BLOOD TRANSFUSION MATTERS:

A NARRATIVE INQUIRY INTO PATIENTS’ EXPERIENCE OF RECEIVING REGULAR BLOOD TRANSFUSIONS IN A DAY UNIT SETTING WHILST IN A PALLIATIVE STAGE OF A HAEMATOLOGICAL MALIGNANCY

Laraine Lloyd
2018

The thesis is submitted in partial fulfilment of the requirements for the award of the degree of Professional Doctorate Nursing of the University of Portsmouth
Abstract
As patients reach the palliative stage of a haematological malignancy such as leukaemia, lymphoma, myeloma or myelodysplasia, most will require regular blood transfusions. This thesis reports my professional doctorate study, the purpose of which was to gain a deep insight into the everyday life experiences of this patient population, who were receiving their blood transfusions in a day unit setting.

A narrative inquiry approach, underpinned by a pragmatic philosophical foundation, was employed. Twenty-two longitudinal, unstructured interviews with a purposive sample of eight participants allowed exploration of rich narratives of everyday-life blood transfusion experiences. During data collection and narrative analysis of transcripts, experiences were explored through three dimensions: sociality, place and temporality. Analysis produced eight narrative accounts. Meaning, implicit within and across these accounts was revealed through resonant plotlines (themes or threads). Plotlines of special interest were those which illuminated feelings, hardships and concerns. These plotlines provided the foundation for the development of five overarching narrative storylines. Found poetry, developed from raw data, supports storyline findings.

Discussion and implications for clinical practice are addressed through a review of the literature and a palliative lens focussed on the six Cs of nursing: compassion, care, communication, confidence, competence and courage. Essentially, to provide compassionate blood transfusion care healthcare professionals should: communicate realistic expectations when explaining benefits of blood transfusions; consider early involvement of the palliative care team to aid with difficulties around goal setting; the setting where blood is administered should be reconsidered; waiting in clinical areas should be significantly reduced and professional competence, courage and commitment should be developed to achieve individualised patient-centred care.
Declaration:

Whilst registered as a candidate for the above degree, I have not been registered for any other research award. The results and conclusions embodied in this thesis are the work of the named candidate and have not been submitted for any other academic award. (Laraine Lloyd, October 2018).

Word Count 53,421 excluding table of contents, references and appendices.
Acknowledgements

First a huge thank you to my husband Bryan who has given me his enduring support throughout this long journey. I cannot thank you enough for your overwhelming patience, love, kindness, encouragement and food, all of which have cushioned the path and kept me going.

Thank you also to my children, grandchildren and father, for always being there and understanding when I haven’t been able to be there for you.

Thank you to my academic supervisors Assaf, Karen and Ann and to my clinical supervisor Dr Sylwia Simpson, consultant haematologist and co-chair of the hospital transfusion committee. Thank you all for your ongoing support, friendship and direction, I could not have achieved this without you.

My gratitude to the consultant haematologists and to Dr Lara Alloway, clinical lead for end of life care, consultant in palliative medicine and lead cancer care clinician, who urged me to undertake this study.

Finally, thank you to those who have shared part, or all, of their own theses with me: Sue, Wendy, Marvel and Lisa. Your kindness and generosity has been overwhelming, appreciated and something I will never forget. Also, to Ruth who kindly proofread this paper.
Table of contents

Abstract ....................................................................................................................... i
Acknowledgements ................................................................................................... iii
Table of contents ....................................................................................................... iv
List of tables ............................................................................................................... x
List of text boxes ......................................................................................................... x
List of figures ............................................................................................................... x
Prologue: Reflection on a scenario from my clinical area ........................................ xi

Chapter 1 .................................................................................................................... 1

1.1 Setting the scene.................................................................................................. 1
1.2 Haematological malignancies: incidence, disease groups, nature and treatment overview ........................................................................................................... 1
1.3 Definition and symptoms of anaemia .................................................................. 2
1.4 Blood transfusions: healthcare use and associated risks .................................. 4
1.5 Literature review ................................................................................................. 5
  1.5.1 Efficacy of blood transfusions administered to patients in a palliative stage of malignancy ........................................................................................................ 5
  1.5.2 Authorisation of blood transfusion administration ..................................... 7
  1.5.3 Blood transfusion guidelines ........................................................................ 8
  1.5.4 The effect of the setting or place on blood transfusion authorisation .......... 9
  1.5.5 Exploration of blood transfusions from the patients’ perspective .......... 11
  1.5.6 The ethical dimension of blood transfusion administration in palliative circumstances ........................................................................................................ 13
1.6 Summary of the research problem ..................................................................... 14
1.7 Research question ............................................................................................... 15
1.8 Research objectives ............................................................................................ 15

Chapter 2: Research context ................................................................................... 17

2.1 Introduction ........................................................................................................ 17
2.2 Research approach to understanding experience .............................................. 17
2.3 Methodological approach employed to study experience .................. 18
2.4 Narrative Inquiry as a research approach in the study of illness and healthcare.......................................................... 21
2.5 Conceptual approach ................................................................ 22
2.6 Limitation of narrative inquiry approach .................................... 25
2.7 Rationale for utilisation of narrative inquiry approach ................. 26

Chapter 3: Research methodology .................................................. 28

3.1 Introduction ............................................................................. 28
3.2 Methodological overview .......................................................... 28
3.3 Method of Sampling and Recruitment ....................................... 29
   3.3.1 Sampling .......................................................................... 29
   3.3.2 Recruitment of Participants ............................................... 29
3.4 Patient flow pathway ................................................................. 31
3.5 Patients referred but not recruited ............................................. 33
3.6 Participants recruited into the study ......................................... 33
3.7 Demographic and descriptor information ................................... 34
3.8 Data collection .......................................................................... 37
   3.8.1 Qualitative interviews ....................................................... 37
   3.8.2 Reflective data ................................................................... 41
   3.8.3 The self-report EuroQol EQ-5D3L Health Questionnaire or WHO performance status tool ........................................... 43
3.9 Ethical considerations ............................................................... 43
   3.9.1 Steering group .................................................................. 44
   3.9.2 Confidentiality .................................................................. 45
   3.9.3 Positionality ...................................................................... 45
3.10 Data analysis: narrative analytical approach ............................. 47
3.11 Found poetry ........................................................................... 52

Chapter 4: Research Findings ....................................................... 54

4.1 Introduction ............................................................................. 54
4.2 Section 1: Personal dimension of experience ......................... 56
   4.2.1 Storyline one: Everyday blood transfusion life hangs in the bag .... 56
   4.2.1.1 Plotline - Blood transfusions mean life .......................... 56
4.2.1.2 Plotline - Blood transfusions as a sustenance for life .......... 60
4.2.1.3 Plotline - An up and down everyday blood transfusion life .... 67

4.3 Section 1: Social dimension of experience ................................ 69

4.3.1 Storyline two: Everyday blood transfusion life hangs in the hands of others ................................................................. 69
  4.3.1.1 Plotline - Life in the hands of physicians ...................... 69
  4.3.1.2 Plotline - Life in the hands of the nurses .................... 78
  4.3.1.3 Plotline - Life in the hands of the ward receptionists ....... 82

4.4 Summary of research objective 1 and 2 ................................ 83

4.4.1 Research objective 1 ..................................................... 83
4.4.2 Research objective 2: ..................................................... 83

4.5 Section 2: Place dimension of experience ............................. 85

4.5.1 Storyline three: Everyday blood transfusion life involves waiting and anxiety ................................................................. 85
  4.5.1.1 Plotline - Waiting in Pathology for blood tests .............. 85
  4.5.1.2 Plotline - Waiting on the haematology day unit .......... 88
  4.5.1.3 Plotline - Anxiety associated with places in the hospital setting 94

4.5.2 Storyline Four - More individualised care associated with the hospice day unit and everyday blood transfusion life .................. 101
  4.5.2.1 Plotline - More individualised care ......................... 102
  4.5.2.2 Plotline - Hospice day unit perceived as a safer place to receive blood transfusions ............................................. 102
  4.5.2.3 Plotline - Hospice day unit perceived as more tranquil place .. 103

4.6 Summary of research objective 3 ........................................ 105
  4.6.1 Hospital setting .......................................................... 105
  4.6.2 Hospice day unit setting ............................................... 106

4.7 Section three: Temporality dimension of experience .............. 107

4.7.1 Storyline five: An everyday SAD life during the late to terminal palliative phase of a haematological malignancy .................... 107
  4.7.1.1 Plotline - Somnolence overwhelms daily life ................ 107
  4.7.1.2 Plotline - Adversities overpower everyday life ............ 108
  4.7.1.3 Plotline - Desperation to hang on to life .................... 112
Chapter 5: Discussion

5.1 Introduction

5.2 Research objective 1: To explore participants’ expectations and challenges around receiving regular blood transfusions in a day unit setting

5.2.1 Storyline one: Everyday blood transfusion life hangs in the bag...

5.2.1.1 Plotline - Blood transfusions mean life

5.2.1.2 Plotline - Blood transfusions as a sustenance for life

5.2.1.3 Plotline - An up and down everyday blood transfusion life

5.3 Research objective 1: Summary of key findings

5.4 Research objective 2: To explore healthcare professional’s role on participants’ experience of BT.

5.4.1 Storyline two: Everyday blood transfusion life hangs in the hands of others

5.4.1.1 Plotline - Life in the hands of physicians

5.4.1.2 Plotline - Life in the hands of the nurses

5.4.1.3 Plotline - Life in the hands of ward receptionists

5.5 Research objective 2. Summary of key findings

5.6 Research objective 3: To explore the effect of the place or setting where the blood transfusions were administered on participants’ experiences of BT

5.6.1 Storyline three: Everyday blood transfusion life involves waiting and anxiety

5.6.1.1 Plotline - Waiting in Pathology for blood tests

5.6.1.2 Plotline - Waiting on the haematology day unit

5.6.1.3 Plotline - Anxiety associated with places in the hospital setting

5.6.2 Storyline four: More individualised care associated with the hospice day unit and everyday blood transfusion life

5.6.2.1 Plotline - More individualised care

5.6.2.2 Plotline - Hospice day unit perceived as a safer place to receive blood transfusions
5.6.2.3 Plotline - Hospice day unit perceived as more tranquil place .. 138
5.7 Research objective 3. Summary of findings ........................................ 139
5.8 Research objective 4: To explore the change in participants’ experiences as disease progressed from an early palliative phase, to a late palliative phase, to the terminal palliative phase of a haematological malignancy ................................................................. 140
5.8.1 Storyline five: An everyday SAD life during the late to terminal palliative phase of a haematological malignancy ...................................... 140
5.8.1.1 Plotline - Somnolence overwhelms daily life ............................... 140
5.8.1.2 Plotline - Adversities overpower everyday life ............................. 140
5.8.1.3 Plotline - Desperation to hang on to life .................................... 140
5.9 Research objective 4. Summary of key findings ................................ 143
5.10 Review of study findings ................................................................. 144
5.11 Reflection on the link between Dewey, the study process and the study findings ................................................................. 147

Chapter 6: Conclusions ........................................................................... 155

6.1 Introduction ......................................................................................... 155
6.2 Key conclusions ................................................................................ 155
6.3 Recommendations for clinical haematology blood transfusion practice ......................................................................................... 156
6.3.1 Develop a one-stop service on the haematology day unit .......... 156
6.3.2 Develop a one stop service in the hospice day unit ............... 156
6.3.3 Health care professionals should communicate realistic expectations of blood transfusions ......................................................... 157
6.3.4 The palliative care team could be more involved with the care of palliative haematology patients ......................................................... 157
6.3.5 HCP should allow patients to take a more active role in their blood transfusion care ................................................................. 158
6.3.6 Reorganise clinical service for patients requiring three units of blood ......................................................................................... 158
6.3.7 Attend to blood transfusion patients with compassionate care .. 158
6.3.8 Nurses should perform additional bedside monitoring in elderly, palliative patients and those with a cardiac dysfunction history. They should also weigh patients prior to BT. ........................................ 158
6.3.9 Attend to the hardships associated with chelating agents by raising awareness .......................................................... 159
6.4 Recommendations for advanced nursing practice in blood transfusion care, with reference to the new ‘Advanced Clinical Practice’ descriptors (Health Education England, 2017) ........................................................................ 159
6.5 Recommendations for future research ........................................ 163
6.6 Strengths of the study .................................................................. 164
6.7 Limitations ................................................................................... 165
6.7.1 Sensitivity to the data .............................................................. 165
6.7.2 Commitment and Rigour ........................................................... 166

Chapter 7: Reflection of my Professional Doctorate Path ............... 169
7.1 Introduction ................................................................................ 169
7.2 Why I chose the Professional Doctorate in nursing programme ... 169
7.3 The Professional Doctorate programme: .................................. 170
7.4 Reflection on changes to clinical practice .................................. 171
7.5 Challenges during the PD programme ....................................... 172
7.6 A sincere “thank you” note to all the participants in this study ...... 173

References ....................................................................................... 175

Appendices ....................................................................................... 193
Appendix 1 Examples of haematological malignancies, presenting features, routes and settings treatments administered ............... 193
Appendix 2 Letter of invitation to participant .................................. 195
Appendix 3 Participant information sheet ........................................ 197
Appendix 4 Participant Consent Form ............................................. 203
Appendix 5 Case Report Form .......................................................... 204
Appendix 6 Initial conversation prior to first, second and third interview and prompts employed in study .............................................. 216
Appendix 7 EQ-5D-3L Health Questionnaire .................................. 218
Appendix 8 Findings from participant’s self-reported EQ-5D-3L health questionnaire or WHO performance status tool .................................................. 220
Appendix 9 Ethics Committee approval letter .................................................. 221
Appendix 10 Research risk assessment for Trust sponsorship .......... 226
Appendix 11 An example of step four of data analysis ......................... 243
        Step four – an example of narrative coding of field texts to interim research texts. (Boldened text were placed into a new document) ..... 243
Appendix 12 An example of step five of data analysis ......................... 247
        Step five – an example of categorization of narrative scenes in the interim research texts. Texts colored red highlight the dimensions of experience. ........................................................................................................ 247
Appendix 13 Form UPR 16 Research Ethics Review Checklist .......... 250

List of tables
Table 1 Symptoms associated with anaemia .................................................. 3
Table 2 Framing my Research objectives......................................................... 24
Table 3 Palliative Phase definitions employed in this study (based on Dalgaard, Thorsell, Delmar, 2010, p.88). .............................................................. 29
Table 4 Inclusion and Exclusion criteria ........................................................... 30
Table 5 Summary of information from Case Report Form .......................... 36

List of text boxes
Text box 1. A vignette from Kenneth’s Narrative Account ......................... 51

List of figures
Figure 1 Patient flow pathway ...................................................................... 32
Figure 2 Dewey’s model of reflective thought and action linked to study process and findings (Adapted from Miettinen, 2000, p. 65) ................. 154
Prologue: Reflection on a scenario from my clinical area

My personal motivation to explore patients’ experiences of blood transfusions arose from a disturbing encounter with a haematology patient who attended our Haematology Day Unit for a blood transfusion. As highlighted in the scenario below, reflection on this clinical situation made me question whether the care we were providing this patient was compassionate.

John (pseudonym) was sixty-two, married and had been diagnosed with multiple myeloma five years previously. Chemotherapy had been stopped several months previously, and he was now coming to the Haematology Day Unit of the hospital for blood transfusions. He was desperately poorly, cachexic, barely able to walk and covered in bruises. It was his second visit to the hospital that week. During the first visit he had attended the Pathology Department for blood tests to check his haemoglobin, white cell, red cell and platelet count and to cross match his blood. Today, his second visit, he attended the unit to receive his three-unit blood transfusion. He would be on the unit for the whole day. Three nurses all expert in intravenous cannulation had tried, in total, nine times to gain intravenous access without success before calling on me as the haematology nurse practitioner to try. John was in bed and clearly in the terminal phase of his disease. The skin on his arms was fragile and broken, with no veins to be seen or felt. Intravenous access was established, but at what expense to this man who would need to repeat the whole episode again within the next two weeks. Sadly, John died the following week.

The scenario was not new to me. I have witnessed many seriously ill, palliative phase haematology patients struggling with fragility, breathlessness and fatigue, come to the day unit of the hospital. Generally, these patients attend the hospital once or twice a week, every two to three weeks, to have their blood tests and receive blood transfusions (BT) to help alleviate the symptoms of anaemia. Although the scenario was not new to me, this incident with a patient I knew very well provoked a critical reflection concerning nursing care. It made me wonder “what is going on” in this situation from a moral perspective, and “what is the fitting action” (Niebuhr, 1963, p. 60ff), in terms of
the right course of action in these circumstances. I wondered how John felt about having to attend the day unit so often when he was so unwell, and how was he expecting to feel after he had received his blood transfusion. I wondered whether this was the right place to administer BT to a patient who was obviously in the palliative stage of his disease and I questioned whether blood transfusions increased, rather than alleviated, his suffering. I asked myself whether the care he was receiving was truly compassionate; that is, attended to with a reflective kindness that could serve to ease his situation (Tierney, Seers, Tutton & Reeve, 2017).

**Personal rationale for undertaking study**

In my senior nursing role as haematology Nurse Practitioner I, as all nurses, am duty bound to adhere to our Professional Code of Conduct (Nursing Midwifery Council, 2015). Of importance in John’s circumstances this relates, to: Section 1.1 of the code, to treat people with kindness, respect and compassion; 3.2 to recognise and respond compassionately to the needs of those who are in the last few days and hours of life; and 3.4 to act as advocate for the vulnerable, challenging poor practice.

My Haematology Nurse Practitioner role was established, within the Trust, to comply with the guidance manual “Improving Outcomes in Haematological Cancers” (NICE, 2003), which states that every haematology patient should have access to a haematology clinical nurse specialist. One of my responsibilities in this senior position (band 8a) is to reflect on nursing care locally and undertake research to ensure that the clinical care provided is up to date and evidenced-based. It is also to ensure that haematology patients receive appropriate information, and excellent individualised, physical and psychological care appropriate to their needs. Values recognised as inherent to excellence in nursing care are the 6Cs of nursing: compassion, communication, care, competence, courage and confidence (DH, 2012). As a nurse, committed to providing compassion and excellence in nursing care, and reducing patients’ suffering, I determined that this clinical practice was an area demanding further exploration.
My first step was to determine how many patients were transfused in our day unit setting while in the palliative phase of a haematological malignancy. A retrospective audit over an eight-month period demonstrated that ten patients in a palliative stage had received BT; nine in the acute Haematology Day Unit (HDU) and one in a hospice day unit. The fact that the case of John was not an isolated incident provided powerful evidence that this matter, which fell under the remit of nursing care, should be investigated. A discussion with members of the Haematology and Palliative Care Team and my academic supervisor followed. All believed that exploring the experiences of palliative patients receiving blood transfusions was an important area to explore. This was in the recognition that gaining the perspectives of patients, particularly the most vulnerable, is vitally important to improving clinical services and healthcare provision (National Quality Board, 2015).
Chapter 1

1.1 Setting the scene

All blood cells, that is red blood cells, white blood cells and platelets are produced in the bone marrow. Bone marrow disorders, which arise from genetic abnormalities, result in haematological malignancies, such as leukaemia, lymphoma (hodgkins or non-hodgkins), myeloma and myelodysplastic syndrome. As patients with these blood cancers are no longer able to produce their own healthy red blood cells, most will become anaemic at some point in their disease trajectory, especially when a palliative stage of disease is reached. To help alleviate the symptoms of anaemia, which include breathlessness and fatigue, patients require blood transfusions, generally every two to three weeks. These transfusions are most commonly administered in the day unit of secondary care hospitals. This narrative inquiry study explores the experiences of patients who receive regular blood transfusions in a day unit whilst in the palliative phase of a haematological malignancy.

1.2 Haematological malignancies: incidence, disease groups, nature and treatment overview

Haematological malignancies (HM) are the fifth most frequently occurring type of cancer in the United Kingdom (NICE, 2003), with over thirty-nine thousand new cases expected each year in the UK (Haematological Malignancy Research Network, 2018). The incidence of acquiring a HM generally escalates with advancing age (Sant, et al., 2010), with a suggested median age of 70.6 years (Smith, Howell, Patmore, Jack, & Roman, 2011, p. 1684).

These malignancies are a diverse group of cancers that affect blood, bone marrow and lymph nodes. The World Health Organisation recognises twelve major haematological malignancy disease groups that are subdivided into at least a hundred and twenty-five differential diagnoses (Swerdlow, et al., 2008). In clinical practice, however, HM are generally subdivided into four main disease groups: leukaemia, myeloma, lymphoma and myelodysplastic syndrome (MDS).
The nature of HM and the treatment of these diseases varies enormously. For instance, acute leukaemia is an aggressive disease that is life threatening and requires immediate, intensive inpatient chemotherapy treatment. In comparison, MDS is not considered an aggressive disease. Individuals can live for many years with just the support of blood transfusions. (see Appendix 1 for examples of HM, presenting clinical features, treatment administrative route, and settings in which chemotherapy treatments are administered).

Despite the huge variation in haematological malignancies a commonality is that most patients will develop anaemia as their illness deteriorates to a palliative phase. For instance, every patient diagnosed with leukaemia will become anaemic throughout the course of their disease; over seventy percent of those with myeloma or lymphoma will be anaemic when first diagnosed; and up to eighty percent of those with MDS will suffer with anaemia at some point in their disease trajectory (Schrijvers, De Samblanx & Roila, 2010).

1.3 Definition and symptoms of anaemia

Anaemia is generally defined as a reduced haemoglobin (Hb) concentration. It may be classified as mild, moderate, severe or life threatening according to the Hb level. Generally, a Hb level that lies between 10 and 11.9g/dL is characterised as mild anaemia; between 8 and 9.9g/dL a moderate anaemia; below 8g/dL is considered severe anaemia (Schrijvers, De Samblanx & Roila, 2010, p. 244), and a level of below 6.5g/dL is associated with an increased risk of death (Wilson, et al., 2007).

Symptoms of anaemia in adults vary significantly. Some patients show no symptoms or signs, despite having a Hb level below 8g/dL, and others are severely incapacitated by mild anaemia. The signs and symptoms of anaemia are related to adaptive changes in the cardiovascular system and in decreased tissue oxygenation (Hughes-Jones, Wickramasinghe & Hatton, 2008). Elderly patients are more susceptible to the effects of anaemia, due to cardiac dysfunction and cerebral vascular disease (Hoffbrand & Pettit, 1993). Symptoms of anaemia frequently observed in clinical practice include
breathlessness, lethargy and fatigue, however, a multitude of symptoms associated with anaemia may occur (see Table 1).

**Table 1 Symptoms associated with anaemia** (Watson & Royle, 1987, p. 250) Adapted.

<table>
<thead>
<tr>
<th>Part of body affected</th>
<th>Compensatory mechanism</th>
<th>Dysfunction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain</td>
<td></td>
<td>Fatigue/tiredness, headaches, dizziness, difficulty thinking or concentrating, depression</td>
</tr>
<tr>
<td>Eyes</td>
<td></td>
<td>Retinal damage</td>
</tr>
<tr>
<td>Heart</td>
<td>Rapid pulse palpitations</td>
<td>Angina</td>
</tr>
<tr>
<td>Lungs</td>
<td>Rapid breathing</td>
<td>Breathlessness</td>
</tr>
<tr>
<td>Kidneys</td>
<td></td>
<td>Water retention</td>
</tr>
<tr>
<td>Gut</td>
<td>Loss of appetite</td>
<td>Indigestion, irregular bowel movements</td>
</tr>
<tr>
<td>Muscles/legs</td>
<td></td>
<td>Fatigue, reduced exercise capacity, oedema</td>
</tr>
<tr>
<td>Skin</td>
<td>Pallor, feeling cold</td>
<td>Brittle/broken nails</td>
</tr>
</tbody>
</table>

One of the most overwhelming symptoms of anaemia in patients at the end-of-life is fatigue (Brown, Hurlow, Rahman, Closs & Bennett, 2010; Orme, Still, Day & Evans, 2013; Woodwark and Dean, 2017). In a recent study, which involved looking at electronic patient records retrospectively over a 54-month period, Woodwark and Dean (2017) found that fatigue was the most frequent reason for administering BT (84% of cases) in patients who were dying in a hospice. Fatigue, along with other recognised symptoms of anaemia have a significant impact on patients’ quality of life in terms of limiting mobility and the
ability to carry out usual activities of daily living (Campos, Hassan, Riechelman & Del Giglio, 2011; Jabbour, Kantarjian, Koller & Taher, 2008; Szende, et al., 2009). Nineteen percent of patients with advanced disease are said to be so debilitated by fatigue that “they felt they wanted to die” (Curt, 2000, cited in Brown, Hurlow, Rahman, Closs, & Bennett, 2010, p.1327).

1.4 Blood transfusions: healthcare use and associated risks
The most common therapeutic choice to treat anaemia in patients with an advanced haematological malignancy is the administration of blood transfusions (BT), which may be required over many months or years (Killick, et al., 2013; Bishop, Faithful, & Allan, 2011). Erythropoietic agents are not generally employed in these patients to alleviate anaemia, as it is suggested that they are not comparable with BT in terms of “response rate, time to onset and duration of response” (Tanneberger, Melilli, Strocchi, Frenquelli, & Pannuti, 2004, p. 840).

BT are widely used within the National Health Service (NHS) with approximately two million units of blood per annum provided to hospitals in England and Wales alone (NHS Blood and Transplant, 2011). Historically, BT were associated with transmission of infectious diseases such as HIV and Hepatitis B, however due to improved screening there is now negligible risk of acquiring blood transfusion associated infections (BMJ, 2000; Bolton-Maggs and Cohen, 2013) Other risks remain, including: the accumulation of iron which cannot be excreted and hence accumulates in organs, such as the heart and liver and which can lead to significant morbidity and mortality; administration of the wrong blood type; acute anaphylactic reactions; and transfusion associated circulatory overload (TACO). TACO, which can be a serious, life-threatening condition, has been noted by a host of researchers (Alam, Lin, Lima, Hansen, Callum, 2013; Agnihotri, & Agnihotri, 2014; Bolton-Maggs & Cohen, 2013; Bosboom, et al., 2018; Hendrickson, et al., 2016; Henneman, et al., 2017; Popovsky, et al., 2006; Robinson, et al, 2017; Roubinian, et al., 2018). Indeed, it has recently been recognised as the most frequent cause of blood transfusion associated morbidity and mortality (Robinson et al. 2017).
1.5 Literature review
Despite BT being the therapeutic option to treat anaemia in patients diagnosed with a palliative phase HM, there is much debate in the academic literature around their administration to patients in a palliative stage of cancer. Most of the discussion surrounding administration of BT to patients with an advanced cancer is concerned with efficacy in these circumstances, the place of administration and the ethical issues involved.

1.5.1 Efficacy of blood transfusions administered to patients in a palliative stage of malignancy
There has been much debate regarding the effectiveness of BT for those with an advanced cancer in terms of longevity of effect. Some researchers suggest that BT are associated with beneficial effects, in terms of relieving fatigue, breathlessness and improving quality of life (QoL), proposing that these positive effects are maintained over a sustained period (Gleeson & Spencer, 1995). Other studies suggest that, although patients may experience beneficial effects shortly after receiving blood transfusions these are short lived (Chin-Yee, et al., 2018; Mercadante, Ferrera, Villari, David & Riina, 2009: Preston, Hurlow, Brine, & Bennett, 2012)

One of the first landmark studies to assess the effects of BT in a palliative population was undertaken by Gleeson and Spencer (1995). These researchers employed a Visual Analogue Scale\(^2\) to measure well-being, strength and breathlessness following BT in a population of 91 patients with a variety of advanced cancers. Their findings suggest that over seventy percent of patients showed improvement in these parameters after two days, most sustaining the beneficial effect at two weeks post transfusion. However, as almost a third of their participants died during the two-week assessment period, their findings must be taken with some caution.

---

\(^1\) The term employed in this thesis to describe the phase of patients’ malignancy is, palliative ‘stage’ or ‘phase’. However, where different terms have been used in the literature with evidence quoted, the term used by the authors (advanced cancer, terminal cancer, late, or end, or final (stage or phase) cancer) was kept.

\(^2\) A self-report measure consisting of a 10-centimetre line with a statement at each end representing one extreme of the dimension being measured (Crichton, 2001).
In comparison, Mercadante, Ferrera, Villari, David and Riina, (2009) suggest that any beneficial effect experienced post BT was short lived. They measured fatigue and breathlessness in sixty-one participants who had a variety of tumour types using a symptom assessment scale. Some of the participants were terminally ill, while others were still receiving oncologic chemotherapy. They report that patients experienced relief of fatigue and breathlessness shortly after receiving BT, but this effect was not significant 15 days post transfusion. They also suggest that any beneficial effect reported by participants may have been due to a psychological or placebo effect because participants held such faith in BT to reduce their symptoms of anaemia, which is a suggestion shared by others (Brown, Hurlow, Rahman, Closs & Bennett, 2010; Mercadante, Ferrera, Villari, David & Riina, 2009, p. 62; Monti, Castellani, Berlusconi & Cunietti, 1996).

Other authors have also suggested that BT administered to those with an advanced cancer has little influence on quality of life, in terms of relieving symptoms of breathlessness or fatigue, when administered in the last four (Monti, Castellani, Berlusconi & Cunietti, 1996, p.21) to five (Brown and Bennett, 2007) weeks of life. Indeed, some authors found minimal association between anaemia and fatigue in patients with an advanced cancer, stressing instead that the fatigue experienced by these patients is multi-factorial (Brown, Hurlow, Rahman, Closs & Bennett, 2010; Dunn et al., 2003; Munch, Zhang, Willey, Palmer & Bruera, 2005; Wang, 2008).

More recently, Goksu, et al., (2014) proposed that patients with a terminal cancer who received BT lived significantly longer than those who did not (15 days versus 8 days: p. 4251). This finding they suggest warrants the administration of BT to patients in the final stage of their disease. Two literature reviews have explored the administration of BT in palliative patients (Chin-Yee, et al., 2018; Preston, Hurlow, Brine & Bennett, 2012). According to both reviews there is still limited evidence to support or guide the administration of BT in patients who are in a palliative stage of their disease. The authors suggest that BT may confer some relief of anaemia-related symptoms such as breathlessness and fatigue, although this effect is small and of limited duration.
However, as stressed by: Chin-Yee, et al., (2018), and Preston, Hurlow, Brine and Bennett (2012), due to the clinical diversity of the palliative population involved in their reviews, and the fact that no large-scale studies or random controlled trials have been undertaken, it was not possible to compile the findings of studies together.

One Cochrane Review (Preston, Hurlow, Brine & Bennett, 2012) correlates the administration of BT to patients with advanced cancer with an increased risk of mortality. These researchers report that between twenty-three percent to thirty-five percent of participants died within 14 days of receiving a blood transfusion. They suggest that the increased mortality rate, post BT, may be due to either “fluid overload or higher plasma viscosity” (p. 9). Woodwark and Dean (2017) also noted that fifty percent of patients died within four weeks of receiving a blood transfusion. The finding associated with increased risk of adverse events and lack of efficacy was, perhaps, what prompted Preston et al., (2012) to suggest that physicians should try other options prior to prescribing a blood transfusion:

Clinicians that treat patients with advanced cancer who present with anaemia, fatigue and breathlessness (not related to cancer treatment or haemorrhage), need to consider whether alternative management strategies should be tried before prescribing blood transfusion (Preston, Hurlow, Brine & Bennett, 2012, p.9).

This suggestion is perhaps countered in the NICE (2003) guidance, ‘Improving Outcomes in Haemato-Oncology Cancer’, in which BT are recognised as essential supportive therapy for prolonging life in those in the later stages of leukaemia and myeloma (NICE, 2003, p. 101).

1.5.2 Authorisation of blood transfusion administration
Traditionally, BT were prescribed only by medical physicians. In recent times, however, it has been noted that BT cannot be prescribed as they are not legally defined as a medicine (Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee, 2013), rather, BT are authorised. Authorisation of BT can be undertaken by
appropriately trained and competent nurses, midwives or other healthcare professionals if this lies within their scope of practice. In this study, BT were only authorised by physicians.

The decision to administer a BT to terminally ill cancer patients is significantly influenced by the medical team (Leibovitz, et al., 2004) and by blood transfusion guidelines. As numerous factors need to be taken into consideration, such as age and co-morbidities (Jabbour, Kantarjian, Koller & Taher, 2008), this potentially difficult decision may account for some of the variation in clinical practice surrounding BT (Bishop, Faithfull, & Allan, 2010; Hinka, Kosunen, Metsanoja, Puustelli, & Kellokumpu-lehtinen, 2002).

1.5.3 Blood transfusion guidelines
The UK National Institute for Health and Care Excellence (NICE, 2015) and NHS Blood and Transplant (2016) have recently suggested that, where possible, a single unit of blood should be administered in patients who are haemodynamically stable and who are not actively bleeding. Following administration of this transfusion, a reassessment of the patient’s haemoglobin should be made to determine if a subsequent unit of blood is required. NICE and the NHS Blood and Transplant guidelines recommend that a haemoglobin concentration of between 70-90g/litre is maintained post BT. The NICE guidance, which recommends a restrictive blood transfusion policy, does not specifically address patients who have an advanced disease (Carson & Kleinman, 2018; NHS Blood and Transplant, 2016). However, the NHS Blood and Transplant (2016) guidance suggests that the recommendation of administering one unit of blood and then the reassessment of the patient should be maintained in palliative circumstances. This recommendation is not applicable to those with chronic transfusion dependency.

Carson and Kleinman (2018) advised a target range of between 80–100g/L for elderly patients; those with cardiac or renal dysfunction; and for haematology and oncology patients who have chronic transfusion dependency. In their recommendations they specifically note that when authorising BT, each patient’s physical and psychological condition be considered, to ensure that
patients receive individualised care appropriate to their needs (Carson and Kleinman, 2018). It has been argued that, in everyday clinical practice, individualized care is not happening as physicians have been seen to authorise BT based on haemoglobin level alone, rather than also considering a patient’s unique physical and psychological circumstances (Cheng, Sham, Chan, Li & Au, 2015, p. 224; Bishop, Faithful & Allan, 2011).

1.5.4 The effect of the setting or place on blood transfusion authorisation

The administration of BT has been shown to be five times higher in the hospital setting compared to the hospice setting, particularly in the six weeks prior to death (Watchel & Mor, 1985). Watchel and Mor (1985) suggest that patients with advanced malignancy were found to be transfused inappropriately in the hospital setting (twenty-seven percent) compared with the hospital-based hospice setting (eight percent) and home-care setting (four percent). A later study undertaken in Italy suggests that there is overuse of BT in the hospital setting and an incongruous withholding of BT in the hospice and home setting (Mercadante et al., 2009).

In the UK, BT administered to haematology patients with a palliative diagnosis are generally performed in a day unit of a secondary care hospital, rather than in a hospice (Boyce, McHugh and Lyon, 2003) as patients are not referred to the palliative care team by haematologists (Cheng, Sham, Chan, Li & Au, 2015). Several reasons have been suggested to account for the lack of referral by haematologists to the hospice setting:

First, patients diagnosed with a HM can deteriorate very quickly with a concomitant drop in Hb level, platelet count and white blood cell count. A low platelet count predisposes them to the risk of a fatal bleed and a low white count to overwhelming infection, conditions thought to be difficult to deal with outside of the hospital setting (McGrath, 2014; McGrath & Holewa, 2007).

Second, haematology patients have been shown to show signs of recovery even when close to death, thus the distinction between the curative phase and the palliative phase is not clear (McGrath & Holewa, 2007).
Third, treatment of HM may continue over many years which allows close, trusting bonds to be formed between patients, physicians and the haematology unit staff. Disrupting these bonds by transferring care to the palliative team and adopting a palliative approach in hospice is believed to be very difficult for all those involved (McGrath & Holewa, 2007; LeBlanc & El-Jawahri 2015). Transferring the care of these patients to a hospice is recognised as especially difficult when patients and their families are reluctant to cease any active treatment (NICE, 2003).

Fourth, there is a recognition that haematologists feel responsible for maintaining patients’ hope of survival (Bernacki & Block, 2014; LeBlanc & El-Jawahri, 2015). Referral to a palliative care physician has the potential to shatter patients’ hopes and expectations, even though they want truthful prognostic information regardless of how dire the information is (El-Jawahri, et al., 2015; LeBlanc & El-Jawahri, 2015; McGrath, 2001).

Lack of referral to the palliative care team (PCT) is thought to result in palliative services being used less often in haematological cancers than in solid tumour cancers (Cheng, Sham, Chan, Li & Au, 2015: McCaughan, et al 2018; McGrath, 2001; McGrath & Holewa, 2007; NICE, 2003, p.4). Although this situation is believed to be improving (Corbett, Johnstone, Trauer & Spruyt, 2013; McCaughan et al, 2018), still only fifty-four percent of haematology patients are referred to the PCT (Corbett, Johnstone, Trauer & Spruyt, 2013). Indeed, as reported by McCaughan et al., (2018) who recently undertook the first UK study to explore palliative care specialists’ perceptions concerning referral of haematology patients to their services, this is an ongoing, complex situation. Many patients with a palliative HM may not therefore be receiving appropriate end of life care that addresses their psychological, emotional and spiritual needs, which may help them make important goal setting decisions concerning their treatment (LeBlanc & El-Jawahri, 2015; McGrath, 2001; McGrath & Holewa, 2007), although McCaughan et al (2018) suggest that this is something that needs to be determined. LeBlanc and El-Jawahri (2015), advise that palliative care should be integrated from the moment of diagnosis in those with a HM, however, they suggest that how to do this effectively needs
to be explored. Cheng, Sham, Chan, Li & Au (2015) suggest that joint ward rounds between haematologists and the PCT may promote more effective transition of haematology patients into the hospice setting (p. 221), while McCaughan et al, (2018) suggest that co-location of services provides an optimal way of promoting more integrated working relationships.

Lack of referral of those with a HM leads to these patients dying in the hospital rather than in the hospice or home (Cheng, Sham, Chan, Li & Au, 2015; Howell, et al., 2013; McCaughan, et al., 2017). Indeed, research indicates that between sixty-one and seventy-nine percent of patients with a HM in the UK die in hospital (National Cancer Intelligence Network, 2011, p.2), despite most patients suggesting that they would prefer to die at home (McCaughan, et al., 2017).

1.5.5 Exploration of blood transfusions from the patients’ perspective

Little scholarly attention has been given to the perspectives of patients who are diagnosed with a palliative haematological malignancy and who require regular BT in a day unit hospital or hospice. It is not known, therefore how patients perceive this procedure, what they expect from BT and what challenges they perceive to be associated with BT. An important consideration that was recognised by Cheng, Sham, Chan, Li & Au (2015) is that the burdens of treatment for patients at the end-of-life should not exceed the perceived benefits; however, little is known about patients’ burdens associated with the administration of BT.

Orme, Still, Day, Evans, and Perkins (2013) undertook a phenomenological study to explore the views of ten palliative haematology patients regarding their views of living with anaemia and undergoing blood transfusions in a day hospice setting. They found that tiredness was the overwhelming symptom of anaemia, that participants preferred the hospice setting to the hospital setting because of easier parking, shorter waiting times and space to ask questions about their care. Most participants said they would like to return to the hospice for future BT. These researchers conclude that the hospice day unit is
associated with a good experience for patients with a haematological disorder and that the hospice service should be more commonly available (p. 171).

Fitzgerald, Hodgkinson, and Thorpe (1999) undertook an interpretive phenomenological study in Australia to obtain participants’ experiences of preparing for and receiving BT. Their sample included nineteen participants of whom only two were haematology participants (it is not recorded whether they were palliative or not). They conclude that receiving BT is a relatively un-stressful procedure compared to some other procedures in the hospital, minimal pain is experienced, patients knew and accepted the reason for BT, and although they remained anxious about acquiring HIV and Hepatitis infections from the BT, their anxiety was less than if they had not received BT (pp. 593-600).

A study by Adams and Tolich (2011) explored non-palliative patients’ understanding of the role of BT in their treatment, and whether it caused them any discomfort. Their findings suggest that participants understood the role of BT in their treatment and that nurses were the healthcare professionals who gave them information about BT. They highlight that participants believed it was the physicians’ responsibility to prescribe BT, but alternatives to BT, such as erythropoietin, were not offered or discussed. Participants, in this study, were found to express concerns about the safety of BT but were reassured by the fact that the nurses adhered to safety checks at the bedside.

A study by Szende et al., (2009) explored the perspectives of non-palliative patients with MDS who required regular BT. Their aim was to assess how patients valued life without BT compared to a life dependent on BT by using health-related QoL descriptor cards. They suggest that participants found being dependent on BT so overbearing that they believed a shorter life would be preferable, and a small number of participants found dependency on BT so challenging they considered it “worse than being dead” (pp. 1-2).

Other studies shed light on the hardships of patients who attend regularly to receive BT, and have highlighted the necessary, frequent and prolonged
attendance at hospital, the excessive waiting times involved and the travel costs that patients with a HM and their families incur (McGrath & Holewa, 2007; Craig, Milligan, Cairns, McClelland & Parker, 1999, p. 31), and also the lengthy hospital day that BT require (Engert, 2000; Gray & Craig, 1994, cited by Craig, Milligan, Cairns, McClelland & Parker, 1999).

1.5.6 The ethical dimension of blood transfusion administration in palliative circumstances

A Cochrane Review (Preston, Hurlow, Brine & Bennett, 2012) explored the effect of BT in patients with advanced cancer and found minimal effectiveness and shortened life expectancy. This caused scholars (Preston, Hurlow, Brine & Bennett, 2012; Smith, Cooling & Davenport, 2013) to question the medical futility of administering BT to patients who have a limited life expectancy with no possible chance or hope of getting better medically. According to Brody, Campbell, Faber-Langendoen, and Ogle (1997) and Ferrell, (2006, p. 922), medical futility may be defined as: “care that prolongs life but is unlikely to end in meaningful survival”.

Medical futility is a challenging ethical concern as it is dependent on goals of care (Smith, Cooling & Davenport, 2013). Some researchers have noted the cost and scarcity of blood (Preston, Hurlow, Brine & Bennett, 2012: Smith, Cooling & Davenport, 2013), suggesting that these scarce resources should be used efficiently. Smith, Cooling, and Davenport, (2013, p. 699), for instance, suggest that in medically futile situations, BT should be avoided where possible, BT should not be given to patients at the end of life if a blood shortage develops, and rare blood types, which are particularly scarce resources, should not be given to those considered to be palliative. Using finite resources in futile situations, they suggest, may expend resources that could be administered to save the life of another patient (p.699). Smith, Cooling and Davenport (2013) recognise the ethical tensions that exist between an individual's desire to prolong their life for just one extra day and the broader social dimensions.
1.6 Summary of the research problem

Much of the research, to date, that has explored the administration of BT to patients in a palliative stage of malignancy have been quantitative, medically orientated studies that have assessed the efficacy of BT. These studies have employed positivist research methods, such as before and after studies which have sought to quantify the effect of BT on breathlessness, fatigue and quality of life. These studies have used a variety of standardised quantitative assessment tools, like Visual Analogue Scales and Edmonton Symptom Assessment System to enumerate effect. The population recruited into these studies have mainly been patients from an in-patient hospice setting who have been diagnosed with a solid tumour.

Despite the volume of studies reviewed in section 1.5 none could be found that have asked haematology patients who are in a palliative stage of disease to describe their experiences regarding BT in profound detail. Thus, it is not known what patients expect to happen post-BT either physically or psychologically or both, what challenges they associate with BT and what factors affect their experience of BT. Gaining the perspectives of patients is viewed as important in evaluating health care (DH, 2012), as it is believed that patients’ experience of the NHS, can be improved by, “asking, monitoring and acting upon patient feedback” (DH, 2012, p.1).

Gaining knowledge of patients’ experiences also allows disparities between patients’ perception of their experience and healthcare professionals’ perceptions of the same experience, to be illuminated (Gullick & Shimadry, 2008). Improvement in the quality of clinical care and service provision can then be made from the patients’ viewpoint.

Improving palliative and end-of-life care must be viewed as a priority, as care provided to these sick and vulnerable people has been shown to be inconsistent (National Palliative and End of Life Care Partnership, 2015). Some palliative patients have been shown to receive excellent care while others do not, and this inconsistency is unacceptable and needs to be addressed by healthcare professionals (ibid, p. 6). To ensure everybody
receives excellent care it is recommended that ‘person-centred care’ becomes standard clinical practice (National Palliative and End of Life Care Partnership, 2015).

Furthermore, most palliative patients with a HM who attend for BT are elderly. In the document “Compassion in Practice Nursing, Midwifery and Care Staff Our Vision and Strategy” (DH, 2012), it is stressed that to meet the needs of patients, and particularly the needs of older people, it is vital to look after people with “care, dignity, respect and compassion” (p. 5). To attain excellence in provision of healthcare it is suggested that six values (known as 6Cs), that is, compassion, care, communication, confidence, competence and courage that underpin the role of all nurses and healthcare staff, are adopted by everyone involved in commissioning, planning and delivering care (p. 5).

In view of the gap in the academic literature, the aim of this thesis was to gain a deep insight into the everyday life experiences of participants who had a palliative stage HM and received regular BT in a day unit. The purpose of this study was to understand participants’ experiences surrounding this therapy and any challenges that they faced, and to use these insights to inform current clinical care.

1.7 Research question
The study research question was as follows:

What are patients’ experience of receiving regular blood transfusions in a day unit setting whilst in a palliative stage of a haematological malignancy?

1.8 Research objectives
The study research objectives were:

1. To explore participants’ expectations and challenges around receiving regular BT in a day unit setting.
2. To explore healthcare professional’s role on participants' experience of BT.
3. To explore the effect of the place or setting where the blood transfusions were administered on participants' experiences of BT.
4. To explore the change in participants' experiences as disease progressed from an early palliative phase, to a late palliative phase, to the terminal palliative phase of a haematological malignancy.
Chapter 2: Research context

2.1 Introduction
This chapter introduces the research approach and methodology employed in this study to explore participants’ experiences. It includes a discussion of narrative inquiry (NI) as a research approach in the study of illness and healthcare, its limitations and the rationale for its utilisation.

2.2 Research approach to understanding experience
The aim of this study was to gain a deep understanding of participants’ experiences of BT and gain knowledge about the everyday challenges participants endured. This required a qualitative approach, as qualitative research revolves around people’s experiences and the stories they tell (Strauss & Corbin, 1990). The focus of qualitative investigators is to explore the social world of participants to gain a deep insight into how people experience or understand an event, process or a situation (Denzin and Lincoln, 2011). Qualitative researchers recognise that “our knowledge and experience of the world cannot consist of an objective appraisal of some external reality but is profoundly shaped by our subjective and cultural perspective, and by our conversations and activities” (Yardley, 1997a, cited by Yardley, 2007, p. 217). Furthermore, qualitative methodologies can bring fresh insights into health and illness (Yardley, 2000). Thus, a qualitative approach was deemed the most suitable choice to explore participants’ experiences of BT.

An array of qualitative research methodologies can be employed to study ‘experience’. In this study a narrative inquiry methodology was employed. Prior to discussing the study methodology, it is important to first clarify two key terms, story and narrative, which are employed throughout this study.

The terms story and narrative are often used interchangeably in the public domain and within published academic literature, particularly amongst different disciplines. When difference is noted, it is generally to do with the personal meaning associated with the narrative. For instance, Smith (2016, p, 204) highlights that people “tell stories, they do not tell narratives”. Patterson (2000) proposes that a story is an intellectual interpretation of the narrative
made by the reader or listener. Thus stories, Patterson (2000) suggests, are not stable constructs but tales that can constantly alter over time with each telling and retelling and are dependent on the listener, reader and context of the situation.

In contrast, narratives are stable linguistic constructs which have a specific grammatical structure. They serve as a resource from which people frame their personal stories and understand the stories they hear. People make sense of their lives according to the narrative available to them. (Patterson, 2000; Smith, 2016). Indeed, other eminent, expert narrative researchers highlight that narrative is the principal manner by which individuals interpret and make meaning of their everyday life experiences, establish their identity and their place in the world and motivate their actions (Bruner, 1990; Crossley, 2002; Gee, 1986; Mishler, 1986; Murray, 2008; Patterson, 2000; Riessman, 1993; Smith, 2016; Squire, 2013). Narratives reflect the culture and social circumstances of the time, historical context, race and place (Smith, 2016), and are considered universal (Barthes, 1977).

In this study narratives were defined as “all meaningful stories of personal experience” (Squire, 2013, p. 48) that participants delivered to me through their oral accounts. These narratives were specific episodes or courses of action (Kvale and Brinkmann, 2009) that involved “movement, succession, progress or sequence – usually, temporal sequences – and the articulation of development of meaning” (Squire, 2013, p. 48).

2.3 Methodological approach employed to study experience

The narrative research approach employed in this research study was guided by the Narrative Inquiry methodology proposed initially by educators Connelly and Clandinin (1990), and subsequently developed over the years (Clandinin, 2006, 2013; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Connelly & Clandinin, 1990; 2006).

The principal phenomenon of interest that researchers seek to explore in NI is ‘experience’. Experience, thus stands as the ontological position from which
the research endeavour commences (Caine & Estefan, 2011; Clandinin, 2006, 2013; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Connelly & Clandinin, 2006). The ontological philosophical foundation of NI is Dewey’s concept of experience. In this theory “Dewey sought to promote pragmatism by re-orientating philosophy away from abstract concerns and turning it instead to human experience” (Morgan, 2014, p. 1046).

Dewey, an eminent philosopher in the study of experience, recognised principles of “continuity” and “interaction” in his renowned “transactional”, pragmatic, ontological theory of experience (Clandinin & Rosiek, 2007, p. 39). According to Clandinin and Connelly (2000), Dewey’s two criteria of experience, continuity and interaction, provide the grounding for exploring experience through an inter-related three-dimensional inquiry space: place/setting, temporality and sociality (personal and social dimensions), while acknowledging that these dimensions are ontological. This was in the recognition that all experiences are created by a link between a person and the world they live in, and these experiences are moveable, dynamic and continuous: they feed on each other, in that one experience leads to another, that leads to another, through past, present and future. They change with the individual’s personal history, social influences and material environment (Lemley & Mitchell, 2012; Wang & Greenwood, 2015; Clandinin, 2013; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007).

In NI researchers gain an understanding of experience through story or storytelling (Caine and Estefan, 2011; Clandinin, 2000, 2013; Clandinin and Connelly, 2000; Clandinin and Rosiek, 2007; Connelly and Clandinin, 2006). From an epistemological perspective, the justification for this is that humans are by nature storytellers and that individuals make sense of their experiences by recounting personal stories of experience in an interconnected sequence which maintains temporal order (Bell, 2002; Clandinin, 2013; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Murray, 2008). During NI, researchers pay attention to participants’ experience as it goes through time and in situational context (Clandinin, 2013; Clandinin & Connelly, 2000).
Thus, NI is characterised by having a pragmatic, relational, contextual, temporal and continuous epistemology and methodology (Caine & Estefan, 2011; Clandinin & Rosiek, 2007; Shaw, 2017), where attention is paid to the personal, social, place and temporality dimensions of stories. Stories are positioned and shaped by larger narratives that exist within the lives of participants and the lives of researchers and are influenced by cultural, social, and institutional elements (Caine & Estefan, 2011). The shape of stories we tell are thus formed by those we are told from birth, throughout our early years and throughout our time (Bell, 2002; Okri, 1997).

The relational aspect of NI recognises that meaning is created by joint interaction between researchers and participants in certain sociocultural and institutional settings (Clandinin & Connelly, 2000; Tierney, Seers, Tutton, Reeve 2017). It is this relational aspect which shapes the stories told in interviews and in turn shapes the interpretations made by the researcher (Caine & Estefan, 2011). Meaning is made through a process of “narrative emplotment” (Ricoeur, 1991), which organises an array of events sequentially to create a narrative plot (Tropea, 2011) through which individuals make a point about an event or argue a certain perspective (Murray, 2008; Squire, 2013). It is this point that the researcher interprets, and which allows an understanding of the participants’ perception of events or experiences and allows access to the identity of the storyteller and the culture in which they live (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Squire, 2013).

Without plot a narrative is just a sequence of words with no meaning (Haydon, Browne, and van de Riet, 2018; Mattingly, 1994; Tropea, 2011). The plot accentuates tensions inherent within the narrative and moves the narrative forward through a unique “order of meaning which features time and sequence in relation to activity” (Crossley, 2002, p. 2). “Sequence” and “time” are acknowledged as playing a crucial part in allowing oneself and others an understanding of what happened in certain situations and making experiences meaningful (Crossley, 2002, p. 2). Humans define meaning in their own lives and make sense of their existence by looking backwards and into the future (Crossley, 2003). Humans are motivated to survive by considering their future
and following their ambitions (Crossley, 2003). As Frankl (1984), highlighted by Crossley (2003, p. 440) insists, “it is a peculiarity of man that he can only live by looking to the future”.

Sequencing of time and looking to the future may be seen in the illness narrative employed by sick individuals, highlighted by Smith, (2016, p. 205), “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again”.

2.4 Narrative Inquiry as a research approach in the study of illness and healthcare

NI has become popular as a methodology in illness and healthcare because sick individuals need to tell stories about their illness and treatments to make sense of what is happening to them (Murray, 2008). The recognition of this need and the acceptance of storytelling as a valid approach to knowledge production (Bury, 2001), has led to a post-modern explosion to the study of narrative within the healthcare arena (Andrews, Squire & Tamboukou, 2013; Murray, 2008; Riessman, 2005, 2008).

Chronic illness, and life-threatening illness propels people into a state of disarray or incoherence (Bury, 1982; Charmaz, 1997; Crossley, 2000, 2002, 2003; Murray, 2008; Riessman, 1993; Williams, 1984). Incoherence in chronically sick individuals Crossley (2002) notes, occurs because their normal temporal orientation of time, past-present-future, is shattered. Their prognosis can disallow contemplation of a future which, in turn, disrupts the conception they had of themselves, their everyday lives, indeed, their whole world (Crossley, 2002), a situation characterised as “narrative wreckage” (Frank, 1995, cited in Crossley, 2002, p. 10).

Continuity and coherence are vital to a sense of self. When chronic or life-threatening illness disrupts continuity and coherence, individuals need to construct a comprehensible story by a process of narrative emplotment. This allows them to make sense of the confusion and pandemonium in their everyday lives that the illness has wrought (Bruner, 1986; Del Vecchio Good, Munakata, Kobayashi, Mattingly, & Good, 1994; Good & Del Vecchio Good,

According to Bruner (1986) and Good and Del Vecchio Good (1994), two elements are associated with chronic illness narratives: one is that individuals structure their narratives in a manner to draw an empathetic response from their audience; and the other is that individuals experiencing chronic illness express quest narratives which portray themselves to be in a “subjunctive world”, that is, a world in which there is always a possible hope of getting better (Good & Del Vecchio Good, 1994, p. 839). As such, their stories are not finalised, rather they are told in the “midst” of their ongoing story, their future is uncertain (Clandinin, 2013; Good and Del Vecchio Good, 1994).

Physicians have been noted to collaborate with patients in this quest narrative. For instance, in their study of oncologist practice in America, Del Vecchio Good, Munakata, Kobayashi, Mattingly and Good (1994) suggested that cancer patients and clinicians work together during their clinical meetings through a process of therapeutic emplotment of illness, and the treatment regime associated with it. Therapeutic emplotment Del Vecchio-Good, Munakata, Kobayashi, Mattingly and Good (1994) postulated, describes how physicians caring for cancer patients employed metaphors of hope during discussions with patients that promoted a future. They did this by focussing their discussions around available therapies, treatment plans and side effects of treatment, in preference to discussing what the future held. In urging patients to receive chemotherapy treatment, the oncologists tried to preserve patients' hope of survival, dispel feelings of despair and encouraged people to fight against “disease and death” (ibid, p. 856; Crossley, 2003; Murray, 2008).

2.5 Conceptual approach
Conceptually I explored, interpreted and presented participants’ storied experiences by framing them within Dewey’s three dimensions of experience: sociality, place and temporality. These dimensions are consistent with aspects of experience that I sought to explore in the research objectives (see Table 2).
These three metaphorical commonplaces of experience were employed as the conceptual framework throughout this study. Initially to frame my research objectives, to collecting storied data in the field with the aid of prompts, throughout the analysing phase and finally in the discussion of findings. This ensured a coherent and consistent flow throughout the study between the different components of the research process.
Table 2 Framing my research objectives

<table>
<thead>
<tr>
<th>Sociality commonplace: Personal Dimension</th>
<th>Sociality commonplace: Social Dimension</th>
<th>Place / Space Dimension</th>
<th>Temporality / Continuity Dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective one:</td>
<td>Objective two:</td>
<td>Objective three:</td>
<td>Objective four:</td>
</tr>
<tr>
<td>To explore the expectations and challenges around receiving regular BT in a day-case setting.</td>
<td>To explore healthcare professional’s role on participants’ experience of BT.</td>
<td>To explore the effect of the place or setting where the blood transfusions were administered on participants’ experiences of BT.</td>
<td>To explore the change in participants’ experiences as disease progressed from an early palliative phase, to a late palliative phase, to the terminal palliative phase.</td>
</tr>
</tbody>
</table>
2.6 Limitation of narrative inquiry approach

During narrative inquiry, narratives ‘re-present’ experience, refashioning it during expression to display transformation or change (Squire, 2013). Thus, it was acknowledged that the narratives of personal experience employed as data may not have always been exact mirror images or replications of what had occurred (Smith, 2016; Squire, 2013). It is known that people may sometimes forget the details of an experience, tell untruths or get things muddled (Personal Narratives Group, 1989). They tell stories that defend how they interpret themselves and omit those that undermine their perceptions of self-identity (Bell, 2002). Participants’ narratives also change dependant on audience and the cultural and environmental situation patients find themselves in (Riessman, 2008; Squire, 2013).

According to Bell (2002) it is irrelevant whether the stories are true or not, because NI allows the researcher to look deeper to explore the fundamental assumptions that shaped the stories. She explains: “no matter how fictionalised, all stories rest on and illustrate the story structures a person holds. As such they provide a window into people’s beliefs and experiences” (Bell, 2002, p. 209). It is acknowledged that personal narratives “do” still reveal truths in the manner that the teller wants to be understood (Personal Narratives Group, 1989, cited in Patterson, 2013, p. 36).

In this thesis the personal oral accounts that participants provided were viewed as constituting reality, where they made sense of what was happening in their lives as they tried to adapt to their struggles (Crossley, 2003). It was believed that every narrative told was valid to some extent and contained important points that could be revealed through interpretation (Clandinin and Connelly, 2000; Patterson, 2013). As Labov, (1972) maintained; narratives provide, “an imperfect, practical wisdom”, that may not have the generality of a “grand theoretical truth”, but never the less provides important truths (cited in Squire, 2013, p. 51).
2.7 Rationale for utilisation of narrative inquiry approach

To meet the aim and objectives of the study a pragmatic NI approach was adopted. NI, guided by Clandinin (2013), was deemed suitable for studying the narratives of patients receiving BT for several reasons:

Firstly, the aim of this study was to explore participants’ experience and in NI experience is the phenomenon under study and is explored and understood through dimensions: sociality (personal and social dimension); place dimension; and temporality dimension. As such, NI allows a deep understanding of participants’ experience of BT and of their self-identity and allowed the objectives of the study to be met. NI provides a way of focussing on stories around experience that are important to patients such as their worries, concerns and hardships. Having a pragmatic philosophical foundation allows emphasis to be placed on practical application of findings (Kvale, Brinkmann, 2009). It allows practical knowledge to be developed from these stories, aspects which makes NI particularly suitable for healthcare research (Haydon, Brown & van de Riet, 2018).

Secondly, NI is an established approach within nursing and since its inception multitudes of nurse researchers have chosen to use narrative inquiry (Chan, Jones & Wong, 2013; Haydon & van de Riet, 2014; Hsu & McCormack, 2011; Schick Makaroff, Sheilds & Molzahn, 2013; Wang & Geale, 2015). These academics recognise that NI has the capacity to capture important nuances of the personal, everyday life experiences of patients within the complex discipline of nursing and healthcare (Wang & Geale, 2015). NI has been said to reveal the “humanness of healthcare and nursing” (Lindsay, Schwind, 2016, p. 1).

The approach grants access to understanding of experience through stories consciously told by participants, with an awareness that this permits access to deeper information that patients may not consciously have knowledge of themselves (Bell, 2002, p. 209). Stories can be oral, visual, written, or imaginary stories of personal experience (Clandinin, 2013; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007 Connelly & Clandinin, 2006).
In this thesis, exploration of participants’ experience was gained through the oral, personal stories of experience co-constructed between participants and me. I felt comfortable with the approach as stories are ubiquitous within nursing. Patients tell their stories to nurses about all aspects of their lives; their concerns about their illness, their problems related to their medications and lives, and the problems they cause for their families (Sandelowski, 1991). Thus, as a nurse, I gain knowledge about patients’ experiences and the hardships they endure through listening to their stories. It is what I do every day. Listening to their stories and understanding their problems allows me an understanding of the nursing and medical care that is most needed to suit their situation. Indeed, it is “the human impulse to tell tales that gives nursing scholars access to everyday life human experiences” (Sandelowski, 1991, p. 165).

Consistent with NI in this study narratives were employed as data and as representational form. To constitute the narratives, the stories told by participants were appropriated by me and transformed through interpretation into coherent narrative accounts during analysis. Appropriation meant that I gained an understanding of participants’ experience in effect by the experience it provoked in me, which I understood as being socially and culturally situated. Ricoeur (1972, p. 89) defines appropriation as the “ability to make one’s own what was initially alien” (cited in Murray, 2008, p. 43)

Accepting the premise of narrative emplotment provides a strong rationale for employing a narrative inquiry approach to explore participants’ experience of BT.
Chapter 3: Research methodology

3.1 Introduction
This chapter provides a methodological overview. This is followed by discussion of the sampling, recruitment, data collection strategy and the interview protocol. The ethical considerations and the process of ethical approval are then reported, which is followed by the data analysis procedure. The chapter concludes with a discussion of “found poetry”, which is the approach employed to present the raw data and support the findings of this study.

3.2 Methodological overview
Nested within a qualitative research tradition, the research approach employed in this study was an exploratory, longitudinal, narrative inquiry. Twenty-two in-depth interview transcripts from eight participants, as well as participant demographic information, and researcher’s reflective data were all collected between the 2nd of August 2012 and 30th July 2013. Unstructured interviews elicited the blood transfusion experiences of these participants who received a blood transfusion every two to three weeks while in an early, late, or terminal palliative stage of a haematological disease. The participants’ demographic and descriptor information were collected on a Case Report Form and qualitative, reflective information was captured in a study diary.

The participants received blood transfusions in one of three settings: Haematology Day Unit; Hospice Day Unit; or the Day Unit of a community hospital. Data was analysed using a thematic narrative analysis method. Narrative plotlines (themes or threads) that weaved through participants’ stories were elucidated. Storied experiences are presented through storylines (overarching themes) which are situated within the dimensions of sociality, place and temporality. The words of the participants are presented in poetic form, in line with arts-based inquiry in qualitative research (Butler-Kisber, 2005; Sjollema, Hordyk, Walsh, Hanley, & Ives, 2012).
3.3 Method of Sampling and Recruitment

3.3.1 Sampling

A purposive sampling method was used to determine the participants to be included in this study. Purposive sampling allows the researcher to consciously select their subject sample to fit with the purpose of their study (Patton, 2002). Typical case sampling was employed in this study whereby participants were chosen based on the following characteristics: they were all in a palliative phase of a haematological disease as assessed by a consultant haematologist using the palliative phase definitions shown in Table 3, and they all received BT on a regular basis in a day case setting. The participant sample therefore had characteristics which are pivotal to this research study and which allowed collection of pertinent data on issues central to the subject area being studied.

Table 3 Palliative Phase definitions employed in this study (based on Dalgaard, & Thorsell, Delmar, 2010, p.88)

<table>
<thead>
<tr>
<th>Palliative Phase</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Palliative Phase</td>
<td>The patient is incurably ill&lt;br&gt;The condition typically lasts twelve months.</td>
</tr>
<tr>
<td>Late Palliative Phase</td>
<td>The patient is incurably ill&lt;br&gt;The condition typically lasts for six months.</td>
</tr>
<tr>
<td>Terminal Palliative Phase</td>
<td>The patient is terminally ill and dying&lt;br&gt;The condition leads to death within days/weeks/less than six months.</td>
</tr>
</tbody>
</table>

3.3.2 Recruitment of Participants

Recruitment of participants was from one of two settings: The Haematology Day Unit (HDU) of an NHS Hospital Foundation Trust, and the Day Unit of an NHS Community Hospital.

Recruitment was carried out by three consultant haematologists who acted as
'gatekeepers’ to protect the welfare of their patients. These consultants assessed patients’ suitability to take part in this study dependent on the study inclusion/exclusion criteria which is described in Table 4:

**Table 4 Inclusion and Exclusion criteria**

<table>
<thead>
<tr>
<th>Inclusion criteria:</th>
<th>Exclusions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients diagnosed in a palliative phase of a haematological malignancy.</td>
<td>Patients that were unable to provide informed consent due to cognitive impairment, or who were unable to speak or understand English.</td>
</tr>
<tr>
<td>Were no longer receiving curative chemotherapy.</td>
<td>As face to face interviews were the primary data collection method it was essential that participants could communicate with me on a one to one level.</td>
</tr>
<tr>
<td>Attended a Day Unit setting to receive their BT.</td>
<td></td>
</tr>
</tbody>
</table>

This was viewed as crucial as the specific aim of the study was to explore the experiences of participants’ in a palliative stage of their disease. Furthermore, to explore if their experience changed as their condition deteriorated through the early, late, terminal palliative phases.

One of the objectives was to explore participants burdens associated with BT. It may have been too challenging for participants to separate out the problems they encountered with BT, from the problems they suffered during chemotherapy treatment.

Another aspect to explore was the effect of the day unit setting on participants’ experience of BT.
Patients who were below the age of 18.

The day-unit study settings were for adults only (that is, over the age of 18).

3.4 Patient flow pathway
As shown in the patient flow pathway (Figure 1, p. 32) the consultant gatekeepers only spoke to their patients about the study if they believed that the patients were physically and psychologically able to take part in the study. When discussing the study, the consultants would inform their patients about the study objectives and the terms of participating in the study. If the patient showed interest and agreed to their details being passed to me, then the haematologists referred the patient to me so that they could learn more about the study. A letter of invitation (Appendix 2) and participant information sheet (Appendix 3) were given to the patient who then had a minimum period of twenty-four hours to consider participation in the study before being asked to sign the study participant consent form (Appendix 4).
All patients in a palliative phase of a haematological disease who attend a day unit setting to receive regular blood transfusions were screened for suitability to take part in this study by their respective consultant.

If medical consultants felt that patients fitted the inclusion criteria and were able emotionally and physically to participate they informed the patient about the study.

Interested

Referred to Researcher

Pat Information sheet provided along with explanation of study

Patient given a minimum of 24 hours to make decision

YES

On day of blood transfusion patient attends Haematology Day Unit, Hospice Day Unit, or Community Day Unit. Patient Signs Study Consent Form. Filed in patient’s medical notes. Patient kept a copy. Patient’s demographic and descriptors obtained from medical notes and entered on to case report form.

Participants interviewed to obtain stories about their experience of blood transfusions (3 maximum. Length of interview determined by participant).

Interviews were audio-taped and transcribed. All data coded to maintain strict confidentiality and anonymity. Transcribed data checked for accuracy of transcription by clinical and academic supervisor.

Patients discharged from setting on completion of blood transfusion.
3.5 Patients referred but not recruited
Out of twelve patients who were referred to me by a consultant haematologist, four were not recruited:

One of those referred was receiving blood transfusions every six months and had not been diagnosed as being in a palliative phase of his disease, he therefore did not meet the inclusion criteria described in Table 3.

A second patient asked me to interview her immediately following our discussion about the study. I explained that the study protocol requires a twenty-four-hour period to consider taking part prior to signing the Informed Consent Form. Sadly, the patient died before our arranged meeting.

A third patient having read the Participant Information Sheet decided she did not want to participate.

A fourth patient was transferred to another hospital which was out of the study recruitment area, prior to signing the participant consent form.

3.6 Participants recruited into the study
Eight participants were recruited into the study. Recruitment ceased at this point as no new stories or information was forthcoming. As researcher I also adopted the position that ten or less participants are considered a suitable number to sufficiently inform qualitative research studies (Polit, Beck, & Hungler, 2001), as the aim in this type of approach is not about representation of sample, or generalisability of findings. Rather the approach is concerned with participants having sufficient experience with the area under study; that is, their “appropriateness” (ibid, p.250), to provide applicable information to inform the study aim and objectives.

Recommended sample size in narrative research approaches proved difficult to establish from the academic literature. Cresswell (2013) suggested that as few as one to two cases may be sufficient if the researcher is not aiming for a collective story to be developed. Guetterman (2015) highlighted that from his
review of NI studies, in health sciences, the sample sizes ranged from one participant to fifty-two participants. Bell proposed that in NI the “time commitment required makes it unsuitable for a large number of participants” (Bell, 2002, p. 210).

Reviewing the work of other NI researchers suggests that between four and six participants were recruited into their studies: Chan, Jones, and Wong, (2013) for instance, employed five participants in their narrative inquiry study to explore the relationship between communication, care and time on registered nurses’ work; Haydon, Browne, & van de Riet, (2018) who explored person-centred nursing care, suggests that limiting the sample size to between four and six participants was appropriate. Their reasoning was the large amount of data produced from in-depth questioning between participants and researcher during NI, and because exploration of data via three dimensions of experience (sociality, place and temporality) creates a longer and more detailed presentation of findings (Ely, 2007). A sample of eight was considered, therefore, comparable with, if not more than, other published narrative inquiry studies.

3.7 Demographic and descriptor information
Out of the eight participants: six were male and two were female, with an age range of between 41 and 86 years old (six participants were over 65 years of age). Seven were married and one was widowed. All eight had been diagnosed with a haematological malignancy (HM) of which:
five had Myelodysplasia (MDS)
one had MDS and Non-hodgkins lymphoma
one had Acute Myeloid Leukaemia (AML) and one had AML and Non-hodgkins lymphoma.

Three participants (Kenneth, Ernest and Zavier) were in an early palliative stage of their HM. Two (Jim and Lily) were in a late palliative stage and three (Harold, Helen and Bill) were in the terminal palliative stage of their illness:
Supplementary data was collected prior to each interview via a Case Report Form (CRF) (Appendix 5). The CRF contained demographic and descriptor information obtained from participants and their medical notes, and included: gender; date of birth; marital status; haematological malignancy (HM); palliative phase of the participants’ HM; the frequency participants attended the unit; the day unit where participants received their blood transfusions; the date of their first blood transfusion; the number of BT participants had received since their initial blood transfusion to the end of study; the date of last blood transfusion prior to death; and the number of days between transfusion and death. A summary of the information from the CRF is in Table 5. Date of death and date of last BT prior to death is not included for confidentiality reasons.
Table 5 Summary of information from case report form

<table>
<thead>
<tr>
<th>Names (All Pseudonyms)</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Haematological disease</th>
<th>Palliative Phase of disease</th>
<th>Frequency of BT during duration of study</th>
<th>Setting for BT and meeting</th>
<th>Date of 1st BT</th>
<th>Number of BT received between initial BT &amp; final interview</th>
<th>Number of days between BT &amp; Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenneth</td>
<td>Male</td>
<td>79</td>
<td>Married</td>
<td>MDS</td>
<td>Early</td>
<td>Every 3 weeks</td>
<td>Haematology Day Unit</td>
<td>18/05/09</td>
<td>46</td>
<td>9</td>
</tr>
<tr>
<td>Jim</td>
<td>Male</td>
<td>62</td>
<td>Married</td>
<td>MDS</td>
<td>Late</td>
<td>Every 2 weeks</td>
<td>Haematology Day Unit</td>
<td>02/10/07</td>
<td>34</td>
<td>16</td>
</tr>
<tr>
<td>Harold</td>
<td>Male</td>
<td>72</td>
<td>Married</td>
<td>MDS</td>
<td>Terminal</td>
<td>Every 2 weeks</td>
<td>Community Hospital Day Unit</td>
<td>14/09/06</td>
<td>55</td>
<td>30</td>
</tr>
<tr>
<td>Lily</td>
<td>Female</td>
<td>86</td>
<td>Widow</td>
<td>MDS</td>
<td>Late</td>
<td>Every 3 weeks</td>
<td>Haematology Day Unit</td>
<td>08/09/09</td>
<td>34</td>
<td>11</td>
</tr>
<tr>
<td>Ernest</td>
<td>Male</td>
<td>75</td>
<td>Married</td>
<td>MDS</td>
<td>Early</td>
<td>Every 2 weeks</td>
<td>Haematology Day Unit</td>
<td>12/09/07</td>
<td>121</td>
<td>4</td>
</tr>
<tr>
<td>Helen</td>
<td>Female</td>
<td>68</td>
<td>Married</td>
<td>MDS/NHL</td>
<td>Terminal</td>
<td>Every 2 weeks</td>
<td>Haematology Day Unit for one BT and Hospice Day Unit for the other</td>
<td>08/10/12</td>
<td>18</td>
<td>24</td>
</tr>
<tr>
<td>Bill</td>
<td>Male</td>
<td>74</td>
<td>Married</td>
<td>AML</td>
<td>Terminal</td>
<td>Every 2 to every week</td>
<td>Haematology Day Unit</td>
<td>20/12/12</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>Zavier</td>
<td>Male</td>
<td>41</td>
<td>Married</td>
<td>MDS/AML</td>
<td>Early</td>
<td>Every 3 weeks</td>
<td>Haematology Day Unit</td>
<td>05/06/08</td>
<td>52</td>
<td>17</td>
</tr>
</tbody>
</table>
3.8 Data collection
During the study four types of data were collected: Interview data, demographic and descriptor data, reflective data and self-reported health status data. The primary data collection method was through qualitative interviews.

3.8.1 Qualitative interviews
3.8.1.1 Settings
Interview data was collected from participants in one of three settings: interviews with six of the study participants took place within a side room of the Haematology Day Unit (HDU); one participant was interviewed on the day unit of a community hospital; and one participant had one of her interviews on the HDU and another on the Day Unit of the NHS Hospice. Participants were offered a choice of day, time and place, including their own homes to be interviewed. All participants chose to be interviewed while their BT were being administered as they said this was more convenient for them.

3.8.1.2 Frequency and timing of interviews
Twenty-two interviews were undertaken. Six of the participants (Kenneth, Jim, Harold, Lily, Ernest and Zavier) were interviewed three times and two participants (Helen and Bill) were interviewed twice as sadly they died before a third interview could be undertaken.

The frequency of interviews varied as they corresponded with the administration of their BT: four participants were interviewed every two weeks and three participants every three weeks. At the first interview with Bill he had been receiving his BT every two weeks, however, at the second (final) interview his blood transfusion requirements had been increased to weekly.

Interviews took between 30 and 60 minutes depending on what participants wanted to share and how they were feeling. In consultation with the study steering group (see Section 3.9.1) it was decided that a maximum of one hour was the allocated time slot. This decision followed the experience of Melin-Johansson, Odling, Axelsson, and Danielson (2008) whose study was
designed to elucidate the meaning of quality of life, narrated by patients with incurable cancer who were approaching death. These authors suggested that sixty minutes is not too long, on condition that patients were allowed short breaks.

During each of the interviews I was extremely vigilant of each participants’ condition. I asked frequently throughout if they were comfortable and happy to continue; we stopped for breaks whenever they wanted to, and they could stop at any point during the interview without giving a reason. At no time did any of the participants ask me to stop the interview.

All of the interviews undertaken were audio-recorded onto a password-protected tape recorder and transcribed verbatim soon after each interview by a member of our haematology team. This person was chosen because of her excellent secretarial typing ability, her expertise in listening to audio tapes, her transcription skills, her familiarity with medical terminology, and her contractual obligation regarding issues of confidentiality. Having the right person to accurately transcribe this oral information into written text was crucial because these transcripts served as the primary data from which access to participants’ feelings could be gained, their experiences analysed, and their experience communicated to a wider audience, including academics, examiners and other healthcare professionals (Bamberg, 2012).

Transcription of data was according to protocol influenced by McLellan, MacQueen and Neidig (2003). Essentially, everything that was said by each participant was transcribed verbatim. Transcripts included; mispronunciation of words and non-lexical utterances, such as, “erm”, “err”, “well”, “so”, and “like”. Laughs, and pauses were also included. The transcripts were labelled with the participant’s pseudonym, the date the interview took place, sequence number of the interview, and where the interview took place. The researcher’s text was labelled (R), and the participant (P). Every time either one of us spoke, our utterance was transcribed as a discreet unit of text and assigned the appropriate speaker’s label. A line space was inserted between my prompt
and the participants’ response. Identifying information about people and names of hospitals was removed.

3.8.1.3 Interview approach

The interview approach employed was an in-depth, unstructured, face-to-face, conversational, narrative interview approach that centred on participants stories (Mishler, 1986). Conversations were viewed as “a basic mode of knowing” (Kvale & Brinkmann, 2009). Conversations were unstructured and guided by study prompts which were based on the analytical framework and which allowed participants’ stories to be heard and developed in line with the purpose of the study.

Using unstructured interviews for a narrative research study allows exploration of the participants’ ‘lived world’ (Kvale, 1996, p. 105). The approach promotes the concept of participants being experts in their lives and events that take place. Participants are encouraged to tell their own stories, to speak about what they want to discuss rather than the researcher imposing on them what they want to talk about. This allows aspects to be spoken about that may have been difficult to achieve by other data collection methods, such as questionnaires or focus groups where the researcher dictates the subject. Narrative interviews emphasise the temporal, the social, and the meaning structures of the interview (Kvale & Brinkmann, 2009).

Longitudinal data (data that follows the same subjects over a period) was collected from each participant. The initial intention had been to interview each participant three times, during their first blood transfusion and during the administration of two subsequent blood transfusions. Carrying out prospective, repeated interviews with several participants about the same phenomena is commonly employed in narrative inquiry, enabling a deep understanding of the phenomena under investigation (Chan et al., 2013; McCracken, 1988). It allows for the smallest changes in experiences at an individual level to be identified and recorded (Ruspini, 2002). It also has the potential of enabling a more trusting relationship to develop between the researcher and participants, which in turn can promote more open conversations (Murray et al., 2009;
Seidman, 1991). Furthermore, the time between interviews is said to provide space for participants to reflect on and deepen their subsequent stories (Seidman, 1991).

My interview approach was guided by the work of Atkinson (1998) who suggests that rapport between participant and researcher is developed if the researcher demonstrates warmth, friendliness, empathy, sensitivity, support and encouragement. This rapport was achieved by: smiling and nodding at appropriate moments thus demonstrating that I was keen to hear what participants had to say; keeping my own voice in the background when possible to allow participants to take the lead and discuss issues important to them; maintaining an iterative approach and actively listening and seeking clarification or elaboration when required. This meant that challenges and hardships identified in prior interviews were explored and revisited again in later interviews with reference to emerging experiences. Episodically, my understanding of what participants had told me was shared with them to confirm that my understanding was correct (McGrath, 2004).

Generally, the interview started with asking how long the participant had been receiving blood transfusions. I started in this manner because it seemed to provide an informal entrance into our conversation. My aim had been to try and maintain a similar interview approach for each participant, however, this proved difficult to facilitate due to my prior nurse-patient relationship with them. Two of the participants, who I knew very well as I had placed their peripherally inserted central lines and taken their bone marrow biopsies, entered conversations easily with me, taking the lead throughout the interviews. As I had not met the other six participants prior to their involvement in the study, a different approach was required during the first interview, whereby I took the lead and employed study prompts as highlighted in Appendix 6 (Appendix 6. Initial conversation prior to first, second and third interview, and prompts employed in study).
3.8.1.4 Pilot interview

There is conflicting academic literature concerning the need for a pilot interview in qualitative research studies. Holloway (1997) suggested that a pilot interview is not necessary because the research approach has the flexibility for the researcher to develop their interview technique as interviews progress. While others (Denzin & Lincoln, 2011; Robson, 1999) suggested that pilot testing is an essential part of the research process that allows refinement to study aspects prior to embarking on the main study.

Following consultation with the study steering group, a decision was made not to undertake a pilot interview with participants as it was felt to be inappropriate in light of their poorly condition. Instead, the interview process and the prompts to be employed in the study were first discussed with my academic supervisor which resulted in minor revisions to the prompts. Using the revised study prompts, I then asked a member of our haematology team, who had received BT several years earlier, to tell me her stories about her experiences of receiving BT, following which amendments were made to the initial prompt.

3.8.2 Reflective data

Reflection and reflexivity are essential aspects of the research process. Bolton and Delderfield (2018, p. 9) highlight the difference between these two terms: Reflection, they suggest is an in-depth review of events either alone or with a supervisor to understand ‘why’ something happened under certain social and political contexts. These reflections of events may be recorded within a study diary during the research process (Bolton & Delderfield, 2018).

Reflexivity, Bolton, and Delderfield (2018, p. 10) suggest, allows researchers to look inside themselves to question their own beliefs, position, suppositions, intolerances and characteristics and to understand the multifaceted relationship with participants and others in the research endeavour.

Reflection-on-practice allows researchers to; “reflexively critique their personal values, ethics, prejudices, boundaries, assumptions about roles and identity decision-making processes” (Bolton and Delderfield, 2018, p.8). Duke and
Appleton (2000, p.1558) describe key skills necessary during the process of reflection-on-action:

- Describe the experience
- Identify salient features of the experience
- Analyse the feelings evoked by the experience
- Analyse the experience with respect to different sources of knowledge
- Analyse the contextual factors that might have influenced the experience
- Synthesize existing knowledge with the new knowledge gained from reflection
- Evaluate the experience and the learning achieved and the implications for future learning and practice, and plan action to take the learning forward into practice and other learning activities.

A study diary was maintained throughout the study period to record reflection-on-practice and the research process that considered my values, my professional and personal life-experiences and any assumptions or preconceptions held that could influence how I understood and gave meaning to the data collected during the interview and data analysis process. I identified and noted striking features about issues raised and analysed the feelings this evoked in me (Duke and Appleton, 2000), and the emotions that I witnessed during each interview. Notes were written shortly after each interview while they were still fresh in my mind. These notes were helpful in that they retained in written form “bumping” places (Clandinin, 2013, p.63); that is, matters participants brought to light while telling their stories that I found difficult to comprehend from a clinical perspective. One example of a bumping place, for example, emerged during a conversation with Jim who told me that he had persuaded the doctors to change his blood transfusion prescription from every two weeks to every four weeks. His story did not make sense to me from a haematology nurse practitioner perspective since the frequency of BT is expected to increase rather than decrease as disease progresses, however, for Jim this was a perfectly coherent narrative. Analysis of the contextual factors that might have led to this experience (Duke and Appleton, 2000) led
me to understand what Jim was trying to achieve. He was trying to get his body used to managing with monthly blood transfusion support. Training his body in this manner, he believed, would get his body used to going four weeks without a transfusion. He thought this was necessary because he was preparing to go on a four-week holiday where access to blood would be impossible.

Reflection on “tensions” (Clandinin, 2013, p. 107) that participants and I appeared to experience were also recorded in the study diary. These reflective notes served as an aide memoir of issues that required deeper exploration at subsequent interviews. Tensions were recognised by exhibitions of distress, anger or stoicism on the part of participants, which evoked tensions in me identified by feelings of guilt and sadness as I learnt of participants’ physical and psychological hardships.

3.8.3 The self-report EuroQol EQ-5D3L Health Questionnaire or WHO performance status tool
Participants were also asked to complete a EuroQuol EQ-5D-3L Health questionnaire prior to each interview (Appendix 7), and complete a Visual Analogue Scale, where the “best health state imaginable” was marked as 100 and the “worst health state imaginable” was marked as 0. This data is presented in Appendix 8. As one participant was so unwell on the day of his third interview, the validated WHO performance Status tool was completed instead (Appendix 8). The health information, which was collected to provide a descriptive profile of health status as self-reported by participants, has not been discussed throughout this thesis since this supplementary data did not appear to add to a more complete participant description.

3.9 Ethical considerations
Much consideration was given on how to look after the best interests of the participants in this study as it was acknowledged that palliative patients may experience physical, psychological, social and spiritual distress which makes them a particularly vulnerable group in relation to participating in research. In addition, those with a life-limiting condition may not benefit directly from taking
part in research which means the cost of participating in research will always outweigh the benefits. Any research undertaken within an NHS hospital Trust must abide by the primary ethical principles of beneficence, non-maleficence, respect for human dignity and justice (Polit, Beck & Hungler, 2001).

This research study obtained ethical approval on 22\textsuperscript{nd} May 2012 by the NHS Health Research Authority, National Research Ethics Service Committee South Central – Portsmouth, Bristol Research Ethics Committee (Ethics reference number: REC 12/SC/0282) (Approval Letter, Appendix 9). Ethical approval to undertake the study within an NHS Foundation Trust hospital was also obtained. Following a Research Risk Assessment for Trust Sponsorship, approval was given by the Research and Development Office, who confirmed that the Trust were willing to act as a sponsor for the study under the terms of the Department of Health Research Governance framework for Health and Social Care, Second edition (DH, 2005) (RGF). R&D Ref. No: 2012/SUR/10. (Appendix 10. Research risk assessment for Trust sponsorship).

### 3.9.1. Steering group

A study steering group was established consisting of two lay members of the public and a group of healthcare professionals, including: a consultant haematologist (lead clinician in haematology who is also clinical supervisor for the study); the lead clinician of the NHS Hospitals Palliative Care Service who is also Associate Medical Director and end-of-life Consultant at the hospice; a haematology specialist/research nurse; the modern matron and divisional manager for cancer services at my employing trust; my academic supervisor; and me as Chief Investigator.

Following an approach from the patient experience manager at my employing NHS Foundation Trust, it was decided to invite two members from the Hospitals NHS Trust's Patient Voice Forum and Cancer Partnership Group. The two lay members helped ensure that my original study proposal was sensitive to patients’ needs, that it was appropriate and acceptable to patients and that it was ethically sound. The two were actively involved in a collaborative manner at the initiation of the study. Initial feedback over the
study protocol was provided by members of the steering group following which amendments were made. Two suggestions incorporated were the need to involve the Trust Counsellor if participants became upset, and to invite family and friends to be present during the interview if the patient wanted them present. In this study, the support and advice from the Trust Counsellor was not required, and only one participant asked for her husband to be present throughout our two interviews.

The purpose of the group was to discuss the management of the project and ensure adherence to best research practice as highlighted in the document “Research Governance Framework for Health and Social Care” (DH, 2005), a key element encompassing ‘respect for participants’ dignity, rights, safety and well-being’ (ibid, p.15). The steering group met quarterly.

### 3.9.2 Confidentiality
Participant confidentiality was safeguarded in line with the Data Protection Act (DPA, 1998). Each participant was given a pseudonym and a study number which populated all study documentation to ensure anonymity. Only the lead researcher and members of healthcare team had access to the Investigator Site File containing the participants’ initials, dates of birth, hospital numbers and designated study numbers. The coded Case Report Forms and transcripts are all kept in a locked cupboard at the researcher’s home. The recorded interviews and the reflective diary were kept on the researcher’s computer which is password protected. Participants confidentiality will also be protected in the final report and in any future publications.

### 3.9.3 Positionality
As both a nurse and an academic undertaking research it was important to be reflexive (Sheldon & Sargeant, 2009) about my positionality in this study as this dual role evoked personal ethical tensions.

One challenge which revolved around my dual role as a nurse and as an academic researcher was the risk that patients might feel “obliged” to
participate in the study, just to show gratitude for the care they have received (Speck, 2009, p. 279). Participants were not coerced into taking part, indeed it was made clear during the Informed Consent process that there was no obligation to participate and that they were free to withdraw from the study at any point. Sheldon and Sargeant (2009) highlight several ethical issues in qualitative research which were encountered during this study. One of these issues related to the power that health professionals may hold over patients in their care because of their professional knowledge and their hierarchical position within the healthcare organisation. This issue cannot be avoided but measures were taken to minimise this effect during interviews with participants; for example, medical terminology was avoided, and neither my nursing uniform nor bleeper were worn.

Another tension that featured was determining “who am I” (Sheldon and Sargeant, 2009, p. 166) a nurse or a researcher, as participants frequently asked me to undertake nursing care during our study interviews. Clinical supervision with the trust counsellor helped resolve this matter. My primary responsibility was to abide by my nursing and midwifery code of professional conduct, to provide care and to protect the interests of all patients (Nursing and Midwifery Code of Professional Conduct, 2015) as a priority over gaining data for the study.

Supervision with my academic supervisor throughout the study period helped me to be reflexive on my personal and professional experiences which could create values and bias that influenced my interpretation of the findings. That is, as a nurse working within the area being studied preconceived ideas were held about blood transfusion administration. During the research process it was necessary to place these ideas in the background of my cognitive logical thoughts and allow my mind to “wonder” and to explore and understand participants’ experiences from their perspective. Wonder, according to Bolton and Delderfield, (2018, p. 22); “is the beginning of wisdom, because wonder is an open, enquiring state of mind when anything might be possible, when startling inspiration appears as a result of no cognitive logical thought”.
3.10 Data analysis: narrative analytical approach

There are several approaches to narrative analysis of data: thematic, structural, dialogic and visual (Riessman, 2008). A thematic narrative analysis that focused specifically on content, that is, “what was said” rather than “how it was said” (Riessman, 2005, 2008) was employed in this thesis. Language was thus viewed as providing access to meaning, a resource rather than a phenomenon to be explored structurally (Reissman, 2005). Stories were kept intact during this analytical and interpretive processes. They were not fragmented or coded out of context, rather long narrative episodes were included that maintained the chronological pattern of the stories from beginning though to their resolution. The analytical steps employed were influenced primarily by the body of work of many researchers; Clandinin (2013), Clandinin and Connelly (2000), Connelly and Clandinin (1990) and Riessman (2005; 2008).

The analytical process involved “narrative coding” of the transcripts influenced by Clandinin and Connelly (2000, p. 131). These authors proposed that to find narrative meanings the investigator needs to narratively code the data taken from the setting or field, denoted as “field texts”, to prepare “interim research texts”. Narrative coding involves sorting through all the transcripts of field texts to identify important themes (scenes, ideas, aspects) relevant to the purpose of the study then interweave these into the three-dimensional inquiry space. Scenes and ideas, for example included the people participants brought into their stories who have had an impact on their experience, the settings involved and the tensions that were exhibited and perceived.

From the interim research texts, an individual research text for each participant was then created by seaming together the elements gained from each of the individual’s interviews and using the interpretive tools of “broadening” and “burrowing” (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990, p. 11). Broadening brings to the research texts institutional, professional and cultural aspects, and burrowing allows the researcher to try and stand in the shoes of the participants to reconstruct a story of their experiences from their perspective. Finally, “re-storying” (Clandinin & Connelly, 2000; Connelly &
Clandinin, 1990) brought the research texts into chronological, coherent narrative accounts. These narrative accounts were thought of as a patchwork quilt (Clandinin, 2013) that consisted of many narrative themes stitched together to form the whole BT experience.

Scanning across the eight narrative accounts resonant plotlines were discerned. Plotlines in this study were defined as aspects of significance to participants that wove through one or more of the stories that revealed individual perspectives of their blood transfusion experience, aspects that gave coherence and meaning to the stories.

The process of data analysis undertaken was as follows:

3.10.1 Step One: Hearing and feeling the stories
The process of narrative analysis began as soon as participants started telling me their stories. Thoughts and feelings that arose during interviews were recorded immediately on completion of each interview.

3.10.2 Step Two: Transcription of the data
The audio-taped data (field texts) were transcribed as described earlier according to a protocol influenced by McLellan, MacQueen and Neidig (2003).

3.10.3 Step Three: First reading of transcriptions - checking for discrepancies
Once transcribed the transcripts were proofread. This involved me carefully listening to the audio-recordings whilst reading the transcripts to ensure accuracy of transcription, and to re-familiarise with what had been said during the interview. Very few corrections were necessary. Listening to the tapes raised emotions felt during our actual meetings, and these emotions were checked against what had been documented in the study diary but none of any significance were found.
3.10.4 Step four: Second reading of transcriptions - from field texts to interim research texts

The next step involved an intense re-reading of the transcripts and ‘narrative coding’ (Clandinin & Connelly, 2000). At the end of this process, story scenes or ideas expressed (Frazer, 2004, p. 189) related to the study purpose were identified and recorded on a new document, considered as the “Interim Research Text” (Clandinin, 2013, p.47; see an example in Appendix 11).

3.10.5 Step five: Third reading of transcriptions - categorisation of narrative scenes in the interim research texts

During the following reading of the transcripts each of the identified scenes in the interim research text were organised within one of the three dimensional narrative commonplaces of experience: personal and social (sociality), place and temporality (past, present and future) (Clandinin, 2013; Clandinin & Connelly, 2000; see an example provided in Appendix 12). Organising scenes into this framework provided a lens that allowed distinct elements of participants’ experiences to be seen more clearly:

Personal and social dimension: Participants’ feelings, understandings, expectations, challenges, relationships with healthcare professionals, and cultural aspects.

Place dimension: The Haematology Day Unit (HDU), The Hospice Day Unit, The Community Hospital Day Unit and the Pathology Department.

Temporality dimension: Blood transfusion history and changes in blood transfusion effect with disease progression.

3.10.6 Step Six: Fourth reading of field texts – interim research texts to research texts

The next step was to create a research text for each participant. The initial process involved weaving together the categories found in participants’ first, second and third interviews into a single document to create eight ‘research texts’. The tools of broadening and burrowing were employed at this stage to stitch together the narrative categories into research texts that portrayed the participants’ own perspective of their experiences within social and cultural contexts. The compiled research texts consisted of a collage of categories
under one of the three dimensions of experience. Many drafts of these final research texts were compiled until it was believed that an accurate representation of the experiences of each participant had been compiled.

3.10.7 Step Seven: Creation of eight narrative accounts and identification of narrative threads or resonances (plotlines)

The next step involved re-storying the categories into a chronological, coherent, individual participant narrative account for each participant that addressed the three dimensions of experience. Each account was organised in the following format:

1. The account started with an introduction to the participant and included their age, HM, palliative phase, how long they had been receiving BT;
2. The account then detailed personal and social aspects relating to BT, for example; how participants felt about BT, what they expected to happen following BT, any challenges they experienced associated with BT, and social aspects that included their relationships with healthcare professionals;
3. The account detailed places associated with BT and the effect places had on participants’ experience of BT; and finally
4. Temporal aspects were then detailed in the account which showed how participants experience changed over time.

The process of re-storying helped me to discern similar narrative themes or characteristics that ran through each of the narrative accounts. These themes, which Clandinin (2013) refers to as “threads” or “plotlines” captured key features of each participants’ blood transfusion experiences. For example, their perspective of BT, their concerns, their fears, their expectations, their hopes and their revelations.

Scanning across the eight narrative accounts, common plotlines emerged that resonated with receiving blood transfusions in a day case setting when
diagnosed in a palliative phase of a haematological disease. An example of how plotlines were derived is provided below.

The plotline, *Blood transfusions mean life* was a thread echoed in all participants’ narrative accounts. Text box 1 presents a vignette from Kenneth’s narrative account to help demonstrate how his message “without blood transfusions it would be a box job”, provided the foundation for this plotline. Kenneth’s quotes are bold text.

Text box 1. A vignette from Kenneth’s Narrative Account

Kenneth’s story began when he was in an early palliative stage of his disease and he had been told by a consultant haematologist that they “can’t do anything else”. The only thing that the doctors can do, he understands, “is top your blood up because you’ve got immature red blood cells, simple as that”. He understands that “there’s no other tablets or magic pills or anything like that”, BT are the only therapy available for him that will keep him alive. Frequent blood transfusions he announces, “are part of my life. I have no choice, without blood transfusions it would be a box job”.

3.10.8 Step Eight: Development of storylines

The following step was to develop storylines, as they encapsulate and depict in a single line or phrase specific elements of participants’ everyday life experiences. As Brown and Addington-Hall (2008) suggest “storylines help make sense of complex narratives… and serve as organising threads to help patients, families and healthcare professionals better understand” (p. 200).

Storylines, in this study, were thought of as overarching plotlines or themes which spoke across and within participants’ stories. Built from a foundation of plotlines, they represented a shared understanding of participants’ personal accounts of experience which had been informed by broader societal and cultural narratives. Development of storylines fashioned a way for me to present and discuss my findings academically and to my peers, in a way that would allow them to relate to the storylines as being applicable or non-
applicable to their own practice. From the storylines they could draw their own conclusions regarding credibility, dependability, confirmability and transferability.

3.11 Found poetry
Initially, my plan had been to include direct participant quotes taken from the field to aid with trustworthiness of findings, presenting participant quotes exactly as they had been spoken. However, this approach did not recount participants’ experiences in the manner that I wanted. They seemed too long and did not invoke the empathy personally experienced when talking to participants. To address this presentation problem, “found poetry” (Richardson, 1994) was created to present the words of participants.

Found poetry is a subjective interpretation of the words of participants by the researcher (Butler-Kisber, 2002) who “takes the words of others and transforms them into poetic form to re-create lived experience and evoke emotional responses” (Richardson, 1994, p. 521). Representing narrative findings in an arts-based form, such as found poetry, is becoming increasingly popular as researchers realise that poems can grasp and captivate the mind of the audience (Clandinin, 2013). Mishler (1999), decided to present his transcripts verbatim in a style close to poetic form, “where the poetic shape provides an accessible structure for the story” (Kvale & Brinkmann, 2009, pp. 154-155). My decision to do this was greatly influenced by the work of many researchers, (for example, Butler-Kisber, 2002, p. 232; Clandinin, 2013; Duke, 2007; Gee, 1986, 1991; Mishler, 1999; Reilly, Lee, Laux & Robitaille, 2018; and Richardson, 1994, p. 521).

To display the words spoken by participants in a style close to that of a poem or stanza form the following guidelines were adopted (Butler-Kisber, 2002; Duke, 2007; Gee, 1986, 1991):

- Each line of the poem was kept short and contained a new piece of information. There was generally a pause before the next line began
• Poetic stanzas were assembled by grouping sets of lines together that depicted a scene or image in the narrative
• Each stanza was distinguished from other stanzas by a blank line. In creating these stanzas participants’ words were kept in a similar order to that spoken by them as generally their verbal accounts had a sequential, temporality associated with them. However, occasionally it was necessary to slightly rearrange the words in a line to create rhythm, pauses, emphasis and to keep themes together. This was achieved without changing the meaning of the text.
Chapter 4: Research Findings

4.1 Introduction

The findings presented in this chapter emerged from the analysis of stories told by eight palliative participants with a haematological disease, who between them had until the end of study received 378 blood transfusions. Throughout the chapter a recap of each participant is made, highlighting their age, which ranged from 41 - 86 years old, their haematological disease, and the frequency each received their BT.

Four research objectives were established with the purpose of exploring participants’ experience. These objectives were met by undertaking a thematic narrative analysis of the storied data which addressed three dimensions of experience. This analysis led to common plotline findings which highlight challenges associated with blood transfusions which participants or I interpreted as having a detrimental effect on their care and everyday lives. The analysis was discussed with my academic supervisors and my clinical supervisor; however, it is appreciated that the interpretation of the data was subjective, as another researcher with a different set of experiences, from a different discipline could have interpreted the transcriptions differently.

Nine plotlines were found to resonate with receiving BT when diagnosed in a palliative phase of a haematological disease:

1. Blood transfusions mean life;
2. Blood transfusions as a sustenance to life;
3. An up and down everyday blood transfusion life;
4. Life in the hands of physicians;
5. Life in the hands of the nurses;
6. Life in the hands of ward receptionists;
7. Waiting in pathology for blood tests;
8. Waiting on the haematology day unit; and
9. Anxiety associated with places in the hospital setting.

Three plotlines resonated with receiving blood transfusions within the Hospice Day Unit:
1. More individualised care;
2. Hospice day unit perceived as a safer place to receive blood transfusions; and
3. Hospice Day Unit perceived as a more tranquil place.

Three plotlines resonated with the everyday lives of participants who were receiving BT in the late to terminal phase of their haematological disease:
1. Somnolence overwhelms daily life;
2. Adversities overpower everyday life; and
3. Desperation to hang on to life.

These plotlines provided the foundations for five overarching storyline findings that corresponded with the research objectives and presented throughout this chapter in three sections:
- **Section 1** illuminates the personal and social dimension of experience.
- **Section 2** illuminates the place dimension of experience
- **Section 3** illuminates the temporality dimension of experience.

Conveying the findings in separate sections, related to dimensions of experience might give the impression that these dimensions are not connected to each other. This is not the case. All the dimensions of experience were considered as being completely interrelated and pieced together like a jigsaw puzzle to provide an overall picture of participants’ everyday blood transfusion experience.
4.2 Section 1: Personal dimension of experience

4.2.1 Storyline one: Everyday blood transfusion life hangs in the bag

This storyline elucidates the personal dimension of experience and responds to objective 1: To explore participants’ expectations and challenges around receiving regular BT in a day unit setting.

Three narrative plotlines provided the foundations for this storyline: blood transfusions mean life; blood transfusions as a sustenance for life; and an up and down blood transfusion life.

These plotlines allow an insight into how participants felt about BT, what BT meant to them, their expectations, and the perceived effect on their day-to-day lives. Gaining an understanding of these aspects was one of the objectives of the study as there are limited studies that have addressed participants’ views about BT. Most researchers, appear to have undertaken positivist research that has focussed on the efficacy of BT in reducing symptoms of anaemia in patients with an advanced cancer, the financial cost of BT, and the futility of BT at the end of life. With the current emphasis in healthcare on costs and the suggestion that BT are a scarce resource that may be futile at the end-of-life, addressing participants’ feelings and understanding what blood meant to them was believed to be important.

4.2.1.1 Plotline - Blood transfusions mean life

Most participants in this study felt that receiving BT meant they could live a little longer. Without this essential supportive therapy, administered in the form of packed red cells, they recognised that they would die quite soon. As none were receiving any chemotherapy treatment all their hope of prolonging their lives lay in the bags of blood they received. As such, BT were viewed as a life-line, an elixir of life that sustained and controlled their everyday lives. Like insulin for the diabetic patient or GTN for the patient suffering from angina, their lives became dominated by BT and the rituals associated with them. Participants spoke of their resignation to this situation and told how they were prepared to adjust their lives as required, so that they could attend the day unit for a day every two to three weeks to receive BT. This willingness to spend much of their time in the hospital was because they had been informed by their
consultant haematologist that there were no other treatments available, and BT maintained hope of survival.

**Kenneth (early palliative phase):** Kenneth, for instance, articulated this plotline well. Kenneth was 79 years old and had been diagnosed with MDS. He was aware that the immature red blood cells in his bone marrow would not mature into healthy red blood cells, cells essential for life. He understood from a consultant haematologist that the administration of BT would provide him with the healthy red blood cells he required for survival. Frequent blood transfusions he said, “are part of my life”, he has “no choice”. With his reliance on BT to survive, he states he has resigned himself to attend the HDU of our District General NHS Foundation Trust, every three weeks to receive BT. He comments that he has got used to coming to the HDU frequently and it no longer causes him any worry, but stresses that this has taken time. His acceptance of the situation he suggests came about by toleration of the infusion time involved and by adjusting his circumstances to accommodate whatever needs to be done.

- There’s no choice
- I’ve got immature red blood cells
- it’s part of the problem I’ve got

- There’s no magic pills
- to keep me alive
- only thing they can do
- is give me a blood transfusion

- They keep me going
- cos without it
- it would be a box job
- you learn to live with that.

**Ernest (early palliative phase):** Ernest was 75 years old and had MDS. Ernest had been receiving blood transfusions for over four years and had
received 121 since first diagnosed and up to the time of our final interview. He explained that the consultant haematologists aimed to keep his “normal Hb level” around “10”, which he understood was lower than that considered a “normal” Hb level for most people. But, he states, at this level he could still maintain a “normal life”, doing “normal things”, like playing “darts on a Friday night with friends”. To maintain this Hb level Ernest required frequent BT. When first diagnosed he had received them every eight weeks. However, over the past few months the frequency had increased significantly, from every eight weeks, to every six weeks, to three weekly and finally to every two weeks. Ernest associated this increased frequency with “the end of my life is approaching”.

He knew that BT had kept him alive for the past four years but believed that he couldn’t go on living because BT were “not doing their job properly”. He judged the blood to be accountable for his increased requirement, rather than acknowledging it was down to a deterioration in his bone marrow function. As BT were the only treatment available for him, he said he wished that the haematologists could find another way to keep his Hb level at one compatible with life. It made him question me if there was an alternative to BT, misguidedy suggesting that he would be willing to try a “bone marrow transplant” as a “simpler option” to raise his Hb. As Ernest vocalised his worries, it became startlingly apparent that despite being in the final stage of his life, his medical and nursing care still lay wholly with the haematology team. He had not been introduced to anybody from the palliative care team.

I need the blood to keep me alive
if I don’t have it I don’t survive
I worry that it used to be every 8 weeks
then every six, then three,
now it’s every two
where do we go from here?

There’s not much further
the end of my life is approaching
nothing you can do about it

I wish they could find another way
of topping up my levels
cos the blood transfusions
they're not doing their job properly

If there was a simpler way
of having my haemoglobin boosted
by a bone marrow transplant or whatever
I would be willing to go ahead with it
to prevent me having BT.

Zavier (early palliative phase): Zavier was 41 years old and had been diagnosed with MDS/AML. He had endured several attempts to cure his disease with intensive chemotherapy, but these had failed. During his final attempt with chemotherapy Zavier had almost died from overwhelming sepsis. Following this episode he had decided that he did not want any more chemotherapy. A consultant haematologist had informed him that he would require regular BT to keep him alive. Zavier had gone home and searched the internet for more information about BT. From this source Zavier understood that as he did not have “much blood in your system”, receiving BT would help him to survive. They would extend his life, he had “no choice”. As the frequency of his BT increased Zavier did not associate his increased need with disease progression, rather he was under the misconception that this was related to the level of physical activity he undertook at home. Zavier mistakenly believed that if he undertook strenuous physical activity this lowered his Hb level.

I don’t have a choice
I really need it
if there’s no blood transfusion
I wouldn’t survive any more

Blood transfusions prolong your life
because every single moment
my blood level is dropping

If I make a lot of movements
or do things in the house or outside
I easily lower my haemoglobin.

Jim (late palliative phase), Lily (late palliative phase) and Harold (terminal palliative phase): These participants had also been diagnosed with MDS. Jim was 62, Lily was 86, and Harold was 72. All stated that they really needed BT as they would die quite soon if they were stopped. Recognising that survival was dependent on BT was their paramount motivation for having them. Harold stated that the doctors strived to maintain his Hb level “as high as possible”, above “100” (10g/dL), but that he rarely attained this level despite regular administration of three units of blood. His understanding was that the haematology doctors would continue to prescribe BT for as long as they remained beneficial to him, which reassured him.

Bill (terminal palliative phase): Bill was 74 years old and had AML. The intensive chemotherapy treatment that he had received in our inpatient facility to treat his disease had been unsuccessful so had been stopped. He now received supportive BT in our HDU. At our first interview Bill was receiving BT every two weeks, however, by the time of our second and last interview this frequency had increased to weekly. Bill was pragmatic about this burdensome requirement as he understood that BT allowed him, he stated, “to exist”. Exist, perhaps, was an appropriate word for Bill to have chosen, as he could no longer partake in any of the activities of daily living that he had previously enjoyed with his family and friends.

4.2.1.2 Plotline - Blood transfusions as a sustenance for life
Three participants (Kenneth, Ernest and Zavier) expected BT to provide them with some relief of their anaemia related symptoms. For them BT were considered a fuel that provided a source of strength that supported and
maintained them, even if the effect was transient. Two participants (Lily and Jim) stated during our first two interviews together that they expected some relief from their symptoms, however by the time of our final interview together, this beneficial effect was virtually non-existent. Three participants (Harold, Helen and Bill) expected no beneficial effect.

As shown in the narratives below, those who did feel some benefits chose to stress how the effect of BT brought a sense of normality to their lives.

**Zavier (early phase):** Zavier for instance, chose the words “Superman” and “normal person” to describe how he felt after receiving BT. Zavier insisted that they alleviated his physical symptoms of anaemia, that is his breathlessness, tiredness, lack of energy, tachycardia, and made him feel “much better”. Indeed, they allowed him to feel like “a normal person, doing the same things as normal people”. If his Hb fell below 80 he suffered chest pain, felt tired and breathless to the point he would be forced to slow down his activity level.

> Every time I have a blood transfusion  
> my strength, my energy, comes back  
> and I feel like I am a normal person  
> doing the same things as normal people

> If my haemoglobin goes down to 80  
> I can feel it  
> I feel tired  
> I can't breathe  
> my heart beats a lot faster  
> and then I’m having chest pain  
> so, I slow down.

**Ernest (early phase):** Ernest was the most effusive of the participants when describing what he expected to feel post BT. He expected to experience a “good boost”, to get a “buzz”, a “little burst of energy”, to have “a little bit more breath in the early stages” and “to be slightly more elated”. He used the term
elated, he said, because “you feel freshened” and able to do more than you did before. Following his BT when his Hb had been increased he didn’t feel as if he was ill at all; indeed, he stove to be “normal”, he would go to the pub with his friends to play darts.

I get a buzz
I feel good
I expect to have a bit more breath
and to be slightly more elated
because you feel freshened
and able to do more than you did before

When my blood levels are quite high
I don’t even know that I’m ill
I keep my chin-up
I try to be normal.

Lily (late phase): During our first two interviews, Lily told me that receiving BT made her feel much better physically. Lily used the word “marvellous” to describe the difference she felt post blood transfusion explaining that it “bucked her up” and gave her a “bit more oomph”, more energy to do a few more jobs. During these two interviews, Lily used humour to describe how she felt following her BT explaining, she could “run after a bus” after it, like that Road Runner’ character. However, during our last interview Lily was different. She was feeling very unwell, “really horrible”, “barely able to walk”. She described her everyday life as “just sitting in a chair”, sleeping a lot, unable to motivate herself to do anything, unable to concentrate enough to do the knitting or sewing that she loved to do. Lily put this down to the fact that she was “short of blood” as her haemoglobin level had dropped to “91”. She did not equate it to a deterioration in her condition.

I do feel the benefit of it
it makes an awful lot of difference
it bucks me up a bit
I can do a bit more
I could run after a bus after it
like that Road Runner

It takes it out of me going so low
I can’t do anything
I don’t want to do anything
I just can’t concentrate
everything comes to a standstill
I am exhausted all the time
I feel like a wet week.

Jim (late stage): Jim did not expect any physical symptomatic relief from BT. However, he reported that they helped him mentally to “think a bit quicker” and to “feel a bit brighter”. In the past when in an earlier palliative stage, he said receiving BT had helped “a little bit” to relieve the breathlessness he experienced on exertion. However, by the time of our interviews when Jim was in a late palliative phase, the beneficial effect on his breathlessness had diminished almost completely. Equally, they did not relieve his fatigue as he became easily tired even after the administration of blood which led him to be relatively inactive at home.

It doesn’t help so much, physically
as it did before
but mentally, you think a bit quicker
which is quite good.

Helen, Bill and Harold who were all in a terminal palliative stage of disease did not experience any significant beneficial effects. Although Harold (terminal), in our first two interviews together did suggest that he “sometimes” felt “slightly better”.

Helen (terminal phase): Helen, did not think of blood as a sustenance. She explained that she held no hope that receiving a blood transfusion would
provide her with any beneficial symptomatic relief. Her optimism had been dashed because she had received blood on several occasions but only experienced benefit once. On this isolated occasion she had felt “so well”, “not quite so tired” and “more alert” the day after receiving a blood transfusion. Elaborating on her story Helen stressed that she had “more energy” and felt more-lively, she felt “good”. She remarked that she couldn’t believe what was happening highlighting that she had thought “if this is what it’s going to do this is wonderful to what I’d been feeling”. The symptomatic relief she experienced on this one occasion, however, had been short lived. She had hoped that this could happen again but had not felt any beneficial effects with subsequent BT.

One transfusion I had
made me feel well
I had more energy
I felt more lively
I felt good

I thought
if this is what it’s going to do
this is wonderful
then the other transfusions I’ve had
I haven’t felt much different

Helen was unable to carry out many activities of daily living due to extreme fatigue and breathlessness. Even cleaning her teeth seemed a mammoth task. Helen brought the idea of hope into the two interviews we undertook together. Helen maintained hope that BT would help her to feel a bit more energetic and not so sleepy even though they had only helped on one occasion.

Hopefully I’ll feel more energetic
and not so sleepy
it’s horrible not having any energy
you can’t explain it to anybody
Everything just seems an effort
even to clean your teeth
you think oh I’ve got to do that
even to do that I get so breathless

So, we don’t do a lot
I get up and have a bath every morning
and that quite tires me out
and I make the bed, usually
sometimes I can’t do that anymore

I don’t Hoover anymore which I used to
I mean I can wash up and wipe up
and I can do vegetables
but I am so tired after it.

Bill’s story was like that of Helen. Following his first blood transfusion he had found the beneficial effect unbelievable. Bill described the effect as a “super drug” that had given him a “big uplift”. He told a story to highlight why he felt this way. Essentially when he had arrived on the HDU he had been unable to walk, however following his blood transfusion he had walked out of the unit. He believed this transformation to be so “incredible” that he “felt like shouting out what a difference it made”. Seemingly, the blood he received on this occasion gave him energy to walk and helped with his breathlessness. Subsequent BT had not helped with his overwhelming symptoms of fatigue which made it impossible to do any physical activity.

I couldn’t believe my first blood transfusion
it was like a drug
the big uplift, unbelievable
I came in and I couldn’t walk
the nurse got me a wheelchair
and when I’d had my blood transfusion
what a difference it made
I walked out
it was incredible

Since then I don’t do nothing
I just sit in the chair or on the settee
all day long watching the television
I feel ill, I lack energy, I feel tired
I don’t seem to have no strength
I get very out of breath.

Two weeks later during our second and final interview, Bill told me he had not wanted to attend the HDU for his blood transfusion that day as he had felt so ill. Crying frequently as we talked, Bill brought up the subject of his low mood telling me he felt really “low”. He had to “force” himself to come to the HDU, “felt compelled to come”, because he hoped that receiving blood would make him “feel a hundred percent better”. Bill had recently been referred to a Macmillan nurse. He had met up with her twice, but he felt she had not been able to help him in any way. He preferred he said to talk to the doctors and nurses on the HDU as he knew them better. Perhaps, if he had met one of the Macmillan nurses earlier in his disease trajectory he may have found it easier to communicate with her.

I didn’t feel so good today
and I didn’t feel so good yesterday
or the day before that
and I thought well I’ve got to go up there
force myself to come up here
because I’ve been feeling a bit low

I seem to get low in mood
little things can switch it on or off
some days you’re just lower like
and I know I'm coming in here
and hopefully it's going to make me feel better
just got to do it.

4.2.1.3 Plotline - An up and down everyday blood transfusion life
Kenneth, Ernest and Zavier explained how the good effect they experienced following BT was transient which led them to experience an ‘an up and down life’. They would reach an up and feel better, not immediately post transfusion, but two to three days later. Ernest who was receiving BT every two weeks would remain in this up state, feeling normal, it appeared, for four to five days. Kenneth and Zavier who were receiving BT every three weeks stated they would feel better for approximately fourteen to fifteen days. Then their symptoms of anaemia would return, and they would feel down physically and mentally until they received their next transfusion. It was during this ‘down’ time that they needed to come to the hospital for their blood tests and to receive their BT.

Ernest (early phase): Ernest articulated his feelings about the up and down effect particularly well. He described how after each transfusion, which he received every two weeks, he would start to feel good two to three days post BT. When this happened, he did not think of himself as being ill, rather he felt normal. He would feel the beneficial effects for four to five days before he would start to slowly decline and feel sluggish, tired and breathless again. His concentration would be affected, and he would forget to do things, which he attributed to being too tired to remember things. Ernest said that this up and down effect was repeated time and time again. He reported that during the time he felt better, he had a clear week at home with no hospital commitments, however on the second week post blood transfusion when he was “on the slippery slope going down slowly”, he was “expected” to attend the hospital twice.

I get an up and down situation
after the blood transfusion
you get a good boost
not at the time
two to three days later
and I feel good for about four or five days

And then the whole thing starts to reverse
to go downhill
to making me feel tired and breathless
to the stage when you don’t want to do anything
listless in fact
and that sort of repeats itself
time and time again

When my blood levels are quite high
I don’t even know that I’m ill
I keep my chin-up
I try to be normal

If I drop below eighties I feel weary and tired
you sit in the armchair more
and become more of a vegetable
you are more of a hindrance than a help
to the household

My concentration tends to go as well
and I can’t think clearly
it’s not that I am forgetting to do things
it's just I’m too tired
to remind myself that I should do it

When I’m on the slippery slope going down
I am expected to come
and get blood tests on Tuesday
and blood transfusion on Wednesday.
4.3 Section 1: Social dimension of experience

4.3.1 Storyline two: Everyday blood transfusion life hangs in the hands of others

This storyline which elucidates the social dimension of experience responds to objective 2: To explore healthcare professional’s role on participants’ experience of BT. That is, how cultural, institutional and social relationships with healthcare personnel influenced participants’ experience of receiving BT. This storyline was built from the plotlines: life in the hands of physicians; life in the hands of nurses; and life in the hands of ward receptionists. These plotlines illuminate how the lives of all those who took part in this study hung in the hands of their consultant haematologists, the nursing staff and the ward receptionists.

4.3.1.1 Plotline - Life in the hands of physicians

The lives of all those who took part in this study lay in the hands of their haematologists. Institutionally, these physicians were responsible for authorising their life blood. They determined how often BT should be administered and the number of units to be transfused. As highlighted below, this decision it appeared was often influenced by the participants’ Hb level alone, rather than alongside the symptoms they exhibited.

Kenneth (early phase): Kenneth, for instance, spoke about the haematology consultants abiding by a “magic number” of 80. This magic number referred to the minimum threshold level which the haematologist strove to keep his Hb. Kenneth told of an occasion when he had met one of the haematologists in the corridor. The physician had told Kenneth that his Hb had dropped down to 75g/dL and asked him when he was coming in to the HDU, as he needed another transfusion to top him up. Although Kenneth did not feel that his body needed another blood transfusion, he complied with the physician’s decision and attended the HDU to receive his transfusion.

The doctors, they have this magic number
if my haemoglobin falls below 80
I have a blood transfusion
regardless of how I feel
I can be feeling ok
my body doesn’t feel it needs another blood transfusion
but no, the doc says you have to come in

I saw a doctor and he said
when are you coming in for a top up
because your haemoglobin dropped to 75
I said Thursday
and he said good because you need it
so, he felt I needed it
but I didn’t feel any side effects of it going down that low.

**Lily (late):** Lily’s narrative also suggested that physicians authorised BT according to numbers, that is Hb level alone. Describing an event during one of our interviews together, Lily reported that the doctor had not authorised a blood transfusion when her Hb level was “101”. Lily believed that she had really needed the blood transfusion when her Hb level had been, at what she described as, “borderline” level. When she saw the doctor two weeks later her Hb had dropped to 91. Lily said she always knew when her Hb level fell below 100 because she would experience significant symptoms of anaemia. Lily explained that between her two clinic visits to see the doctor, everything had come to a “standstill”. Lily had been dismayed that the doctors had let her Hb level fall to 91, reiterating many times her belief that the doctor should “prescribe” blood when the level is “borderline, so as to help support patients”.

Despite her feeling that they were wrong in not authorising a blood transfusion, Lily did not feel she could query their decision stating “they’re the doctors and I’m the patient, no, no, I leave it to them”. This suggested that she believed that she should leave the decisions regarding her treatment to the physicians. She passively put her life in their hands with the understanding that they knew best what was right for her.
I really needed the blood last month
my blood was 101 and they said
it was a borderline case
so they didn’t give it

And it ended up I was 91
so, the last week has been horrible
I haven’t been able to walk at all
I was like a wet weekend

When they say it’s borderline
they ought to err on the good side
they should go on the good side to help you
not leave you which was done this time

I knew it was going wrong
but they have their reasons
there again, there we go
they’re the doctors and I’m the patient
No, no, I leave it to them.

**Helen (terminal):** Helen also told a story concerning the haematologists’ authorising practice. She highlighted, unprompted, that there had been variation in the authorising of BT between a haematology registrar and consultant haematologist. According to Helen, the registrar “prescribed” blood according to her haemoglobin level whilst the consultant haematologist also ascertained and accounted for how she was feeling physically. Helen was unhappy that a blood transfusion had not been authorised by the registrar when her Hb had been 90. Although she believed she should have received blood to help with her physical symptoms of anaemia, she had not challenged the doctor about his decision not to transfuse. Instead, she requested to see a consultant at her next visit as she believed they would authorise her BT according to her symptoms.
We've seen the registrar for two weeks
we weren't very happy.
and yesterday we saw the consultant
and I was much happier

Last week the blood was a little bit higher
but I was still not feeling quite right
but the registrar said no you don’t want a BT
it's like the consultant said
some people cope on 9 and some people don’t
perhaps I’m one that doesn’t cope on it

The registrar did seem to go on figures
more than feelings
now when we told the consultant yesterday how I felt
he said I think you need a transfusion.

The haematology physicians are also responsible for monitoring blood ferritin
(iron) levels, as patients who have received “ten to twenty” units of blood will
generally have a raised level (Goa, et al., 2014). To help reduce the iron
overload, a chelating agent, that is, either Desferrioxamine or Exjade may be
prescribed by the physician. The decision to prescribe a chelating agent is
influenced by the participants’ ferritin level, as excess iron in the blood deposits
in and causes damage to vital body organs, such as the heart, liver
and pancreas. Participants’ tolerance of the two agents is also considered. To learn
of the hardships three participants (Kenneth, Harold and Ernest) experienced
with chelating agents was enlightening and distressing.

Kenneth (early): Kenneth brought to my attention without any prompting
during both our first and second interview the difficulties he had experienced
with chelating agents. The chelating agent he had initially been started on was
subcutaneous Desferrioxamine. He reported that the drug was delivered by
“this horrible pump you wear round your neck of a night and then you have to
put it into your own stomach”. Finishing this story with the comment “and that
really upset my kidneys, really upset my kidneys and the doctor picked that up". Kenneth stressed several times that he had to inject himself. He appeared to abhor the process of self-administering this drug subcutaneously into his abdomen. He was also concerned about the negative clinical effect it had on his kidneys. Despite these challenges, Kenneth continued to self-administer this drug until he was told by a haematologist to stop.

The next time I saw the doctor
he said we've got to concentrate on your iron
we've got to get it down it’s higher than it should be

First, they gave me this horrible pump
you wear round your neck at night
and you have to put the needle into your own stomach

You have to do it yourself
and that really upset my kidneys
and doctor said stop taking that stuff.

Due to the problems he experienced with Desferrioxamine his treatment was changed to Exjade an oral chelating agent. Initially he was prescribed two tablets to take at night and two in the morning. Kenneth describes this drug as a “white, chalky, horse table”. He highlights that when the haematologist tried to increase the dosage of Exjade as a means of reducing his iron level “a bit quicker” this had made him feel unwell. His stomach had become congested which caused him some discomfort and he had become “quite down in the dumps because of it”. Kenneth had at this point taken the matter in his own hands. He told the doctor that he would not increase the dosage because of the problems he experienced. The Haematologist, he said, had been “very blasé about it” and advised him that it was okay to keep to his original dosage. He had also said “simply stop taking it for a couple of days” if any problems were experienced. Kenneth did not worry about taking this action because the haematologist had informed him that Exjade was secondary to his BT. Simply
stopping it for a few days when it caused him to feel unwell made taking the drug more tolerable for him, his coda was “you learn to live with it”.

Now they’ve got me on Exjade
it’s a horse tablet about that size
its white, its chalky
they tried to increase that to four a day
and that really upset my stomach,
so, we knocked that on the head

Well I knocked it on the head
I said I’m not doing this because it’s upset my stomach
I had a terrible time last weekend
I was down in the dumps
with stomach problems due to the Exjade

I said I’m going back to two a day
and that seems to be doing what it needs to do
but sometimes I knock it on the head
for a couple of days

It’s what the doctor told me to do last time
just don’t take it because it’s a secondary thing
the blood transfusion is more important
Again, you learn to live with it.

**Ernest (early):** Ernest also went to great lengths via several long stories to explain the concerns he encountered with chelating agents. This topic he brought early into our conversations, unprompted. Ernest’s serum ferritin level was extremely high due to the large amount of blood he had received. To try and reduce it he had tried both Desferrioxamine and Exjade. Ernest described the administration process of Desferrioxamine in huge detail, before going on to say he had developed a problem. He reported that despite cleaning himself
with sterile pads before putting the needle into his abdomen he had developed a very large ulcer at the injection site. This had proved to be “very difficult to clear up”. Ernest showed me the site where the ulcer persisted. He stressed emphatically that he had cleaned his skin prior to injecting himself, seemingly anxious for me to know that it was not his fault, afraid that I may assume that the ulcer had developed due to poor hygiene. The Desferrioxamine had been discontinued.

Exjade was subsequently tried. Ernest had initially started on two tablets, but the dose had been increased to five, which meant it was necessary to split the dosage into two glasses of water to make a drink that was a “lot looser type”, and thus more palatable. Ernest reported that while on an inpatient ward the previous year, a nurse had dissolved all five tablets in one glass of water and had presented him with “a great big thick porridgy lump”. Ernest had explained to the nurse that he always dissolved them in two glasses of water but apparently the nurse had refused to do this and told him, “tablets you take in one go and not separate goes”. Ernest had asked to speak to the consultant haematologist. The nurse had telephoned the doctor who had told her to discontinue the drug.

Ernest was concerned that he had not received any chelating agent for over a year. Labouring the point, on several occasions during all three interviews he quite unprompted told me of his concerns. He was aware that his current ferritin level was significantly raised and that it was getting higher with each unit of blood he received. He was afraid because a haematologist had informed him, “with too much iron in my system other parts of my body functions will start to shut down”. Ernest did not know at what point this would happen. Ernest poignantly labelled this concern as his “catch 22” situation. He did not, however, question the haematologists about it. He trusted their decision to cease treatment believing that it was because Exjade had been ineffective.

**Harold (terminal):** The subject of chelating agents also appeared to be a pressing concern for Harold, who similarly appeared to find the administration
of these two drugs quite challenging, indicated by the fact that he peppered our first two interviews with this topic. For instance, almost immediately into our first interview together, Harold brought the topic of Desferrioxamine unprompted into our conversation. He reported having to wear the administering pump four times a week, each time for approximately ten hours. The pumps which are big and bulky, Harold suggested, were more “intruding” than the BT. Harold was aware that he could infuse overnight whilst he slept, but he worried about the needle coming out as he was a “restless sleeper”.

The concern Harold felt became most apparent during our second interview. He provided a long story to enable me to understand what it was like for him to manage his situation with Desferrioxamine day-by-day. His story detailed challenges and adversities which were articulated so well that it brought a picture to mind. I imagined him; sticking the needle into his emaciated abdomen four mornings each week; the difficulties he encountered with vision and dexterity as he tried to secure the needle in place with Micropore tape and plasters to ensure that the needle stayed in place for the next ten hours; the multiple bruised injection sites on his emaciated abdomen which he said were sore for a few day; his struggles with a tube that was “so long” he said it needed to be wrapped round his neck; the conspicuous lump in his trouser pocket; the bright orange urine that had initially shocked him; and the inconvenience of having to keep 12 sizeable administration pumps filled with Desferrioxamine in his fridge at home. These hardships associated with administration of Desferrioxamine Harold had to endure whilst in the terminal palliative phase of his disease.

The other major treatment I have is to get rid of the excess iron in my system that is done by using a Desferrioxamine pump via a subcutaneous needle it won’t ever get down to normal levels but it will keep it under control

I put that together myself and stick it in my stomach
I have experimented with ways to put the needle in it’s subcutaneous so, you put it in there I try and pick different spots and then I use a couple of lengths of micropore round the plaster that surrounds the needle and that helps keep it in place it’s maybe sore for a day or so and then its fine

These pumps are much more obtrusive let’s say than transfusion but I have worked out ways of handling it and sorting out somewhere to put the pump tucking it away where it isn’t a nuisance or anything

The pump goes in my left trouser pocket the tube to the needle goes around my neck as it’s a bit longer than its intended to be the spare length of tube I tuck inside my shirt where it might not get tugged by anything

I wear the pump for about ten hours four days a week I know some people wear it overnight but I am a restless sleeper so, I think it’s safer to do it during the day.

Harold had originally been prescribed Exjade but he had not liked taking it as the tablets had caused him to experience nausea and vomiting. This had adversely affected his appetite which, he said, had resulted in significant weight loss. Exjade had also been unsuccessful in reducing his ferritin level. Due to the problems he endured, and the lack of efficacy associated with Exjade, a haematologist had changed to Desferrioxamine.
During our final interview together, Harold had been extremely unwell and had been brought to the Community Day Unit by ambulance. He had been vomiting on the way in. On arrival the nurse had rung the haematologist for advice. She had been told not to give the blood and to discontinue the Desferrioxamine. I was with Harold when he received this news. Although distressed not to receive his blood transfusion, he was overwhelmingly “relieved” that the Desferrioxamine had been stopped, sharing what a “nuisance” it had been for him to administer “four pumps a week”. Harold died 30 days later.

From a social perspective, all participants in this study were dependent on haematologists to involve the palliative care team (PCT) as they were all at “the end-of-life” stage with twelve months or less to live (GMC, 2010). The findings from this study indicate that most of the participants were not referred to the PCT. Only two participants, Helen and Bill, met a Macmillan nurse and this only shortly before their deaths.

4.3.1.2 Plotline - Life in the hands of the nurses

All the participants in this study praised the nurses who cared from them. They spoke about “how wonderful” they all were, highlighting that “nothing was too much trouble” for them. Five of the eight participants, however, spoke about the speed their BT were administered. Helen and Harold expressed concern about the rate the nurses had administered their BT, while Kenneth, Lily and Ernest simply suggested that their BT had, sometimes, been put through a bit quicker than usual. Lily qualified this by suggesting it happened on the occasions she received three units of blood. As a senior nurse responsible for clinical nursing practice, this participant experience concerned me. Particularly as I learnt about variation in administration rates over two sites and a suggestion that nurses were putting the blood through quicker to complete the BT within their working day and the opening hours of the HDU.

Nurses, when administering BT, do so according to medical authorisation, but they are allowed by protocol some slight discretion over the rate at which they administer the blood. Increasing the rate of BT is not without risks. The risk of
administering blood too quickly, especially in older people, is developing Transfusion Associated Circulatory Overload (TACO), which can be fatal.

**Ernest (early):** Ernest thought it was a good thing for him when the nurses put the blood through quicker as it meant he was not going to get home late. He also thought it was good for the nurses, as it meant that they would not be delayed at the end of their working day. They would finish between four and five which was, he stated, their contracted time for finishing work.

It’s never been that quick before
but it’s good
because I know that I’m not going to be late
finishing at the end of the day

And It’s good from the staff point of view
because they start going home at four, or five
and by then I am going to be done
so, they don’t have to worry about me, good for them.

**Harold (terminal phase):** Harold told of the variation in the blood transfusion process between the main hospital and his local community hospital where he had received BT for the last three months. He stated that he did not think about the blood that was being transfused into him apart from to ask the nurses how big the bag of blood was. He was interested in the number of millilitres (mls) of blood in the bag as this determined the rate at which his BT were administered on the Day Unit of his local community hospital. He explained that the community hospital had a different procedure for administering BT than that followed on the HDU. In the community hospital the nurses would administer the blood over two hours. That is, if the bag of blood held 340mls the rate set on the pump would be 170mls per hour and if it was 360mls the rate was set for 180mls per hour.

In the main hospital, Harold explained, the protocol was to administer the blood between two to three hours, as medically authorised on the pre-printed blood
prescription charts. This allowed the nurses discretion to alter the rate set on the pump to allow the blood to be given during this time. Harold said that the nurses on the HDU always set a pump rate of 140mls per hour for him. This meant that if it was a 340mls bag of blood it would take approximately 2 hours and 25 minutes to transfuse. Harold preferred the longer infusion time, highlighting that it didn’t matter if it took longer as what was important was that he knew he could cope with blood being administered at this rate. He had received blood administered at 140mls/hour for many years and was concerned he could encounter problems when the rate was set higher than this. He did not mention his concerns to the nurses as he believed that each place had a different transfusion protocol and he would have to accept that.

I only ask how big the bag is and, therefore, how long it’s going to take here they set it to infuse over two hours so, if it is 340 millilitres that would mean a flow rate of 170

I don’t think that’s really a good idea even if it takes longer than two hours I would rather see the flow rate at 140 which I know I can tolerate rather than 170 which might cause problems

In the hospital they did it differently they did it by flow rate they would set it to 140 if it was a small bag it would take less than two hours and if it was a big bag it would take a bit more

But they concentrated on flow rate rather than the length of time
and I think honestly that’s better
but you know each place has its protocol.

Helen (terminal): Helen’s story about rate of infusion of BT was the most disconcerting. Helen held an ongoing belief that there was a risk that she would die from life-threatening heart problems brought on by the administration of BT and explained how this fear had arisen. For her first ever blood transfusion, Helen had been prescribed three units of blood. Each unit had been administered over two hours at the discretion of the nurses on the HDU. She had been discharged home feeling well. However, at five o’clock in the morning, Helen had experienced significant tachycardia and feelings of impending doom. An ambulance had been called and she had been rushed to the Accident and Emergency department. The doctors at the hospital, she stated, were not convinced that her heart rate of over 300 beats per minute had been related to the administration of blood. She had been prescribed additional heart medication.

Helen, however, was convinced that this episode had been caused by the blood being administered “a bit too quick”. She was certain of this because “it was the very next morning and ‘that’s why it’s slower now’. She stressed she had never experienced her heart “going out of rhythm before”, not following chemotherapy treatment or having a heart valve replacement. Since this first occasion, Helen had suffered recurrences of these “heart turns” following her BT. This was even though during subsequent BT the rate had been slowed down to administer the blood over three hours instead of two. These disturbing experiences clouded Helen’s perceptions of BT and caused her to worry each time she received blood that “it’s going to happen again”.

The first time I had a blood transfusion
it was three units of blood over two hours each
and the very next morning at 5 o’clock
my heart went all out of rhythm
and I was rushed in here
it was going up to 300 beats per minute.
I thought I was dying

They can’t say it was definitely the blood transfusion
but I feel it was
because it was the very next morning
and all the chemo I’ve had
I never had any problems
the heart replacement valve in 1999
and I have never had any problems with that
until that blood transfusion

We think it might have been a bit too quick
that’s why it’s slower now
now it’s two units and roughly over six hours.
but I’ve had several of those turns in the hospital since
so, each time I have blood now I worry
I’m worried now that it’s going to happen again
but they have got me on extra heart pills now.

4.3.1.3 Plotline - Life in the hands of the ward receptionists
The HDU ward receptionists were responsible for booking all the blood transfusion appointments. Generally, patients would come back on the same day, two or three weeks later. Kenneth, Lily, Ernest and Zavier reported that the day on which they received their BT had been changed on several occasions. Kenneth reported that this was not a good thing for him and his wife, as he put all their appointments in his diary, and having to change his day caused them much inconvenience. Ernest also explained why it made him unhappy when this happened. He said that having the same day was important as it allowed him to plan and organise his lifestyle around this day. However, the day he received his BT had been changed on many occasions “to fit with the demands on the unit”. When this happened, he felt that it was “a bit of a push around” where “ad-lib” changes were made. He stressed that patients were not given a choice regarding the day, the day was chosen by the receptionists who were governed by the bed spaces available on the unit.
Ernest made a valid point about the change in day that was important from a clinical perspective. He pointed out that even if his blood transfusion was delayed by just “a couple of days”; the tiredness and shortness of breath he experienced were exacerbated. This in turn caused him to experience more difficulties with his mobility and self-care activities while at home; and it affected his everyday life.

4.4 Summary of research objective 1 and 2

4.4.1 Research objective 1

First. Participants’ felt that BT were essential for life, they had no choice as there was no other therapy available. This belief was influenced by communication with physicians.

Second. Participants’ adjusted their everyday lives to accommodate the administration of BT.

Third. Some participants became cognisant that their disease was deteriorating when their need for BT increased; others did not.

Fourth. Participants’ expectations in terms of relief of anaemia-related symptoms were variable. Some expected beneficial effect, either physical in terms of less fatigue, or psychologically to think a bit quicker. However, beneficial effects were short lived which led to up and down lives. This meant many days when participants were down. During their down period they were required to come to the hospital for blood tests and to receive their BT.

4.4.2 Research objective 2:

1. Participants placed their lives in the hands of the haematology doctors, nurses and receptionists which caused hardships and anxiety.

2. The authorisation of BT by more junior physicians who relied on Hb levels alone rather than taking a holistic approach.

3. The administration of chelating agents caused hardships.
4. The rate at which BT were administered to suit hours of HDU opening and the variation in rate between the acute, secondary care hospital and the community hospital.

5. The disruption to diary planning when the dates of BT were changed to fit with demands of the HDU.

6. The inadequate communication between participants and healthcare professionals which led to misunderstandings about BT.

7. The poor communication about chelating agents in that participants had not been warned of the bright orange urine which had caused shock, and reasons for discontinuation had not been discussed with Ernest, and he was left to worry that iron would accumulate in his organs and cause them to shut down.

8. The lack of referral to the Palliative Care Team.
4.5 Section 2: Place dimension of experience

Storylines three and four elucidate the ‘place’ dimension of experience and respond to research objective 3: To explore the effect of the place or setting where BT were administered on participants’ experiences of BT. The storylines illuminate how ‘place’, as a dimension of experience, lightens or creates burdens experienced by participants receiving regular BT while in a palliative stage of a HM.

Storyline three reveals how the hospital setting created burdens for participants receiving regular BT, while storyline four sheds light on one participant’s experience of receiving a blood transfusion within a Hospice Day Unit.

4.5.1 Storyline three: Everyday blood transfusion life involves waiting and anxiety

This storyline was developed from three plotlines: waiting in Pathology for blood tests; waiting on the haematology day unit; and anxiety associated with places in the hospital setting. These plotlines demonstrate that most places related to the administration of BT were found to negatively affect the blood transfusion experience. For instance, the primary resonant plotline related to place that all participants voiced was that they spent much of their time queuing or waiting. They queued in the Pathology Department to have their blood tests taken and they queued on the HDU to be cannulated, or between bags of blood. Waiting for long periods in several environments, usually twice a week on a regular basis, when so unwell with a limited life expectancy, caused them much distress. Participants associated waiting with poor quality of service.

4.5.1.1 Plotline - Waiting in Pathology for blood tests

Waiting or queuing in Pathology for one to two hours to have their blood tests taken every two to three weeks was a usual occurrence that most participants complained about. It was a hardship voiced by Kenneth, Ernest, Jim, Lily, Bill and Zavier.
Kenneth (early palliative phase): Kenneth, for instance, believed the frequent, long waiting time he was required to endure in Pathology were both “unacceptable and inconvenient”. He highlights that on one occasion he had to wait two hours “just to have my blood taken”. Kenneth suggested that “waiting” was an example of “poor quality service” that led to dissatisfaction with the care he received. He points out that, as there is no appointment system within the Pathology Department, patients need to know the best time to come to avoid the wait. He stressed that at certain times of the day there may be twenty to thirty people waiting for their blood to be taken. Kenneth stated that he never comes late morning or early afternoon because it is exceptionally busy at these times. Instead, he gets up early to arrive in the Department at seven thirty in the morning. It is a hardship for him having to attend at this early hour, but he feels he has no choice. He has tried to have his blood tests done at his General Practitioner’s surgery as it was more local to his home and he can book a timed appointment, however, on the occasions he has tried the nurses or phlebotomist there had been unsuccessful. Frequent venepuncture and intravenous infusions had made his veins difficult to access. Thus, he had made the decision to always come to the hospital because he believed that the phlebotomists in the hospital had more experience, “they know what they are doing more, they’re doing it full time all day long”.

Ernest (early palliative phase): Ernest, like Kenneth, highlighted that he waits a long time in Pathology. He pointed out that he waits between an hour, to an hour-and-a-half for his blood tests, in an uncomfortable chair, in an uncomfortable place. Ernest found the Pathology setting to be oppressive, “hair raising, and absolutely manic at times”. This stifling, distressing situation he found was exacerbated by his poor health. He suggested that the service should be more streamlined to avoid the long wait he, of late, had no choice but to endure twice a week, every two weeks.

It’s a terribly hot situation in there
it’s even a hot place on a cold day
there’s no air
which is an uncomfortable situation
when you are not feeling too good

It’s hair raising
absolutely manic at times
you can wait
I have waited about an hour
an hour and a half

It’s a long time to be sat
in a not very comfortable chair
it’s an area somebody could look at
they need to streamline it more.

Lily (late palliative phase): Lily who was the oldest participant at 86, was in the late palliative stage of her disease. On the day Lily attended for her blood tests she would also see the haematologist which meant she waited at least three-and-a-half hours at different places around the hospital every three weeks. She would arrive at eleven o’clock and wait an hour in Pathology to have her blood taken. She would then go to the café and wait there until two fifteen. From there she would go to the haematology clinic for her two thirty appointment with a haematologist. This physician would review her medical condition and blood test results and authorise a transfusion for later that week. Lily stated that on the days she attended the hospital, she had to get up earlier than on other days of the week to get herself ready. She did not grumble about waiting, “more or less two hours to kill” between her blood test and being reviewed by the doctors; rather she explained she was “a patient sort of person”. She argued, “you can’t expect to go in and have it done and come out again, you know”. Perhaps what made Lily believe that it was okay to wait was her overwhelming conviction that “it is important to be grateful for the NHS care one received”, and her mantra that it didn’t matter if she enjoyed it or not, as the treatment was “free”.

I come up on a Tuesday
I get up here about eleven
to have the blood match done
it's a long wait
a long wait of an hour
but you can't expect to go in
have it done
and come straight out again

Then I go and have a cup of tea
as my appointment with the doctor is about two-thirty
my daughter always comes with me
to see the doctor on a Tuesday
but there's no sense in her coming up at eleven
because we've got two hours at least to wait
before we see the doctor
and she's got other things to do.

4.5.1.2 Plotline - Waiting on the haematology day unit
Waiting on the HDU was a hardship reported by five of the participants in this study: Zavier, Kenneth, Ernest, Jim and Bill. It revealed aspects of care related to their blood transfusion experience that they believed should be addressed.

Zavier (early palliative phase): Zavier was vehement when he informed me about his problems of waiting on the HDU for his BT. This wait he found to be particularly unnecessary and depressing. Explaining the situation, he reported that it was commonplace for the nurses to ask him to come to the HDU early to receive his BT. This meant he had to wake up earlier than usual to arrive on the HDU by nine o’clock. He emphasised the point by telling of one occasion when he had arrived at nine and had not received his blood transfusion until two o’clock in the afternoon. The delay in starting the transfusion meant he was not finished until late in the evening. As the HDU closed between five thirty and six o’clock this meant he was transferred to the haematology inpatient ward area to complete his transfusion, and discharged home from there at “nine” in the evening.
Zavier said he became upset and aggrieved when he arrived early to be told his blood was not ready. He had a young family which made getting to the hospital by nine in the morning difficult for him and his family. Sometimes, when this situation arose, Zavier would ask the nurses if he could go home. He would then wait at home until the nurses phoned to say his blood was ready. This solution, he said, was preferable to him, it was “better than waiting around” on the HDU. Zavier suggested that the nurses should ring patients to let them know their blood would not be available until later, rather than asking them to come in early, have them wait for long periods of time and then be transferred to the inpatient ward to complete their transfusion.

They've asked me to come early
so, I came at nine o'clock
but the blood was not ready
I had to wait until two o'clock in the afternoon

So, you need to wait
for a long, long, long time
and then finish at nine o'clock in the evening
so, I need to stay over there on the ward

It's a bit depressing
because you need to wake up early
prepare yourself and then
when you get to the unit your blood is not ready

Sometimes I ask the nurses if I can go home
and wait for a while
and come back when my blood is ready

The thing that they need to do
they should tell the patient
that their blood is not ready
so that they are not waiting.
Waiting on the HDU in the morning for a nurse to cannulate them to commence their BT infusions was another problem mentioned by Kenneth, Jim, Ernest, Bill and Zavier. It caused some of them distress because waiting made them feel “unimportant”. Ernest suggested that patients having their chemotherapy treatment were more of a priority for the nurses to deal with. This hardship of waiting, the participants ascribed to the nurses on the HDU being too busy or short staffed.

There has been a couple of occasions when it’s been slow in the morning getting the cannula in to start off with that’s because they are so busy or they are short of staff.

These participants also articulated a complaint about waiting between bags of blood for a “quarter of an hour or so” between each unit.

**Ernest (early palliative phase):** Ernest verbalised his discontent about this issue best. He was upset that once the blood transfusion had been started it was not a continuous process, rather there were breaks during administration. The lack of continuous flow occurred when one unit of blood finished and there was a wait before the nurse commenced the second unit. Ernest found it difficult to understand why the nurses couldn’t keep it flowing properly.

The only thing I can say is when a bag has run out it takes quite a while before they come up with the next bag of blood

It used to be a continuous thing between the units of blood now there are some delays that sort of thing upsets you
You think why don’t they try
and keep it flowing properly
because you need a regular flow
to finish by five o’clock.

Several hardships were associated with delays in waiting on the HDU for nurses to cannulate or between bags of blood. One was that if the participant was receiving three units of blood, this meant that sometimes their transfusion had not finished by six pm. As the HDU closed at this time, this meant that patients would be transferred to the inpatient ward to be cared for by the nursing staff there. This had happened on several occasions to Zavier and Ernest.

It had not worried Zavier to go and sit on the inpatient ward, perhaps because he had been an inpatient there for many months and knew the nursing staff well. Ernest, on the other hand, had been distressed on the occasions this had happened to him, primarily because he had been made to sit in the “foyer” of the ward where everybody could see him. Ernest had felt out of place sitting in the foyer. He described how it had made him feel as if he was not as important to the nursing staff there as the inpatients. This feeling arose because he would sometimes have to sit there with his pump bleeping until the nurses were free to come and attend to him. He believed that the nurses, “rightly”, prioritised the inpatients who were being treated on the ward with chemotherapy as he felt they were more poorly than he was. However, the situation left him feeling as if he was a hindrance to the nurses, “in the way”, “somebody not worth looking at”. During these episodes, it appeared that Ernest, perhaps, lost his feelings of self-worth, dignity and privacy, areas conducive to compassionate nursing care.

It’s happened, in the past
that they were still transfusing at six o’clock
when the ward was locked-up
so, they have walked me down with my pump
to the other end of the main ward
And I used to sit down there
next to the vending machines
so that everybody could see me
sat in the middle of the foyer
and there I sat until the blood transfusion was finished
and that could be anything up to seven thirty

Down there on the ward
the nurses they’ve got their priorities to do
before they can attend to some blood patient sat there
so, consequently if my pump was bleeping for attention
mine was the last on the list to get looked at
that made me feel as if I was in the way
as if I wasn’t anybody worth looking at.

The second hardship associated with waiting for the nurse to cannulate to commence the infusion or between bags of blood was elaborated on by each of these five participants. Each told me, unprompted, that they were required to get up much earlier than they would on normal days of the week. The early morning start and waiting around for the nurses on the HDU exacerbated their “long day” spent on the day unit.

Kenneth for instance arose one hour forty-five minutes earlier on his BT days and Jim, Ernest, Bill and Zavier an hour earlier. They did this because they needed to prepare themselves to come in and allow time for parking to arrive on the HDU between eight-thirty and nine, the time at which they had been asked, by the nurses, to arrive. What appeared to be burdensome for them all was that despite their efforts to arrive by the specified time, they were made to wait until the nurses were ready to cannulate them.

**Ernest** highlights what he believes was the unfairness of the situation:

**Ernest** highlights what he believes was the unfairness of the situation:

On a transfusion day
I always get up at least an hour earlier
six thirty in the morning

to be here for eight thirty

One is requested not to get here before that
as the girls don’t get here until half past eight now
which sometimes feels a bit unfair
as the girls used to be here at eight o’clock

When I do get on the unit
the girls won’t cannulate until nine o’clock
which puts me at least an hour behind
on transfusion of three units of blood

And three units of blood takes
seven sometimes eight hours
So, I feel that’s a bit of a hindrance
in lots of ways.

The need to get up much earlier in the morning was a theme also raised by
the other three participants. Harold, Helen and Lily all reported that they got
up about two hours earlier on the day of their blood transfusion day to arrive
on the HDU early as requested. Kenneth believed the long day would be “more
tolerable” if he was prescribed two units, rather than three as the day would
be much shorter. He could be home early in time for dinner and he could also
rest at home as he became more tired in the afternoons.

**Lily (late palliative phase)** highlighted that it was a long day as her daughter
picked her up at 07.30hrs. In her usual, acquiescent manner, Lily said she can
“put up with it”, as “it’s for my own good”, “the thing that’s going to make you
better”.

**Jim (late):** Jim, however, found the long day on the HDU and the challenges
he endured there almost impossible to bear. He found the long day ‘just sitting
there all day’ on the unit hard to cope with mentally. He stressed that by the
end of the day he had “had enough”. Unprompted, he said that he would have preferred his BT to be administered in his own home rather than on the HDU. On being asked what made him feel this way, Jim explained that he would prefer not to have BT at all, however, as he needed them it would be much more tolerable for him if he was offered the choice to have them at home. Having them at home, he believed, would make an enormous difference to him because he would have his home comforts. It would also be more convenient for his wife, he stated, as it would “save her coming all the way up from the front and that”.

I’d rather not have them but
well if I had them at home
it would be ok
if there was a choice
You could sit and watch your own telly
obviously, you can’t do that here.

Once the idea of home BT had been mentioned by Jim, I brought the topic up in conversations with the other seven participants. Of these only Bill thought that “it might be worth a try”.

4.5.1.3 Plotline - Anxiety associated with places in the hospital setting
So far in this section of the chapter, a description of waiting in specific places has been presented with the aim of highlighting participants’ anxieties and hardships. I would like also to highlight how the HDU environment itself caused anxiety for participants Kenneth, Ernest, Jim, Lily and Zavier.

The HDU is a noisy, busy, crowded environment where up to forty patients a day receive their treatment as a day case patient in one of two large bays. In one of the bays eight chairs are arranged, and in the other bay eight beds. Treatments administered here include BT, platelet transfusions, administration of chemotherapy and administration of antibiotics. Most of the participants in this study found the day spent in this place terribly difficult as multiple hardships were encountered that provoked anxiety.
Kenneth (early palliative phase): Kenneth found being on the HDU challenging commenting “you see it all in that ward”. Being situated in an environment close to patients who were receiving chemotherapy, he found saddening and distressing. He told a story to indicate why he felt this way. Basically, Kenneth’s lack of symptoms meant that he felt well. So, when he witnessed a young mother of a small child receiving chemotherapy to treat her breast cancer, he believed her condition to be graver than his own. It made him feel as if he did not need any treatment when compared to her. This episode, he said, made him “feel a fraud”. Considering that he was in a palliative stage of his illness with a limited life expectancy, this was a misapprehension that gave an indication that he was not aware of his own prognosis.

I come up here
and I see people coming for chemo
and I feel a fraud
I don’t feel as if I need it at all

A lady came who had breast cancer
and they pulled the curtains around
and I felt sorry for her
and thought you are worse off than I am

And after she finished her chemo
her husband came in with their four-year old
that finished me off

You realise how lucky you are
cause you’re not really suffering like they are
you see it all in that ward.

Ernest (early palliative phase): Ernest, like Kenneth, also found being in the same proximity as patients receiving chemotherapy saddening and uncomfortable. The anxiety he felt had come about following an incident on
the HDU. Ernest explained that while talking to a patient who was receiving chemotherapy for a solid tumour he had inadvertently made her cry. As she talked, Ernest came to learn that the young lady had only a short time left to live. Learning that she had only three to four weeks left to live had made him feel very distressed “to the point of tears”. It had shocked him as he had not anticipated what she was going to say to him. This incident, he reported, made him wary of talking to patients who were having chemotherapy. He described this situation as having to be “like a cat on hot bricks”, desperately afraid of saying the wrong thing. Being afraid to talk to others on the HDU was isolating for him and perhaps a difficult predicament for him to be in as he was known on the HDU as a cheerful, social man who liked to talk.

Ernest reiterated several times that it was “an uncomfortable situation to be in when you don’t know how far down the line these people are”, “you know, younger people, who have a shorter time left to live than you have yourself”. Ernest, like Kenneth, was aware that his disease was progressing, but he did not know how long left he had to live. His prognosis had not been discussed with him by the haematology team.

It’s uncomfortable for them
and for me as a blood patient
because I am desperately frightened
of saying something
that might upset them

I was talking to a nice young lady
who had lost her hair
and suddenly she began to weep
I said I’m ever so sorry
if I have offended you

She said you haven’t
I’ve been given notice that
I’ve only got 3 to 4 weeks to live
So, when you are in there
you don’t know how far down the line these people are
who are having treatment
you have to be like a cat on hot bricks
in case you upset someone

That day I felt really upset myself
I was virtually in tears
because I had done something
that might have offended someone.

Jim (late): Compared to Kenneth and Ernest, Jim expressed a different problem associated with other patients on the HDU. He did not want to talk with others around him. Jim described how being around people chatting made him feel extremely anxious and depressed. Unprompted, he expressed a strong desire for quiet, peace and solitude, “to be able to sit and think of nothing in particular”. Patients situated around him talking led him to get “irritable”, he wanted them to “just shut up”. The peace, quiet, solitude, to be alone with his own thoughts, unfortunately this was not something that could be acquired on the noisy, busy HDU.

Some days it’s okay
other days I find it hard
to cope mentally
just sitting there
and other days
well I cope with it

Like, it’s not too bad today
but other times I find it hard
like the lady next door was yack, yack, yack
just gets you down a bit
you just want her to shut up for a minute
I know it’s not her fault, it’s just me
your brain gets tired
you just want to sit there
and think of nothing much.

There were three places within the hospital that were associated with fear, which also caused much anxiety. Zavier was afraid when on the HDU, in Pathology and in the lifts and Helen was afraid when she was on the HDU, and in Pathology.

**Zavier (early phase):** Zavier found the long day, lack of privacy and hustle and bustle on the HDU challenging. This was because of the number of patients who attended the HDU. Zavier explained that during his intensive chemotherapy treatment to treat his acute myeloid leukaemia he had been nursed in isolation. During this period of chemotherapy treatment, he had been warned not to be in the same place as people with coughs and colds due to his neutropenic state, a state that put him at great risk of acquiring an infection that could become overwhelming and fatal. Although Zavier was no longer receiving chemotherapy, he remained neutropenic. This made him feel afraid of being on the HDU, travelling in the lift to the HDU and being in Pathology, all places where there were many people, some of which he feared might be infectious. His wife also feared him getting an infection and had advised him to wear a mask. His fear of infection led Zavier to suggest that patients having chemotherapy should be separated from those whose “system is a bit low”, that is, neutropenic. This, alongside his feelings that he did not have enough privacy on the HDU, appeared to indicate that he thought this place the wrong setting to receive his BT.

The level of privacy
it’s fifty, fifty
if you are having a long day
you want a quiet place to relax
but what can you do
because lots of patients need to come into the hospital
If your system is a bit low
I think it is much better
if you can separate them from
patients having chemotherapy

If I go in the elevator and other areas
where there are many people
my wife told me wear a mask
especially now because I am neutropenic.

**Helen (terminal):** Helen held the same fear of the HDU and Pathology as Zavier. She articulated her fear so well, I came to truly understand her substantial fear of infection associated with these two places. Helen had in the past been treated with intensive chemotherapy for non-Hodgkins lymphoma at a hospital in London. During her treatment there she had been nursed in isolation, in an air filtered room and warned by healthcare professionals that, because she was neutropenic, she was at risk of getting life-threatening infections. On her discharge from the ward she had been advised to stay away from crowded areas and people with obvious infections. Helen had not required any BT during her treatment in London, however she had gone on to develop MDS. As she was terminally ill at this point, she had been referred from London to our Haematology Department to receive supportive blood transfusions. Although our hospital was twenty miles from her home, it was more local and convenient for her.

Like Zavier, being in close contact with other patients on the HDU filled her with apprehension. Helen described a scenario she had experienced concerning a visitor of a patient who was receiving chemotherapy. The man who had “the most awful cough and cold” had been given a mask by the nurses. Appallingly, the man had discarded the mask on the floor next to Helen’s bed as he left the unit. This had caused Helen immense fear and anxiety as she was aware of her neutropenic state.
Helen reported that she did not mind being around patients having their chemotherapy treatment, but she did not want to be around people with infections. Her unprompted comment brought an awareness that she was no longer eligible to receive this active treatment for her disease. It brought into consideration that, perhaps, it was not compassionate to nurse her in the same environment as people who were receiving curative therapies and who maintained hope of cure.

When I was an inpatient in the hospital
I was in a room on my own
because of infection risk

But when we came for the first blood transfusion
I worried about the environment
we did say about it
but there was no single room for me to go in

They gave me a mask
because the visitor at the next bed
had the most awful cough and cold
and when he went he threw his mask down
next to where we were

Things like that really worry me
I don’t mind being around chemotherapy patients
it’s cold and things that worry us

It really does concern me
because I don’t know
if I’d be able to fight the infection.
4.5.2 Storyline Four - More individualised care associated with the hospice day unit and everyday blood transfusion life

This storyline also elucidates the place dimension of experience and responds to research objective 3: To explore the effect of the place or setting where the blood transfusions were administered on participants’ experiences of BT. The storyline sheds light on one participant’s experience of receiving a blood transfusion in a hospice day unit. It was developed from the plotlines: more individualised care; hospice day unit perceived as a safer place to receive blood transfusions; hospice day unit perceived as a more tranquil place. These aspects associated with the hospice day unit setting Helen brought to light in her stories.

Most patients with a HM will die in the hospital setting (Cheng, et al., 2015; Howell, et al., 2013; McCaughan, et al., 2017; National Cancer Intelligence Network, 2011). Sadly, they do not die in a hospice or their own homes which may be their preference. Many reasons are given by healthcare professionals to explain this situation. For example, it is frequently purported that these patients, due to the nature of their disease, require intensive therapies including BT, intravenous antibiotics and platelets until the last weeks of their lives. Without these treatments they may succumb to unmanageable and frightening situations at home, situations their families or home-care health professionals may have difficulty in dealing with (McGrath, 2014; McGrath & Howlena, 2007). A further reason why haematology patients die in the hospital, it is suggested, is that they are not referred to the hospice or palliative care team by their haematologist (Howell, et al., 2013; McCaughan, et al., 2017).

A hospice day unit service was established after this study began to provide a blood transfusion and phlebotomy service to patients with a palliative haematological or oncological disease. The hospice is within the hospital grounds and is housed in a glass conservatory overlooking gardens on each side. Palliative medical and nursing care is on hand. Generally, only one or two oncology patients are in the day unit of the hospice, a place where chemotherapy is not administered.
Only one participant, Helen, received a blood transfusion in our hospice day unit. Being aware of Helen’s fears associated with the HDU and her terminal diagnosis, I asked her during our first interview together if she would like to try the day hospice. Helen agreed to have her next blood transfusion there. My next interview with her, therefore, took place on the hospice day unit during her final blood transfusion. The familiarity with both the HDU and the hospice day unit environment enabled Helen to compare and report her experiences of receiving BT in these two places.

4.5.2.1 Plotline - More individualised care

Helen attributed many positive aspects to both places. For instance, she praised the physicians and nurses in both areas. She pointed out, however, that the nurses based in the HDU were far more rushed due to the number of patients they “had to cope with”, which left them with little time to talk. Whereas the nurses in the Hospice, Helen reported, had a lot more time to concentrate on her as an individual, and to sit and talk. Helen felt this made a positive difference, as she felt she was getting more individualised nursing care. Her healthcare in the hospice resonated with more compassionate care provision.

They are wonderful over in the hospital
but they are much more rushed
they have such a lot to do
a lot more patients to cope with

Here they concentrate on me
whereas over there
there are other patients
that’s the difference

4.5.2.2 Plotline – Hospice day unit perceived as a safer place to receive blood transfusions

Another aspect Helen mentioned was that she felt safer receiving her blood transfusion on the day unit of the Hospice. She came to this conclusion for two reasons. First of all, on the day she received her blood transfusion in the
hospice there were no other patients, and only her husband was present. This was in complete contrast to her experiences on the HDU. Helen perceived that having no other patients around reduced her risk of infection, stating “it’s the risk factor of infection, it would be a lot less having it done here”. Secondly, she commented that she felt safer having her blood transfused in the Hospice as the rate of transfusion was much slower. In the hospice each unit of blood was transfused over four hours and not three as she had recently experienced on the HDU. Helen reported that she was going to be on the hospice day unit for the whole day as “they are doing it very slowly”. “It’s a bit slower than what it was over there”. Helen didn’t mind the blood transfusion taking a long time as she felt it was safer. However, although she said she felt safer, she remained scared. She reiterated several times that she was still nervous that her heart rhythm might be affected, and she didn’t know how she was “going to feel by the end of it”.

Because of what happens with my heart rhythm 
they are doing it very slowly 
I am going to be here all day. 
two units over four hours each

It’s going to be a long time
I don’t mind
but I don’t know
how I’ll feel by the end of it.

4.5.2.3 Plotline - Hospice day unit perceived as more tranquil place
Making an evaluation between the two places, Helen determined that the hospice environment was “nice, just lovely and peaceful”. When asked which environment she would prefer to receive her BT in the future, Helen initially said she did not mind. However, she then concluded that the hospice day unit would be her preference next time, highlighting “it has been so lovely here today”. Comparing the two places Helen emphasised the tranquillity of the hospice ‘without all the pump buzzers going off’ as in the HDU. She employed a variety of words to describe the hospice environment: lovely, tranquil, calm,
relaxing, peaceful and nice to be in “with the garden and everything”. She wondered how it would look in the summer with “all the flowers and everything”.

I don’t feel good
but it’s nice to be able to sit here
it’s lovely with the garden
it’s so peaceful
it’s so tranquil
instead of hearing all the buzzers going off.

Zavier (early): Understanding Zavier’s fears associated with the hospital I asked him how he would feel about having his BT in the hospice day unit. Initially Zavier said he did not want to receive his BT there, explaining he had been attending the HDU for many months which meant he now felt at home there, “part of the family”, “loved” by the medical and nursing staff. If he went to the hospice to receive BT, he said he would have to familiarise himself with a new environment and the healthcare professionals there. He was loath to do this he said, because of the affection he had been shown on the HDU and inpatient ward.

I want to come here to the hospital
I know everybody here
I know all of them
doctors, nurses and everything

I seem to be part of the family here
it’s like home
I can see people, nurses, doctors, everyone
they look at me and I see their love

Going over there
at the Hospice would be entirely different
I need to meet new people again
the doctors, the place and everything.

The next time I saw Zavier he had changed his mind and decided that he would like to try the hospice for his BT. He reasoned “the place might be nice, there’s a car park” and he would not need to use the lift or other places where there were lots of people while he was neutropenic. An appointment to visit the hospice day unit was made for him. Despite feeling that the hospice might be a good place to receive his BT, Zavier did not visit the hospice and chose to receive all his BT on the HDU.

4.6 Summary of research objective 3
This section has addressed research objective 3: to explore the effect of the place or setting where the blood transfusions were administered on participants’ experiences of BT. A summary of findings follows:

4.6.1 Hospital setting
First, there was a dissatisfaction with healthcare provision in the hospital as most places linked with BT were associated with waiting, anxiety and distress. Long waiting times were experienced frequently in a variety of places throughout the hospital. Waits were equated to poor quality of service. Waiting in Pathology, for instance, was reported by most participants. They queued for one to two hours in an environment that was found to be manic, stifling and distressing. The large number of patients attending Pathology was reported to provoke fear of infection in those who were neutropenic. Participants recognised their GP practice took blood tests, however this was not considered a good option as the healthcare professionals there found it difficult to take blood due to participants’ poor venous access. Waiting on the HDU was found to be “depressing and unnecessary”. It intensified the “long, boring days” which were exacerbated by the need to get up much earlier. Being made to wait to be cannulated for their BT, or between bags of blood, caused hardships for participants because it delayed them going home. It meant that they sometimes had to go to the inpatient facility to complete their BT. Being nursed on the inpatient ward was associated with feelings of being unimportant
and less of a priority to the nurses as they were not receiving active chemotherapy treatment.

**Secondly**, anxiety was associated with HDU for several reasons. It was said to be noisy and busy which proved challenging when solitude and peace was desired. Some participants found being cared for in the same place as younger patients, who were receiving chemotherapy treatment and who had a poor prognosis, upsetting. A participant reported he felt unable to talk to other patients for fear of causing distress which, perhaps, was isolating for him as he was a social person who liked to talk.

**Thirdly**, participants reported that staff on the HDU were too busy or short staffed to talk.

**Fourthly**, participants who were neutropenic experienced fear of infection due to the large numbers of patients in the unit, and which caused Zavier to suggest it was the wrong place for his BT to be administered.

### 4.6.2 Hospice day unit setting

**Firstly**, the hospice day unit was associated with more individualised care, as nurses had more time to spend talking with patients.

**Secondly**, life in the hospice was perceived as more tranquil, more relaxing and peaceful with a garden. Helen also felt safer being nursed in the hospice day unit due to the slower rate of administration of the blood transfusion and the lack of others around her.

**Thirdly**, Zavier declined receiving his BT in the hospice day unit because he felt part of the family, loved by medical and nursing staff on the HDU. The affection proffered made him loath to change, as going to the hospice day unit he associated with having to familiarise to a new environment and different HCP.
4.7 Section three: Temporality dimension of experience

4.7.1 Storyline five: An everyday SAD life during the late to terminal palliative phase of a haematological malignancy

This storyline which elucidates the temporal dimension of experience responds to objective 4: To explore the change in participants’ experiences as disease progressed from an early palliative phase, to a late palliative phase, to the terminal palliative phase.

Looking across the stories of those in the early palliative stage (Kenneth, Ernest and Zavier), to those in the late (Jim and Lily) and those in the terminal palliative phases (Harold, Helen and Bill), allowed an insight into how experiences surrounding BT changed with disease progression. As participants’ haematology malignancy progressed through the palliative stages, everyday blood transfusion life resonated with three plotlines: Somnolence overwhelms daily life; Adversities overpower everyday life, and a Desperation to hang on to life. This led to the acronym SAD. These plotlines which emerged from participants’ stories were not distinct from each other, rather they melded together to provide the building blocks for this storyline.

4.7.1.1 Plotline - Somnolence overwhelms daily life

One of the striking differences between participants in the early palliative stage of disease compared to those in the latter stages related to the profound sleepiness experienced by those with more advanced disease. Overwhelming somnolence was a symptom reported by all five participants who were in the late to terminal palliative stage of their haematological disease: Jim (Late), Lily (Late), Harold (Terminal), Helen (Terminal) and Bill (Terminal).

Jim (late): Jim reported on several occasions that he slept virtually all the time. He told me that he had been surprised to learn that his haemoglobin had fallen to 54g/dL, as he had not been aware of being more breathless. He had felt more tired and weaker limbed, but he had not felt “too bad”. Jim suggested that he hadn’t really noticed the effect of his Hb being so low because he’d
been “sleeping a lot at home” and as such had not been participating in much physical activity.

Even with the transfusions
I still get easily tired
so, I’m not doing much
I sit down
I go to sleep
I wake up
and then I go to sleep.

Excessive day-time sleeping for these participants did not appear to offer the usual restorative benefits that individuals expect from sleep. Participants felt just as tired post sleep as they had before they went to sleep. The administration of BT did not appear to help with this incapacitating condition, a condition which hindered their everyday lives.

In the past, during the early palliative stage of their disease, they had not experienced this overwhelming sleepiness. Indeed Kenneth, Ernest and Zavier who were still in the early phase spoke of being tired and lethargic, but they never spoke of somnolence. In comparison, they talked about striving to be “normal”, “trying to do everything they had done before”, “trying to do the same things as other people do”.

4.7.1.2 Plotline - Adversities overpower everyday life
As participants’ disease deteriorated over time to the late and terminal palliative phase adversities overpowered their everyday lives. Each of the five participants presented overriding burdens, burdens which mostly related to an incapacity to undertake activities of daily living. For example, all expressed an inability to walk even the smallest of distances; none could dress themselves or wash themselves or travel to the hospital independently. These challenges are perhaps consistent with the problems any individual at the end stages of a deteriorating illness could expect. Importantly for this study, however, was that administration of BT did not help. In fact, many of the tribulations
associated with BT identified earlier in the chapter were exacerbated as participants’ disease worsened with time. This happened simply because they needed to come more frequently to receive blood. Rather than every three or four weeks as they had when in an early palliative stage, they were now required to attend every week or two weekly. So, the burdens of, for instance, leaving their beds, homes, families, getting to the hospital, waiting around at the hospital, and being in the hands of others all occurred more frequently which made the impact on them worse. This could be described as uncompassionate healthcare.

**Bill (terminal):** Bill, for example, was leaving his home every week to spend a whole day on the HDU to receive his BT. Getting to the hospital was a mammoth task for him and his wife. Bill was totally dependent on his wife at this stage of his disease. His wife helped him to dress, she drove him to the hospital and then transported him in a wheelchair to the HDU. Attending for BT enforced him to leave his bed and home comforts to suffer these burdens on a weekly basis. Bill admitted to feeling “low in mood” and having to “force” himself to attend for his BT.

**Harold (terminal):** Harold in the past had been a strong, independent man, serving as a senior officer in the armed forces. For most of his life he had been the person people depended on. As Harold’s condition deteriorated to the terminal palliative phase, he reported that he spent his time in bed “almost constantly”. His debilitated, frail, condition made him become totally dependent on his wife and family to support him with all his activities of daily living.

I used to do the cooking
But now I’m feeling very tired and sick
and I’m fairly immobile and frail
So, the wife has to do things for me now.

**Jim (late):** Jim also demonstrated that he had been self-reliant until his disease had deteriorated to a late palliative stage. Jim had been self-employed
throughout most of his life. He prided himself on his independence, his work achievements and his ability to provide for his family. Indeed, his work appeared to be a vitally important aspect of his life demonstrated by the many stories about his employment that he reiterated, unprompted, throughout our meetings. On one occasion Jim relayed the story of his refusal to have a bone marrow transplant and splenectomy several years previously. He declined what could have been potentially life-saving procedures because he had been informed that he may not have been fit enough to work for twelve months post procedures. Being unable to work and having no money to support his family, he said, was an intolerable thought to him. Until this point in his disease, he had asked not to be told anything about his prognosis. He said he chose not to think too deeply about his plight, acknowledging that his manner of dealing with distressing or unpleasant news and managing his illness situation was to “bury his head in the sand”. Sadly, during our third interview Jim asked, “I suppose it’s too late for the spleen to come out now isn’t it”. His everyday life had become so constrained by the overwhelming somnolence, tiredness and weakness he experienced that he was desperate to try any treatment available.

When Jim and I met at our first interview, his grossly enlarged abdomen caused by a massive spleen made walking difficult for him. Jim was, however, still able to walk from the front of the hospital to the HDU, albeit “very slowly”. At this point, he reported that he could walk 50 metres on the flat although he could not manage to walk an incline as he became breathless and felt overwhelming fatigue the next day. He was still able to drive. By our third interview, Jim’s condition had deteriorated so much that he could no longer drive or walk from the car park to the HDU or Pathology Department. He needed his wife to bring him in a wheelchair. Getting the chair out of the car was very difficult for her. The effect on his wife worried him and caused him to tell the haematologists that, as he was attending the hospital three times in one week (twice for blood tests and once for BT) every two weeks, he needed to reduce the frequency of his visits. It was organised that Jim attended only once a week, every two weeks. He first attended Pathology, then he came to the HDU to wait for his blood test results to be reviewed by a haematologist
and have his blood prescribed, then later in the day his blood transfusion was administered. Prior to leaving the unit Jim would make his subsequent appointment at the reception desk. Although much waiting was involved with this one stop service, Jim believed this arrangement to be much better. Like Lily, he used humour to make light of his situation. He joked that as he no longer needed to come so frequently to the hospital it saved him money in the hospital café. Bringing his situation to light made me wonder if this arrangement would be better for all haematology patients in this end-of-life situation.

It’s a bit of a problem now
getting into the hospital
my wife needs to take the wheelchair
out of the car
which is not good for her

So, I’ve changed it round
I get the blood test when I get here
then see the doctor
then have the transfusion
then book the appointment
all in the one day

So, it saves coming three times
in one week
which will be useful
coz it cost me a fortune in Costa.

By the time of our last interviews, all five participants with advanced disease had become different individuals from those whom I had met during our first meetings. They were no longer autonomous individuals, rather dependency on family, friends and healthcare professionals had become the norm. In comparison, participants in the early palliative stage did not suffer with these
burdens. They remained autonomous in their self-care and daily living activities; they felt normal, “able to do the things normal people do”.

4.7.1.3 Plotline - **Desperation to hang on to life**

Harold, Jim, Lily, Helen and Bill who were in the late-terminal palliative phase of their disease illustrated an unquestionable desperation to hang on to their lives through the administration of BT. Despite the challenges they faced every day all remained stoic trying each day to do a little something, retaining hope that BT would keep them alive a little longer.

**Harold (terminal):** Harold, on the day of our final interview, told me that he had been putting off coming into the hospital to receive a blood transfusion as he had been feeling so unwell. However, he had made the decision to come in as he had “thought it would be worth giving it another try”. Harold stated that he didn’t know if the blood transfusion was going to help him, but he did not “feel it would do any harm”. So, despite being in dreadful physical condition, he had asked his wife to call an ambulance to bring him to the hospital to receive his blood transfusion. Harold knew that he would need to spend the whole day on the day unit of his community hospital, however this did not deter him.

The hope of prolonging his life through BT provided him with the emotional resilience, strength and stamina to keep going. Harold was therefore distressed when told by the nurses that they were not going to give him his blood transfusion. He had been so desperate to receive it that he had endured the dreadful ambulance journey to reach the hospital. Harold, in an unaccustomed manner, accepted their decision not to transfuse on that day. He had been too ill to persuade the doctors to give it a try. He was, however, under the illusion that it had been a postponement, to wait and see if he was well enough the following week to receive blood. He did not acknowledge that the doctors might not want him to have BT in the future.

I thought it would be worth trying
to have another one today
I don’t know if it will help
I don’t feel it would do any harm
I honestly don’t know

We’ll see what the doctor advises
The delay, it’s really a one off
see how I am next week.

Jim (late): Jim, for a long time in his usual stoic manner resisted the doctors’ attempts to increase the frequency of his BT from every month to every two weeks. Jim had been trying, he told me, to accustom his body to receiving monthly BT to “get his body used too” a four-weekly regime. It had been important to him as he had planned a twenty-four-day holiday away during which time he would be unable to receive BT. With his disease deterioration and his desperation to stay alive, Jim reluctantly accepted the physicians’ advice to have them every two weeks. He was, however, under the misapprehension that by increasing BT to every two weeks his Hb level might stabilise at an acceptable level sufficient for him to go on his holiday.

The doctor said about
having the blood a bit more often
I said yes, and then we can see how things go
if I do get to the holiday
its twenty-four days
we’ll know how things are panning out by about June
and things might just stay at that level
mighten it?

Bill (terminal): Bill was desperate to hang on to his life, he told me, for the sake of his wife and family. Bill’s wife was his “rock” and regardless of how difficult he found attending the HDU, he somehow found the emotional spirit to force’ himself, to do it on a weekly basis. This frequent attendance, perhaps, deprived him of a more peaceful time with his family at the end of his life.
Helen: Helen likewise clung to life. She travelled forty miles to get to the hospital and back home. She made this journey to receive her BT despite extreme fatigue and feeling so poorly she could not do anything. She could not dress or walk unaided, and her husband helped her with all her activities of daily living. Even though BT were not helping, they allowed her to maintain hope that they would keep her going a little longer for her husband’s sake. Indeed, each of those in the terminal palliative stage stated that they wanted to survive for their spouse.

Section Three has illustrated the effect of temporality on participants’ experience. These findings are summarised below.

4.8 Summary of research objective 4
The findings that addressed objective 4 highlight that as participants’ diseases deteriorated into a late or terminal palliative phase, their everyday lives changed dramatically, and their lives became SAD.

First, they experienced overwhelming somnolence and BT did not help with this symptom.

Second, adversities overwhelmed their lives to such an extent that they were incapable of undertaking activities of daily living, even cleaning their teeth became an effort. As such they became totally dependent on their family and HCP.

Third, their stories of experiences were vitally different to the experiences of those in an early palliative stage of their haematological disease who felt normal following their BT, able to do things normal people do.

Fourth, these participants in the late to terminal palliative stage held a desperation for BT. Regardless of how poorly they felt, how dreadful their physical condition, or how dependent they became, they exhibited a desperation to hang on to their lives at any cost. It appeared their desperation to receive BT revolved around their beliefs that BT were an elixir of life. They
were the life-blood that allowed them to survive and as such all their hope hung in the bag of blood.

**Fifth**, regardless of their dire situation, two participants employed humour to disguise their concerns during our interviews. The stoicism they all exhibited was demonstrable and unmistakeable through the emotional fortitude they exhibited.
Chapter 5: Discussion

5.1 Introduction

This study set out to understand the experiences of palliative patients who received regular blood transfusions in a day unit setting. The key findings from this research study are embedded throughout this discussion chapter and illuminated via five storylines which are interpreted in the context of the academic literature and in relation to compassionate clinical practice. The structure of the chapter links together the research objectives, the storyline findings and the three dimensions of experience, sociality (personal and social), place and temporality, as follows:

First, addressing the personal dimension of experience allowed the first research objective to be met: to explore participants’ expectations and challenges surrounding receiving regular BT in a day unit setting and this is personified by findings in storyline one - everyday blood transfusion life hangs in the bag.

Second, addressing the social dimension of experience allowed the second study objective to be met: to explore healthcare professional’s role on participants’ experience of BT and this is personified by findings in storyline two - everyday blood transfusion life hangs in the hands of others.

Third, addressing the ‘place / setting’ dimension of experience allowed the third study objective to be met: to explore the effect of the place or setting where the blood transfusions were administered on participants’ experiences of BT, and this is personified by findings in storyline three - everyday blood transfusion life involves waiting and anxiety, and storyline four - more individualised care associated with the hospice day unit and everyday blood transfusion life.

Fourth, addressing the temporality dimension of experience allowed study objective four to be met: to explore the change in participants’ experiences as disease progressed from an early palliative phase, to a late palliative phase, to the terminal palliative phase of a haematological malignancy, and this is personified by findings in storyline five - an everyday SAD life during the late to terminal palliative phase of a haematological malignancy.
5.2 Research objective 1: To explore participants’ expectations and challenges around receiving regular blood transfusions in a day unit setting

5.2.1 Storyline one: Everyday blood transfusion life hangs in the bag
This storyline elucidates the personal dimension of participants’ experiences of BT, as such it complied with the first research objective.

5.2.1.1 Plotline - Blood transfusions mean life
This plotline stood as the core theme that illuminated participants’ feelings, understanding and expectations of BT. Participants’ feelings were that BT mattered to them as it kept them alive. “Without them I couldn’t survive”, most participants said. This feeling was the thread which ran through all the participants’ stories. It connected all the other storyline findings and set the scene of everyday blood transfusion life. The centrality of this narrative storyline helps explains why participants put themselves through the burdens they voiced.

It is unknown whether BT allowed the participants who were in a terminal palliative phase to live longer. Goksu et al., (2014, p. 4251) suggest that patients who receive BT when close to death live significantly longer than those who do not (15 days vs 8 days), but other authors report that BT administered at this late stage may be associated with increased mortality (Preston et al., 2012; Woodwark & Dean, 2017). However, it was a eureka moment for me when it became apparent that participants’ primary aim in receiving BT was not to reduce their anaemia-related symptoms of breathlessness and fatigue. They were putting themselves through the hardships which they associated with BT simply to stay alive and to lengthen their lives for as long as possible. Thus, they were willing to spend a whole day in a day unit every two to three weeks to receive this elixir of life because BT maintained their hope of survival.

Hope has been recognised as an important concept in everyday life, and one that underpins the foundation of palliative care principles in terms of providing realistic life aspirations (Herth, 1990, cited in Woods, Beaver, & Luker, 2000,
p. 318). According to Woods and Beaver, ‘hope’ may often be associated with unrealistic ambitions of extending the “quantity” rather than the “quality of life”. In these circumstances patients frequently tolerate the many hardships associated with hospital care, for example, the need to comply with hospital appointments (Woods, Beaver, & Luker, 2000, p.318) and the annoyances associated with the long waits in outpatient clinics (ibid, p. 321).

The findings from this study appear to suggest that physicians upheld participants’ hope of prolonging their lives through the process of therapeutic emplotment (Crossley, 2003; Del Vecchio Good, Munakata, Kobayashi, Mattingly, & Good, 1994, p. 855; Murray, 2008). That is, rather than discuss “death” and “dying” during their clinical encounters, haematologists preserved patients’ hope by focusing in on the benefits of BT, in terms of prolonging their lives, and detailing practical aspects of the procedure. Authorising BT until the week a participant died, perhaps, exemplifies this point. Bill, for example, was in the terminal stage of his disease, in authorising BT weekly the doctors instilled “an emphasis on temporality and on experience for the moment […..] the horizon of the future is deliberately blurred, even as patients may struggle to live into the future” ( Del Vecchio Good, et al., 1994, p. 857). Collaborating with Bill in his “quest” to survive physicians portrayed a “subjunctive world, one in which healing is an open possibility, even if miracles are necessary” (Good & Del Vecchio Good, 1994, p. 839). Receiving BT perhaps encouraged Bill ‘to struggle against his death’ (Crossley, 2003; Del Vecchio Good, et al., 1994, p. 856; Murray, 2008, p.22).

It may be that therapeutic emplotment in Bill’s situation was not an unkind act as healthcare professionals were aiming to maintain his hope of surviving a little longer. However, promoting hope by continuing futile treatment with blood transfusions at this stage of his disease may have added to his suffering as “the creation of an experience of hope…. is often fraught with great anxiety for patients, who seek knowledge of prognosis and certainty of illness course” (Del Vecchio Good et al, 1994, p. 857). Breier-Mackie (2001) presents an eloquent argument concerning the nurse’s role in treatments viewed as futile in end of life situations. She argues that nurses are in a good position to
advocate on behalf of patients in ethical circumstances but highlighted that ultimately the patient must be allowed to decide whether a treatment is futile for them or not (p.514).

In this study all of the participants coveted BT, which is in contrast to the findings of Szende, et al. (2009). These authors found in a study of participants with non-palliative MDS, that some rated blood transfusion dependency as “worse than death” (2009, p. 1-2). By comparison, participants in this study did not feel this way, even though study participants voiced anxieties and hardships, none suggested that the problems they experienced with BT were intolerable.

On the occasions when participants held a different opinion to their haematologist, they still followed their physician’s advice and placed their lives in the hands of their doctor. For instance, when Kenneth believed he had not required a blood transfusion because he was asymptomatic, he would not go against the physician’s advice. When Lily believed she really needed a transfusion and the doctor did not authorise one, she would not argue with the doctor. This was, perhaps, because they believed that the physician knew what was best for them, as in the case of Lily, or perhaps by doing what the doctor suggested Kenneth demonstrated that he was taking responsibility for his own health (Charmaz, 1997).

With knowledge of participants’ feelings about BT, it appears unthinkable to me as a nurse who is committed to providing compassionate care for all patients to imagine discontinuing BT. Even when administration of blood appears futile, when minimal or no beneficial physical effects are experienced, withdrawing this lifeblood support does not feel appropriate or reasonable so long as participants’ faith persists. There is strong support among nurses for this assertion as demonstrated in a survey assessing medical and nursing staff attitudes regarding the administration of BT to terminally ill patients (Leibovitz, et al., 2004). The majority of the 500 healthcare professionals surveyed believed that BT should be administered to terminally ill patients (p. 542). More recently, Hayward, Hiersche and Watson, (2012), also suggested that the
majority of healthcare professionals surveyed, during an on-line questionnaire, did not think that BT should be withheld in palliative circumstances.

However, as will be seen throughout this chapter, the clinical service associated with administration of BT to those in a palliative phase of a haematological disease warrants much consideration. That is, healthcare professionals need to give much thought to: the place blood transfusions are administered, the rate blood is administered, the application of chelating agents, their relationships and communication with patients and involving the palliative care team earlier in the patients’ disease trajectory.

5.2.1.2 Plotline - Blood transfusions as a sustenance for life

Three of the eight participants (Kenneth, Ernest and Zavier) considered BT a sustenance to life as it helped to relieve their symptoms of fatigue. This relief of fatigue enabled them to carry out everyday activities of daily living and engage in outdoor activities. Kenneth, for example, reported that post BT he did not “even know he was ill at all”. However, in the final interview with the other five participants, none thought of BT as a sustenance to life, as following BT they were still unable to participate in normal activities of daily living due to extreme fatigue.

Fatigue is one of the most overwhelming symptoms of anaemia in patients at the end-of-life (Brown, Hurlow, Rahman, Closs, & Bennett, 2010; Orme, Still, Day, & Evans, 2013; Woodwark & Dean, 2017). The varied beneficial response in relieving fatigue in these patients found in this study is comparable to that of other researchers (Orme, Still, Day, Evans, & Perkins, 2013; Woodwark & Dean, 2017; Preston, Hurlow, Brine, & Bennett, 2012). Woodwark and Dean (2017) for instance, found that thirty-nine percent of patients at the dying stage of life found some benefit from BT in relieving the symptoms of anaemia. While a Cochrane Review (Preston, Hurlow, Brine, & Bennett, 2012, p. 7) found that seventy percent of participants with advanced cancer achieved some relief of their fatigue, even though this relief lasted only up to fourteen days. The discrepancy between the findings of these two studies relates perhaps to the palliative phase of the population involved in
their research. That is, Woodwark and Dean studied only participants who were at the dying stage of life while Preston et al. explored all participants who had advanced cancer, that is, those in the early, late and palliative phases (although differentiation into palliative phases in the Cochrane Review is not specified).

Stratifying patients into different palliative phases to explore the effect of BT appears to be a novel approach, as no other studies could be found that have employed this method. Due to the small sample size and narrative methodology it is impossible to categorically point to a definite cause and effect in the findings, however, grouping participants in this manner in this thesis allowed a greater insight into the effect of BT at the end-of-life and allowed for clinical observations to be made. For example, an interesting observation that adds to the knowledge base around this topic is that those participants who stated that they felt normal following BT, were in an early palliative phase of disease, albeit still recognised as at the end-of-their-lives as defined by the General Medical Council (2010). But those participants in the late or terminal palliative stage did not experience any feelings of normality following a blood transfusion as they were unable to participate in everyday activities of living.

5.2.1.3 Plotline - An up and down everyday blood transfusion life
From the stories told it appears that any positive effect, following the administration of BT, was transient and led the participants to experience what might be described as an up and down life in relation to the BT they received. For example, Kenneth, Ernest and Zavier reported that they generally started to feel better between one to three days post blood transfusion, but that this beneficial effect started to diminish quite quickly and appeared to be dependent on the frequency of transfusion. For example, Ernest, who was receiving BT every two weeks, stated that he would feel better for about four to five days but then he would slowly start to decline and feel sluggish, tired and breathless again. Ernest reported that this up and down effect was repeated time and time again. For Kenneth and Zavier, who received their BT every three weeks, the decline in beneficial effect would happen at about day fourteen to fifteen. From the narrative findings, it appeared that Ernest would
feel better or ‘up’ for between four to five days, while Kenneth and Zavier on a three-weekly blood transfusion regime remained feeling up for about fourteen days. These findings are coherent with those noted by Preston et al., (2012), who found that the beneficial effect is felt from “day two and begins to wane from day fourteen” (2012, p. 7). An important finding not previously expressed in the academic literature is that when the effect of BT diminishes these participants spent much time feeling ‘down’, physically, mentally or both.

From participants’ narratives it appears that on the up days, participants could engage in normal activities of daily living and their everyday life felt normal. However, what was striking from participants’ narratives was that those in the late or terminal palliative stages did not report any up days, they only reported down days. On these down days, which was most days for Harold, Jim, Lily, Helen and Bill, their illness took over and they could not function normally. Their activities of daily living ceased, and they sat in the chair or lay in bed most of the day. They were unable to do even the simplest of tasks, anything that required physical strength became too much of an effort. However, on these down days, they were required to come to the hospital for their blood tests and to receive their BT.

The stories participants told, in this study, to describe their up days and down days resonated with the terms “good days” and “bad days”, described by Charmaz (1997, p. 49-53) who used these terms to explain meticulously what it is like to live with a chronic disease, a state all patients in this study found themselves to be in. A good day, according to Charmaz, means that that the effects of illness are minimal, individuals manage to maintain everyday activities and they rarely engage in thoughts of symptoms. On a good day they feel “relatively normal between exacerbations” and are able to be the person they recognise as “self” (Charmaz, 1997, p. 51). A bad day means that their illness takes over their whole lives and they lose sight of who they were, their normal “self” (p. 51). Other researchers too have noted that patients with cancer suffer “up’ and ‘down” days, suggesting the effects of disease and its treatment on everyday life are relentless (Crossley, 2003; Murray, 2008).
5.3 Research objective 1: Summary of key findings

First, the central point in participants’ narratives was their overwhelming expectation that BT would prolong their lives. This expectation, perhaps, was influenced by their discussions with the haematologists who strive to maintain hope during consultations with patients through a process of therapeutic emplotment (Delvecchio-Good et al., 1994, p. 855). While patients retain this expectation, BT should continue to be administered to this population (Leibovitz, et al., 2004; Hayward, Hiersche & Watson, 2012), as part of providing compassionate care.

Secondly, as shown in Table 4 half of the participants in this study died within fourteen days of receiving a blood transfusion. It is unknown if BT contributed to their mortality through increased circulatory overload (Preston, Hurlow, Brine, & Bennett, 2012).

Thirdly, the challenges associated with BT were not considered by participants to be so overwhelming that they considered death to be “a better option” (Szende et al., 2009).

Fourthly, three participants expected a beneficial effect from BT, but they expected this positive effect to be short lived.

Finally, those in the early palliative phase experienced a sense of normality following BT. Those in the late or terminal stages did not experience such sense of normality post BT. The up and down days experienced post BT were consistent with the good days or bad days described by Charmaz (1997).
5.4 Research objective 2: To explore healthcare professional’s role on participants’ experience of BT.

5.4.1 Storyline two: Everyday blood transfusion life hangs in the hands of others

This storyline corresponds with the social dimension of participants’ experiences of BT. As such it complied with the second research objective as it illuminated the effect the healthcare professionals’ role had on participants’ experiences of BT, which in turn was influenced by personal, cultural and institutional aspects. This storyline was developed from plotlines: life in the hands of physicians; life in the hands of the nurses; and life in the hands of ward receptionists.

5.4.1.1 Plotline - Life in the hands of physicians

This theme appeared in all participants’ stories and is, perhaps, an obvious plotline as participants were dependent on physicians to authorise their BT. However, participants’ lives were found to lie in the hands of their physicians in several other ways. One example, revolved around the variation in the physicians’ authorising of BT, which caused confusion and distress for some participants. Some physicians, for example, would prescribe BT to reach a target haemoglobin (Hb) level of 8g/dL, whilst others aimed for a target level of 10g/dL.

According to the literature this variation in target Hb levels is acceptable in patients with haematological malignancies like MDS. For instance, Fenaux, Haase, Sanz, Santini and Buske (2014), on behalf of the European Society for Medical Oncology working group, recommend that blood should be administered to reach a target of “8g/dL, 9g/dL, or 10g/dL” (p. iii64) in patients with MDS. They did, however, add a proviso to suggest that physicians, when authorising BT, should pay attention to patients’ subjective factors, (those who are elderly and those who are unable to carry out any physical activities) and authorise transfusions according to these factors rather than on Hb level alone.

A finding in this study was that there appeared to be a variation in the authorisation of BT between junior and consultant physicians. Two participants
suggested during our interviews that the more junior physicians did not always take account of their subjective factors, that is, how they were feeling physically when the BT was authorised. Rather the junior doctors appeared to authorise to haemoglobin levels alone. This clinical practice of authorising BT according to Hb level alone has been previously noted by Bishop, Faithful, & Allan, (2011) and by Cheng, Sham, Chan, Li, and Au (2015) who analysed the level of medical care received by haematology patients who were dying in a hospice and suggested that; “in daily practice blood products were given empirically, when doctors responded to figures from complete blood picture rather than patients’ individual needs” (Cheng et al., 2015, p. 224).

The discrepancy between junior doctors and their senior consultant haematologists is perhaps understandable due to the lack of experience the more junior physicians have, and the time pressure involved with reviewing numerous patients in the day care setting and the temptation to go on figures alone. However, the apparent lack of holistic assessment which was observed in this study and which is reflected in participants’ narratives needs addressing. Provision of education in relation to the authorisation of BT on an individualised, case by case, clinical assessment basis (Gray, et al., 2016), could be a starting point and could suggest that further examination of junior doctors’ busy working schedules in day units and clinics is indicated.

Two participants said they found the experience concerning variation in the prescribing practice of BT amongst haematology doctors distressing and confusing. An observation made from the study findings was the divergent manner that these two participants, Lily and Helen, chose to address the situation. Lily at 86 years of age chose an acquiescent, passive route allowing the doctors to take a dominant role, while Helen who was much younger chose to be more active in her approach. Lily believed that “the doctors know best”, while Helen knew what was best for her.

Addressing the literature, it appears there could be several reasons for the deference Lily portrayed throughout all her stories, and Helen’s ability to advocate for herself. Lily, perhaps, was more familiar with a society where the
relationship between physician and patient was unlike that today. According to Agarwal and Murinson (2012), in the past it had been believed by patients that doctors alone boasted specialist medical knowledge and experience of treating their illnesses. This understanding made patients obedient to their doctors’ decisions while disregarding their own feelings. In more recent times, and perhaps in those younger like Helen, this situation has changed. Patients are now much more likely to challenge a physician’s decisions and want to take an active role in clinical decisions. Agarwal and Murinson (2012) argue that to ensure patients are allowed to make autonomous decisions about their care, it is vital that healthcare professionals take special care to communicate with their more elderly patients (Agarwal & Murinson, 2012). Allowing all patients to be involved in the decision-making process would help provide compassionate blood transfusion healthcare where patients’ rights are upheld.

The administration of chelating agents was a further aspect that illustrated participants’ lives lay in the hands of their haematology physicians. It is a doctor’s responsibility to prescribe this treatment if they believe it is necessary, and to choose between Desferrioxamine or Exjade as part of treatment. The findings from this study highlight that this decision was influenced by the participants’ diagnosis, their ferritin level and their tolerance to these two agents. Four participants with MDS had been prescribed these therapies, but at the time of this study, one of these participants (Ernest) had ceased chelating treatment entirely due to the difficulties he experienced tolerating either Desferrioxamine or Exjade. Two of the other participants spoke, unprompted, in enormous detail of the hardships they experienced that were associated with the administration of these drugs. For example, Harold, who was in the terminal phase of his disease, explained the challenges he experienced with injecting himself subcutaneously four times a week with Desferrioxamine and infusing the drug for ten hours. He also explained the difficulties he experienced with the storing of twelve large diffuser pumps in his fridge at home. In view of the hardships participants in this study experienced with both Exjade and Desferrioxamine, administration of these drugs in patients with a palliative diagnosis is perhaps debatable.
There is confusing and contentious research evidence in recent literature concerning the use of iron chelation therapy (ICT) in patients with MDS who are at the end of their lives (Mast & Field, 2012; Zeidan, Pullarkat, & Komrokji, 2017). Indeed, according to Killick, (2017, p. 375) “there is little so hotly debated within the MDS community as iron chelation therapy, with two camps being created, the believers and the non-believers”. Gattermann (2008) presents a summary of the recommendations proposed by an international working group of experts which demonstrates differing approaches to ICT in participants in a palliative stage of disease. The Italian group suggests providing ICT if life expectancy is greater than 6 months and the Japanese guidelines, and those of the MDS UK Foundation suggest administration if life expectancy is greater than a year.

Participants were also dependent on the haematologists to refer them to the palliative care team (PCT) as they were all at the end-of-life phase (GMC, 2010). Only two participants, Helen and Bill, met with a Macmillan nurse, and this meeting occurred only weeks before their death. The lack of referral of patients diagnosed with a haematology malignancy to the PCT has been noted by other researchers (Howell, et al., 2011; McCaughan, et al., 2017; McGrath, 2002; McGrath & Holewa, 2007). This lack of referral to the PCT earlier in their disease trajectory meant that these participants may not have had the opportunity to discuss the dying process with a healthcare professional specialised in discussing death. This appeared to be the case with Helen who asked me during our final conversation, in the presence of her husband, “how will it happen, how will I die”, “what will cause me to die?” Helen, who sadly died shortly after this interview it appeared was deprived of the psychological, spiritual, holistic, compassionate care that the PCT can offer.

Participants’ narratives suggest that communication between participants and haematologists about their prognosis was lacking. Although some participants associated the increased frequency of their BT as a sign that the end of their life was approaching, others did not. Jim, for instance, whose stance until our final interview was to “bury my head in the sand”, did not appear to connect the relationship between increasing blood transfusions and his prognosis, as
he had paid the deposit on a holiday scheduled for eight months later. Details of the dying process and what to expect had not been discussed with him by the haematologists. A further example was Helen’s final conversation with me that showed she was aware that she was seriously ill but the subject of her dying had not been raised by any healthcare professional. During our final conversation, Helen had wanted to talk about her forthcoming death. She wanted to know what would cause her to die and what should she and her husband expect to happen. Helen had been referred to a Macmillan nurse, but this was only shortly before her death.

According to McGrath (2002), if patients are referred to the PCT earlier in their disease trajectory this could allow these patients and their families to say goodbye and finalise their affairs in preparation for death. McGrath, (2002) in her study of haematology patients dying in an intensive care setting, suggests that patients were instinctively aware that they were terminally ill but had not been told by physicians that they were dying. McGrath suggested that participants revealed that they needed HCP to specifically communicate the fact that they were dying to help them and their families through the dying process.

5.4.1.2 Plotline - Life in the hands of the nurses
This plotline highlights that the everyday lives of participants were affected by the nurses at the bedside who held the responsibility for administering their BT. The plotline emerged from the stories of five participants who each reported that nurses working on the HDU sometimes increased the rate of their BT. Participants suggested that nurses increased the rate of their BT when they were receiving three units of blood. Increasing the rate of BT can predispose patients to transfusion associated circulatory overload (TACO), a potentially fatal condition that can arise when a large volume of fluid, such as three units of blood, are administered too quickly, although it can happen when just one unit is transfused (Bolton-Maggs, & Cohen, 2013: Gray, et al., 2016). TACO is a condition grossly under-diagnosed and underreported (Alam, Lin, Lima et al, 2013; 2015; Bolton-Maggs, & Cohen, 2013), but remains a serious and frequent complication that occurs following the administration of BT,
despite the restrictive blood transfusion practice advised by NICE (2015) and BSH (2012) (Roubinian, et al., 2018). Recently TACO has been recognised as the most frequent cause of “blood transfusion mortality and major morbidity” (Robinson, et al., 2017, p. 7).

Patients’ lives lay in the hands of nurses because nurses are responsible for administering the blood to patients and monitoring the patient as the transfusion is being administered. Inadequate monitoring of patients, by nurses at the bedside, has been shown to cause avoidable complications of BT (Robinson, et al., 2017). Thus, nurses hold a crucial role in the prevention of TACO by ensuring that a slow rate of infusion is set on the infusion pump and there is close monitoring during the transfusion (Henneman, et al., 2017; Robinson, et al., 2017). These preventative measures are especially important in patients known to have a cardiac dysfunction history, and in the elderly (Robinson, et al., 2017). Nurses can also help prevent TACO by ensuring that patients have a mandatory weight check prior to transfusion (NHS Blood and Transplant, 2016), as it has recently been documented that patients with low body weight are predisposed to this condition (Robinson, et al., 2017).

5.4.1.3 Plotline - Life in the hands of ward receptionists
Half the participants (Kenneth, Lily, Ernest and Zavier) reported that they were given no choice over the days their BT were administered as the day of transfusion was frequently changed by the ward receptionists. One participant reported that the day change was done in an “ad hoc fashion to fit with the requirements of the ward”, another spoke about how he and his wife put his blood transfusion days and associated appointments in their diaries and changing the day caused them distress. Changing the day of their BT, the four participants said, resulted in them feeling frustrated, possibly because the need to change their plans deprived them of the small amount of choice and control they still had left in their lives. Charmaz (1997, p.134) appreciates how the thoughts of people with chronic illness become immersed in “planning, scheduling, and timing”, and how “frustration and anxiety” arise when their plans are thwarted.
Planning their next few weeks allowed the participants to maintain a level of autonomy and some command over their lives (Charmaz, 1997). Taking away participants’ autonomy demonstrates a lack of respect for them as individuals and is not commensurate with compassionate care. Alternatively, their anxiety and frustration may have been caused because the delay in receiving their BT exacerbated their hardships. Ernest reported that if his blood transfusion was delayed by just a few days, this meant that the anaemia-related symptoms he experienced were exacerbated and this made his life at home more difficult.

Considering the short amount of time left to live for all the participants in this study, allowing this delay to happen appears uncompassionate. It does not follow two of the key aims set in the document “Every moment Counts” (2015), which suggests that all HCP should allow people near the end of their lives to maintain as much control as possible in their lives, and that those involved in their care should ‘make a special effort to understand the patients’ life’ (National Council for Palliative Care, 2015). The National Council for Palliative Care shapes healthcare for patients in a palliative condition based on patients’ voices and discovering what matters to them. The council employs as the cornerstone for NHS England’s “Actions for End of Life Care: 2014-16” (NHS England, 2014, p. 4), the following narrative, “You matter because you are you, and you matter to the end of your life” (Dame Cecily Saunders, 1919-2005).

This narrative, first proposed by Dame Cecily Saunders who was a nurse, physician, writer, and founder of the hospice movement, stands as the foundation for the care of all sick people.

5.5 Research objective 2. Summary of key findings
Firstly, participants in this study suggested that junior doctors did not take into consideration how they were feeling physically when they prescribed their BT. Rather, junior physicians prescribed BT according to haemoglobin level alone without considering other factors like the fatigue participants were experiencing or their inability to undertake any activities of daily living. The variation in care between junior doctors and consultant haematologists led
some of the study participants to be dissatisfied with the blood transfusion care they received.

Secondly, in the case of this study, communication between participant and HCP appeared to be poor as participants did not appear to know their prognosis or be involved in decisions about their blood transfusion care.

Thirdly, participants who received chelating agents to reduce the iron level in their blood that had occurred because of the large number of BT they had received, experienced several hardships with both oral and subcutaneous administration. One participant reported that he was relieved when told by the physician that he could stop administering the Desferrioxamine, as injecting himself frequently and maintaining a needle in place for ten hours had been a nuisance to him and caused pain. His Desferrioxamine treatment was discontinued shortly before his death.

Fourthly, all the participants in this study were in a palliative phase of their disease but most were not referred to a member of the PCT, something which potentially could have helped them and their families through the dying process.

Fifthly, participants reported that on occasion, the nurses on the day unit would speed up the rate of their BT which caused them concern as they worried that they may not be able to tolerate the faster infusion; indeed, one participant suggested it might cause her death.

Finally, the participants BT experience was also negatively affected by HCP because they were sometimes thwarted in their ability to plan their schedules which resulted in frustration and anxiety.
5.6 Research objective 3: To explore the effect of the place or setting where the blood transfusions were administered on participants’ experiences of BT

5.6.1 Storyline three: Everyday blood transfusion life involves waiting and anxiety

This storyline elucidated the place or setting dimension of participants’ experiences of BT, and so complied with the third research objective as it illuminated the effect of the hospital on participants’ experiences of BT. This storyline was developed from the following plotlines: waiting in Pathology for blood tests; waiting on the HDU; and anxiety associated with places in the hospital setting. The study findings related to the hospital settings were believed to be of utmost importance because they caused all participants to experience distress and dissatisfaction with the healthcare they received.

5.6.1.1 Plotline - Waiting in Pathology for blood tests

A common plotline recognised in the stories of most participants was the theme related to queuing in Pathology for blood tests. Waiting in this department was believed to demonstrate a lack of compassionate care for these individuals. Participants who were in a late or terminal palliative phase of a HM with less than six months left to live attended Pathology twice in the same week, generally every two weeks. In Pathology they had to wait in uncomfortable, hectic situations for one to two hours. This equates, approximately, to between fifty-two hours (six and a half working days) to one hundred and four hours (thirteen working days) over a twelve-month period. Charmaz (1997) highlights the potential tragedy of this wasted time; “wasted days, wasted time, time that could never be recovered, they were moments lost forever” (Charmaz, 1997, p. 248).

Some participants became so distressed by the ordeal of waiting to see a healthcare professional and the subsequent effect it had on their lives, that they took matters into their own hands to avoid waiting. Most of the study participants however believed that they had no choice but to wait to see a healthcare professional, and so they lost control over their time.
Charmaz (1997, p. 30-33) discusses ‘waiting time’ for individuals with chronic disease, perfectly capturing the meaning of this wasted time on patients’ experience:

‘Waiting becomes dead time. Lying undercover alone in a chilly examination room for half an hour wastes time. Standing in long lines at a clinic is frustrating and grating. The meaning of waiting lies in the irritating concrete experience of it. Waiting time means lost time and a loss of control over time’ (Schwartz, 1975, cited in Charmaz, 1997, p. 31).

In the past, Craig, Milligan, Cairns, McClelland, & Parker (1999) highlighted the waiting time associated with blood tests that patients endured. These authors suggested that the employment of a home nurse practitioner, who assessed patients clinical condition and took patients’ blood tests while they were at home, reduced clinic attendance and was preferred by patients. Indeed, many researchers have highlighted that keeping patients waiting in the hospital setting results in them being dissatisfied with the care they receive from HCP (Charmaz, 1997; Bleustein, et al., 2014; von Plessen & Aslaksen, 2005; Street, Khan, Tong, & Shanbhag, 2017; Thomas, Glynne-Jones, & Chait, 1997; Trimm & Sanford, 2010). Moreover, the NHS Patient Experience Framework (2012) highlights the importance of not keeping patients waiting. Despite this knowledge, waiting in clinical environments is still recognised as an area of healthcare practice that begs serious improvements (Bleustein, et al., 2014).

To provide compassionate care for vulnerable, palliative patients, this “waiting” situation in Pathology, where the wait time was described as ‘unacceptable and inconvenient’, must be addressed. Patients have “the right to excellence in treatment and care to support them in their lives to live as well as possible until their moment of death” (GMC, 2010, p. 1).

5.6.1.2 Plotline - Waiting on the haematology day unit
Participants also reported that waiting was a problem associated with the HDU. Although most participants stated that all the nurses working on the HDU were “wonderful” and “nothing was too much trouble for them”, waiting on this
unit caused them much distress and dissatisfaction with the care they received. Some participants were able to reorganise their lives to avoid the waiting, but this too caused inconvenience as it involved them adjusting their everyday life routines. Other participants believed that they had no choice but to sit and wait until the nurses were ready to cannulate them as they believed that patients receiving chemotherapy were more important than they were. This belief made them feel as if they were less worthy than patients who were receiving chemotherapy. These feelings were exacerbated for Ernest if he had to go to the inpatient ward to complete his blood transfusion. During these episodes of waiting, it appeared that Ernest, perhaps, lost his feelings of self-worth and dignity, areas key to compassionate nursing care. Participants believed that the waiting they endured on the HDU was due to the nurses being over-stretched because of the number of patients each nurse had to care for. However, in terms of providing compassionate care, this waiting situation and the feelings it evokes in patients is unacceptable and requires attention.

The findings from this study associated with waiting for blood transfusions to start has been previously highlighted in the literature (Craig, Milligan, Cairns, McClelland, & Parker, 1999). The findings also strongly echo those of McGrath (2002) who studied the end of life care for haematology patients being nursed on an ITU. McGrath suggested that the staff working in ITU were too busy providing physical care to be able to sit and talk and provide the emotional support required by these terminally ill patients: “Although the health professionals were viewed as caring and dedicated, they were seen as too busy to be emotionally supportive […] the physical demands of patient care had to be prioritised over psychosocial and spiritual issues” (McGrath, 2002, p.110). Robinson, et al., (2015, p. 17), also suggest that when nursing staff caring for palliative care patients are ‘too busy’ and patients are “left waiting for care, patients feel like they are an inconvenience, invisible, forgotten”.

Extensive personal experience of working as a senior nurse over the past twenty years, in four busy HDUs in four large hospitals, has furnished me with a deep insight into the enormous pressures placed on nurses to treat the large
number of patients during each day shift. Much of the nurses’ time in cancer day units is spent on administering intravenous, bolus chemotherapy. This means that each nurse is tied up with an individual patient, on a one-to-one basis for long periods. They cannot be distracted by other patients or nurses during this time to prevent the risk of extravasation. Whilst administering chemotherapy, the nurse has time available to show humanity and talk through concerns with the patient. However, it leaves the nurses with very little time to talk to those who are receiving BT, a therapy considered to be “more ubiquitous and of low hierarchy in the cancer setting” (Bishop, Faithful, & Allan, 2011, p. 203). Showing kindness and empathy while undertaking clinical procedures has been demonstrated to make patients feel, “reassured, safe, and cared for as an individual” (McCabe, 2004, p. 46). However, under the busy working conditions inherent to a day unit, and the commonplace and relatively low concern associated with BT (Bishop, Faithful, & Allan, 2011) in comparison to chemotherapy administration, it may be difficult for the nurse to deliver excellent nursing care to those receiving BT.

5.6.1.3 Plotline - Anxiety associated with places in the hospital setting
Exposure to certain places within the hospital caused anxiety for most participants. For example, both the Pathology Department and the HDU caused Helen anxiety, while the Pathology department, the lifts and the HDU settings provoked distress for Zavier. This anxiety arose because of the perceived risk of infection associated with these places due to the crowded and cramped conditions. However, the setting that caused the most distress was the HDU, where patients receiving BT were nursed in a multi-bedded ward which cared for both haematology and oncology patients.

Helen and Zavier were both neutropenic which made the extremely susceptible to acquiring an infection. Being nursed close to other patients and patients’ relatives on the HDU made them afraid because they feared contracting an overwhelming infection from them. This fear was understandable as they had been nursed in isolation during their chemotherapy treatment and warned to stay away from people who may be infected with colds and flu.
Kenneth and Ernest stressed fervently that being nursed in a proximity close to young patients receiving chemotherapy made them feel ill at ease as they were intensely saddened by their plight. This led to Kenneth feeling a fraud, as he believed that the young people’s plight was worse than his own. Ernest found it difficult to talk to other patients who were in the next bed or chair, in case he said the wrong thing and upset them. Not being able to socialise with patients close to him led him to feel isolated. The situation, however was different for Jim as he wanted solitude, he found the close presence of other patients challenging.

Charmaz (1997) recognises how for some individuals, being able to socialise with others allows them to maintain “self”, who they are. Others prefer to maintain an aloofness:

‘even superficial sociability can assume weighty symbolic significance to an isolated ill person. Such sociability affirms that the self remains, that illness has not claimed all of ones being. The significance of social contact lies in its meaning. Many ill people, especially elders welcome social contact from whoever they can get it [...]. Other people remain aloof Charmaz’ (1997, p. 97).

Other studies have explored the effect of the hospital or hospice environment on the experience of participants with advanced disease, their findings adding support to the findings of this thesis. Robinson, et al., (2015) undertook a qualitative study in New Zealand to explore the impact of the acute secondary care hospital environment on palliative patients’ experience of care. They found that when participants were nursed in close proximity to other patients who were near to death or who were infectious, it caused them distress. Rowlands and Noble (2008) studied the effect of a cancer centre environment on the quality of life for participants with advanced cancer, and Williams and Gardiner (2015) assessed patients’ preference for a single room in a hospice compared to a shared room in a hospice setting. Both studies concluded that most participants favoured being in an environment that allowed them to mingle with other patients when they felt well enough, but preferred being in a single room when they felt extremely unwell or were dying. The need for both types of setting was recommended in their findings.
Sadly, the opportunity to nurse patients who are having BT as a day case in a single room is neither available nor appropriate as most are elderly and need frequent monitoring, and single rooms are generally not found in day units. However, the findings made me wonder whether nursing those who are no longer eligible to receive active chemotherapy treatment in the same place as those who are receiving potential curative therapies is unkind. In light of the findings, I would argue that it is not compassionate care to nurse these two populations of patients in the same environment. As the following storyline suggests, providing nursing care for these patients in the day hospice unit is believed to provide more individualised and compassionate care.

5.6.2 Storyline four: More individualised care associated with the hospice day unit and everyday blood transfusion life

This storyline was also consistent with research objective 3: to explore the effect of the place or setting on participants’ experience of BT. The effect of the hospice day unit was gleaned from the stories told by Helen who voiced the following plotlines: more individualised care; hospice day unit perceived as a safer place to receive BT; and hospice day unit perceived as more tranquil place.

5.6.2.1 Plotline - More individualised care

The hospice day unit, which is in the grounds of the acute secondary care hospital, is where one study participant (Helen) received one of her BT. She reported that this was her preferred place to have any future BT because the care she received in this environment was more individualised. Inside there are large, squishy chairs and a television, there is a dining table where people can go and join other patients if they want to chat, and there is space to allow patients to be alone if that is what they want. The unit allows for patient-centred care to be delivered that focuses on the individual needs of each patient and allows for patients to receive the palliative blood transfusion care they require while still living at home. Within the hospice day unit much emphasis is placed on allowing patients to retain their dignity and privacy, and to grant access to psychological, emotional, practical and spiritual support from the palliative
care team who are specialised in the provision of palliative care. The World Health Organisation (2014) defines palliative care as:

‘An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual’ (WHO, 2014, p.5).

Of paramount importance to palliative care principles is to help relieve patients’ distress and suffering and to offer a support system that affirms life, and which regards dying as a normal process.

5.6.2.2 Plotline - Hospice day unit perceived as a safer place to receive blood transfusions
Of importance was that Helen said she felt safer in the hospice day unit because her blood transfusion was administered more slowly. She also said she felt safer from acquiring infection because the hospice day unit was not overcrowded with other people from whom she could, potentially, catch an infection. In fact, the only other person present throughout her transfusion was her husband.

No prior research could be found that has reported patients “feeling safer” when cared for in the hospice setting. It is an interesting concept and raised the possibility of addressing this subject in future research, as potentially if this suggestion is shared by other patients with a HM, it could provide a way to encourage future haematology patients to have their BT in the hospice day unit.

5.6.2.3 Plotline - Hospice day unit perceived as more tranquil place
Comparing the hospice and HDU, Helen associated the hospice day unit with tranquillity. She felt the garden setting added to this tranquillity and imagined what it would look like in the summer. In comparison she associated the HDU with noise, from the pump alarms constantly bleeping, and hustle and bustle because of the busy environment.
The findings from this study associated with the hospice are consistent with those found by Hopkinson and Hallett (2001), who undertook a phenomenological study to explore patients’ perceptions of a hospice day care unit. All participants had an advanced cancer (type not specified). They suggested that when nursed in the hospice participants felt valued and less isolated because the care offered to participants was “humanistic” (p. 117). That is, participants were given time to share and receive input about their personal concerns, feelings and understandings. In addition, the environment was flexible enough to assist participants to manage their illness in the way they saw fit. The findings are also strongly endorsed by other researchers. Orme, Still, Day, Evans, & Perkins (2013), highlighted participants’ preference of the hospice day unit, over the hospital, because of the benefits of easier parking and the time available to chat with HCP, while others recognised that patients feel more comfortable in the hospice due to the homelier and relaxing environment (Evans, et al., 2006; Brereton, et al., 2012; Robinson, Gott, Gardiner, & Ingleton, 2015).

5.7 Research objective 3. Summary of findings

Firstly, waiting was a common hardship that participants experienced while being nursed on the HDU and in the Pathology Department. Waiting in these settings, which was associated with lack of privacy and noise, caused participants much anxiety, distress and dissatisfaction with the healthcare services they received.

Secondly, patients who were neutropenic found exposure to the HDU, the lifts and the Pathology Department frightening due to their fear of contracting an overwhelming infection.

Thirdly, participants experienced anxiety and fear when being nursed in proximity close to other patients.

Finally, the hospice day unit was believed to offer more individualised, safer and more tranquil care where the nurses had more time to provide more holistic care.
5.8 Research objective 4: To explore the change in participants’ experiences as disease progressed from an early palliative phase, to a late palliative phase, to the terminal palliative phase of a haematological malignancy

5.8.1 Storyline five: An everyday SAD life during the late to terminal palliative phase of a haematological malignancy

This storyline elucidates the temporality dimension of participants’ experiences of BT, and so addressed the fourth research objective as it illuminated how participants’ experiences changed with time and disease progression. It was developed from plotlines: Somnolence; Adversities; and Desperation, which resonated throughout the stories told by Harold, Jim, Lily, Bill and Helen.

5.8.1.1 Plotline - Somnolence overwhelms daily life

In the late and terminal palliative phases of disease, participants experienced overwhelming somnolence. BT did not help relieve the tiredness and sleepiness that these participants experienced.

5.8.1.2 Plotline - Adversities overpower everyday life

As participants’ conditions deteriorated they found it difficult to undertake many activities of daily living. Despite experiencing these challenges in their everyday lives, they remained stoic. Helen, for instance, kept on trying to help do the dishes and make the bed although she found it difficult “even” to clean her teeth; Jim found a way to get to the HDU regardless of his disability caused by his grossly distended abdomen; and Bill forced himself to attend the HDU although he was obviously very depressed, crying frequently as we talked.

5.8.1.3 Plotline - Desperation to hang on to life

Despite being in dreadful physical condition these participants in the late – terminal palliative stage of disease maintained a desperation to have BT. Despite their dire situation, most participants retained a sense of humour to describe their experiences. None expected BT to cure them, but they hoped BT would enable them to live a little longer. Even to spend one extra day alive,
to spend time with their families was important to them (Smith, Cooling, & Davenport, 2013).

This situation that these participants in the late to terminal palliative phase of disease found themselves to be in is explained articulately by Charmaz (1997) who suggests that, when suffering with chronic illness, individuals do not hope for a complete recovery, rather they just hope to resume some small amount of performance ability: “ill people will trade efficiency for being able to function at all” (p. 147).

Maintaining hope is believed to provide a way for those at the end of their lives to persist and manage their suffering (Duggleby, 2000). According to Groopman (2006), hope allows people to prevail in the face of illness, because “every disease has an uncertain outcome and in that uncertainty we find real hope, because a tumour has not read the text book and a treatment can have an unexpectedly dramatic effect” (p. 210).

This study appears to suggest that those participants in the early palliative stage (Kenneth, Ernest, and Zavier) were, as Charmaz (1997, p. 178) described, “living one day at a time”. They managed their lives and their regimes associated with their BT on a day to day basis. They were not overwhelmed by constant struggles to survive and were able at times to have a normal life. Rather than dwell on the future, these participants in the early palliative stage coped emotionally and physically in their everyday lives by taking things one day at a time (McGrath, 2002).

Those in the late or terminal palliative phase (Harold, Jim, Lily, Helen, and Bill) simply existed “from day to day”. (Charmaz, 1997, p. 185). Their ability to partake in everyday normal life activities had been lost as they had lost control of their health. They existed by simply getting through each day in the best way they could. Harold’s family read to him; Jim watched television all day; Lily on occasion still tried to knit; Helen pottered around the house as best she could; and Bill had his friends visit him or his wife would take him for “little drives in the car”. The adversities that beset their daily lives and their
desperation for BT overwhelmed their lives at this point in their disease. BT did not help to make life better for these individuals, it simply, as Bill suggested, allowed them to “exist”.

Despite all participants being in a palliative stage of disease, only two participants, Helen and Bill, both of whom were in the terminal stage of disease, met with members of the PCT. This delay in referring palliative haematology patients to the PCT has been something recognised in the recent literature (Cheng, Sham, Chan, Li, & Au, 2015; McCaughan, et al, 2018; McGrath & Holewa, 2007). It occurred in this study, perhaps, because it is difficult to estimate accurately an individual’s prognosis, as there may be no clear distinction between the curative and palliative phase (McGrath & Holewa, 2007). However, it has been suggested that people approaching the end-of-life should be identified early (NHS, 2014). McCaughan, et al (2018) highlight that due to prognostic uncertainty it is difficult for haematologists to identify the most appropriate time to start talking about end-of-life care. They suggest that “the development of ‘indicators’ or ‘triggers’, based on diminishing response to treatment” (p. 8) could help determine when an appropriate time for referral to the PCT should be made. An indicator that was gleaned from this research is that patients may need to be referred to the PCT once their blood transfusion requirement increases to every two to three weeks, as it appeared that increased frequency to this level of blood support was consistent with disease deterioration and overwhelming symptoms of anaemia. An increase in regime to two weekly, or even three weekly BT, could provide an indication that patients have reached a palliative phase and indicates that this is the right time to commence discussions around end-of-life care.

The publication “Every moment counts: a narrative for person centred co-ordinated care for people near the end of life” (National Council for Palliative Care, 2015), emphasises the need for brave conversations between healthcare professionals and patients. In the acute hospital setting, however, discussions around end-of-life care with the PCT are frequently not taking place (Gott, Frey, Raphael, O’Callaghan, & Boyd, 2013). Improving the care
of those with palliative conditions in an acute hospital has been recognised as an area that needs to be addressed internationally (ibid).

It is possible that earlier involvement of the PCT in the care of those with a HM could address participants’ desperation for blood, as they are able to provide more psychological and spiritual support and afford a more holistic approach to goal setting. End of life discussions with members of the PCT, could help participants to make difficult but critical decisions about the necessity or benefit of BT (Woodwark & Dean, 2016). Indeed, the PCT could help participants come to terms with the idea that BT every week are not acceptable, and to accept that it may be preferable to spend their limited time at home rather than in the hospital, and to view it as a time for saying goodbye and for showing forgiveness and gratitude (Geifand, Raspa, & Briller, 2007).

Palliative care is frequently thought to be only for those in a terminal palliative phase of disease when the patient is dying, but it is important that nurses and doctors recognise that this is not the case. In those with a haematological disease, it is useful at any stage throughout the disease trajectory. Alongside their medical colleagues, senior haematology nurses are in a prime position to refer patients to their palliative care colleagues.

5.9 Research objective 4. Summary of key findings

Firstly, from the patient experiences reported in this study, it appears that participants in the early palliative phase were able to manage their lives and their regimes associated with their BT on a day to day basis. They were not overwhelmed by constant struggles, rather they “lived their lives day by day” (Charmaz, 1997).

Secondly, those in the late or terminal palliative stage reported experiences that showed they were overwhelmed with somnolence, adversities and desperation, and BT did not help with these aspects, which meant that these participants simply “existed day to day” (Charmaz, 1997). Two participants in the study, despite their dire situation, retained humour to describe their experiences, and all participants hoped that BT would prolong their lives.
Thirdly, from an observation of the study findings, it appears that once the frequency of BT had been increased to every two or three weeks, this coincided with a deterioration in the participant’s disease. Due to the difficulties in accurately assessing prognosis, perhaps this frequency of blood transfusion support could be employed as an indication that it is the right time to discuss end-of-life care and refer patients to the PCT.

5.10 Review of study findings

The WHO (2014) definition of palliative care (see 5.6.2.1 p. 138) highlights the importance of improving patients’ end-of-life care by assessing physical, psychological and spiritual problems and implementing measures to help relieve suffering.

Given their frail physical condition an aspect that kept appearing in participants’ narratives as a hardship that increased their suffering, was their need to attend the hospital two or three times a week, every two to three weeks. The requirement to arrive early at the hospital exacerbated this problem, as participants reported that they had to get up very early to prepare for their visit.

The long waits to have their blood tests taken and waiting on the HDU to receive their BT also did not appear to enhance participants’ quality of life, as they found waiting in clinical areas to be particularly challenging and distressing. Indeed, some participants linked the long waiting time they experienced with poor-quality healthcare. Most simply accepted the wait while others organised their lives to avoid the wait. One study participant suggested that waiting on the HDU made him feel less important to the nurses on the unit as those patients who were receiving chemotherapy.

Another observation from the participants’ narratives was that it appeared that haematologists did not appear to discuss death or the dying process with these palliative participants. Rather, it appears that they engaged in a process of therapeutic emploiment which involved physicians during clinical encounters
“creating for patients an experience of immediacy rather than chronology” (Crossley, 2003; Del Vecchio Good, et al., 1994, p. 855; Murray, 2008). That is, they focussed on discussing with participants their haemoglobin results and the transfusion process rather than prognosis which served to maintain patients’ hope of survival. Therapeutic employment appeared to sustain participants’ faith that BT would prolong their lives, to the extent that they did not consider their death until it was imminent. Referral to the PCT, a process which the WHO recognise is applicable early in the illness trajectory (World Health Organisation, 2018) was not adhered too.

From the experiences described by participants it appears that only two had met with a member of the PCT, and this meeting took place only a few weeks before their deaths. It appeared that by the time they were referred to the PCT it was too late for them to build any form of trusting relationship with the Macmillan nurse they met. Thus, most participants did not appear to have any contact with members of the palliative healthcare team who are specialised in providing emotional, psychological and spiritual support. Participants also suggested that because the nurses on the HDU were so busy administering chemotherapy, they did not have time to sit and talk to them about aspects of their care.

Narratives describing their blood transfusion experiences suggest that the participants did not understand the nature of their disease. For instance, one suggested that the increased frequency of his BT was because “the blood was not doing its job properly” while another participant said that reducing his physical activity could maintain his “haemoglobin level at a higher level for longer”. This raised concern that communication between healthcare professionals and participants was lacking.

Participants described the day they spent on the HDU as a “long day” and “a challenging day” because of the time it took to administer three units of blood. This led one participant to state it would be better to have two units of blood rather than three, because it meant he would only be on the HDU for four or five hours rather than six or seven hours. As he became very tired in the
afternoon, he thought getting home earlier would be beneficial. Several participants described how when they were to have three units in one day the nurses would increase the rate of transfusion to ensure that they were completed before the scheduled HDU closing time. This practice worried two participants who were concerned that they would not be able to tolerate the faster rate of infusion.

Three of the participants explained the difficulties they experienced with chelating agents, which they described as horrible. One participant said that it had been a nuisance for him and that it was a relief when he was informed that he could stop administering the Desferrioxamine because of the sore injection sites on his abdomen and the difficulties he experienced securing the needle in place for ten hours, four times a week. Three participants described the nausea and vomiting that they experienced with the oral formulation.

Participants described the overwhelming hardships that they experienced in their everyday lives as their disease progressed to the late to terminal palliative phase. From the experiences reported, it appears that BT did not help to relieve their anaemia-related somnolence or fatigue which meant they could not perform normal daily activities like washing or dressing themselves. Describing his torpor led one participant to say, “I don’t do nothing I just exist”. The narratives of participants in the late or terminal phase suggest that they became totally dependent on their families, friends and healthcare professionals to help them with every aspect of their everyday lives. They became powerless in their everyday lives with no choice over aspects of their blood transfusion care, such as choosing the day or time they came for their BT. Despite their dire circumstances, however, all the study participants remained desperate to receive BT and adjusted their lives to accommodate its administration.
5.11 Reflection on the link between Dewey, the study process and the study findings

Dewey’s pragmatic philosophical approach, his pragmatic theory of experience and his conception of inquiry were employed within this study. The following section reflects on the way these aspects are linked to the study process and findings.

Eminent philosophers such as Peirce, James and Dewey, promoted different versions of pragmatism, however, it is the work of Dewey that served as the underlying philosophical foundation for this narrative inquiry study. Dewey argued that pragmatism was not orientated towards abstract concerns like other research paradigms, such as post-positivist and constructivist traditions, but rather its concern lay with consequent phenomenon and possibilities of action (Cherryholmes, 1992):

“Pragmatism... does not insist upon antecedent phenomena but upon consequent phenomena; not upon the precedents but upon the possibilities of action. And this change in point of view is almost revolutionary in its consequences.... When we take the point of view of pragmatism we see that general ideas have a very different role to play than that of reporting and registering past experiences. They are the bases for organising future observations and experiences” (Dewey, 1931, p. 32-33 cited by Cherryholmes, 1992, p. 13).

Dewey’s pragmatic approach allows researchers to transcend the ongoing debates between, for example, positivism and constructivism (Kalolo, 2015; Morgan, 2014), as Dewey recognised the positive aspects of both post-positivist assumptions “that the world exists apart from our understanding of it”, and to constructivists assertions “that the world is created by our conceptions of it” (Kalolo, 2015; Morgan, 2014, p. 1048).

Dewey wanted the philosophical foundation of knowledge to be grounded in the concept of human experience. His version of pragmatism endorsed practical problem solving, through a process of inquiry, as the primary means to gain practical knowledge. Dewey’s theory recognises that when the principles of continuity and interaction are taken together this forms a situation. To understand Dewey’s view of knowledge creation one must give credence
to his notion of situation which highlights the transaction between people and the environment. Dewey recognised two types of situations; habitual or determinate, and indeterminate. An indeterminate situation emerges when there exists a state of uncertainty or confusion (Miettinen, 2000; Vo, Mounoud, & Rose, 2012). In defining the concept of inquiry Dewey’s acknowledged that there was transformation of an indeterminate situation into a determinate one:

“inquiry is the controlled or directed transformation of an indeterminate situation into one that is so determinate in its constituent distinctions and relations as to convert the elements of original situation into a unified whole” (Dewey, 1938, p. 108).

In his concept of inquiry, Dewey (1938) recognises that knowledge and action are intertwined, and that critical reflection is of central importance in the transformation of an indeterminate situation to a determinate one (Vo, et al, 2012). For Dewey, one of the founders of experiential learning, the underlying reason for reflection was the necessity of solving problems faced in habitual situations. As such, reflective thinking about situations is a crucial component of Dewey’s theory of learning from experience and one that acts as a powerful tool within nursing (Benner, Hughes & Sutphen, 2008).

The employment of Dewey’s pragmatic philosophical approach has much to offer those undertaking nursing research as it allows the tracing out of practical consequences from the research data, which leads to the creation of nursing knowledge that advances clinical nursing practice (Benner, Hughes, & Sutphen, 2008; Nowell, 2015; Vo, Mounoud, & Rose, 2012). Patricia Benner, a venerated and influential nurse researcher, employed Dewey’s pragmatic theory as the basic underpinning for her highly influential work to nursing practice; ‘From Novice to Expert: Excellence and Power in Clinical Practice’ (1984). Benner’s employment of a pragmatic paradigm in the nursing research arena introduced the innovative idea that clinical nursing practice itself could be used as a knowledge base to inform nursing knowledge and theory. This fact was inspirational, as like Benner I wanted to gain practical, nursing knowledge by giving priority to people’s everyday experiences by listening to patient’s everyday life problems and concerns. Employing Dewey’s pragmatic
approach allows nurse researchers the opportunity to use dynamic approaches to address the complex and multifaceted research problems often encountered in nursing practice (Doyle et al, 2009 cited by Nowell, 2015).

As the bedrock to this study Dewey’s theory of experience and his concept of inquiry were invaluable in the creation of knowledge applicable to nursing and clinical healthcare practice. Dewey’s concept of continuity, the idea that experiences cannot be separated from each other, and interaction, the interaction between external conditions in the environment and internal feelings and desires, was apparent in the stories of experience told by participants in this study. It became obvious that one experience led to another, as participants critically evaluated aspects of blood transfusion clinical practice and took appropriate action to alleviate or change what they perceived was causing them difficulty. Examples of interaction and continuity coming together to form a situation was seen for instance in the story told by Helen. Helen was dissatisfied with her contact and communication (interaction) with a junior physician during a clinic review as she believed the doctor did not consider how she was feeling physically when authorising her BT. The feeling of discontent she experienced during this clinic review led her to make the decision to be reviewed only by a consultant haematologist at subsequent clinic visits (continuity). Another example related to Kenneth’s decision to attend the Pathology department early in the morning to avoid the long queues that occurred later in the day. Experiential learning in this context required critical reflection to make sense of and learn from experiences. This experiential knowledge was acknowledged as being “personal, practical, shaped by, and expressed in practice” (Clandinin, 2013, p 9).

Dewey’s systematic problem-solving approach to inquiry (Figure 2, p. 153) appealed to me as a nurse because it may be likened to the cyclical problem-solving nursing process, a process that ensures quality in nursing care. It resonates in two ways: a). a situation within everyday life is recognised as being a problem or ‘a puzzlement’, and steps are taken in a systematic manner to address the problem, and the situation is resolved through taking the appropriate action to resolve the dilemma; b). both seek to create new
knowledge or truths to improve the individual’s outcome. The obvious, but important difference lies in the fact that during inquiry research is carried out meticulously, employs rigorous methods of analysis and provides sufficient information for readers to assess claims of validity. Primarily, however, it was Dewey’s emphasis on actions and practical outcomes that drew me to his philosophical way of thinking. Pragmatism allows the outcomes from my qualitative nursing research to be practically useful in clinical practice. As, patients’ everyday life experiences are of overriding concern to nurses, aspects of Dewey’s pragmatic approach that were particularly ascribed to included; the ability to help solve real world problems through inquiry, the recognition of the affinity between research and everyday life, and the crucial importance that knowledge created was of practical significance. Employment of Dewey’s concept of experience allowed a deep understanding of the transactional relationship between the study participants and the study environment (Vo, Mounoud, & Rose, 2012), and allowed participants’ experience “to be honoured as an important source of knowledge and understanding” (Clandinin, 2013, p. 17).

Miettinen, (2000, pp. 66-67) outlines Dewey’s phases of reflective learning during the inquiry process. In the following section it is adapted to demonstrate how reflection and action were employed throughout this piece of research.

Step 1. *The indeterminate situation: the habit does not work*

Dewey’s concept of scientific inquiry begins with the researcher locating the problem or puzzle that has arisen during everyday life situations that is of primary relevance to practitioners. Generally, habitual actions are undertaken without reflection, however, when a situation arises that causes consternation “reflective thought brings about hesitation and delay that is essential to thinking” (Miettinen, 2000, p. 66). Reflective thought initiates a study of the conditions that are causing the problematic situation (ibid).

In this current study, reflection on an incident in clinical practice that caused concern led to an in-depth search of the literature associated with the perceived problem. Dewey’s pragmatic approach allowed a dynamic interplay
between theory and practice, where the notion of multiple truths was embraced, in the understanding that there is no knowledge that is certain and/or universal. Thus, a diversity of viewpoints about the phenomenon of blood transfusion experience is supported. Adopting Dewey’s pragmatism allowed precedence to people’s everyday life experiences. The underlying philosophy of pragmatism allows the researcher to start their inquiry with a personal feeling of puzzlement around an aspect of everyday life in clinical nursing practice. This was consistent with my belief that clinical nursing practice itself could and ought to inform nursing knowledge and theory (Benner, 1984). Furthermore, “Dewey argued that concentrating on a problem that does not grow out of an actual situation is merely an intellectual exercise, not science” (Dewey, 1938, p. 16, cited by Vo, et al. 2012, p. 16).

Step 2. Intellectualisation: defining the problem
Miettinen, (2000) highlights that the next stage in Dewey’s reflective cycle involves intellectualisation and definition of the problem. Dewey stresses the relevance of accurately defining the problem:

Without a problem, there is a blind groping in the dark. The way in which the problem is conceived decides what specific suggestions are entertained and which are dismissed; what data are selected, and which rejected; it is the criterion for relevancy and irrelevancy of hypotheses and conceptual structures (Miettinen, 2000, p. 66).

In this study intellectualisation of the problem was met by the formulation of the research question and research objectives that addressed Dewey’s two criteria of experience, continuity and interaction, and which had been adapted by Connelly and Clandinin (2006) into dimensions of sociality, temporality and place.

Step 3. Studying the conditions of the situation
Following Dewey, Miettinen suggests that analysis and diagnosis of the conditions then takes place.
In this step of the research process the conditions associated with participant’s experience of BT were studied through the stories participants told which gave rise to the meaning BT had in their lives, and the hardships they encountered.

Step 4. **Reasoning**

In Dewey’s model of reflective thought and action, *reasoning* is a vital component in finding solutions to the dilemma. Miettinen, (2000, p. 66-67) suggests that

“reasoning is composed of the elaboration of the meaning of ideas in relation to each other…. In reasoning, thought experiment can be done. These thought experiments are important because they allow the return to the beginning again”.

In this study *thought experiments* were undertaken by personal immersion into participants’ stories during the narrative analytical approach. Through this approach, which involved; narrative coding, broadening, burrowing and restorying, the process of reasoning was undertaken which finalised in an individual narrative account for each participant. Each narrative account was thought of as a patchwork quilt which incorporated many narrative themes stitched together. This allowed *elaboration of meaning of ideas in relation to each other* which brought together a holistic picture of what everyday blood transfusion life was like, as perceived by the participants in this study and which had been the purpose of the study. The insight gained, through the thought experiments, allowed for clarification of the hardships endured by participants and provided ideas by which to resolve these problems.

Step 5. **Testing the hypothesis by action**

The practical outcomes of the research inquiry are of crucial importance for Dewey. According to Miettinen, (2000, p. 67) the outcome of Dewey’s reflective thought and action during inquiry finalises in either the resolution of the problem, or in the formulation of meaning (an idea or concept), that can be used as a resource in future problem situations. Dewey (1938) recognised that it was impossible to acquire a definitive solution to any inquiry, as with the resolution of the situational problem new conditions are instituted, which in turn leads to new problems, and thus the cycle starts again. Clandinin refers to this
situation in inquiry as ending “in the midst, of ongoing experiences” (Clandinin, 2013, p.43 - 44).

In this study, following Dewey, the primacy of practice knowledge in elucidating practical solutions was viewed as being of essential importance and indeed had been one of the principle reasons for undertaking this research. It was recognised that implementing practical solutions to resolve issues raised by participants could potentially lead to new dilemmas in clinical practice. Abiding by Dewey’s cyclical manner of reflective inquiry, however, led to recommendations for clinical nursing and healthcare practice (presented in Chapter six), which it is believed may serve to improve the blood transfusion experience of future patients.
Figure 2 Dewey’s model of reflective thought and action linked to study process and findings (Adapted from Miettinen, 2000, p. 65)

Key:
Black text Dewey’s model (Miettinen, 2000, p. 65).
Red text study process and findings.

1. An incident in clinical practice caused concern
2. Formulation of research question and objectives
3. Exploration of sociality, temporality and place
4. Critical reflection of findings and bringing together a holistic picture of everyday blood transfusion life
5. Recommendations for clinical practice to improve patients’ blood transfusion experience

1. Disturbance and uncertainty: Habit
2. Intellectualization and definition of the research question and objectives
3. Studying the conditions of the situation and formation of a working hypothesis
4. Reasoning
5. Testing the hypothesis by action

Idea, concept

Solution of the problem and control of the action
Chapter 6: Conclusions

6.1 Introduction

This chapter commences with the study’s key conclusions. This is followed by; a) recommendations for clinical haematology blood transfusion practice based on the study findings; b) recommendations for advanced nursing practice, with reference to the new ‘Advanced Clinical Practice’ descriptors (Health Education England, 2017) and c) recommendations to future research direction. The chapter concludes with a discussion of the study’s strengths and limitations.

6.2 Key conclusions

Improving patients’ experience of care is a key aim of the NHS (National Quality Board, 2015). Improving care services for vulnerable patients in a palliative stage of their disease is of major importance (ibid). The findings of this nurse-led narrative inquiry study serve to address this ambition. Listening to the stories participants told, allowed their experiences associated with blood transfusions to be explored in great depth to uncover nuances in healthcare and service delivery. The findings of this study provide a path to improve on future patients’ experiences of clinical blood transfusion care based on the matters that were important to those who participated in this study. Furthermore, the uniqueness of studying the end of life journey for this population of patients informs healthcare professionals what it is like for patients to receive blood transfusions at the end-of-life. As such, methodologically, this narrative inquiry study offers an important and unique contribution to the literature and demonstrates the way in which the interpretive methodology of NI allows everyday life experiences to be captured through stories told about healthcare practice.

Narrative Inquiry has not been used to gain knowledge of patients’ experience of blood transfusions before. The approach allowed me to develop a close, trusting relationship with participants, which in turn enabled me to attach clear meaning to the challenges they experienced which were interwoven into a meaningful story that illustrated their values and their beliefs.
6.3 Recommendations for clinical haematology blood transfusion practice

Based on the experiences of participants in this study, and observations made in connection with these experiences, it is suggested that blood transfusion clinical care for palliative haematology patients could be improved in several ways:

6.3.1 Develop a one-stop service on the haematology day unit

As palliative haematology participants found getting to the hospital arduous, the care of future patients could be improved by organising a one-stop service on the HDU; blood tests, review by a haematologist and administration of BT could be organised to take place on the same day and in the same place. This would mean that patients did not have to make the journey to the hospital as frequently, which could be beneficial in allowing them to spend more time at home and less time in the hospital, reduce travel costs and decrease the number of times that they are required to get up early to prepare themselves for their hospital visit.

6.3.2 Develop a one stop service in the hospice day unit

A hospice day unit was established for haematology and oncology patients to receive blood transfusions and have their blood tests taken. Patients generally have their blood taken on one day and return on another to receive their blood transfusion. To improve care for palliative patients who require BT a further option would be to develop a one stop service in the hospice day unit. The hospice day unit was said to provide an environment which was safer, more tranquil, more comfortable and homely. From a participant’s experience, the care provided in the hospice was found to be more individualised and compassionate as the nurses working there were said to spend more time talking with her. Furthermore, the phlebotomy service offered in the hospice day unit could prevent the long wait associated with the Pathology Department. These long waits could be viewed as uncompassionate care. Referral of haematology patients to the hospice day unit is not currently commonplace although it has the capacity to deal with the relatively small
number of palliative haematology patients that could be referred there without compromising its own standard of care.

6.3.3 Health care professionals should communicate realistic expectations of blood transfusions
Participants in this study described their overwhelming belief that BT would prolong their lives. In the knowledge that BT have been associated with increased mortality when administered to those with advanced cancer, and the lack of proven beneficial effect in these patients (Preston, Hurlow, Brine, & Bennet, 2012; Woodwark & Dean, 2017), it is suggested that all HCP could communicate realistic expectations when explaining the benefits of blood transfusions.

6.3.4 The palliative care team could be more involved with the care of palliative haematology patients
From the experiences of those who took part in this study, it appeared that there was a lack of involvement of the palliative care team (PCT) in the care of these palliative haematology participants. More consideration should be given by haematology physicians and nurses to involve the PCT whenever patients are believed to be in a palliative phase of their disease. Involvement of the PCT would help ensure that these patients receive the best end-of-life care. Involvement of the PCT could potentially reduce the desperation for BT that participants in this study exhibited whenever they were in the late or terminal palliative phase of their disease. Provision of palliative care could have provided the psychological, spiritual and emotional support that these participants, at the end-of-life stage, were entitled to receive, but which appeared difficult to provide in the busy environment of a day unit. Due to the difficulty in estimating prognosis, given the experiences of those who took part in this study, once patients reach the stage where they need BT every two to three weeks, this might provide an indication that is time to involve the PCT.
6.3.5 HCP should allow patients to take a more active role in their blood transfusion care
Some participants in this study described a lack of autonomy concerning their blood transfusion administration. HCP should improve their communication with the more elderly and vulnerable haematology patients to help maintain their autonomy and allow them to take a more active role in decision making around aspects of their blood transfusion care.

6.3.6 Reorganise clinical service for patients requiring three units of blood.
All the participants said they found the “long and boring day” on the HDU challenging when they were authorised to have three units of blood, because it took six to seven hours to administer this volume which made them feel very tired by the end of the day. It is suggested that consideration is given to reorganising this clinical service so that patients who require three units of blood are admitted to the inpatient ward to receive them.

6.3.7 Attend to blood transfusion patients with compassionate care
It is recognised in the literature that because of the commonplace nature of BT in cancer patients, receiving BT are frequently considered to be of low concern in comparison to those receiving chemotherapy (Bishop, Faithful, & Allan, 2011). One participant in this study reported feeling “unimportant”, “less of a priority to the nurses” when he was kept waiting for his BT. Another said he felt “a fraud” when nursed close to patients who were receiving chemotherapy. It is suggested, therefore, that nurses locally need to make a resolute effort to be aware that these patients are vulnerable palliative patients with a limited life expectancy, and as such in need of much individualised compassionate care and support.

6.3.8 Nurses should perform additional bedside monitoring in elderly, palliative patients and those with a cardiac dysfunction history. They should also weigh patients prior to BT.
Nurses responsible for administering BT at the bedside should, in accordance with the academic literature perform additional bedside monitoring in elderly,
palliative patients and those with a cardiac dysfunction history (Robinson, et al., 2017). They should also weigh patients prior to their BT (NHS Blood and Transplant, 2016). These measures may help reduce the risk of transfusion associated circulatory overload which is the leading cause of death associated with BT (Robinson, et al., 2017).

6.3.9 Attend to the hardships associated with chelating agents by raising awareness
Three participants described significant hardships associated with chelating agents. These agents were prescribed to reduce their high ferritin level which was a result of the many BT they had received. It is important to raise awareness of this amongst other healthcare professionals so that they are aware of the challenges that these agents impose, which do not appear to be consistent with the provision of compassionate healthcare to patients at the end of their lives.

Recommendations for advanced nursing practice in blood transfusion clinical care, with reference to the advanced clinical practice (ACP) descriptors, are discussed in this section.

A major impact on clinical practice, the quality of care provided, and the patient’s experience has been the impact of the European Working Time Directive, and the increasing elderly patient population (2005; Green & Pirie, 2009). To address the impact on clinical care, associated with the changing face of modern healthcare practice, the need for increased multi-professional working between nurses, doctors and allied health professionals was recognised (RCN Policy Unit, 2006). Multidisciplinary health teams, which involved listening to patients, families and carers, were perceived to be “the indivisible units of high quality health services” (RCN Policy Unit, 2006, p. 5).
Working within a multi-professional team, specialist nurses as key frontline caregivers to hospitalised patient-care, were perceived to have a major role in helping to address the issues inherent in current healthcare (Draper, Felland, Liebhaber, Melichar, 2008; Green and Pirie, 2009). This resulted in an expansion in the number of NHS senior nursing positions, positions that bore an assortment of job titles, including for example: nurse specialist, nurse practitioner, advanced nurse practitioner and nurse consultant. No standardised academic qualifications or experience criteria, however, associated within the roles had been established. This situation was addressed in 2017 by Health Education England (HEE) who published the first national advanced practice framework which sets out the key principles of a multi-professional framework and stipulates the capabilities expected of advanced clinical practitioners. A definition of multi-professional advanced clinical practice was developed by HEE, in unison with professional bodies, academics and patient representatives:

Advanced clinical practice is delivered by experienced, registered health and care practitioners. It is a level of practice characterised by a degree of autonomy and complex decision making. This is underpinned by a master’s level award or equivalent that encompasses the four pillars of clinical practice, leadership and management, education and research, with demonstration of core capabilities and area specific clinical competence.

Advanced clinical practice embodies the ability to manage clinical care in partnership with individuals, families and carers. It includes the analysis and synthesis of complex problems across a range of settings, enabling innovative solutions to enhance people’s experience and improve outcomes (HEE, 2017).

HEE (2017), recognises that advanced clinical practitioners must be educated to masters or doctoral level and have expertise within four areas of healthcare; clinical practice, leadership and management, education and research. This allows a genuinely multi-professional team approach, whereby, regardless of the professional background of the practitioner, the patient receives the same care if treated by a nurse, allied health professional or physician (HEE, 2017). Furthermore, understanding of the advanced clinical practice curriculum by healthcare organisations allows them to identify and plan their workforce. This is in the knowledge that practitioners working at an advanced level of practice
have developed their skills and knowledge to the standard outlined in this framework and can transform services to improve patient experience and outcomes (HEE, 2017).

Employed as a haematology nurse practitioner I have developed the skills and knowledge underpinning the four pillars of practice to the standard outlined in the multi-professional framework. In line with these capabilities recommendations for advanced nursing practice in relation to blood transfusion care and service delivery are proposed in the following section:

Clinical care

“Nurses and midwives work more closely with patients requiring BT than other health professionals” (Green & Pirie, 2009, p. ii). As key frontline caregivers this places nurses in a prime position to focus on the needs of the patient and improve on the quality of clinical blood transfusion care and service delivery. However, it is recommended that nurses working within their professional code of conduct and scope of practice (NMC, 2015) as advanced clinical practitioners, who are empowered to lead their teams (RCN Policy Unit, 2006), lead on innovative models of blood transfusion care to improve patient experience and quality of care.

One of the concerns raised in this study related to a lack of clinical continuity and another involved a lack of patient-centred care. The haematology advanced clinical practice role entrusts a commitment to; improve on issues associated with clinical continuity; to help provide more patient-focused care; and to enhance multi-professional team working (HEE, 2017). By implementing the recommendations for clinical practice that arose from this study, and outlined in section 6.3, these senior haematology nurses can address the lack of continuity of care between haematologists and the PCT and the lack of patient-focused care. To act on the outcome of learning from this study, however, requires a significant cultural leadership change within the organisation.
Leadership and management
Rather than a top-down leadership approach, it has been recognised that patients and the frontline multidisciplinary healthcare team are best positioned to develop solutions to improve patients’ experience of healthcare services (Care Quality Commission, 2018). Nurses, working in the frontline as advanced clinical practitioners have developed good leadership and management skills. They also have the vision to lead new practice service improvements in response to feedback from patients, families, carers and other members of the multi-professional team. Excellent leadership and management skills are vital to implementing the recommendations of this study, as it requires members of the haematology team and the PCT to come together to facilitate better team working to shape the best end-of-life care for patients requiring BT. This requires the haematology advanced clinical practitioner to “pro-actively initiate and develop effective relationships, fostering clarity of roles within the teams to encourage productive working” (HEE, 2017, p. 9). To do this necessitates a determination to facilitate ways to provide consultancy across professional and service boundaries to promote joint working and collaboration between the two disparate teams, who must unite to agree upon joint standards of care and shared values (RCN Policy Unit, 2006). Joint working, which is recommended, is dependent on the advanced haematology nurse clinical practitioner being able to facilitate between the teams an understanding and respect of the expertise and contribution each team can offer.

Education
Working within the multi-professional four pillar framework it is suggested that advanced clinical practice haematology nurses use the conclusions and recommendations for clinical blood transfusion practice that emerged from this study to educate their colleagues and other members of the multi-professional team. In doing so they apply their clinical expertise across professional and service boundaries to enhance the quality of BT care, reduce unwarranted variation in care and promote the sharing and adoption of blood transfusion clinical practice based on research findings.
Research
It is recommended that nurses working at this level of advanced practice engage in research activities at masters or doctoral level. This facilitates constructive networking with university scholars and other researchers to develop evidence-based recommendations that can be applied into their own clinical practice and disseminated to others to improve the quality and safety of care (HEE, 2017).

6.5 Recommendations for future research
Based on the findings from this study several recommendations for future research are offered. One of the study findings was that participants receiving blood transfusions in a day unit appeared to lose feelings of self-worth, as they felt “ignored”, “unimportant”, and “a fraud”. Further qualitative research could explore the experience of blood transfusions from the perspective of nurses. Gaining this understanding may shed further light on this experience and allow changes to nursing practice to be made, to reduce some of the negative feelings held by the participants.

Another natural extension to the study findings would be to seek the stories of haematology consultants and palliative care consultants to explore why referral to the new hospice day unit are not occurring. Reasons for lack of referral to the PCT have been highlighted in the literature, but little qualitative research has been undertaken to gain a deep insight into healthcare professionals’ perspectives on this matter. Gaining this knowledge, by listening to their stories could help bring about change in physician referral practice which may lead to better end of life care for those receiving blood transfusions.

A further extension could be to explore the concept of home blood transfusions and investigate why this practice is not taking place within the NHS, especially for those patients with a palliative diagnosis. From the few studies that have been undertaken to explore BT in the home, it appears that patients perceive it to be beneficial both physically and psychologically, and it is said to be cost-effective.
6.6 Strengths of the study

One of the strengths of this study lies in the methodological and conceptual foundations of the narrative inquiry design which is based on Dewey’s (1938) pragmatic theory of experience. This theoretical foundation differentiates it from other qualitative research approaches as the central phenomenon of interest is ‘experience’, which in narrative inquiry is explored through the metaphorical dimensions of sociality, place and temporality. Employing this framework allowed a focus on the social, personal and changing nature of participants’ experiences by exploring; “inwardly to the participant’s personal feelings, emotions and hopes; outwardly towards existential conditions, that is, the physical environment where the study took place; and temporally, that is, past, present and future” (Clandinin, 2013, p. 58). Addressing experience in this manner allowed a rigorous exploration of study participants’ experience and provided a deep insight into this aspect of clinical practice. Furthermore, the methodology is closely aligned with the research aim and objectives and there was a close fit between the research undertaken and clinical practice (Swanson et al., 1997 cited by Yardley, 2000).

Second. A further conceptual and methodological difference between the approach taken in this study and previous research lay in the novel stratification of participants’ disease phase into: early, late and terminal palliative phases. Grouping participants in this manner allowed for an insight into how the participants’ blood transfusion experience changed throughout the palliative trajectory, something that has not been illuminated in academic literature before.

Third. The issue of gaining the trust of participants, whom I had not met before, was overcome by “prolonged engagement”, which meant that I interviewed most participants three times. This also allowed for sufficient data to be collected to gain an in-depth understanding of the phenomena of interest (Lincoln & Guba,1985, cited by Polit, Beck, & Hungler, 2001, p. 313). The longitudinal approach over a twelve-month period allowed me to capture each individual participant’s meaning of their experience at subsequent interviews. This allowed for any differences in perceptions between participants to
become clear, for example, some found blood transfusions beneficial, while others did not. Some participants wanted to be able to socialise with other patients, while another did not. Moreover, discussion and agreement with my academic supervisors, who reviewed three of the transcripts and narrative accounts, confirmed the overarching storylines (themes) and plotlines (subthemes) (Cresswell, 2009). Discussions with my clinical and academic supervisors allowed alternative explanations to be explored and discussed which helped to validate confidence in the findings (Patton, 2002).

Fourth. As this study originated from a practical stance, that is, to understand from the patients’ perspective if the administration of BT were adding to their suffering, I believe, following Yardley (2000), that the criterion of “coherence” was met. Yardley, in describing the work of another researcher (Hartwell, 1998), outlines that coherence was met despite,

‘There is virtually no explicit consideration of theory, and the literature reviewed relates mainly to the prevalence of recidivism, and hence the scope of the problem. But although the treatment of interviewees’ statements appears theoretically unsophisticated, taking descriptions of their lives more or less at face value’ (ibid, p. 227).

Even so, Yardley (2000) suggested that the study met the criterion of coherence because “it is consistent with the practical approach adopted, and with the implicitly phenomenological aim of elucidating the perspectives of the interviewees” (p. 227).

6.7 Limitations
Yardley (2017, p. 295-296) suggests that during qualitative analysis the researcher must, crucially, be able to show: sensitivity to the data; commitment and rigour; transparency; and importance of findings.

6.7.1 Sensitivity to the data
Yardley (2017, p. 295) promotes the idea that the researcher should not impose their own thoughts onto the data by ‘imposing pre-conceived categories from the data but carefully considering the meanings generated by
the participants’. As a nurse with much experience in caring for haematology patients, it was challenging not to be influenced by my own perceptions when analysing and interpreting the participants’ stories. There was an ongoing conflict between my role as an academic researcher and my instinct to act as an advocate for patients, which derived from my commitment to my professional role. The subject of my “positionality” or “insider/outsider” position and the inevitable imbalance in power relations that this causes has been discussed in section 3.9.3 (p. 45) and below.

During interviewing, it was impossible to maintain the position of a detached observer and remain “neutral” (Yardley, 2000, p. 221) as the study and participant’s illnesses progressed. For example, some participants were in such dreadful physical condition by our third interview that I could not help myself but let the nurse take over. I wanted to look at the ulcer on an abdomen or the dreadful swelling of a participant’s legs and I wanted to take a participant to the toilet. Touched by their condition and my need to care for them was overwhelming and I became extremely soft and gentle in my approach. This invoked the relative, hierarchal, power identity of me as the ‘expert’ and the participants as patients despite efforts to downplay my position as described in 3.9.3. My concern over my insider position, in this case was handled through several strategies: using thick description (Lincoln & Guba, 1985; Polit & Beck, 2010, p. 1453-1454), which provides information about the study participants, the research settings and the research processes, in addition to descriptor and demographic information; analysing the narratives in relation to a clear analytical framework (Chapter 3); and by maintaining a reflexive and critical stance through ongoing discussions with my supervisory team. Moreover, my insider position equipped me with insightful sensitivity and an awareness that helped me to relate to participants’ narratives and experiences.

6.7.2 Commitment and Rigour
Recruitment of study participants continued until I believed that no new emerging themes from participant stories, that linked with the study aim, were forthcoming. It is possible to suggest that data collection would have benefited from including more stories concerning the hospice day setting, as this data
was acquired from only one participant, which was also the case in the community day unit hospital setting. This would have offered the potential for “replication” of themes in participants’ stories (Polit & Beck, 2010). However, conducting interviews in these settings was not possible due to lack of physician referral to these areas.

Reissman (2002) recognises that “evolving theories, disciplinary preferences and research questions lead to a number of possible interpretations, dependent on the focus of the researcher”, that is, there is a, “possibility of multiple truths” (Freeman, 2003, cited by Squire, 2013, p. 57). Polkinghorne (2007) also recognises that narrative researchers engaging in interpretation will make different claims about their understanding of a text depending on the position they take (p. 483-484). This limitation may be addressed potentially by “participant validation” of the interim and finalised research texts. Ongoing validation of aspects captured in the interim texts was shared with participants at subsequent interviews, to check that I had captured the essential features of what the experience meant to them (Polkinghorne, 2007), however, it was impossible to share the final research texts as sadly, participants had died by the time these were produced.

Another limitation of this study was that I chose to focus solely on the content of participants’ stories. I did not employ another analytical method to triangulate and perhaps strengthen the findings. For instance, Riessman (2008, p. 80) suggests that incorporating a structural analysis to a thematic narrative analysis “allows topics and voices to be included in qualitative analysis that might be missed otherwise”. Although Reissman, (2008, p. 77) also recognises, that a detailed structural analysis (as she demonstrates on pages 87-88), can complicate the project by making the interview excerpts unreadable for those new to narratology.

Structural analysis has not been demonstrated in my thesis analysis, however this approach was utilised while reading through the transcripts, where I examined for six elements: an abstract; orientation; complicating action; evaluation; resolution and coda (Labov, 1972; Labov & Waletzky, 1967).
Indeed, I analysed each poem in this manner and sent copies to my supervisors, although, I did not feel that in this study undertaking this additional analytical approach added to my thematic findings. At the same time the process did help me to explore my thematic findings in more detail, and identification of the evaluative component in particular helped me to determine what an event meant to a participant.

Participants were initially informed about the study through a haematologist. It is difficult to know if this influenced the stories they told, or indeed whether it was why they chose to participate. However, I do not believe that it had an impact on such decisions. Participants were keen to tell me about the hardships they endured because they believed that what they told me would go towards improving the blood transfusion service for future patients.
Chapter 7: Reflection of my Professional Doctorate Path

7.1 Introduction
This chapter is a critical reflection of my Professional Doctorate in Nursing pathway. It details how I made the decision to complete this programme and highlights my learning and development journey. It describes how undertaking this programme has increased my professional standing in my employing Trust and allowed me to implement changes to clinical practice within the Trust and in my own professional area.

7.2 Why I chose the Professional Doctorate in nursing programme
Employed as a Band 8a Haematology Nurse Practitioner, I held a senior position within the nursing hierarchy, which according to the National Core Competency Framework for Cancer Nursing equates to “Knowledge and Skills Framework” (KSF) Level 3/4. However, I had not reached my goal of becoming a Consultant Nurse KSF Level 4/5. To achieve this within my workplace required me to attain a doctoral level education, as post qualification learning is linked with the KSF framework.

As a working mother with three children and grandchildren undertaking a full time PhD was not an option. Turning to the literature I found an article by Costley (2013) which highlighted the knowledge contributions of the Professional Doctorate (PD):

‘PDs are usually independent and original contributions to a professional practice; practitioner research is often a central activity. PhD students can develop and apply research in the same way, although this is not a key characteristic of the PhD as it is with the PD’ (ibid, p. 1).

As the aim of PDs is to give primacy to practical knowledge and to develop an original contribution to practice through practitioner-research (Costley, 2013), I was drawn to this prospect. The approach was one I was familiar with as I had taken a practitioner-research stance during my part-time MA in Healthcare Leadership and Practice. Despite completion of my degree, my confidence to study at doctoral level was lacking. As the PD programme offers taught
elements, it was believed that this preparatory knowledge would provide the necessary research skills and confidence to prepare for and complete the final thesis component.

7.3 The Professional Doctorate programme:
After successful application to undertake the PD programme at the University of Portsmouth, I was both delighted and scared. The first module, “Professional Review and Development”, allowed development of a personal portfolio, a necessary requirement for nurses but one that I had not previously achieved.

The second module, “Advanced Research Techniques Unit” introduced me to qualitative data analysis computer software packages (MAXQDA and NVivo) and the “Hierarchy Framework Analysis” described by Richie and Lewis (2006). The statistical part of this module I found incredibly challenging. I learnt advanced statistical methods and concepts which left me feeling a more competent and confident research student, one armed with much knowledge about the theory and practice of qualitative and quantitative research methodologies applicable to healthcare.

During the third module, “Publication and Dissemination” the learning involved covered issues of plagiarism, journal impact factors, the political influence of journal editors and editing. This essential knowledge prepared me for dissemination of my research findings to the wider community through journal publications. Due to time commitments involved with study, work and family, I have not been able to publish during the programme. However, I do plan to publish in a high impact journal such as the Journal of Advanced Nursing, or the British Journal of Nursing, and present my findings at the ‘British Committee for Standards in Haematology’ Conference following completion of the course.

The outcome of the final taught module was successful completion of a research proposal and submission through an NHS research ethical
committee. This module introduced me to the ethical and research governance frameworks (DH, 2005) within the NHS and my own working environment. Over the eighteen months I expanded my academic horizons which helped my professional development and clinical practice. It was tremendously hard work, requiring excellent time management skills and determination to enable me to complete on time and fit with my other obligations and responsibilities. However, it fully prepared me for Part 2 of the thesis programme during which I developed academically, professionally and personally.

During Part 2 of the PD I became more autonomous in the planning and management of my own learning. I gained the confidence to provide authoritative solutions when presented with practical problems within my professional arena and became more able to make significant and original contributions to professional practice. With my increased knowledge and confidence, my relationship with colleagues changed. I gained their attention and respect in providing professional and intellectual leadership, inspiration and motivation, and became mentor to two students undertaking their degrees in haematology nursing. I was also involved in regular teaching both to individuals and to groups about haematological cancer issues.

7.4 Reflection on changes to clinical practice
The standing I attained from undertaking the Professional Doctorate has allowed me the autonomy to lead changes for patient benefit in numerous areas of clinical practice:

- I instigated and operated my own nurse-led Myeloproliferative Disease clinic once a week.
- I set up and operated my own nurse-led Peripherally Inserted Central Catheter (PICC) service which I audited. The audit findings were presented at a Trust conference which the Chief Executive and Director of Nursing attended. The service was established after winning the ‘Researcher of the Year’ award for my MA findings, which presented me with a £1000 prize. I spent the money training to insert PICC lines
to establish this single-handed service, where I placed over 1000 PICCs in; haematology and oncology patients, coronary care unit patients and intensive care unit patients.

- I set up and operated my own weekly bone marrow biopsy service performing almost all the biopsies required by haematology patients.
- I co-authored the Trust Central Venous Line Policy and personally wrote two Patient Group Directives.

7.5 Challenges during the PD programme

During the final stage of my PD, there have been several challenging personal issues to address which delayed completion of my thesis. My interruption from studies ended on 18th April 2016 and I returned to my study. I have been given assurance by my haematology clinical supervisor that the findings from my thesis and implications for clinical practice are relevant and applicable to the clinical area. My supervisor has also confirmed that shortly before submission some changes have been made.

A further issue, which was overwhelmingly disappointing, was that the Trust decided not to appoint any more nurse consultants, this decision being made after I and five other nurses had completed a 64-hour workshop to complete a consultant practitioner development training programme. Although disappointing, I was bolstered by the fact that I had been chosen from a substantial number of applicants, because of the intellectual standing and respect I had gained within the Trust from undertaking the PD programme and the learning experiences this had provided.

Another stumbling block was the change to my original PD proposal which was to explore the effect of cranberries in reducing infection in haematology patients. After spending many months of writing the proposal for an “NHS National Institute for Health Research, Research for Patient Benefit” grant, collaborating with the Research and Development unit at my employing Trust to secure “Trust sponsorship”, collaborating with the lead trust pharmacist, the statistician from the University of Portsmouth and with my academic supervisor, we were unsuccessful in securing the grant and the project had to
be abandoned. It was, however, an important learning experience, which involved interacting and networking with multidisciplinary teams across different sites, which is a necessary facet of the research process.

I had anticipated that the NHS ethical review process would be harrowing. To complete the Research Ethics Committee Submission form, I had researched in depth, through published literature and by discussing with the palliative/end of life consultant at my employing Trust how to manage any issues that arose at the ethics meeting. My PD learning provided the knowledge and confidence I required at the review meeting which was successful first time.

In the act of narrating participants’ stories, I was able to make sense of their experiences, but keeping to the word count has proved incredibly difficult. I tend to be a verbose writer and examining experience through three dimensions resulted in copious data, but with my PD learning and the help of my supervisors, I have learnt to master this weakness and write more succinctly.

Undertaking this Professional Doctorate qualification has been arduous but incredibly rewarding and has fulfilled my lifetime ambition. In broadening my academic horizons, my self-esteem has grown, I am a changed person, broader in knowledge and able to challenge those I once believed superior or with higher intellect. But it is work in progress, I have spent a lifetime learning, it is my comforter and I cannot imagine life without study. It gives coherence and meaning to my life and allows me to make a positive difference to peoples’ lives, therefore my learning and sharing of knowledge must continue.

7.6 A sincere “thank you” note to all the participants in this study
This thesis ends with my overwhelming gratitude and a sincere “thank you” to all the poorly participants in this research study who gave their time altruistically to highlight matters associated with BT that were important to them, solely for the benefit of future patients. Thus, in gratitude and dedication to the stoic participants who took part in this study, this thesis ends with the words of Dame Cicely Saunders (1919-2005), words which provide a key
message for all healthcare professionals in their daily clinical practice and relationship with patients:

You matter
because you are you
and you matter
to the end of your life

We will do all we can
not only to help you die peacefully
but also
to live until you die
(Dame Cicely Saunders, 1918-2005).
References


BMJ. (2000). Risk of infection from blood transfusion in UK is negligible. *British Medical Journal* Feb 12; 320(7232): 0. PMCID: PMC1117520 PMID:10669474


ISSN 1438-5627. Available at: http://www.qualitativeresearch.net/index.php/fqs/article/view/2290


treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. *Palliative medicine.* May; 16(3):195-204.


Vo, L.C., Mounoud, E., Rose, J. (2012). Dealing with the opposition of rigor and relevance from Dewey’s pragmatist perspective *M@n@gement* Vol. 15. No. 4: 367-390


Appendices

Appendix 1 Examples of haematological malignancies, presenting features, routes and settings treatments administered

<table>
<thead>
<tr>
<th>Haematological Diseases</th>
<th>Common Presenting Clinical features</th>
<th>Routes and settings treatments administered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute leukaemia (myeloid or lymphoblastic)</td>
<td>Patients commonly very unwell with symptoms of fatigue and serious infection, anaemia, bruising/bleeding</td>
<td>Aggressive induction intravenous chemotherapy, followed by cycles of consolidation chemotherapy and bone marrow transplant if eligible. Patients with acute lymphoblastic leukaemia may in addition receive intrathecal chemotherapy. Months of in-patient hospitalization necessary. Elderly patients not suitable for intensive treatment may receive oral or subcutaneous chemotherapy with blood transfusion support.</td>
</tr>
<tr>
<td>Chronic myeloid leukaemia</td>
<td>Fatigue, weight loss, night sweats, anaemia, splenomegaly.</td>
<td>Generally oral chemotherapy as an out-patient. Occasionally bone marrow transplant and blood transfusions.</td>
</tr>
<tr>
<td>Chronic lymphoblastic leukaemia</td>
<td>May be asymptomatic, or present with night sweats / symptoms of anaemia.</td>
<td>May require no treatment / oral or intravenous chemotherapy, generally, as a day case patient. Blood transfusions may be necessary.</td>
</tr>
<tr>
<td>Lymphomas (Hodgkins or Non-hodgkins)</td>
<td>Many patients present with palpable lump. weakness, fatigue, fever, anaemia, night sweats, weight loss, enlarged spleen /liver</td>
<td>Low grade may require no treatment initially following a ‘watch and wait’ regime for instance in follicular lymphoma. High grade lymphomas generally require intravenous cycles of chemotherapy / radiotherapy administered in an outpatient hospital setting. Or may need BMT. Blood transfusions may be necessary</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Myeloma</td>
<td>End organ damage, frequently presenting with bone fractures, kidney problems, anaemia.</td>
<td>Numerous chemotherapy treatments available – oral or IV as an inpatient or day case patient. Blood transfusion supportive therapy.</td>
</tr>
<tr>
<td>Myelodysplastic syndromes</td>
<td>Patients are generally anaemic with related symptoms</td>
<td>Most patients require a blood transfusion. Chemotherapy administration, however, is largely dependent on factors, for instance, age, previous chemotherapy, number of blast cells in the blood or bone marrow. Some patients may receive AML treatment regime</td>
</tr>
</tbody>
</table>
Appendix 2 Letter of invitation to participant

Blood Transfusions in Palliative Haematology: Patient Stories

Dear Mr / Mrs

My name is Laraine Lloyd. I am a registered nurse specialised in the care of Haematology patients. I am currently undertaking a research study as part of a professional doctorate in nursing at the University of Portsmouth.

The purpose of the study is to try and understand the experiences of patient’s (like yourself) of attending the hospital or hospice for regular blood transfusions after being diagnosed with a palliative stage haematological illness. Little research has been conducted on outpatients like you who need regular blood transfusions. I would like to hear your experiences as it is hoped that by asking patients themselves about their experiences it may help the nurses and doctors to understand patient’s needs so that we may find more ways to support them.

I am hoping to interview 15-20 patients during a twelve-month period between April 2012 and April 2013. If you are willing to take part, you will be invited to share your stories about your experiences of having blood transfusions. Taking part in the study would involve you being interviewed by me on three occasions. The interviews will take place on the same day and in the same setting as you are having your blood transfusion, unless you would prefer for me to come out to your home to conduct the interview. Family or friends are invited to be with you during the interview, if you prefer.

The interview will be audio recorded and will last between 20 minutes to 1 hour, depending on what you would like to share at interview. You can stop the interview at any time.
I have attached a copy of the information sheet, which gives more details on what taking part in the study involves. Take your time reading this information and please feel free to show it to your family, friends or GP. If you would like to find out more about taking part in this research study or would like to discuss the study further, any of the following people would be more than happy to discuss it with you:

**Laraine Lloyd** Haematology Nurse Practitioner 01256 313925 or 01256 433202 Bleep 1143

*(Names have now been removed for confidentiality).*

**Thank you for reading this letter.**

Laraine Lloyd
Appendix 3 Participant information sheet

Study title

Blood Transfusions in Palliative Haematology: Patient Stories Version 1

Invitation paragraph

You are being invited to take part in a research study about your experiences of having a blood transfusion. Before you decide whether to take part, it is important for you to understand why this research is being done and what it will involve. Please take as much time as you wish to read the following information carefully and discuss it with your family, friends, GP or any of the contacts at the end of this information sheet, if you wish. Please do not hesitate to ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of this study is to try and understand what it is like for patients to attend the hospital or hospice regularly to have a blood transfusion after being diagnosed with an illness that affects your bone marrow (haematological illness)

Why have I been chosen?

You are being asked to take part in this study because you have a haematological illness and you have blood transfusions regularly.

Do I have to take part?

You do not have to take part in this study. It is completely up to you whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form during your next appointment for your blood transfusion. If you decide to take part, you are
still free to withdraw at any time and without giving a reason. This will not affect your legal rights or the standard of care you receive now or in the future.

What will happen to me if I take part?

- The researcher will ask for your permission to write to your GP to let them know that you are taking part in this study.
- The researcher will ask your permission to take information from your medical notes. Information such as, your date of birth, your diagnosis, your marital status, the date when you had your first blood transfusion and the dates of all the blood transfusions you have had since
- On the day of your blood transfusion you will be asked to fill out a short health questionnaire. The questionnaire has 5 short questions which will ask you to rate your health on that day. It is expected to take just a few minutes to complete. Please do not worry the researcher will show you the questionnaire and go over it with you and explain what is needed.
- You will be interviewed about your experiences of having blood transfusions. The interview will take place where you are having your blood transfusion (either the haematology day unit or the hospice day unit), or if you prefer the researcher can come to your home to interview. Family or friends are invited to be present during the interview if you would like them to be.
- Following your first interview you will be interviewed on the day of your next two blood transfusions. **You will be interviewed a maximum of three times in total**
- It is anticipated that interviews will last about 20 minutes to an hour depending on what information you want to share. When you want to stop the interview, it will be stopped immediately.
- The Researcher will check with you during the interview to make sure you are comfortable and would like to continue. If you want to stop for any reason and continue the interview at another time it is ok to do this.
- The interviews will be tape recorded and later written up by the researcher. If you do not want to be taped the researcher may take
notes throughout the interview to make sure that what you have told her is noted down and not forgotten.

• You will be offered a copy of what has been written up (a transcript) so that you can change, cross out or add anything on this transcript. You do not have to read the transcript if you do not want to

If you decide to take part in this study, you will not be required to make any additional visits to the hospital or have any additional blood tests.

**How long will I be in the study?**

Once you have consented to take part in the study you will be interviewed at your next blood transfusion appointment. Following this first interview you will be interviewed two more times. It is hoped that these interviews will happen consecutively (that is one after the other at each blood transfusion appointment). Usually blood transfusions are given 2 - 3 weeks apart. This means that you may be in the study between 6 – 9 weeks in total.

The study will be conducted over a 12-month period and it is hoped to recruit between 15 - 20 people in total.

**What are the possible disadvantages and risks of taking part?**

Discussing your experiences may make you feel sad or emotional and may be distressing.

A counsellor, who is specialised in caring for patients with your type of illness, is employed at the Trust to provide support and advice. She is available to help you if you would like to see her.

**What are the possible benefits of taking part?**

You may not receive any direct benefit from taking part in this study, however, we are hoping that talking about your experiences and ‘sharing your stories’ may help you and other patients in the future.

It is hoped that the information you provide will enable our blood transfusion care to be improved based on what you tell us.
What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. Any of the people listed at the end of this information sheet will be happy to advise you on how to do this, if needed.

Will my taking part in this study be kept confidential?

- Your GP will be informed that you are taking part in this study
- Only the researcher and the medical team taking care of you will have access to any study information
- The researcher will need your permission to use personal details taken from your medical notes, including for instance; your date of birth, your diagnosis and your marital status. Confidentiality of your medical records will be maintained throughout the study
- All information which is collected about you during the course of this study will be kept strictly confidential. Information about you will not have your name on it, so that you cannot be recognised from it.
- All study data will be kept in a locked cupboard that can only be accessed by the researcher
- Any study information on the researcher’s computer will be password protected
- When the final report of the study is made, and the results are published you will not be individually identified.

What will happen when the research study stops?

When the research study stops you will be offered a summary of the information gained during the study. This information may help decide how best to treat patients, like you, in the future.

What will happen to the results of the research study?
• A report of the study will be written up. The researcher will seek to publish an article in a suitable nursing journal. The results may also be presented at a suitable conference.
• You will be offered a copy of this report if you would like to receive a copy. The researcher will discuss this with you during your blood transfusion.

Who is organising and funding the research?

Sponsorship for the study has been gained from (name of the employing hospital) Hospitals NHS Foundation Trust. There has been no application for funding.

Who has reviewed the study?

• The study’s research steering group from The NHS Trust. This group includes two members from the ‘Patient Voice Forum’ and ‘Cancer Partnership Group’ (who are a panel of general public volunteers).
• A letter explaining the study has been sent to your medical consultant, the director of nursing and the modern matron for cancer services.
• The University of Portsmouth Ethics Committee.
• The Hospitals Research and Development Clinical Governance Committee

(Address removed for confidentiality)

The Local Research Ethics Committee has approved this study. Approval does not mean that you are recommended to take part. You are entirely free to make that decision yourself.

What will happen if I have questions when I am in the study?

If you decide to take part in the study please feel free to ask questions concerning the study, or seek help or advice, at any time from any of the following people;

Names removed for confidentiality
How you can get more information before you decide whether to take part or not?

If you have any questions concerning this study or require additional information, please do not hesitate to contact any of the people listed above who will be more than willing to offer advice or support. Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London, N16 0BW. Your CNS (names) will be pleased to obtain a copy for you.

You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.
Appendix 4 Participant Consent Form

Blood Transfusions in Palliative Haematology: Patient Stories Version 1

please write your initials in each box

I have read and understood the information sheet (version 1, dated 11 January 2012) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.

I understand that the interviews will be tape recorded but that I can stop the interview at any time without having to give an explanation.

I understand that my medical notes may be looked at by the researcher and that all information will remain strictly confidential.

I agree that all information collected about me as part of the study can be stored and analysed by the research team in this study.

I understand that what I say may be quoted anonymously when the results of this research study are reported.

I agree to take part in the above study.

Name of participant        Signature        Date

Name of practitioner        Signature        Date
CASE REPORT FORM

Blood Transfusions in Palliative Haematology: Patient Stories.

Version 1. 11/01/2012

CLINICAL STUDY SITE: (Name of Hospital)

Chief Investigator: Laraine Lloyd

SITE BLOOD TO BE ADMINISTERED: (Please circle as appropriate)

- Haematology Day Unit
- Hospice
- Community Hospital

I am confident that the information supplied in this case record form is complete and accurate data. I confirm that the study was conducted in accordance with the proposal and any proposal amendments and that written informed consent was obtained prior to the study.

Investigator’s signature:

Date of Signature:
SCREENING VISIT

Date:

Inclusion Criteria: [Please circle as appropriate]

1. Has the participant willingly given written Informed Consent? YES NO

2. Is the participant aged between 18 and 90? YES NO

3. Does participant have a palliative phase haematological malignancy or illness? YES NO

4. Has participant ceased to receive curative chemotherapy? YES NO

5. Is participant receiving blood transfusions within HDU or Hospice or community hospital? YES NO

If any criteria are circled NO then the participant is not eligible for the study

Exclusion Criteria:

1. Participant is unable to provide Informed consent YES NO

2. Participant is cognitively impaired YES NO

3. Participant is unable to speak or understand English sufficiently to take part in this study YES NO

4. Participant is aged below 18 or over 90 YES NO

If any criteria are circled YES then the participant is NOT eligible for the study
### SCREENING VISIT

#### INFORMED CONSENT

Please note: written informed consent must be given before any study specific procedures take place for the purpose of participation in this study.

Has the participant freely given written informed consent? (Please circle as appropriate) **YES** **NO**

#### DEMOGRAPHIC DATA: (please circle as appropriate)

- **Age (years):**
- **Gender:** FEMALE MALE
- **Marital Status:** Married (M) Widowed (W) Single (S) Divorced (D)

#### PREVIOUS BLOOD TRANSFUSION (BT) HISTORY: (please circle)

Has the participant previously had a blood transfusion? **YES** **NO**

How many previous BT has participant had?

Date of first ever BT?

#### HAEMATOLOGICAL DIAGNOSIS: (please circle as appropriate)

Does the participant have a haematological malignancy **YES** **NO**

If yes, please circle disease category below:

- AML
- ALL
- CML
- CLL
- NHL
- HD
- MYELOMA
- MDS
## SCREENING VISIT

**MEDICATIONS TAKEN:** (please circle as appropriate)

Is Participant currently taking any medicine? **YES ** **NO**

If **YES** Please record all medications below:

1. 
2. 
3. 
4. 
5. 

---

### PHASE OF HAEMATOLOGICAL DISEASE / ILLNESS

(Opinion regarding phase of disease to be assessed only by participants' medical team and phase documented in medical notes)

<table>
<thead>
<tr>
<th>PHASE</th>
<th>DEFINITION (please circle as appropriate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Palliative Phase</td>
<td>The patient is incurably ill</td>
</tr>
<tr>
<td></td>
<td>The condition typically lasts twelve months</td>
</tr>
<tr>
<td>Late Palliative Phase</td>
<td>The participant is incurably ill</td>
</tr>
<tr>
<td></td>
<td>The condition typically lasts for months</td>
</tr>
<tr>
<td>Terminal Palliative Disease</td>
<td>The patient is terminally ill and dying</td>
</tr>
<tr>
<td></td>
<td>The condition leads to death within days/weeks/less than six months</td>
</tr>
</tbody>
</table>
SCREENING VISIT

<table>
<thead>
<tr>
<th>HAEMOGLOBIN LEVEL PRE-TRANSFUSION (TODAY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date today</td>
</tr>
<tr>
<td>Haemoglobin level (g/dL)</td>
</tr>
</tbody>
</table>

End of visit checklist: to be completed by investigator (Please circle as appropriate)

1. Does the participant satisfy inclusion and exclusion criteria  YES NO

2. Have all screening procedures been completed  YES NO

3. Has concomitant medication page been completed  YES NO

4. Is the Participant willing to proceed  YES NO

Investigator

Is the Participant to continue  YES NO

Signature  Date
FIRST BLOOD TRANSFUSION SINCE RECRUITMENT

Date

<table>
<thead>
<tr>
<th>PHASE OF HAEMATOLOGICAL DISEASE / ILLNESS (Opinion regarding phase of disease to be assessed only by participant’s medical team and phase documented in medical notes.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHASE</td>
</tr>
<tr>
<td>Early Palliative Phase</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Late Palliative Phase</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Terminal Palliative Phase</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HAEMOGLOBIN LEVEL PRE-TRANSFUSION (TODAY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date today</td>
</tr>
<tr>
<td>Haemoglobin level (g/dL)</td>
</tr>
</tbody>
</table>

HAS PARTICIPANT COMPLETED EUROQoL HEALTH QUESTIONNAIRE (Please circle as appropriate)

**YES** **NO**

If NO Investigator to complete WHO Performance Status below:
### FIRST BLOOD TRANSFUSION SINCE RECRUITMENT

#### WHO PERFORMANCE STATUS

<table>
<thead>
<tr>
<th>Status</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. Light housework, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of self-care but unable to carry out work activities. Up and about for more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self-care, confined to bed or chair for more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry out any self-care. Totally confined to bed or chair</td>
</tr>
</tbody>
</table>
**SECOND BLOOD TRANSFUSION SINCE RECRUITMENT**

**Date**

<table>
<thead>
<tr>
<th>PHASE OF HAEMATOLOGICAL DISEASE / ILLNESS</th>
<th>(Opinion regarding phase of disease to be assessed only by participant’s medical team and phase documented in medical notes.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHASE</strong></td>
<td><strong>DEFINITION</strong> (please circle as appropriate)</td>
</tr>
</tbody>
</table>
| Early Palliative Phase                  | The patient is incurably ill  
The condition typically lasts twelve months.                                      |
| Late Palliative Phase                   | The participant is incurably ill  
The condition typically lasts for months **YES**                                               |
| Terminal Palliative Phase               | The patient is terminally ill and dying  
The condition leads to death within days/weeks/less than six months **YES** |

**HAEMOGLOBIN LEVEL PRE-TRANSFUSION [TODAY]**

Date today

Haemoglobin level (g/dL)

**HAS PARTICIPANT COMPLETED EUROQoL HEALTH QUESTIONNAIRE**  
(Please circle as appropriate)

**YES**  **NO**

If NO Investigator to complete WHO Performance Status below:
## SECOND BLOOD TRANSFUSION SINCE RECRUITMENT

### WHO PERFORMANCE STATUS

<table>
<thead>
<tr>
<th>Status</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. Light housework, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of self-care but unable to carry out work activities. Up and about for more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self-care, confined to bed or chair for more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry out any self-care. Totally confined to bed or chair</td>
</tr>
</tbody>
</table>
THIRD BLOOD TRANSFUSION SINCE RECRUITMENT

Date

<table>
<thead>
<tr>
<th>PHASE OF HAEMATOLOGICAL DISEASE / ILLNESS</th>
<th>(Opinion regarding phase of disease to be assessed only by participant’s medical team and phase documented in medical notes.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHASE</strong></td>
<td><strong>DEFINITION</strong> (please circle as appropriate)</td>
</tr>
<tr>
<td>Early Palliative Phase</td>
<td>The patient is incurably ill</td>
</tr>
<tr>
<td></td>
<td>The condition typically lasts twelve months.</td>
</tr>
<tr>
<td>Late Palliative Phase Disease</td>
<td>The participant is incurably ill</td>
</tr>
<tr>
<td></td>
<td>The condition typically lasts for months <strong>YES</strong></td>
</tr>
<tr>
<td>Terminal Palliative Phase Disease</td>
<td>The patient is terminally ill and dying</td>
</tr>
<tr>
<td></td>
<td>The condition leads to death within days/weeks/less than six months <strong>YES</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HAEMOGLOBIN LEVEL PRE-TRANSFUSION [TODAY]</th>
<th>Date today</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Haemoglobin level (g/dL)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HAS PARTICIPANT COMPLETED EUROQoL HEALTH QUESTIONNAIRE</th>
<th>(Please circle as appropriate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

If NO Investigator to complete WHO Performance Status below:
## THIRD BLOOD TRANSFUSION SINCE RECRUITMENT

### WHO PERFORMANCE STATUS

<table>
<thead>
<tr>
<th>Status</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. Light housework, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of self-care but unable to carry out work activities. Up and about for more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self-care, confined to bed or chair for more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry out any self-care. Totally confined to bed or chair</td>
</tr>
</tbody>
</table>
## OFF STUDY FORM

**DATE OFF STUDY:**

<table>
<thead>
<tr>
<th>Reason Off Study</th>
<th>(Please circle only the primary reason. Reasons other than completed study require explanation next to the response)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed Study</td>
<td></td>
</tr>
<tr>
<td>Lost to follow up</td>
<td></td>
</tr>
<tr>
<td>Non-compliant participant</td>
<td></td>
</tr>
<tr>
<td>Concomitant medication</td>
<td></td>
</tr>
<tr>
<td>Medical contra-indication(s)</td>
<td></td>
</tr>
<tr>
<td>Withdraw consent</td>
<td></td>
</tr>
<tr>
<td>Death</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 6 Initial conversation prior to first, second and third interview and prompts employed in study

#### Prior to the start of our first interview
Hello (patient’s name) Thank you very much for agreeing to take part in our study and for agreeing to talk to me today. I really appreciate it. I would like you to tell me in your own words and in your own way about your experiences around blood transfusions. I want you to know that it’s fine to stop whenever you want. Please just tell me when you want to stop. Perhaps we could talk initially about ‘how did it all begin’, when did you start having blood transfusions, and ‘then what happened’?

#### Prior to the start of our second interview
Hello, thank you for agreeing to see me again today and talk through your experiences of blood transfusions. The last time we talked about your experiences of blood transfusion we talked about how they made you feel and any benefits that you got from them, we talked about your knowledge of blood transfusions and the importance of them to you. We also discussed any worries or concerns that you may have about BT. Perhaps we can just go over some of that again to make sure I understood what you meant. Then, perhaps today we could also talk about what it’s like for you coming up here to the unit for your blood transfusion, but let’s just start off by you telling me how you have been since your last transfusion.

#### Prior to the start of our third meeting (interview).
Hello. Thank you for agreeing to see me again. Please we could go over a few things to make sure I understood what you meant when we talked about…. First, perhaps you could tell me how you have been since we last met. Please stop whenever you want. Are you ok to continue? Do you have any other stories about blood transfusions that we haven’t talked about that you could share with me?
Examples of prompts employed in this narrative study that related to the three-dimensional space

**Personal / social (feelings, expectations, challenges, concerns);**

Please could you tell me how you feel about BT
Please could you tell me how receiving BT affects you
Please could you tell me any worries or concerns that you may have about BT
The effect of your last BT how was it?
How do you think you would be today, if you had not had your last blood transfusion?
Could you imagine any circumstances that would make you not want to come in for your BT?
I would like to move on to what has happened today.
Please could you tell me in as much detail as possible about your day so far, since you got up this morning

**Place (feelings about setting, difficulties associated with setting);**

Please could you tell me about your day here on the day unit
Please could you describe in as much detail as possible your day so far since you got to the Unit.
What happened when you got here?
Could you tell me what you expect to happen today?

**Temporality: how the experience changed over time;**

Please could you tell me how did it all begin, when did you first start having blood transfusions?
In the beginning how often were you having BT. Then what happened
Please could you tell me if you think your experiences have changed since you first started having blood transfusions
Appendix 7 EQ-5D-3L Health Questionnaire

REC: 12/SC/0282
Participant study Name/number:
Date:

**Blood Transfusions in Palliative Haematology: Patient Stories**

Version number 1. 11/01/2012

Health Questionnaire

*English version for the UK*

*(validated for Ireland)*
By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** (e.g. work, study, housework, family or leisure activities)
- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed
### Appendix 8 Findings from participant's self-reported EQ-5D-3L health questionnaire or WHO performance status tool

<table>
<thead>
<tr>
<th>PARTICIPANT NAME &amp; INTERVIEW NUMBER</th>
<th>MOBILITY SCORE</th>
<th>SELF-CARE SCORE</th>
<th>USUAL ACTIVITIES SCORE</th>
<th>PAIN DISCOMFORT SCORE</th>
<th>ANXIETY DEPRESSION SCORE</th>
<th>VAS HEALTH STATE SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenneth.1 Int.1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>55</td>
</tr>
<tr>
<td>Kenneth.1 Int.2</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>80</td>
</tr>
<tr>
<td>Kennet. 1 Int.3</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>75</td>
</tr>
<tr>
<td>Jim. 2 Int.1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>40</td>
</tr>
<tr>
<td>Jim. 2 Int.2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>40</td>
</tr>
<tr>
<td>Jim. Int.3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>40</td>
</tr>
<tr>
<td>Harold. Int.1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>70</td>
</tr>
<tr>
<td>Harold. Int.2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>75</td>
</tr>
<tr>
<td>Harold. Int.3 Unable to complete self-reported health questionnaire WHO status 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lily. Int.1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>50</td>
</tr>
<tr>
<td>Lily. Int.2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>50</td>
</tr>
<tr>
<td>Lily. Int.3</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Ernest. Int.1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>40</td>
</tr>
<tr>
<td>Ernest. Int.2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>35</td>
</tr>
<tr>
<td>Ernest. Int.3</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>55</td>
</tr>
<tr>
<td>Helen. Int.1</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>45</td>
</tr>
<tr>
<td>Helen. Int.2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>29</td>
</tr>
<tr>
<td>Bill. Int.1</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>50</td>
</tr>
<tr>
<td>Bill. Int.2</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Zavier. Int. 1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>90</td>
</tr>
<tr>
<td>Zavier. Int. 2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>40</td>
</tr>
<tr>
<td>Zavier. Int. 3</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>50</td>
</tr>
</tbody>
</table>
Appendix 9 Ethics Committee approval letter

Health Research Authority
NRES Committee South Central - Portsmouth
Bristol Research Ethics Centre
Level 3, Block B
Whitefriars Lewins Mead
Bristol BS1 2NT
Telephone: 0117 3421334
Facsimile: 0117 342 044

22 May 2012

Mrs Laraine Lloyd
Haematology Nurse Practitioner
(Name and address of hospital removed)

Dear Mrs Lloyd

Study title: Blood Transfusion Storylines: Qualitative Study of Patients' Experience of Receiving Blood Transfusions throughout Late-Terminal Palliative Trajectory of a Haematological Malignancy

REC reference: 12/SC/0282

The Research Ethics Committee reviewed the above application at the meeting held on 18 May 2012. Thank you and your colleague, Dr Simpson, for attending to discuss the study.

The research intends to listen to the voice of the day patient who regular attends hospital for blood transfusions despite being terminally ill. The Committee asked you to give the context of the participant's prognosis. You reported that you would be interviewing those who are in the terminal stage of their disease and at the palliative stage of their treatment, so within the last 12 months of their life. The participant may have between around six months and a few weeks left to live.

The Committee asked you to give your rationale for your sample size. You reported that a recent audit has shown that patient numbers have recently greatly increased on your unit. You have considered that you may need to extend the study period to two years.

The Committee asked you whether you were concerned that the consultants will not refer any patients to you as potential participants. You reported that you know those you are working with very well and you have no concerns that they will refer to you if they feel the patient is suitable to take part. The clinicians are well experienced at working with palliative patients and do not treat them paternalistically.

The Committee asked you to clarify your reasoning for completing three interviews. You explained that you wish to capture the experience of those who are close to death but are still coming in and out of hospital regularly for transfusions. You reported you are interested in how the experience changes for the patient as they move towards their death and their disease progresses. You wish to interview the same individual at different time points as this makes for more valid and comparable results. The burden on the participant has been considered and discussed at the steering group. You reported that you appreciate the time taken by the participant and will lead a gentle conversation taking regular breaks to check on the participant and whether they wish to stop or rest.
You asked the Committee for their advice regarding the feedback of results to study participants. You explained that you have received divided opinions regarding how best to manage this. There is an argument that asking the participant to read their transcript is burdensome, however, the counter argument states that by giving the participant their transcript to read they are able to take ownership of their contribution and make any changes they wish to. You reported that you had considered the best solution to be discussing the results with the participant and offering them the opportunity to receive feedback if they wish. The Committee reported that it had had very similar deliberations and agreed that you had offered an appropriate solution. The Committee suggested it was made clear to participants that even where they do agree to receive feedback, they are still free not to read it if they so wish. You agreed this would be conveyed.

You asked the Committee for its opinion regarding patients who die before the results become available to feedback and whether their relatives should be informed of the results in their place. The Chair reported that the Committee would give the issue some consideration. You reported that you had considered methods of dissemination such as including a summary in the leukaemia newsletter. You confirmed that if relatives of deceased participants did receive the results, these would be themes only; they would not be individual transcripts. Dr Simpson explained that when a patient dies; their relatives are offered an appointment to discuss clinical matters and any other related information, such as participation in research.

The Committee asked you to clarify whether you are involved in the care of the participants. You explained that you will know the majority. You clarified that you are not generally involved in giving transfusions but is called upon if there is a problem. You have given some consideration to the issue of being a researcher and a nurse and explained that you will be very clear that you are a researcher not a nurse, will not wear uniform nor carry a bleep. However, your duty as a nurse remains and you would advise if and when necessary. These dual roles will be documented in the study write up.

The Committee noted that the application refers to a counsellor from the Trust and questioned whether this counselling would be available immediately if required and whether the counsellor was aware of the planned project. You explained that there is always a counsellor on hand (i.e. there is cross cover) and this is made known to patients at the time of their diagnosis. The counsellor will be well informed that the study is underway.

The Committee noted that you have considered your own safety by providing your risk assessment and lone working policy for any potential home visits.

The researchers were thanked for attending and left the meeting. The discussion continued as follows:

The Committee commented that it had been useful to meet the student researcher who had managed the discussion well and agreed it was confident in her ability to conduct the interviews despite the sensitive nature of the discussion.

The Committee discussed how to manage the dissemination of results to relatives of
patients who die during the research or before the results become available. It was agreed that the most appropriate course of action would be to offer the relatives information about receiving the study results at the follow up appointment described by Dr Simpson.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Please label the information sheet 'Participant Information Sheet' rather than 'Patient'.

In the invitation letter, please re-word the sentence 'At the moment, little is known about the experiences of patients like you... ' to read 'Little research has been conducted on out patients like you...' as it is less alarming to the reader.

Please confirm that you will ensure that quotes are not only anonymous but also unidentifiable, i.e. if a participant's quote contains information that could identify them such as details of their condition or family composition, you will change or remove these sections.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:
Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Dr Markham, Dr Saunders and Mr Cassidy work in the same department as Dr Ann Dewey, the supervisor on this project. The members have no knowledge of the project and it was agreed they should remain in the room and take full part in the discussion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review - guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td></td>
<td>26 April 2012</td>
</tr>
<tr>
<td>GP/Consultant Information Sheets</td>
<td></td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>10 April 2012</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td>23 April 2012</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: CV for Academic Supervisor</td>
<td></td>
<td>24 April 2012</td>
</tr>
<tr>
<td>Other: CV for Laraine Lloyd</td>
<td></td>
<td>10 April 2012</td>
</tr>
<tr>
<td>Other: Appendix 3 Patient Pathway</td>
<td></td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: Appendix 8 GANTT Chart</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: Appendix 5 CASE REPORT FORM</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: Appendix 9 Confidentiality Policy CO/226/1O</td>
<td></td>
<td>18 October 2010</td>
</tr>
<tr>
<td>Other: Appendix 10 Information Governance Policy CO/192/11</td>
<td></td>
<td>24 March 2011</td>
</tr>
<tr>
<td>Other: Appendix 11 Lone Worker Policy CO/310/10</td>
<td></td>
<td>17 December 2010</td>
</tr>
<tr>
<td>Other: Appendix 14 Consultant Information Sheet</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: Appendix 15 thematic Analysis of Data</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: Appendix 16 WHO Performance Status Tool</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Other: CV of Haematology Nurse Specialist</td>
<td></td>
<td>15 June 2010</td>
</tr>
<tr>
<td>Other: CV of Clinical Supervisor</td>
<td></td>
<td>22 February 2010</td>
</tr>
<tr>
<td>Other: Board of Examiners Progression Letter</td>
<td></td>
<td>02 April 2012</td>
</tr>
<tr>
<td>Other: Research Risk Assessment for Trust Sponsorship</td>
<td></td>
<td>12 April 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Appendix 2 Patient Consent Form</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: Appendix 1, Patient Information Sheet</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
<tr>
<td>Protocol</td>
<td></td>
<td>1.0</td>
</tr>
<tr>
<td>Questionnaire: Appendix 7, EQ-5D health Questionnaire</td>
<td></td>
<td>1.0</td>
</tr>
<tr>
<td>REC application</td>
<td>1.0</td>
<td>01 May 2012</td>
</tr>
<tr>
<td>Referees or other scientific critique report</td>
<td>1.0</td>
<td>11 January 2012</td>
</tr>
</tbody>
</table>
Notifying substantial amendments
Adding new sites and investigators
Notification of serious breaches of the protocol
Progress and safety reports
Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/SC/0282 Please quote this number on all correspondence

12/SC/0282 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project Yours sincerely

Dr Chris Markham
Chair

Email: scsha,sehrec@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review - guidance for researchers" - sent via e-mail

Copy to: Mrs C P, name of hospital
Appendix 10 Research risk assessment for Trust sponsorship

Please complete the box below with details of the study:

Chief Investigator: Laraine Lloyd
Study title: Blood Transfusions in palliative haematology: Patient Stories [Version 1. 11/01/2012]

| study of medicines: | Yes [ ] No [x] |
| R&D Reference Number: |
| Funding Body: | Not Applicable |

Please use the guidance tables (included on the 'Ratings Guide' worksheet) to rate the likelihood and different impacts of each of the risks below. Please also document the controls that are in place and how effective they are.
|   | Participant rights | 1.1 | Entry onto the study without fully informed consent | LL | 1 | 1 | 2 | L | All clinical staff involved in the study are up to date with GCP training. The following controls are in place to ensure that entry to the study without Informed Consent is negligible: The patient's Consultant will act as 'Gatekeepers' to protect the interests of their patients. They will only refer a patient if the patient would like to learn more about the study and agrees to their name being given to the researcher. Physicians will only refer to the researcher if they believe that: taking part in the study will not be detrimental to patient and patient has capacity to consent. L. Lloyd will consent patients. No interviews will be undertaken until written consent obtained & documented. | 1 | F | L. Lloyd takes 'Informed Consent' as a normal part of her clinical practitioner role, for instance, prior to doing a bone marrow biopsy, insert a central line or administer chemotherapy. All potential participants will be provided with a letter of introduction and a Patient Information Sheet to read. They will be given a minimum of 24hrs to think about participating. When they return to the hospital L. Lloyd will ask them if they have any concerns and if they would like to participate. If Yes she will obtain 'written Informed Consent' from those wishing to take part. One copy of consent will be filed in medical notes and one copy will be given to the patient. | Consider: Vulnerability of the patient/ study group and capacity to give consent, participant information, and training of those taking consent |
| 1.2 | Failure to act on patient's request to withdraw from the study | LL | 1 | 1 | 2 | 2 | L | If a patient requests to withdraw from the study, Lloyd will immediately withdraw that participant. Any data that has been collected on the participant will be destroyed if the participant requests this. | 1 | F | Tape recordings and transcripts will be destroyed at the patient's request if they no longer want to participate in the study. | Consider: Communication and recording systems |
| 1.3 | Failure to protect the privacy of participants | LL | 1 | 1 | 2 | 2 | L | All data collected on participants will be anonymised by coding with a study number. The Investigator file will be kept in a locked cupboard in the researcher's office. Analysis of coded data will be on the researcher's home computer which is password protected. Data will be backed up on an encrypted key. Her home has an alarm system. | 1 | F | Consider: Data protection and security systems, anonymisation |
| 2 | Participant safety | 2.1 | Expected adverse effects of the intervention | LL | 1 | 1 | 2 | 2 | L | Patient’s may become emotional or sad as they talk about their BT experiences. If a participant becomes distressed during the interview it will be stopped and only resumed when the participant feels comfortable to continue which may be another day or time or not at all. The over-riding responsibility of the researcher during this study is to abide by the NMC Code of Professional Conduct and protect the interests of the patients as a priority over gaining data for the study. The researcher has much experience in supporting patients who become distressed, alternatively, The Trust counsellor the haematology team, Palliative care team or PALS are always available to provide support and advice. | F | Much consideration was given to the ethical issues surrounding talking to these vulnerable patients about their experiences surrounding having a blood transfusion [BT]. Detailed considerations have been documented on the IRAS Ethical Review Form. | Consider: The nature of the intervention, experience of staff, susceptibility of the population (disease, genetic, age, sex), and if a medicinal product - development phase, licensing status, indications, clinical experience, pharmacology, drug handling requirements |
2.2 Unexpected adverse effects of the intervention

| LL | 1 | 1 | 1 | L | **No unexpected adverse effects are expected from participating in this study** | F |
### 2.3 Risks of the intervention outweigh the benefits

<table>
<thead>
<tr>
<th>LL</th>
<th>1</th>
<th>1</th>
<th>2</th>
<th>2</th>
<th>1</th>
<th>F</th>
</tr>
</thead>
</table>

The risks of participating in this study may outweigh the benefits for individual patients. Addington-Hall et al. [2009, p.4], highlights that because of the life-limiting condition of palliative patients there may not be a direct benefit from taking part in research, and the cost of participating in research will always, therefore, outweigh the benefits. They also stress, however, that even very sick patients may wish to participate in research because of: altruistic reasons in the hope that they can benefit others, to give something back to society, to make sense of their situation, enhancement of personal value, the assertion of continuing autonomy.

It has been suggested that interviewing patients, who have a palliative cancer diagnosis, about their experiences of care and treatment can be ‘therapeutic and empowering’. Sheldon and Sargeant [2009, p. 175] also make a valid point when they suggest that it is important not to deny palliative care individuals their right to choose to participate and the opportunity of having their voices and experiences heard and valued.

Consider: Systems to monitor and review adverse effects, maintain awareness and act on new knowledge. Ability/reliability of participants to report adverse events/outcomes.
<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2.4</td>
<td>Assessment methods are hazardous</td>
<td>LL</td>
<td>0</td>
<td>0</td>
<td>Not applicable</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Completion of the study</td>
<td>3.1</td>
<td>Insufficient resource to support the study</td>
<td>LL</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.2</td>
<td>Insufficient staff competence and experience</td>
<td>LL</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**Consider:** Procedures, e.g. biopsy, xray.

**Consider:** Staff resource required for the study

**Consider:** Skills and training required, e.g. Good Clinical Practice (GCP).
| 3.3 | Study and post-study costs exceed estimates | LL | 1 | 1 | 1 | L | As the study involves a very small questionnaire [which takes minutes to complete] and interviews, the study costs are minimal. L. Lloyd will assume the costs of this study | 1 | F | Consider: Estimation process, potential for additional costs |

| 3.4 | Collaboration with other organisations fail | LL | 0 | 0 | 0 | Not applicable | 0 | Not applicable | Consider: Number of organisations involved, written agreements/contracts/protocols, resource in the other organisations |
An audit demonstrated that 10 palliative haematology patients during an 8-month period last year received blood transfusions, that is approx. 15 per year. The number of palliative patients rises year on year. It is hoped to recruit 15-20 patients and to interview each individual a maximum of 3 times [that is, 45-60 interviews]. The published literature suggests that only 46% of palliative patients provide follow up data at 8 weeks. The minimum number of interviews for this study will be 20 interviews which will allow for saturation of data. [that is no new stories will be forthcoming]. The study period will be extended, if necessary to ensure that saturation of data has been achieved.

Consider: Profile of participants
<table>
<thead>
<tr>
<th></th>
<th>Reliability of Results</th>
<th>4.1 Expected effects are not plausible</th>
<th>LL</th>
<th>1</th>
<th>1</th>
<th>1</th>
<th>L</th>
<th>The research proposal for this study has been submitted to the University of Portsmouth Board for peer review. The board passed the submitted proposal with recommendations to be considered for strengthening the study. The recommendations will be incorporated into the study proposal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>F</td>
<td>Consider: Validation process for research project proposal</td>
</tr>
</tbody>
</table>
It is anticipated that a minimum of 15 patients will be recruited. This number will allow for saturation of data with no new insights or new stories forthcoming. As a qualitative approach is to be employed a 'non-probability' sampling method for selecting participants will be employed as statistical representation is not the aim. This allows the researcher to focus in on individual patients or groups which provide the most pertinent information relating to the research problem. What is most important is that the sample has the right characteristics to enable the researcher to collect 'rich' data to allow detailed exploration and understanding of the area under study.
| 4.3 | Major violation of eligibility criteria | LL | 1 | 1 | 1 | L | Minimal participant criteria will be applied to ensure that the study is fair and open to all those who would like to take part. |

**Inclusions** All adult patients who:
- have a documented late – terminal palliative phase haematological malignancy,
- are no longer receiving curative chemotherapy but may be receiving supportive therapy, for example, antibiotics, antiviral medications, platelet infusions
- are attending the haematology day care or hospice setting at (name of hospital) hospital for a BT
- are able to provide Informed Consent

**Exclusions:** Only patients who are unable to provide Informed Consent due to cognitive impairment, or who are unable to speak or understand English. Patients below the age of 18 or over 90 will be excluded. Also, those who decline to participate

**Consider:** Importance to the study, need for checking and possible procedures, unduly restrictive/ prescriptive eligibility criteria
| 4.4 | Fraud committed | LL | 1 | 1 | 2 | L | No finances are involved. Patient participation will be voluntary. No funding has been applied for. The data collected via interviews and the findings will be validated by Dr Simson and Dr Dewey academic supervisor. Participants will be given the opportunity to validate the transcripts | F |
|---|---|---|---|---|---|---|---|
| 4.5 | Failure of randomisation/blinding/unblinding processes | LL | 0 | 0 | 0 | Not applicable | 0 | not applicable |
| 4.6 | Incorrect outcome assessment | LL | 1 | 1 | 1 | L | The research findings / discussion will be submitted to the University of Portsmouth as a thesis | F |

**Consider:** The potential, financial/ non-financial incentives, consequences, options for checking

**Consider:** The robustness of the procedure, potential for loss of allocation concealment/unblinding

**Consider:** Single / double blinding, objectivity of measure, standardisation of assessment, independent review, external verification
4.7 Data is incomplete/inaccurate

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>LL</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>L</td>
<td>2</td>
</tr>
</tbody>
</table>

Interviews will be audio-recorded and transcribed verbatim. Participants will be offered the opportunity to check a copy of the transcripts to allow them to check that what they have said has been recorded accurately. DRs will act as 'Gatekeepers' on this matter and I will be guided by their advice.

Language texts will be entered into a qualitative data management computer program and analysed thematically. Initial coding and themes will be independently reviewed by a medical consultant and by an academic supervisor who has substantial experience in analysing qualitative data. Differences in themes will be discussed and adjusted where appropriate.

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

L. Lloyd has successfully completed an assessment module in qualitative data analysis during Professional Doctorate at University of Portsmouth. Also, she has attended a 3 day training course in the analysis of qualitative data at the University of Southampton. She has undergone training in the use of MAXQDA computer software for analysing qualitative data at the University of Southampton.

Consider: Data type and complexity, collection method, data entry method, verification methods
| 4.8 | Breach of research governance procedures | LL | 1 | 1 | 1 | L | All staff will have up to date GCP training (within 2 years) to ensure they are aware of current guidelines. The research will be carried out to the standards outlined in the Research Governance Framework | F |

**Consider:** Complexity, staff training and experience, reporting requirements
<table>
<thead>
<tr>
<th></th>
<th>Post-study</th>
<th>5.1 Poor academic value</th>
<th>5.2 Intellectual property rights lost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>LL 1 1 1 1</td>
<td>LL 0 0 0 0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Consider: Publication potential</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F</td>
<td>Consider: Confidentiality of the study, expected outcomes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The research is being undertaken in fulfilment of a Professional Doctorate in Nursing. The findings will be published in a peer reviewed nursing journal that has a wide distribution, such as: Oncology Nursing or Cancer Nursing or Journal of Advanced Nursing. Findings may also be presented as a poster at the annual British Society for Haematology meeting and disseminated to specific patient groups, for example; leukaemia care and lymphoma support for publication in their newsletters.
<table>
<thead>
<tr>
<th>This study is (please tick):</th>
<th>□ Accepted as being within an acceptable level of risk</th>
<th>□ Not accepted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher:</td>
<td>Research and Development:</td>
<td>Governance:</td>
</tr>
<tr>
<td>Signature:</td>
<td>Dr J K Ramage</td>
<td>Catharine Carter</td>
</tr>
<tr>
<td>Date:</td>
<td>Director of Research and Development</td>
<td>Date:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Date:</td>
</tr>
</tbody>
</table>
Appendix 11 An example of step four of data analysis.

Step four – an example of narrative coding of field texts to interim research texts. (Boldened text were placed into a new document)

R. Perhaps today we could talk about what it’s like for you coming up here to the unit for your blood transfusion. Perhaps we could start from the morning.

P. Well I don’t have to worry about getting up in the morning for a start, not that I lie in bed very long, or go overboard in sleeping very long. I’m usually awake on most average day around about seven, seven thirty because I’ve always worked all my life. All my life I’ve worked, and I’ve had to go to a job that starts at eight o’clock in the morning, so I have always been used to getting up reasonably early in the mornings. So, I might get up around, on a transfusion day, no on a normal day I would probably get up around seven thirty to eight o’clock and have my breakfast and watch breakfast television, etc. **On a transfusion day I always get up an hour at least earlier, six thirty in the morning.** And by the time I have made a cup of tea for me and the wife. **I don’t generally have any breakfast** until, I might not have any breakfast at all. I go for a shower because I wouldn’t dream of coming up here, like today I’ve had a shower, I wouldn’t dream of coming here with what might be a perspiration body, it’s not so much I’m dirty it’s just that I might be a bit smelly. Ha, ha. So I don’t like to think that is me that’s indicating that to anybody else, so I always have a shower prior to coming which gives me 20 minutes in the shower I suppose, and then I go downstairs and I will have sometimes have a few flakes, or sometimes nothing at all because I tend to have my lunchbox, which is a big joke… (patient’s name) has got his lunchbox again. But, I’m not very keen on the sandwiches that are supplied, I like a cup of tea which I know I’m going to get up here, at least one anyway. I always make a little sandwich box of my own whether it be a sandwich or something of that nature. But I tend to bring one of those Granola bars which are breakfast bars and so when I get here
I can have a little breakfast if I like, have a sandwich at lunch time and some fruit and a couple of biscuits with the afternoon tea if I feel that I need them.

So, I know that the hours of work for the girls on the floor are not until after half past eight now, and one is requested not to get here before that, because we can’t get on to the ward until they’ve opened up, which feels a bit unfair sometimes. Because when I first started having a transfusion, four years ago, the girls were here at eight o’clock. And I used to go straight into the ward and (name of nurse), or (name of another nurse), or one of the other nurses that might have been available at the time would cannulate me straight away, even though I might not get my blood until half past eight because the haemoglobin department wasn’t working until half past eight, but I was ready.

But now the girls don’t get here until half past eight, well the first crew doesn’t get here until about half past eight, and the rest of them will be in by nine, so I don’t come in here now until at least half past eight. I either wait in the waiting room if I can’t get in the ward, and then when I do get in the ward, I go in the girls won’t cannulate unless they’ve got complete freedom of time until nine o’clock which puts me at least an hour behind on a transfusion of three units of blood. And three units of blood takes somewhere in the region of seven sometimes eight hours depending on how busy or how awkward the pump plays up, whatever.

So, I feel that’s a bit of a hindrance in lots of ways because before when I used to be able to get in just after eight o’clock and get cannulated, and when my blood was ready, which it usually was, and if it wasn’t I had to wait some. If it was ready I used to get transfused or start my transfusion by nine o’clock which gave me a good stretch of the day to get dispersed from the ward by five o’clock. But now that can change completely although the girls do very, very well at the moment, If I
have two units it's not a problem I might get away by four. If I have to go over to three units, it's not much difference in time because they know they've got to try and keep the blood changed quickly to help with the time to get you finished in time during the working time of their employment.

R. What happens if you don’t get finished during the time?

P. Well in the early days, I had this happen to me they were still transfusing at six o’clock when the ward was locked-up, and they used to have to take me down to, well walk down to, with my pump, to the other end to the main ward. And I used to sit in an armchair down there, or in an ordinary wooden chair down there next to the vending machines, so that everybody could see me sat in the middle of the foyer, if you want to call it a foyer, and there I sat until such times the blood transfusion was finished and that could happen anything up to seven, seven fifteen or seven thirty. Basically, (names of nurses), they’ve got their priorities to do before they can even attend to some blood patient sat there. So, consequently if my pump was bleeping for some attention, whatever it needed, mine was the last on the list to get looked at, because there was some other people with more priority than me or us whatever.

R. So how did that make you feel?

P. Well it partially made me feel as if I was in the way and secondly as if I wasn’t anybody worth looking at, coz a) I don’t think blood patients should be mixed up with cancer patients, I think they should be separated, bed wise, ward wise, whatever you want to call it, it should be separated from the cancer patients because we are not …. They are looking for life saving treatment and although we are still looking for lifesaving treatment we are not liable to….., because the treatment has started, you are not liable to be going to die or anything so your
treatment is going to be okay. But with the cancer patient I feel they have got to have their treatment otherwise if it's broken and not attended to as and when it's necessary, then they might be in serious trouble with their individual problem. I don't know whether that's right or wrong I don't know, but that's what I feel. (Ernest, first interview, p. 15 – 18)
Appendix 12 An example of step five of data analysis

Step five – an example of categorization of narrative scenes in the interim research texts. Texts colored red highlight the dimensions of experience.

Researcher (R). Perhaps today we could talk about what it’s like for you coming up here to the unit for your blood transfusion. Perhaps we could start from the morning.

Participant (P). On a transfusion day I always get up an hour at least earlier, six thirty in the morning. I don’t generally have any breakfast). (Related to Sociality dimension of experience)

So, I know that the hours of work for the girls on the floor are not there until after half past eight now, and one is requested not to get here before that because we can’t get on to the ward until they’ve opened up (Experience related to Setting / Place dimension as the Haematology Day Unit does not open until 08.30am when the nurses come on duty).

which feels a bit unfair sometimes, because when I first started having a transfusion, four years ago, the girls were here at eight o’clock. But now the girls don’t get here until half past eight so I don’t come in here now until at least half past eight (experience related to Sociality, that is, the existential conditions in the environment. Experience regulated by the nursing staff.

I either wait in the waiting room if I can’t get in the ward (setting) and then when I do get in the ward I go in the girls won’t cannulate unless they’ve got complete freedom of time until nine o’clock (social existential conditions- sociality)

which puts me at least an hour behind on transfusion of three units of blood. And three units of blood takes somewhere in the region of
seven sometimes eight hours depending on how busy or how awkward the pump plays up, whatever (setting).

So, I feel that I'm a bit of a bit of a hindrance in lots of ways (personal feelings - sociality).

If I have to go over to three units, it's not much difference in time because they know they've got to try and keep the blood changed quickly to help with the time to get you finished in time during the working time of their employment (social existential conditions - sociality).

R. What happens if you don't get finished during the time?

P. Well in the early days, I had this happen to me they were still transfusing at six o'clock when the ward was locked-up, and they used to have to take me down to, well walk down to, with my pump, to the other end to the main ward and I used to sit in an armchair down there or in an ordinary wooden chair down there next to the vending machines, so that everybody could see me sat in the middle of the foyer, if you want to call it a foyer, and there I sat until such times the blood transfusion was finished and that could happen anything up to seven, seven fifteen or seven thirty. (personal feelings-sociality and setting).

Basically, because the nurses (names of nurses), they've got their priorities to do before they can even attend to some blood patient sat there. So consequently, if my pump was bleeping for some attention, whatever it needed, mine was the last on the list to get looked at, ha, ha, because there was some other people with more priority than me or us (personal feelings - sociality).

R. So how did that make you feel?
P. Well it partially made me feel as if I was in the way and secondly as if I wasn’t anybody worth looking at, *(personal feelings - sociality)*

coz a) I don’t think blood patients should be mixed up with cancer patients, I think they should be separated, bed wise, ward wise, whatever you want to call it, it should be separated from the cancer patients *(setting)*

They are looking for life saving treatment and although we are still looking for lifesaving treatment we are not liable to, because the treatment has started, you are not liable to be going to die or anything so your treatment is going to be okay, *(temporality)*

but with the cancer patient I feel they have got to have their treatment otherwise if its broken and not attended to as and when its necessary, then they might be in serious trouble with their individual problem *(sociality).* (Ernest, first interview, p. 15 – 18)
Appendix 13 Form UPR 16 Research Ethics Review Checklist

FORM UPR16
Research Ethics Review Checklist
Please include this completed form as an appendix to your thesis (see the Research Degrees Operational Handbook for more information)

Postgraduate Research Student (PGRS) Information

Student ID: 412688

<table>
<thead>
<tr>
<th>PGRS Name:</th>
<th>Laraine Lloyd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department:</td>
<td>School of Health Sciences and Social Work</td>
</tr>
<tr>
<td>First Supervisor:</td>
<td>Dr Assaf Givadi</td>
</tr>
<tr>
<td>Start Date:</td>
<td>2012</td>
</tr>
<tr>
<td>Study Mode and Route:</td>
<td>Parttime</td>
</tr>
<tr>
<td>Title of Thesis:</td>
<td>BLOOD TRANSFUSION MATTERS: A NARRATIVE INQUIRY INTO PATIENTS’ EXPERIENCE OF RECEIVING REGULAR BLOOD TRANSFUSIONS IN A DAY UNIT SETTING WHILST IN A PALLIATIVE STAGE OF A HAEMATOLOGICAL MALIGNANCY</td>
</tr>
<tr>
<td>Thesis Word Count:</td>
<td>53,421</td>
</tr>
</tbody>
</table>

If you are unsure about any of the following, please contact the local representative on your Faculty Ethics Committee for advice. Please note that it is your responsibility to follow the University’s Ethics Policy and any relevant University, academic or professional guidelines in the conduct of your study.

Although the Ethics Committee may have given your study a favourable opinion, the final responsibility for the ethical conduct of this work lies with the researcher(s).

UKRCIO-Finished Research Checklist
(If you would like to know more about the checklist, please see your Faculty or Departmental Ethics Committee rep or see the online version of the full checklist at: http://www.rrcio.org.uk/ethics/for_researchers/)

a) Have all of your research and findings been reported accurately, honestly and within a reasonable time frame?
   YES [X] NO

b) Have all contributions to knowledge been acknowledged?
   YES [X] NO

c) Have you complied with all agreements relating to intellectual property, publication and authorship?
   YES [X] NO

d) Has your research data been retained in a secure and accessible form and will it remain so for the required duration?
   YES [X] NO

e) Does your research comply with all legal, ethical, and contractual requirements?
   YES [X] NO

Candidate Statement:
I have considered the ethical dimensions of the above named research project, and have successfully obtained the necessary ethical approval(s).

Ethical review number(s) from Faculty Ethics Committee (or from NRES/SCREC):
12/SC/2262

If you have not submitted your work for ethical review, and/or you have answered 'No' to one or more of questions a) to e), please explain below why this is so:

UPR16 – April 2016

Signed (PGRS): [Signature]
Date: 07/03/2019