. There were two elements of significance; one concerning the requirements for approval which were a little unclear at times in addition to it being my first experience of R&D since 2001 and the other concerned severe staffing issues within the R & D departments at both specialist centres. Whilst the research approval itself proved straightforward, having limited staff to process the information led to delays of eight months. Honorary contracts were obtained at both centres and involved very thorough processes including occupational health checks and assessment of infection risk. I was particularly impressed with this level of surveillance since I was interviewing participants who were still immune-compromised.

**Data collection**

I thoroughly enjoyed being the research instrument and felt that I could utilise my skills as a clinical practitioner in building sufficient rapport with the participants and members of their
family to create an atmosphere conducive to narrative enquiry. Although the participants knew I was both a nurse and a researcher and assumed I had a degree of knowledge in the specialist area, it was not my perception that this created any imbalance of power between us. I wanted to conduct all of the interviews myself to ensure a standard approach and also that I was able to start to pick up themes. Had the interviews been more structured and the sample size greater it would have been a consideration. However, the philosophical underpinnings of phenomenological methodology support the development of a relationship between the researcher and the participant and a shared effort in interpretation of meaning. Therefore consistency throughout the interviews was felt to be an important concern. I was keen to transcribe all of the recorded interviews time permitting, as I consider this a valuable way of becoming familiar with the data and to recognise the emergent themes. I did however, have several people who were willing to undertake audio typing if required.

Challenges
The main challenge other than the practical ones already mentioned has been achieving a balance between professional work, academic work and life in general. However, with support from people within all of these areas I have ultimately been able to overcome them. Prioritising work is not an unfamiliar task for many people and I am more skilled than previously in doing so.

Writing the thesis
One of the most noteworthy and interesting aspects of completing the thesis concerns the writing itself. Initially, the thought of producing a relatively long thesis in comparison with anything undertaken before was daunting. However, I now appreciate the importance of knowing when to stop writing and to concentrate on reading, revising, modifying, editing and finalising the thesis in order to produce a comprehensible piece of work. The volume of rich data and the potential for discussion emanating from it made me reluctant to leave anything
out. However, I now appreciate that there are opportunities to publish further findings and to share these with future patients and clinical staff.

Constant discussions with my academic supervisors both in person and electronically were invaluable, particularly concerning the analysis and findings. An important development as a result of these discussions and those with other doctoral students has been the ability to defend certain actions or decisions with a greater knowledge base and confidence than previously. Significantly, personal and professional growth have emanated from the most challenging times throughout this journey, for example recognition of the breadth and depth of knowledge required to achieve this academic level, failure of the service evaluation and leadership module but a successful resubmission and times when certain chapters have required significant adjustments. I have learnt so much throughout these times.

Finally regarding the writing element, I have had the privilege of two inspiring and dedicated ‘critical friends’ who have constantly shown interest in this research, offered their advice and most importantly proof read significant parts of it to whom I am indebted. One of these has no affiliation to health care but has undertaken research as part of a higher degree and is involved in policy development. It was extremely helpful to useful to receive her comments which led to a number of minor revisions. The most reassuring comment she made was ‘I understand exactly what's going on even though I've never heard of any of this stuff - so it's really clear!'
### Appendix I: Supervision and Progress Record

The Table below charts a number of supervisory tutorial discussions and a timetable of the project and its milestones

<table>
<thead>
<tr>
<th>Date</th>
<th>Discussion</th>
<th>Action Points</th>
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<tbody>
<tr>
<td>29.11.2010</td>
<td>Returned to the programme having taken 7 months out due to family circumstances. Discussed drafts for ARM assignment and advice given regarding methodology, developing more robust rationale for choice and expanding arguments to demonstrate understanding and critical thinking. Agreed 7-10 days to review drafts and one supervisor to send comments on behalf of both to avoid confusion.</td>
<td>Submit ARM assignment by the 17th December 2010. Create a Gantt chart relating to the research project so that progress can be reviewed at each meeting. Future meeting dates to be suggested by Liz in an e-mail to Anne and Stephanie Fuller – these will be monthly by Skype or conference call with quarterly face to face meetings.</td>
</tr>
</tbody>
</table>
| 27/07/2011 | Annual review – went well. Assignments completed 23/07/2011. NHS Institute for Innovation and Improvement guides were very useful for service evaluation. Research timetable discussed: Literature review – Dec 2011 Proposal - January 2012 NRES application - February 2012 (discuss in more detail at future tutorial) Discussed project plan and advice given re timing & detail of actions. Lay involvement discussed and guided to INVOLVE website, JD’s for lay reps and lay group available at Surrey who would | Revise Gantt chart with more detailed breakdown of actions e.g. literature review to include search strategy, databases used, chart of research & key findings including design, limitations etc. NB use this as annex to thesis. Literature flow chart suggested and example provided.  
- Include supervisory tutorials and dates to send matters for discussion on the chart.  
- Training dates on Gantt e.g. GCP (December 2011) and interview skills/techniques (Nov 2011).  
- Provide search strategy in 2 weeks i.e. 10th August 2011.  
- Continue with opportunities to consult with patients i.e. in clinics, Day Unit and KCH/RMH patient support groups re areas worthy of research.  
- Utilise Trust library (in addition to Surrey, RCN and British Library) and engage with librarian. |
<table>
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<tr>
<th>Date</th>
<th>Notes</th>
<th>Notes</th>
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<tr>
<td></td>
<td>be prepared to read proposal etc if local group not possible. Meetings are Sept and December 2011. Advised to seek feedback regarding potential research burden on participants with the user group and issues of confidentiality.</td>
<td>• NHS R and D – ascertain dates of meetings.</td>
</tr>
<tr>
<td></td>
<td>Patient support groups not taken up at own place of work. National group attended by one family only – have volunteered to arrange another with European Bone Marrow Transplant (EBMT) committee member Michelle Kenyon, KCL following EBMT conference in April 2011. Include this information in research proposal.</td>
<td>• Continue to read widely → hone questions.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Joined James Lind alliance and enjoyed website information/essence of patient/public involvement in guiding research required.</td>
</tr>
<tr>
<td>25/08/2011</td>
<td><strong>Discussion:</strong> Failed evaluation/leadership assignment 44%. Feedback highlighted requirement for: Aims of evaluation design &amp; how conducted; theoretical underpinnings of the evaluation model. Leadership type required; skills for communicating the vision; leading &amp; managing. Assignment due to be returned with ratified mark on September 26th 2011. Contact Wendy Knibb and arrange help + re-submission.</td>
<td>Literature search strategy:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Aims and objectives</td>
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<td></td>
<td></td>
<td>• Explicit statement re type of review e.g. systematic giving the rationale for choice</td>
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<tr>
<td></td>
<td></td>
<td>• Include time period, eligibility criteria for studies to be included, language e.g. all written in English, information sources</td>
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<td></td>
<td></td>
<td>• Peer reviewed journals through databases: Medline, EMBASE, CINHAL, NHS evidence, Psychinfo.</td>
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<td></td>
<td></td>
<td>Be clear on the focus of interest and what is driving you. Write thoughts in simple language, leave for a few days and review.</td>
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<tr>
<td></td>
<td></td>
<td>Many avenues to pursue but need to make a decision.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Utilise librarian.</td>
</tr>
</tbody>
</table>
**12/12/2011**  
Supervisory tutorial postponed due to a pressing incident at work.  
October and November sessions were cancelled due to the requirement to work on a failed essay. Gained a great deal from re-submission in terms of leadership concepts and theoretical underpinnings of service evaluation. I had a helpful tutorial with Wendy Knibb and Jacky Eyers on October 3rd 2011. Re-submitted on November 18th 2011 as per regulations. Work on literature review halted temporarily during this period.

<table>
<thead>
<tr>
<th>Work on:</th>
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</thead>
<tbody>
<tr>
<td>a) A paragraph on the area/topic of interest</td>
</tr>
<tr>
<td>b) A preliminary research question of interest</td>
</tr>
<tr>
<td>c) What drives interest</td>
</tr>
<tr>
<td>d) Potential impact of the research and who it would involve/benefit</td>
</tr>
<tr>
<td>e) Identify ways the study could be conducted</td>
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</tbody>
</table>

**29/03/2012**  
Feedback on initial literature review and points to expand e.g. survivorship, quality of life,  
Think of using sub headings for the section on psychosocial aspects.

<table>
<thead>
<tr>
<th>Suggested further reading:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Complete literature review and include a summary at the end of literature review</td>
</tr>
<tr>
<td>2. Identify research question/s</td>
</tr>
<tr>
<td>3. Identify different possible research approaches that suit the research questions</td>
</tr>
<tr>
<td>4. Use of grid to identify key research and key findings</td>
</tr>
</tbody>
</table>


Schou & Hewison  *Experiencing Cancer.* Open University Press
<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>4/10/2012</td>
<td>Provisional opinion from NRES committee subject to changes in right hand column</td>
<td>Storage and disposal of data – confirmed that no data to be stored on a lap top and clarification of storage of data at Surrey University Two amendments on participant information sheet: 1. Change ‘post graduate degree’ to ‘doctoral higher degree’ 2. Confirmation that the study has been reviewed by the National Research Ethics Service Committee – London Queen Square</td>
</tr>
<tr>
<td>9/11/2012</td>
<td>Favourable opinion from NREC</td>
<td></td>
</tr>
<tr>
<td>25/01/2013</td>
<td>Research and Development approval Centre B</td>
<td></td>
</tr>
<tr>
<td>13/03/2013</td>
<td>Research and Development approval Centre A</td>
<td>Discussed recruitment strategies</td>
</tr>
<tr>
<td>February</td>
<td>Flyers posted to patients at Centre B. Distributed in clinics at Centre A &amp; B</td>
<td></td>
</tr>
<tr>
<td>to 23/09/2014</td>
<td></td>
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<tr>
<td>November 2013</td>
<td>Post Graduate Research Conference 3rd &amp; 4th February 2014</td>
<td>Submit abstract</td>
</tr>
<tr>
<td>February 2014</td>
<td>Progress on next theme.</td>
<td>1. Send 12.02.2014 2. Poster presentation at PGR conference at Surrey University 3. Presentation to fellow doctoral students</td>
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<table>
<thead>
<tr>
<th>Month 2014</th>
<th>Task Description</th>
<th>Timeline</th>
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</thead>
<tbody>
<tr>
<td>February/March 2014</td>
<td>First draft of findings</td>
<td>Send completed draft sections to supervisors February/March 2014</td>
</tr>
<tr>
<td>April 2014</td>
<td>Complete methodology chapter</td>
<td>1. Submit abstract for British Sociological Association Conference 2. Continue analysis</td>
</tr>
<tr>
<td>May 2014</td>
<td>Findings</td>
<td>1. Continue analysis</td>
</tr>
<tr>
<td>June 2014</td>
<td>Discussion</td>
<td>Send first draft to supervisors</td>
</tr>
<tr>
<td>July 2014</td>
<td>Conclusion</td>
<td>1. Identify examiners internal/external 2. Draft of conclusion for review</td>
</tr>
<tr>
<td>August 2014</td>
<td>Additions/amendments/editing Academic paper</td>
<td>1. Exam entry form 2. Commence work on academic paper 3. Chapters sent to proof readers</td>
</tr>
<tr>
<td>September 2014</td>
<td>Structure of findings chapter not good</td>
<td>1. Oral presentation at the British Sociological Association Conference at Aston University. 2. Work on structure and signposting in findings chapter 3. Revisions to paper for publication (for submission to the Journal of Advanced Nursing)</td>
</tr>
<tr>
<td>October 1st 2014</td>
<td></td>
<td>Submission of thesis</td>
</tr>
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</table>
Overview of the Integration of Knowledge, Research and Practice

by

Liz Dunn

THESIS

Submitted for the degree of Doctor of Clinical Practice

PART ONE

Faculty of Health and Medical Sciences

Division of Health and Social Care

University of Surrey

September 2014

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10.0 Overview of the Integration of Knowledge, Research and Practice

This paper provides an overview of the integration of knowledge, research and practice within the context of the four year Doctorate of Clinical Practice Programme. Taught modules, discussion with professional and educational colleagues, reading, thinking and reflection have contributed to my overall learning. Most importantly the taught elements and the supervisory tutorials have provided direction but also developed my ability to think critically, take nothing at face value and to gain deeper understanding of phenomena through exploration and challenge. Firstly, the strengths, opportunities, weaknesses and threats (SWOT) to the researcher were identified and outlined at the beginning of the study programme, shown in the table below. This is followed by an overview of the course modules undertaken and their application to clinical practice and research. The paper concludes by providing a summary of the key components of my professional and personal development and dissemination of the research findings.
10.1 Table 1: SWOT analysis

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Opportunities</th>
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<tbody>
<tr>
<td>• Committed to improving clinical care</td>
<td>• To carry out research</td>
</tr>
<tr>
<td>• Effective professional networks</td>
<td>• Networking</td>
</tr>
<tr>
<td>• Support of family and friends</td>
<td>• Communities of practice</td>
</tr>
<tr>
<td>• Experience of research at MSc level</td>
<td>• Peer support</td>
</tr>
<tr>
<td>• Experience of writing for publication</td>
<td>• Academic support</td>
</tr>
<tr>
<td>• Determination</td>
<td>• Educational development</td>
</tr>
<tr>
<td>• Integrity</td>
<td>• Learn new skills</td>
</tr>
<tr>
<td>• Sensitivity to needs of others</td>
<td>• Increase knowledge</td>
</tr>
<tr>
<td></td>
<td>• Build relationships within new organisations through research process</td>
</tr>
<tr>
<td></td>
<td>• Use software package to manage data for analysis</td>
</tr>
<tr>
<td></td>
<td>• Improve writing ability</td>
</tr>
<tr>
<td></td>
<td>• Present research findings</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weaknesses</th>
<th>Threats</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Self doubt</td>
<td>• Resources e.g. balancing work pressures</td>
</tr>
<tr>
<td>• Time taken to define research question</td>
<td>• Life events</td>
</tr>
<tr>
<td>• Limited experience of undertaking research</td>
<td></td>
</tr>
<tr>
<td>• Limited in depth knowledge of research methodologies</td>
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</table>

Course Modules

10.2 Introduction to Doctoral Studies

This module set the scene for the four year study period both in conveying the expectations of Doctoral level study and developing the foundation of core competencies in order to achieve these. The module is supported by an e-learning facility enabling on-line discussion with fellow students and lecturers. Students were encouraged to articulate their area of interest for the research thesis at an early stage to begin to formulate ideas and express these to colleagues in a range of healthcare disciplines. I found that this cemented my topic of interest though narrowing this down to a more defined research question was dependent on a depth and breadth of reading on the subject.

10.3 Communities of Practice Module

The development and synthesis of professional knowledge forms the basis of this module considering historical, cultural and political influences. Exploration of the links between
philosophy of science and knowledge encouraged me to consider my stance on how learning and understanding is best advanced in contemporary practice. Further reading and examination of philosophical approaches led me to consider interpretive phenomenology as a possible way to investigate patients’ experiences in my chosen area of interest. I found the module particularly helpful in considering ways in which to transfer and disseminate new knowledge between disciplines and across organisational boundaries.

10.3.1 Application to Clinical Practice and Research

This taught element reinforced the importance of professional networks in clinical practice and was of great benefit in carrying out the research. When the research was first visualised, the stem cell transplant programme was based in my hospital. During the project however, the SCT services at two hospitals merged and whilst colleagues moved with the speciality this served to extend the community of practice further. Introductions to clinical staff at the new facility provided excellent opportunities for discussion about my research, advice and access to the study participants. Consultant haematologists agreed to support the project in line with requirements of the Research & Development. Meeting relevant staff at the second specialist centre was made easy by having a wide network of colleagues who provided links and could facilitate introductions. This aspect was particularly rewarding since old and new haematology colleagues generously gave me their time, the benefit of their expertise and welcomed me into their clinical teams during the period of identifying and interviewing participants.

10.4 Advanced Research Methods Module

This module incorporated in depth training in a range of quantitative and qualitative methodologies. The assignment challenged students to defend a methodology, design and methods suited to specific research questions and contributed significantly to my knowledge of research approaches in addition to extremely interesting and challenging areas for inquiry. I gained greater knowledge of ethical issues which I could apply to my own study as
it took shape. These were particularly in relation to involvement of vulnerable patients, professional gate-keeping and gaining access, patient illness and attrition. Other considerations include engaging with participants in a way which minimises power differentiation between interviewer and interviewee and allows both to interpret events in order to gain greater depth of understanding.

10.4.1 Application to Clinical Practice and Research
On a practical level, the breadth and depth of reading involved in this module was invaluable for a number of reasons. Firstly, it provided an overview of current research in cancer and other specialties and how clinical practice was developing, for example the use of telemedicine and new approaches to patient follow up. Secondly, in parallel with the philosophy of science introduced in the earlier module it gave me an insight into interpretive phenomenological methodology which proved so valuable in exploring patients lived experience. Thirdly, as mentioned reading and learning from other researcher’s experiences was extremely helpful from both patient access and ethical considerations. Studies involving vulnerable patients highlighted issues related to professional gate-keeping and subsequent lack of access to study participants and also attrition due to ill health or death. This was the reason that two specialist centres were chosen to ensure a sufficient cohort of patients for the study.

10.5 Policy Politics and Power
This module directed me to the review and analysis of the Cancer Reform Strategy which has major significance for my chosen area of study. Contribution to my personal and professional growth includes an enhanced awareness of the critical factors influencing policy development, dissemination and implementation.
10.5.1 Application to Clinical Practice and Research

With a greater awareness of policy development, policy drivers and ‘policy windows’ I have been able to influence a number of changes in clinical practice with greater confidence and evidence. An example has been the development of a local policy to allow nurses to authorise blood within our organisation. Although awaiting finalisation of the National Blood Transfusion Policy to allow its implementation we have been able to adapt the competencies and agree a robust training programme to support two named nurses to take this forward. Authorisation of blood by nurses was a recommendation by my former manager and Doctoral student at Surrey University and evidence from her thesis supports potential patient benefits relating to the effective treatment of anaemia in haematology.

10.6 Service Evaluation and Leadership in Healthcare Organisations

This module served to increase my awareness of quantitative methods since I chose to examine a service development through a randomised control methodology. The area studied is concerned with the main research topic though touched on different but relevant aspects of service delivery including economic evaluation. This was particularly useful because it challenged me to defend a qualitative methodology for the thesis in order to gain a greater depth of understanding from participants’ experiences. Both the service evaluation and leadership in healthcare organisations modules came at a time of major political and organisational change in the National Health Service thereby providing opportunity to engage in lively debates regarding contemporary theory and practice.

10.6.1 Application to Clinical Practice and Research

The theory learned within these modules and associated discussions with doctoral students and academic staff have influenced the way in which I view the clinical services within my remit at work. I actively seek opportunities to innovate and lead change and have a greater knowledge base on which to base decisions. Continuing to work in clinical practice combined with the theoretical underpinnings of the Doctoral Programme have provided me
with the increased knowledge, skills and experience with which to carry out my own research study. I have been able to share much of the knowledge I have gained and used it to inspire others in their professional and academic pursuits, whilst feeling personally motivated and enthusiastic. A summary of the key components of my professional and personal development are listed below:

- Gaining sufficient knowledge to undertake a research study at this academic level by learning, reading a wide range and volume of literature and an improved ability to think critically.

- An increased understanding of the extensive portfolio of research methodologies ethical considerations and practicalities of conducting research.

- The value of discussion with academic supervisors and others (a verbal or written exchange regarding specific and difficult issues can move you miles)

- Development of a greater ability to negotiate, challenge and influence practice within multidisciplinary teams and across organisational boundaries.

- An appreciation of the many colleagues and friends who have contributed to my professional and personal development in so many different ways.

10.7 Dissemination

Receiving a travel scholarship to attend the European Bone Marrow Transplant (EBMT) meeting in 2011 provided a great opportunity to meet and listen to many experts in stem cell transplantation. Being relatively new to the specialist field myself this proved to be an invaluable experience of learning and developing links for my research. During the course of study, I have been able to discuss the development of my research proposal with academic and clinical staff. Presenting preliminary findings to the doctoral student group was very helpful both in focussing my thoughts at that time and in presenting within this specialised
field of haematology. Students contributed by commenting on the development of themes from some of the data extracts from participant narratives which were followed up subsequently. I had the opportunity to present a poster at the University of Surrey Post Graduate Research conference where I met a fellow student from the sociology discipline. Our shared interest in patient’s experience in the oncology setting will continue as our research pursuits continue. An abstract has been accepted for presentation at the British Sociological Association Conference in September 2014 and will be another opportunity to network with people outside the medical discipline. The findings will be shared with colleagues and patients in the stem cell transplant community and I have been invited to present at one of the EBMT meetings on completion.

10.8 Conclusion

In conclusion, undertaking the Doctorate in Clinical Practice has provided me with an unparalleled opportunity to extend my knowledge base in a highly specialised area and to enable me to carry out this research. Some of the most difficult times faced as I have strived to achieve this higher level of academic work have been the most developmental and of significant personal gain. I feel that I have developed the ability to juggle more complex tasks than previously and the resilience to face the inevitable self-doubt associated with research and operating outside of one’s usual ‘comfort zone’.