A mixed-methods study into the quality of life of adult survivors of haematological malignancies

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Abstract

Quality of life in adult haematological cancer survivors

The treatments for haematological malignancies are often complex and intense and given over prolonged periods, leading to potentially debilitating symptoms and reduced quality of life (QoL). Those who survive can still experience long-term effects of both treatments and disease and often fear the recurrence of the disease. This thesis studies the QoL of adults who survived haematological malignancies. **Methods**: This mixed-methods study aimed to examine the QoL of survivors of haematological malignancies and identify unmet supportive care needs. The first quantitative survey phase used QoL questionnaires validated for use in cancer (EORTC QLQ C30 & EQ-5D), and disease-specific questionnaires for survivors of multiple myeloma (MY-20) and chronic lymphocytic leukaemia (CLL-16). The second qualitative phase explored in-depth the quantitative findings. For both the quantitative and qualitative phases, participants were adults aged 18+ years who had completed treatment for a haematological malignancy and were between 1-5 years post-treatment. Demographic data and clinical parameters collected included diagnosis and time since completion of treatment. Descriptive statistics showed that the median and interquartile range when skewed. Age was the only skewed continuous variable. Non-parametric Kendall's tau correlation coefficient was used to determine the associations between age and QoL and associations between socio-demographic, clinical factors and QoL subscales were determined using the Mann Whitney U test. Furthermore, in-depth face-to-face semi-structured interviews were conducted, thematically analysed and grounded in the quantitative findings. **Results:** For the quantitative survey 131 participants completed questionnaires (response rate 66%). The median age was 66 years. The quantitative phase found significant associations between age, global quality of life, physical and role functioning. Men reported better physical functioning and lower symptom scores than women. Employed participants reported a better QoL. Increasing age was associated with lower QoL. Better role functioning was noted in participants who lived beyond 2.5 years following treatment completion. The key qualitative findings centred on unmet supportive care needs, fear of recurrence, loss of continued connection with health care providers and uncertainty about the future. **Conclusion**: Survivors of haematological malignancies have unmet supportive care needs. Enhancing their physical, psychological wellbeing and addressing supportive care needs optimises their QoL.

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"It does not matter how slowly you go as long as you do not stop." Confucius

My MPhil journey has rather been a long one with many to support, encourage, motivate, and lead me along the way to ensure that I had completed it successfully. Like many, this journey of mine had been one of many challenges conquered, rough paths trod and on a positive note many opportunities widened and awards received.

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All of you had made me believe that this journey can be possible. To you, I dedicate this thesis.

Author's Declaration

This thesis is submitted in partial fulfilment of the requirements for a Doctor of Philosophy degree at Bournemouth University. I declare that this is my work and does not contravene any academic offence as specified in the University's regulations.

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Chapter 1 Introduction: Setting the research scene

1.1 Introduction

As of December 2015, around 2.5 million people were living with or after a cancer diagnosis in the United Kingdom (UK) alone and this figure is anticipated to rise to 4 million by 2030 (Guzzinati et al. 2018). This is reassuring news about an illness that was described as a 'killer disease' almost three decades ago (Sontag 1991, p.59), equally dramatically as 'a lethal shape-shifting entity' (Mukherjee 2011, p.13). The question that not enough people ask is: "What does it feel to be a 'cancer survivor'?" Following the completion of treatment for cancer, do people 'get back to normal' or are they always referred to or defined by this common disease and are they so feared that some people still refer to it as the 'Big C' (Mukherjee 2011; Stergiou - Kita et al. 2016). With the advances in early detection, improved treatment modalities and supportive care, cancer survival rates have improved substantially over the past decades (Malvezzi et al. 2015).

In particular, as a nurse who has worked for my entire career in caring for patients with various haematological malignancies, I have always wondered how patients felt and what they experienced following the completion of treatment for haematological malignancy. Some appear to come out of the treatment well. At the same time, I have also observed other patients being treated for cancer but left with debilitating side-effects of treatment which has adversely affected their Quality of Life (QoL). Hence, I was intrigued to explore the QoL among these groups of patients. It also motivated me to find out in this MPhil research project what it meant to be defined as a 'cancer survivor'.

Interestingly, a position for a haematology research nurse at Royal Bournemouth Hospital in the south of England, to pursue an MPhil simultaneously around QoL and cancer survivorship in patients who have survived haematological malignancies was advertised. I was successful in securing this position and commenced a MPhil at Bournemouth University on the topic that has always been of special interest to me. I pursued my research while working as a haematology research nurse across three hospital sites in Dorset, in the South of England (Royal Bournemouth Hospital, Poole Hospital and Dorset County Hospital). I was able to identify potential participants for my study with assistance from the treating haematologists from all the hospital sites. This participants' selection process is explained later in this thesis (**see Section 5.3**).

Having moved to live and work in Dorset as a cancer nurse, I embarked on exploring the QoL among groups of patients who had completed all treatment for a haematological malignancy amongst the three hospitals I worked across. However, there appeared to be a wide range of studies of patients with breast cancers and other cancers but very little undertaken in haematology with no published studies exploring the QoL of patients surviving haematological cancers within Dorset County. This group of people represented a sample of all older people with these diseases and knowing about a local population would inform knowledge about a wider population of patients with the same

diseases. Hence, I felt the need for a study that would be beneficial in investigating the QoL of these groups of patients with haematological malignancies and implementation measures to enhance the same.

This MPhil thesis seeks to examine the Quality of Life of adult survivors treated for a haematological malignancy mainly B-cell malignancies and the impact of living with the illness. This cohort appears to be largely an older group of survivors which represents the majority of patients with malignant disease in Dorset. Dorset is a unique county in the South West of England as it has the largest population of older adults with 28.3% being 65 years and older which is significantly higher than the 18% average for the whole of England and Wales (Office of National Statistics (ONS) 2016). The high proportion of older cancer survivors in this cohort and factors that impact their QoL will provide insight into the future ageing UK cancer survivors' population as a whole. This may, in turn, inform future healthcare planning strategies.

It answers this overarching research question: "What is the QoL of survivors of a B-cell malignancy and what are the identified unmet supportive care needs of these survivors?" The thesis is presented in a way to describe the research and explain the research process undertaken. The undertaking of this MPhil study was a journey for me with many challenges and enlightenment, not just in the deepening of the understanding of QoL and survivorship of patients diagnosed and treated with haematological malignancies but also the development of myself as a researcher.

During the process of planning and undertaking this study, I was: able to enable a deepened understanding of what the unmet supportive care needs that may arise for survivors of haematological malignancy and how this could impact their quality of lives; has shown how resources could be channelled in the right direction to optimise patient outcomes; was able to establish a collaborative network with wider organisations and globally, with the aim and potential to make a difference to survivorship care and also has highlighted areas of future research that could improve clinical practice. For the same reason, I have been intrigued to investigate the QoL of this elderly group of patients in the county of Dorset.

1.1.1 The rationale behind undertaking this research

The profile of cancer is changing. Approximately 363,000 people are diagnosed with a new cancer each year in the UK and the incidence has been predicted to rise by a further 2% by 2035 (Cancer Research UK 2022). Cancer survival has also more than doubled in the last 40 years from 24 to 50% of people living disease-free for 10 years or more (Cancer Research UK 2022; De Angelis et al. 2014). In the 1970s, the median survival following a diagnosis of cancer was only one year (Macmillan Cancer Support 2015). However, between 2010 and 2011, 50% of adults diagnosed with cancer in England and Wales were predicted to survive 10 or more years (Cancer Research UK 2015).

People are living longer with haematological malignancies due to early detection and significant improvements in medical treatments (De Angelis et al. 2014). Although many patients may live well following completion of primary treatments, others may experience a wider range of physical, psychological, emotional, social, and financial issues that impact their QoL (Miller et al. 2016; Jefford et al. 2017). Cancer survival is embedded in the context of an ageing society, with the number of UK residents over 65 predicted to rise to 26% of the total population by 2041, compared to 15.8% in 1991.Therefore, more people are living with and beyond cancer (ONS 2018).

With people living longer, quality of life issues is of paramount importance to individual with haematological malignancies, who generally experience several debilitating symptoms such as severe fatigue, peripheral neuropathy, sleep disturbance, nausea, and pain. It is evident that cancer patients are more likely to have more comorbid conditions and therefore experience poorer physical and mental health than those without cancer (Smith et al. 2008).

While treatments for haematological malignancies dramatically increase survivability, many patients experience late and long-term effects related to cancer and its treatments. While the efficiency of treatment may be, of course, the focus, it is important to preserve the QoL of these patients (Mortensen and Salomo 2016). From my experience as a nurse in the field of haematology oncology nursing for many years, I have observed many patients who have been left with permanent, often devastating, physical impairments. There is, therefore, a need to better understand the support needs of this patient group, and for service developments to further meet their needs effectively (Mason et al. 2014).

Interestingly, there has been a growing interest in evaluating QoL in patients who have completed treatment for haematological malignancy. The advancements of treatments in patients with haematological malignancies have increased the relevance of examining the long-term physical, psychosocial and social QoL of patients who have completed primary treatment for haematological malignancy. Evaluation of QoL helps improve outcomes in healthcare and optimises the lives of those who have completed treatments for haematological malignancy.

An understanding of how a malignancy and its treatments can affect an individual can help inform health care professionals in tailoring treatments and identify specific supportive care needs that may be required to be met (Bottomley et al. 2005; Blazeby et al. 2006). The term ‘cancer survivor’ is used to encompass all individuals living with cancer ‘from the time of diagnosis and for the balance of life’ (National Coalition for Cancer Survivorship 2015).

It is fundamental to recognise the problems faced by survivors and the needs that are unmet to provide timely and appropriate care and offer support. With the issues faced by survivors of haematology malignancy due to intense treatment modalities, there is a pressing need to explore these issues and address specific unmet supportive care needs. There is an increasing focus on improving the experience of living with and beyond cancer and reducing the ‘burden’ of cancer

survivors. A vast body of literature has identified that cancer survivors' experience so-called symptom burden related to the severity and impact of biopsychosocial consequences of their disease and its treatment (Macmillan Cancer Support, 2013). Symptom burden is a complex concept (Eckerblad et al. 2015), which in a concept analysis by Gapstur (2007) included the subjective, quantifiable prevalence, frequency, and severity of symptoms placing a physiological burden on patients and producing multiple negative, physical, and emotional patient responses.

The experience of survivorship can be challenging; individuals living with and beyond cancer can face the burden of survivorship. Cancer survivors not only experience symptom burden (the severity and impact of biopsychosocial consequences of disease and its treatment), but there is also evidence that individuals living with chronic conditions experience treatment burden (the 'work' required of them in managing their condition and its symptoms). The latter notion is discussed in greater detail later in **Chapter two**.

It is evident from current literature that very little research has been undertaken to examine the QoL of survivors of a haematological malignancy. Most of the studies evaluating QoL are mainly quantitative using validated QoL questionnaires. The focus of enquiry can be narrow with the HR QoL (Health Related Quality of Life) findings based on functional and health status domains. Insight into the wider experience of patients following completion of treatment for a malignancy cannot be captured just by undertaking quantitative studies.

Although there has been an ongoing debate about the definition of QoL, it has been broadly stated as a multidimensional construct with objective and subjective dimensions with experiences differing between individuals and with the length of time since the completion of treatment. With the above-mentioned definition, it is apparent that an open approach is needed to be adopted to capture the details of the QoL of individuals who have completed all treatment for haematological malignancy. QoL questionnaires would limit the information captured from such survivors and not all the information captured may pertain to the problems faced by survivors. The questionnaires used in the study focus mainly on cancer patients rather than survivors. Therefore, a qualitative approach with semi-structured interviews is required to gain a detailed understanding of this patient group and how treatment for a haematological malignancy has influenced their QoL and how this may vary over time. This may contribute to improving the measurements of QoL in survivors and also address unmet supportive care needs.

Survivors of B-cell malignancies can experience debilitating physiological effects and psychological stress that can influence their QoL (Baker et al. 2003). Therefore, it is imperative to assess the QoL of survivors and aim at interventions to improve this. QoL studies in patients with a B cell malignancy 1-5 years following treatment are very few. Most studies measure the quality of patients during active treatment or beyond five years. That was why this study set to examine the QoL of survivors of B-cell malignancies during this period.

Furthermore, there is limited nursing research published with a specific focus on patients who have completed all treatment for haematological malignancy. Calman (2011) reflects the same in the research she has undertaken in lung cancer patients with little nursing research focussing particularly on lung cancer. Knowledge of the aspects that may affect the QoL of survivors could enable them to aim at interventions to enhance their QoL. Therefore, this study aims to examine the impact of treatment on the QoL and capture the experiences of survivors following completion of treatment by employing a mixed-methods approach incorporating the use of QoL questionnaires and semi-structured interviews. For the purpose of this study, only those patients who have completed all treatment for a B-cell malignancy were included. In other words, they were not receiving any treatment for the malignancy except for supportive care at the time of recruitment to the study.

The inclusion of survivorship care and research as part of the cancer care continuum and focussing on the QoL after cancer treatment has become integral to the practice of oncology and haematology (Parry et al. 2011). The initiatives aimed to optimise the delivery of comprehensive, coordinated care to all cancer survivors and provide the oncology community with the resources and knowledge to implement survivorship care that can address many unmet supportive care needs and maximise health related QoL (McCabe et al. 2013). Foster and colleagues (2018) argue the importance of generating good quality research evidence relating to the impact of cancer and its treatment on people's lives which, in turn, is pivotal in the process of planning effective services to optimise outcomes. The working definition of a cancer survivor in this MPhil study would be any individual who has completed primary treatment for a B-call malignancy and is in remission at the time of recruitment.

1.2 Aims of this MPhil research

This study aimed to examine the QoL of adult haematological cancer survivors and identify any unmet supportive care needs that this group of people may experience. I aim to gain more knowledge on how a haematological malignancy mainly the diagnosis of a B cell malignancy and its treatments impacts an individual's QoL in the post-treatment phase. The objectives of this MPhil study were to enable the researcher to:

1. develop an understanding of the QoL of survivors of adult haematological malignancies.
2. determine the impact of selected demographic variables on the QoL of survivors of haematological malignancies (e.g., employment, education, living arrangements, gender, age).
3. explore factors that influence that QoL.
4. explore any unmet supportive care needs in adult survivors of a haematological malignancy.

1.3 Haematological malignancies: An introduction

The term 'haematological malignancy' refers to a diverse group of malignancies that affect the blood, bone marrow and lymphatic systems. The most common types of haematological malignancies, mainly the B cell malignancies are lymphomas, myelomas and acute lymphoblastic leukaemias. This diverse group of diseases affect people of all ages, with the highest incidence being among the elderly. According to the National Institute of Health and Care Excellence (NICE), the incidence, prognosis and responsiveness to treatment and survival of each of these types of B cell malignancies vary widely (NICE, 2016). This study focuses mainly on those people diagnosed with a B-cell malignancy and has completed all primary treatments for the same.

They are an important group of malignancies to study within the UK since there has been a steady increase in survival rates of all cancer patients in the UK when compared with the US and Europe, with 50% of patients surviving for ten years and beyond (Cancer Research UK, 2019; De Angelis et al. 2014). In the UK, 13% of people aged 65 years and above are survivors of cancer and its treatment (Cancer Research UK, 2008). The number of older people aged 65 and above living with cancer has grown by 23% in the five years to 2015 (Maddams et al. 2012). However, in the United States, as of 2012, more than 59% of the prevalent population of cancer survivors was age > 65years (Rowland and Bellizzi 2014).

1.3.1 Incidence of B cell malignancies

Haematological malignancies are a heterogeneous group of malignancies that evolve in the blood, bone marrow or immune system (NICE 2003; Butters 2011). Worldwide, in economically developed countries, haematological malignancies are the fourth most diagnosed malignancy (Smith et al. 2011).

Globally, there has been a steady increase in the survival rates of some haematological malignancies (Verdecchia et al. 2007; American Cancer Society 2012; Australian Institute of Health and Welfare 2012). Haematological malignancies are the fourth most frequent type of malignancy in the developed world and incidences are increasing in part secondary to an ageing population (Smith, Howell, Patmore, Jack, & Roman 2011; Chihara et al. 2014; Howlader et al. 2014; American Cancer Society 2018). B-cell malignancies such as chronic lymphocytic leukaemia (CLL), lymphoma and multiple myeloma (MM) are some of the most common haematological malignancies, so this study focused on patients who were treated for these conditions.

In 2011, the numbers of newly diagnosed patients with these conditions registered in the UK were: 12,783 with Non-Hodgkin's Lymphoma (NHL), 1845 with Hodgkin's Lymphoma (HL), 3233 with CLL and 4792 with MM (Office for National Statistics [ONS] 2015). Although some of these malignancies are not curable, the routine use of novel and targeted therapy has led to a steady improvement in survival rates (Hall et al. 2013; Sant et al. 2014; Krok-Schoen 2018). Individuals

treated for a B-cell malignancy are no longer viewed as 'victims' (Park et al. 2009) but as 'survivors', meaning that people who go on to live for several if not many years following their initial diagnosis.

1.3.2 Survival statistics in haematological malignancies

Cancer survival statistics are usually presented as relative survival rates at five years after diagnosis (Cancer Research UK 2014). In England, the five-year overall survival for men diagnosed with HL during 2011–2015 and followed up until 2016 was over 80%, 64.9% for NHL, 53.3% for all leukaemia and 51.9% for survivors of MM. During the same period, women showed survival rates of 83% for HL, 69.4% for NHL, 52.4% for all types of leukaemia and 50.8% for survivors of MM (ONS, 2018). The five-year survival for a patient treated for CLL is 67.0% for men and 73.0% for women in England (De Angelis, Sant, & Coleman, 2014) with these figures showing improvement in survival rates compared to previous years.

1.4 Setting the scene for survivorship and Quality of Life in patients treated for B cell malignancies

Due to advancements in diagnosis and treatment, many cancer survivors now live for a relatively long period (Miller 2009; Throne et al. 2013). These advancements present medical service providers and support teams with additional challenges of striving to extend a cancer survivor's life whilst at the same time maintaining QoL for those individuals (Kim et al. 2007).

While many people live well following the completion of treatment for cancer, others may experience a broad range of distressing physical, psychosocial, social, and financial issues that may impact their quality of life (Miller et al. 2016; Jefford et al. 2017). These physical difficulties (e.g. fatigue, decreased physical capacity) and psychosocial problems (e.g. anxiety, depression, stress, insecurity, grief, decreased self-esteem, hindered job reintegration, social isolation) may lead to a reduction in QoL (Gotay et al. 2002; Tomich and Helgeson 2002; Korszun et al. 2014; Esser et al. 2018). The Living with and Beyond Cancer report (National Cancer Survivorship Initiative, 2013) emphasised the need for the provision of supportive care from the point of diagnosis, through active treatment and beyond into later stages of survivorship. The Supportive Care Framework (Fitch, 2008) states that to be effective, supportive care has to be personalised to the unique needs of the individual.

Cancer treatments are often associated with late complications which may have a negative influence on the physical, psychological and/or social life of a survivor (Doyle and Kelly 2005; Houldin et al. 2006; Richards et al. 2011; Esser et al. 2018), especially when most survivors are over the age of sixty-five and may often have associated comorbidities and age-related functional decline (Snydor et al. 2019).

Cancer and its intense treatments with its side effects, especially in patients with haematological malignancies, can cause deficits in one or more domains of quality of life. According to Baker et al. (2009), Baumann et al. (2009) and Larghousi et al. (2018), the QoL reported in patients treated for cancer is worse in comparison to the general population. In clinical trials and daily clinical practice, QoL has been incorporated as an important outcome parameter enabling clinicians to assess the effectiveness of treatment and guide in making tailored treatment decisions (Lopez et al. 2009)

1.5 The organisation of this thesis

The chapters in this thesis are laid out in the order in which the study was undertaken. The introductory chapter presented an overview of the study, its aims and objectives. A clear rationale for undertaking this study is also mentioned in this chapter.

Chapter two reviews current literature in areas related to this study: haematological malignancies with a focus on B-cell malignancies, treatments and treatment-related effects on the individual, cancer survivorship.

Chapter three presents in the detailed review of QoL, instruments used to measure QoL in this study, measurement of QoL in the post-treatment phase and its challenges. This chapter concludes that there is very little evidence on the QoL of adults who have survived haematological malignancies, specifically B-cell malignancies.

Chapter four outlines the design and its application in this MPhil thesis. Using pragmatism as a theoretical underpinning, a sequential explanatory mixed-methods design was employed to examine the QoL of individuals who had completed all treatments for a B-cell malignancy. This chapter describes the nature of mixed methods research, the rationale for undertaking MMR and its application in this study.

Chapter five outlines the methods underpinning the study. It describes the components of the study, the participants, recruitment, sample size, identification and recruitment of participants, data collection and analysis techniques used in both phases of the study.

Chapter six details the quantitative data from Phase one of the study. This chapter describes the participant demographics and diagnosis and time since completion of treatments for a B-cell malignancy. The analytical method employed in this phase is addressed. In this chapter, a journal article is presented.

Chapter seven outlines the qualitative findings of the study. It describes the participant characteristics, describes themes and subthemes that arose from the interview. This chapter addresses the specific unmet supportive care needs that these individuals experience.

Chapter eight presents a discussion of the study findings and a comprehensive explanation of the quantitative findings with the help of semi-structured interviews; the final but important requirement of mixed methods work.

Chapter nine concludes the thesis. It offers a personal reflexive account of me with reflecting on the dual role of research nurse and researcher, describing the interview-participant relationship and the challenges faced when interviewing participants exclusively with a partner or family member present at the time of interviewing. It offers a discussion of the strengths and limitations of the research.

Chapter ten provides recommendations and offers a discussion of the implication of the findings of the thesis to clinical practice, research, and education.

1.6 Summary of the chapter

The impact of treatment for haematological malignancies can be devastating with some of the effects of treatment lasting for prolonged periods. They can affect an individual in many ways. This study investigates the impact of haematological malignancies, mainly B-cell malignancies, and their treatments on the quality of lives of survivors. Knowledge and understanding of factors that affect the QoL of adult cancer survivors may provide an insight into identifying these unrecognised or unmet supportive care needs and help the implementation of measures to enhance the same. This study contributes to the growing literature surrounding the examination of specific unmet supportive care needs of such individuals diagnosed with and treated for a B-cell malignancy.

Where possible I have used the term “haematological malignancy” and were in more general, I have used the term “cancer survivor”.

Chapter 2 Haematological malignancies: The unique challenge

2.1 Introduction

This chapter presents a detailed overview of the literature on the study of QoL in adult patients who have completed all treatment for haematological malignancy, B-cell malignancies. An in-depth, theoretical understanding of the quality of life (QoL) of survivors of haematological malignancies and cancer survivorship is vital to understand the influence it has on the survivors. Most QoL studies concerning cancer patients have focused on those receiving treatment. By contrast, data available on the QoL of survivors for a haematological malignancy are considerably less although there is clear evidence that studies in survivorship have been increasing steadily (Bellizi et al. 2009; Lobb et al. 2009; Krouse et al. 2017).

First, this chapter will seek to explain the methodology of the literature review. Secondly, it defines and explains in detail the different types of B cell malignancies, their treatments, and treatment-related toxicities. The comorbidity index used in this study to capture the comorbidities in the second, qualitative phase is discussed and finally, this chapter throws light on the concept of survivorship.

2.2 The methodology of literature review

For this MPhil research study, a survivor of a haematological malignancy is a person who has completed all chemotherapy treatment and has been in remission from the disease (i.e., disease-free) for at least a year. The research questions for this scoping literature review (Pham et al. 2015) at the start of the thesis were:

1. What is the QoL in adult patients who have completed all treatment for haematological malignancy?
2. What theories and models can help understand the concept of quality of life (QoL) in survivors of haematological malignancies and cancer survivorship more generally?

To address these questions literature searches were conducted in PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Psych info, Medline, Scopus, Soc INDEX, Science Citation Index, Nursing and Health Sciences Journals. The following combinations of terms were used to search these databases: (quality of life or unmet need* or needs) AND (Multiple Myeloma or Leukemia or Leukaemia, Hodgkin's disease or lymphoma or non-Hodgkin's lymphoma * or haematological/haematological cancer/malignancy* or blood cancer*). Zetoc alerts were set up to receive articles with the following MeSH (Medical Subject Headings) terms: "Quality of life", "cancer survivors", "unmet needs", "leukaemia", "Lymphoma, "Multiple Myeloma", "Haematological malignancies" AND" questionnaires". Since this is a scoping review (Pham et al. 2015) the papers found in the search were only checked for relevance to the two research questions,

the papers had to have been peer-reviewed, but they were not formally appraised on methodological quality per se.

The search was limited to the past 30 years at the outset of my study. This period was chosen as the past three decades have seen a heightened interest in the QoL in survivors of all malignancies. To date, numerous studies have examined the QoL following diagnosis and addressed the physical, emotional, and sexual well-being of cancer patients (Conroy and Blazeby 2003; Avis et al. 2005; Quinn et al. 2015). Due to time and language constraints, only English-language peer-reviewed studies were extracted. References of relevant publications were further searched (so-called 'hand-searching). The literature review was conducted prior to the start of the study and was updated along with the final updates undertaken in March 2022. Many of the studies identified focused predominantly on breast, colorectal and prostate cancer patients. This was expected as research in haematological cancer survivors was limited.

Very little attention has been paid to survivors of leukaemia, lymphoma, myeloma and other haematological malignancies and even fewer studies in the post-treatment phase (Aziz 2007; Parry et al. 2011; Esser et al. 2017). Studies concerning survivorship are increasing; however, most of those identified failed to include patients with haematological malignancies in their sample (Lobb et al. 2009; Hall et al. 2013; Tremolada et al. 2016).

2.3 B-cell malignancies

Haematological malignancies are biologically malignancies of the bone marrow (leukaemia) and the immune system (the lymphomas and myeloma) (Taylor et al. 2016). In the UK alone, in 2017 around 305,683 new cases of cancer were diagnosed with the prevalence increasing worldwide (Cancer Research UK 2019). They are a heterogeneous group of diseases with diverse aetiologies, incidences, and prognoses. They can range from long-term and incurable to acute and aggressive (The National Institute for Clinical Excellence 2003; Dunkel 2017). They are the fifth most common type of malignancy in the UK (Smith et al. 2011; The National Institute for Health and Care Excellence 2016). Diffuse large B cell lymphoma and MM are the most common haematological malignancies (Smith et al. 2011).

Historically, haematological malignancies were classified as follows: leukaemias were classified as malignancies of the blood; lymphomas as malignancies of the lymph nodes and myelomas of the bones (Taylor et al. 2016). However, the modern World Health Organization (WHO) classifications use the cell lines from which the malignancy is derived: myeloid and lymphoid cell lineage (Campo et al. 2011). The B cell malignancies represent a diverse collection of diseases which include most lymphomas, lymphocytic leukaemias and myelomas from the lymphoid cell lineage (Swerdlow et al. 2016) while acute and chronic myeloid leukaemia, myelodysplastic syndromes and myeloproliferative neoplasms are derived from the myeloid lineage. This study focuses mainly on

those patients who had completed primary treatment for a B-cell malignancy and were disease-free. These groups of malignancies are more common with increasing age, with people aged 65 years or above being more commonly diagnosed (HMRN 2014).

2.3.1 Lymphomas

Lymphoma is a haematological malignancy of the lymphatic system, categorised into two main types: Hodgkin Lymphoma (HL) and non-Hodgkin Lymphoma (NHL), each is outlined in turn below.

2.3.1.1 Hodgkin lymphoma

HL is not very common and accounts for less than 1% of all newly diagnosed cases of lymphomas (ONS 2016). HL originates in the white blood cells called lymphocytes. It is differentiated from NHL with the presence of Reed Stenberg cells in the lymph nodes which are seen under a microscope. The Reed Sternberg cells are abnormal B lymphocytes (white blood cells that make antibodies that fight infection) (Hartlapp et al. 2009). This results in the body's inability to fight infection effectively.

HL is a relatively aggressive B cell malignancy that can spread quickly through the body. However, it is also one of the most easily treatable types of malignancies. The most common symptom of HL is a painless, swollen lymph node or nodes that don't reduce in size after a couple of weeks (Linendoll et al. 2016). Many people may present with cough or breathlessness which may indicate lymph nodes in the chest (Miltenyi et al. 2010). Around one in four people may present with what is known as 'B' symptoms which comprise fevers, night sweats and unexplained weight loss (Townsend and Linch 2012). Chemotherapy is the general mode of treatment and survival rates are generally good with more than 90% of patients surviving for five years or more (CRUK 2017).

2.3.1.2 Non-Hodgkin lymphoma

NHL are generally categorised as high or low grade. High-grade lymphomas are usually aggressive and develop rapidly which if left untreated can be fatal (Dunleavy and Wilson 2013). Patients usually present with rapidly enlarged lymph nodes and additional symptoms of unexplained fever, weight loss, night sweats and fatigue (Busson et al. 2019). Treatment decisions are influenced by the nature of the malignancy and how fast it grows. The low grade or indolent ones that develop slowly are usually advanced by the time they are diagnosed. Unless these are caught early and treated, they may not be considered curable (Mounier et al. 2019). Indolent lymphomas may be monitored on a watch and wait for basis and the aggressive, high-grade lymphomas may require chemotherapy, radiotherapy, and newer biological agents.

Treatment for NHL aims to get rid of the lymphoma and achieve a disease-free state called remission (Cancer Research UK 2018; Macmillan Cancer Support 2019). Chemotherapy for NHL is usually given with steroids (Younes et al. 2017). A targeted therapy called Rituximab may also be given during initial treatment and after chemotherapy is given as maintenance therapy (Macmillan Cancer Support 2019). If patients' relapse with the disease, they may require much stronger therapy and also at times, peripheral stem cell transplantation (Dunleavy and Wilson 2013; Macmillan Cancer Support 2019).

2.3.1.2.1 *B cell and T-cell lymphomas*

NHL is grouped into B-cell and T-cell lymphoma depending on the type of origin of the malignancy. If a lymphoma develops from abnormal B-cell lymphocytes, it is called B-cell lymphoma. If it develops from abnormal T-cell lymphocytes, it is called T-cell lymphoma ref. B-cell lymphomas are more common than T-cell lymphomas. Around nine out of ten people with NHL have B-cell lymphoma (Macmillan Cancer Support 2019). Some B cell malignancies are acute and aggressive while some are asymptomatic and chronic (Hoffbrand et al. 2006). NHL is also common in the older patient group (CRUK 2017). NHL is the sixth most common cancer in the UK and being the most common type of haematological malignancy, it accounts for 40% of all cases in both men and women (ONS 2015).

2.3.2 Chronic lymphocytic leukaemia

Chronic lymphocytic leukaemia (CLL) is the most common lymphoid malignancy in adults (Stephens et al. 2005; Jemal et al. 2006). It is common in older people and develops slowly which is why it's called chronic leukaemia (Macmillan Cancer Support 2019). CLL is an incurable, insidious form of leukaemia for which treatment is not required immediately (Cancer Research UK 2017). Unlike most malignancies, people diagnosed with early-stage CLL may be monitored for months or even years before they merit any active treatment (Shanafelt et al. 2006). Although a large proportion of these patients are observed untreated, some of them may receive treatment of moderate toxicity (Holzner et al. 2004).

CLL, malignancy of the white blood cells, develops from the lymphoid stem cells. The body produces too many abnormal white blood cells called immature lymphocytes and these abnormal lymphocytes build up over time in the lymphatic system. This causes enlarged lymph nodes and affects the production of healthy blood cells in the bone marrow (Macmillan Cancer Support 2019). CLL is classified into Stages A, B and C with stage A, not usually requiring treatment and Stages B and C needing treatment (Kharfan- Dabaja et al. 2016). CLL is common in older people especially those over the age of 65 years.

There have been significant developments in the treatment of CLL. Cytotoxic drugs such as fludarabine, cyclophosphamide and a targeted therapy drug named rituximab were recommended as initial therapy for patients diagnosed with CLL (Cancer Research UK 2017). But treatment with a combination of Bendamustine and Rituximab has been accepted as an alternative for patients who could not tolerate triple therapy either due to comorbidities such as advanced age, renal impairment or reduced marrow capacity (Schuh et al. 2018). A combination of the above with chemotherapy and immunotherapy is termed chemo-immunotherapy (Couzin-Frankel 2013).

2.3.3 Myeloma

Multiple myelomas (MM) are a plasma cell disorder characterised by bone marrow infiltration with clonal plasma cells, production of abnormal paraprotein and presence of lytic lesions in the bone, anaemia, renal impairment, and increased calcium levels in the blood (Hameed et al.2014). It develops from abnormal plasma cells in the bone marrow. These plasma cells produce large amounts of abnormal antibodies called paraprotein which inhibits normal fighting off infection and normal antibody production. It can, therefore, occur in the pelvis, spine, or ribcage where there is bone marrow. When they spread throughout the bone marrow, they can cause thinning of the bones and result in pain and spontaneous bone fractures (Hameed et al. 2014; Kyle and Rajkumar 2009).

Myeloma is an incurable malignancy and patients present with more severe symptoms and has a poorer prognosis when compared with other low-grade haematological malignancies. It has a relapsing-remitting course which has an asymptomatic phase and an active phase when treatment is warranted. Treatment aims to control the disease, prolong survival, and optimise patient wellbeing (Sonneveld et al. 2013). Myeloma is the seventeenth most common cancer in the UK accounting for 17% of all newly diagnosed malignancies (ONS 2016). Like certain types of NHL and CLL, myeloma can also be monitored until active treatment is required.

Treatment usually involves chemotherapy and peripheral stem cell transplantation in some cases. Myeloma is incurable with incidences increasing with age and the five-year survival rates were almost 50% (CRUK 2017). A combination of drugs is almost always the treatment of choice for myeloma. It is given over several weeks with or without a rest period (Myeloma UK 2019). Each treatment is a cycle and may involve the patient receiving many cycles of treatment. Treatment can include chemotherapy drugs, steroids, and other anti-myeloma drugs (Myeloma UK 2019).

The most commonly used treatment combinations include.

- Cyclophosphamide, thalidomide, and dexamethasone (known as CTD).
- Bortezomib (Velcade), thalidomide and dexamethasone (known as VTD);
- Bortezomib (Velcade), cyclophosphamide and dexamethasone (known as VCD).

Following this many patients may undergo high dose therapy followed by autologous stem cell transplantation (Myeloma UK 2019).

2.4 Treatment and treatment-related toxicities in B cell malignancies

Treatment for B cell malignancies is usually determined by disease stage with the indolent ones being on a 'watch and wait' pathway being actively monitored to the aggressive ones who may require treatment straightaway and the treatments differ from solid tumours in that they have many subtypes (WHO 2015). Each subtype differs in its presentation and rates of disease progression. B cell malignancies may require multiple lines of treatment as they can relapse and require treatment for intermittent periods continuing for a longer period (NICE 2003; Emanuel 2007).

The therapeutic modalities for treating B cell malignancies in the UK commonly include chemotherapy, targeted therapy, immune therapy and some patients receiving radiotherapy and possibly the inclusion of physical and/or psychological rehabilitation (Gratwohl et al. 2013). Younger MM patients may also receive peripheral stem cell transplantation and supportive care which includes transfusion of red blood cells and platelets which are administered to complement chemotherapy and radiotherapy (Armitage 2012; Mohty and Harousseau 2014). Many novel therapies either individually or in combination are being tested in clinical trials either in newly diagnosed or patients with a relapsed B cell malignancy. The main purpose of treatment is to reduce the risk of disease recurrence, to increase the chances of cure and survival rates and optimise QoL (Andrade et al. 2013).

Contrary to other malignant diseases, haematological malignancies and the chemotherapy treatment regimens used to treat them are often more complex and intense. As a result, they can be more physically and psychologically burdensome with prolonged inpatient admissions and significant adverse effects for patients resulting from the illness and treatment (De Vita et al. 2008; Junlen et al. 2015; Mounier et al. 2015; Pulte, Jansen, Castro, & Brenner 2016).

Various treatments are available for patients with B cell malignancies ranging from single to a combination of drugs which consists of chemotherapy with multiple agents, radiation therapy, immune therapy and autologous or allogeneic stem cell transplantation to achieve a cure (Cullen 2001; Oberoi et al. 2017). These treatments are generally intense patients may have to endure long phases of treatment and this can expose the individuals to a high risk for infection, thereby placing them in isolated rooms for protection. These patients are isolated for a long period (weeks or months) by limiting exposure to other people and preventing any transmission of infection (Cutler 2012; McDonald et al. 2012). Isolation in these positive-pressure rooms can reduce human contact significantly and limit the patient's daily routine (Oberoi et al. 2017; Xuereb and Dunlop 2003).

When a patient is diagnosed with a B-cell malignancy, the treatment not only affects clinical outcomes but can also negatively impact their QoL in the longer term (Fortner et al. 2006; Walker et al. 2017; van de Poll-Franse et al. 2018). The adverse effects of treatment are diverse and can affect most body systems depending on the chemotherapeutic regimens. Some of the side effects of the illness and treatment may be long-lasting or permanent (Takahashi 2016). Delayed effects can

also occur long after completion of treatment such as impaired cardiac or cognitive function and secondary cancers (Stein et al. 2008; Albini et al. 2010; Moore 2014). Studies investigating the long-term adverse effects of treatment for haematological malignancies have identified problems with the eye, endocrine function, neuro-sensory and cardio-pulmonary impairments (Montgomery et al. 2002; Aleman and van Leeuwen 2007; Hodgson, Grunfeld, Gunraj and Giudice 2010; Punnett, Tsang, and Hodgson 2010; Walsh 2010; Hess et al. 2011).

Treatment-related short-term toxicities have been reported as side effects, these side effects include acute confusion and sometimes metabolic disturbances (Hallek et al. 2010; Hassan and Abdi-Valugerdi 2014). The physical alterations that result due to receiving chemotherapy can be loss of hair and weight (McGrath and Phillips 2008; Kelly and Dowling 2011; Potrata et al. 2011). Other short-term toxicities of chemotherapy can cause symptoms of nausea, vomiting, diarrhoea, fatigue, pain, liver and renal problems, peripheral neuropathy and many more.

Along with long-term physical side effects, patients can also experience changes to their emotional and psychological wellbeing (Persson and Hallberg 2004; McGrath and Phillips 2008; Kelly and Dowling 2011; Raphael, Frey, and Gott 2019). Those who survive these adverse effects of treatments and go on to experience prolonged remissions (being clinically disease-free), often continue to live with decreased physical, social-emotional, and cognitive functioning thereby resulting in decreased QoL (Efficace et al. 2007; Recklitis and Syrjala 2017). This is because they continue to deal with the daily challenges of living with the late and long-term adverse effects of treatment and fear of disease recurrence. While survivors of a B-cell malignancy may live for many years, cancer and its treatment significantly impact the long-term health of these individuals (Doyle 2008; Taylor and Monterosso 2015).

With treatment for haematological malignancies generally being more complex and debilitating than treatments for other malignancies, there is an increased need for blood and platelet support due to low haemoglobin and platelet function respectively and an increased risk of a severe infection due to reduced white blood cell function which can at times be fatal (Hassan and Abdi-Valugerdi 2014). During the acute phase of illness and treatment, most patients interact with nursing staff on haematology day units for emotional and psychological support (Swanson and Koch 2010). Most haematology departments also have access to specialist social workers who provide services to both inpatients and outpatients. Therefore, issues that affect physical, social or emotional functioning, thereby having an impact on the QoL of patients during this phase, are mostly addressed and dealt with by either social workers or nursing staff (Lobb et al. 2009).

The current literature illustrates the different possible late-effects of hematologic malignancies. The outcomes and late effects could be attributed to the epidemiology of the disease and its related treatment regimens (Ibrahim et al. 2020). For example, survivors of HL who have been exposed to radiotherapy and chemotherapy are at increased risk of new cancers including

myelodysplasia/leukaemia and solid cancers, even after decades of treatment (Ng et al. 2011; Schaapveld et al. 2015; Henry-Amaret al. 1990). Other late effects for HL patients reported in literature include increased risk of cardiovascular diseases (Bhakta et al. 2016; Galper et al. 2011; Myrehaugbet al. 2008), pulmonary diseases (Lund et al. 1995; Abratt et al. 2004), gonadal dysfunction (Sieniawski et al. 2008) and psychosocial disturbances (Behringer et al. 2005; Daniels et al. 2014). Similarly, patients treated for NHL are at risk of multiple late effects, including new cancers and cardiovascular disease (Tward et al. 2006; Hemminki et al. 2008; Sanna et al. 2007; Moser et al. 2006).

Several late effects have been reported among patients with chronic leukemias, including cardiac toxicity, gonadal failure, psychosocial disturbances, and new cancers. Most of these complications/late effects are again attributed to the regimens used in treating these patients, including chemotherapy and targeted therapy (i.e., tyrosine kinase inhibitors) (Damlaj et al. 2019; Miranda et al. 2016). Patients with MM, are also at risk of several late effects, including increased risk of new cancers (especially those on post-transplant lenalidomide maintenance therapy) (Palumbo et al. 2014; Mols et al. 2012; Boland et al. 2013).

This posed a challenge of having a mixed group of patients with a range of haematological malignancies. For this reason, this study only focused on patients with B-cell malignancies as there were many similarities in the treatment regimens and the incidence of these group of malignancies in an elderly population. As the sample size was not large enough to perform detailed subgroup analyses, the participants were grouped together under B-cell malignancies.

2.5 Co-morbidity Index

Long-term illnesses are more common among the older population and as a result, many older people live with such conditions. Cancer itself is a condition with long-term consequences which can affect a person's health and QoL. This is most prevalent amongst older people and therefore, co-morbidity is more common among cancer patients (Sarfati et al. 2016). Cancer survivors most often present with other medical conditions or ailments that may or may not be related, called comorbidities (Piccirillo 2000; Charles et al. 1987).

Co-morbidity has been defined as the "coexistence of disorders in addition to a primary disease of interest" (Feinstein, 1970, p394). This definition is still widely used. A search for wider definitions keeps coming back to the same definition by Feinstein. Evaluation of comorbidity is important in assessing functionality in a geriatric population, identifying potentially treatable conditions and estimating life expectancy (Fiorica et al. 2012). These conditions require constant assessment as they affect risk, detection, progression and treatment of cancer and place the older cancer survivors at a slightly higher risk of developing additional cancers (Deimling et al. 2009: Extermann 2007). Comorbid conditions can also create complications as they can be complex when it comes to

managing the treatment of them in conjunction with the intense, specialised treatment of cancer (Balducci and Extermann 2000; Extermann 2007).

It has been shown that cancer survivors are at an increased risk of developing chronic comorbidities such as diabetes, obesity, and cardiovascular disease (Demark-Wahnefried et al. 2005). Diseases associated with metabolic syndrome, particularly obesity, have been associated with increased risk of developing secondary cancers (solid tumours such as breast, colon, renal cell carcinoma, endometrial, adenocarcinoma of the oesophagus) (Demark-Wahnefried et al. 2005). Age-related comorbidities such as arthritis, osteoarthritis, increased blood pressure, cardiac problems and diabetes are common in older adults and commonly present alongside cancer (Extermann 2007). There is an increased risk of comorbidities with age, with those above the age of 70 years having on average three comorbid conditions that affect functioning (Deimling et al. 2002: Extermann 2007).

The Cumulative Illness Rating Scale (CIRS) is a tool that is used to measure comorbidity (Salvi et al. 2008) (**refer to Appendix 11**). It is an index that takes the severity of the existing medical illnesses into account. Survivors with an increased number of associated diseases have reported lower quality of life (De Souza et al. 2002; Slovacek et al. 2007). Therefore, it was imperative to identify comorbidities that may also impact the QoL of these participants in addition to their disease and aggressive treatment. There is yet to exist a gold standard approach in measuring comorbidity in the context of cancer (Sarfati 2012). However, there are a few comorbidity scores validated for use in elderly patients with cancer (Piccirillo et al. 2004; Miller et al. 1994; Singh et al. 1994). Although yet another common comorbidity index used was the Charlson Comorbidity Index (CCI), this study employed the CIRS scoring (Salas et al. 2021). This decision was based on the CIRS scoring system used predominantly in older haematological cancer patients in clinical practice. This decision was also guided by the haematology consultant who was my clinical supervisor for this MPhil study.

Patients with mild or no comorbidities had a better chance of survival than patients who presented with moderate or severe comorbidities. This demonstrated that those with increasing severity of comorbidities proved to have a shorter life expectancy (Fiorica et al. 2012). Previous studies have demonstrated the association between comorbidities and QoL and have confirmed that the presence of comorbidities can disrupt daily activities thereby having a negative influence on the health and wellbeing of a cohort of colorectal cancer survivors (Gray et al. 2011; Hornbook et al. 2011; Cummings et al. 2018). Findings from the study reported by Fiorica and colleagues (2012) have suggested the importance of the potential value of including comorbidity in clinical studies to determine overall survival. It is evident from research that the presence of comorbidities has a detrimental effect on the QoL and functioning status of cancer survivors, particularly on women (Deimling et al. 2009).

This MPhil study used CIRS scoring in the second phase of the study. CIRS is often used in documenting the comorbidities of patients diagnosed and treated for cancer (Miller et al. 1994). There is an increasing number of studies that demonstrate the presence of comorbidities that have an increased impact on the QoL of cancer survivors; the higher the number of comorbidities, the lower the QoL (Gijsen et al. 2001; Kriegsmann et al. 2004; Fortin et al. 2004).

2.6 Challenges in measuring QoL

Measurement of QoL in people with B-cell malignancies may be challenging due to prolonged and complex treatment regimens that may result in many of the very same symptoms that these diseases may cause (Efficace et al. 2007). Despite the recognition of its importance and recommendations to include QoL outcome measures in cancer drug trials, few early phase studies include QoL as an outcome measure, especially from patients' perspectives (e.g., patient-reported outcome) (Efficace et al. 2007). Additionally, very few later phases of randomised controlled trials (RCTs) in haematology include QoL as a primary outcome measure. However, there now is seen a steady increase in the capture of QoL data as a secondary outcome measure in clinical trials.

QoL measurement in patients with a haematological malignancy has mainly focused on the acute phase of treatment (Strasser-Weippl and Ludwig 2008; Courneya et al. 2009; Else et al. 2009; Gulbrandsen et al.2004; Johnson et al. 2009). Most published studies measuring QoL have been associated with clinical trials, evaluating their effectiveness on an individual's QoL rather than evaluating the effect the disease has on patient QoL (Else et al. 2005; Eichhorst et al. 2007; Else et al. 2009; Merli et al. 2004; Kroenke et al. 2010).

With increased incidences of comorbidities and mortality associated with haematological malignancies, information can be missed while capturing QoL data amongst the cancer population. Information can be missed as survivors may become ill, may not feel like completing QoL questionnaires, can miss completing a question in a questionnaire, and may experience treatment toxicities, disease relapse etc. The data collected may not be representative as vital information from those survivors who may be ill or are experiencing other problems and treatment toxicities may not be captured (Jensen et al. 2014). These missing data can cause issues in the interpretation of results. Despite missing data, measurement, and interpretation of QoL results are vital in improving clinical practice (Jensen et al. 2013).

In the mid to late 1980s, there was very little quality of measures available that were valid and reliable, however, since this time there are now many validated measures to measure QoL in cancer patients receiving treatment. Each has its strengths and weaknesses (Peterman et al. 2002; Buchanan et al. 2007). QoL measures have been validated for a specific population of interest. It is important to tailor the measures to suit the population at various stages of the cancer care continuum (Ganz

2006). For example, the data captured for cancer patients may differ from that captured for cancer survivors as the experiences, symptoms, side effects and the impact it has on the QoL may all differ.

2.7 The cancer survivor and survivorship

Advances in early detection and cancer treatment have gradually changed the illness from a guaranteed death sentence to a chronic illness. This change has shifted the focus from mere survival to survivorship issues or concerns (Aziz and Rowland 2003; Hewitt et al. 2006; Davies 2009). The past three decades have seen an increase in publications around cancer survivorship (Harrop, Dean and Basket 2011; Siegel et al. 2012; Takahashi 2016).

A cancer survivor is an individual who is at any point in their cancer journey before, during or after treatment (Ganz 2009). This study focuses mainly on individuals who have completed their primary treatment for a B-cell malignancy (chemotherapy, radiotherapy and/or peripheral stem cell transplantation). Wronsky (2015:4) reiterates that a cancer survivor is someone who may not have completed all treatment for malignancy but is continuing treatment. He asserts that the definition of a 'cancer survivor' is not someone who is cured of cancer or not. An individual can be a survivor even if the malignancy is not cured. However, most recently, the concept of survivorship has taken a whole new meaning with an all incorporating definition.

There are multiple definitions for survivorship, and it is a broad term. "Cancer survivorship" is a term that has come to represent the state or process of living following a diagnosis of cancer, regardless of how long a person lives (Maddams et al. 2009). Although it is a widely used term, there is varied consistency in its meaning and application in the literature (Khan, Rose & Evans 2011). Some pieces of literature use survivorship interchangeably with survival and others used it as an umbrella term to denote any ongoing QoL issues following completion of treatment (Salz et al. 2014). Some parts of literature align survivorship closely with personal identity (Deimling, Bowman & Wagner 2007). Cancer survivorship has been described as a positive side effect of more successful cancer treatment (Moser and Meunier 2014).

In 2010, the UK's National Cancer Survivorship Initiative (NCSI) recognised that many different definitions of cancer survivorship are used (NCSI, 2010). The term 'cancer survivor'; originated in the US, as an encouraging psychosocial term to encourage people to "learn to fight" cancer (Twombly, 2004, p.1414). The President of the National Coalition for Cancer Survivorship (NCCS), Ellen Stovall, in the United States of America stated the term was "designed to empower patients to make decisions about their care and to push for better research and treatment" (Twombly, 2004, p.1414). The NCSI (2010) defined 'survivorship' as encompassing:

"Those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease" (Department of Health, 2010, p.21)

Macmillan Cancer Support funded a Cancer Research 'Survivorship' group based at the University of Southampton and while they funded this, they also endeavoured to recognise individuals previously diagnosed with any cancer as 'living with and beyond'. The NCSI acknowledge these various terms and that many individuals prefer to consider themselves, and to be addressed by others, as "living with and beyond" (2010, p.9).

Subsequently, the terms 'survivorship' and 'living with and beyond' are used interchangeably within this field in the UK. For instance, when the NCSI published '*Living with & Beyond Cancer: Taking action to improve outcomes*' in March 2013 (Department of Health et al. 2013), the title included the term 'Living with & Beyond Cancer'. The report comprised ten sections; four of these ten section headings included the term 'survivorship'. None used 'living with and beyond'. Macmillan et al (2014) in reporting the 'Routes from Diagnosis' continue to refer to 'survivorship outcomes' and 'survival times. This, potentially, demonstrates the difference in use of terminology in relation to this population.

An American physician, Dr Fitzhugh Mullan described the way he felt following treatment for an anaplastic primary mediastinal seminoma at the age of 32; he was the first person to coin the word 'survivorship' (Mullan 1985). He describes his personal experiences with cancer and focused on defining the course of cancer in the *New England Journal of Medicine*. This term was used in the broader sense that it incorporated patients who have been cured of malignancy and those still undergoing treatment. It placed a focus on both the positive experiences and the continuing problems cancer patients face during and after treatment (Khan et al. 2012).

Cancer survivorship is a concept used by many healthcare professionals, researchers, and cancer patients to understand not only the physical but also the social, psychological, and spiritual impact of cancer for the remaining part of one's life (Twombly 2004). It can be viewed as a continual, dynamic process that begins at diagnosis and continues for the remainder of one's life and can be defined as the experience of "living with, through or beyond cancer" (Leigh, 1992, p.1475).

Bell and Ristovski-Slijepcevic (2013) also assert the argument about the beginning of survivorship; whether it begins during treatment, completion of all treatment or at least five years have passed by without any disease recurrence. In the past, with advances in treatment, those who survived beyond five years following treatment without any recurrence of the malignancy were termed as survivors (Leigh 2004).

The meaning of survivorship in the United States denotes an individual who is living with and beyond cancer and any individual who lives with a malignancy until the end of his life are termed a survivor (National Coalition for Cancer Survivorship 2013). In the UK, The National Cancer Survivorship Initiative defined a survivor as 'those who completed primary treatment, those who are in remission following treatment, those who are cured, and those with active or advanced disease' (Department of Health, Macmillan Cancer Support, NHS Improvement, 2010, p.9).

Cancer survivorship experience is subjective, and a high proportion of cancer survivors have reported experiencing a very good QoL, good health, little psychological distress and no lack of supportive care needs in their lives (Harrison et al. 2011). However, findings from other studies (Oberoi et al. 2017; Sherman et al. 2005) have demonstrated reduced physical functioning and diminished emotional well-being amongst the survivors. This study by Oberoi and colleagues comprised only patients diagnosed with diffuse large B cell lymphoma and MM. Sherman and colleagues (2005) confirmed that physical functioning was far more affected than mental well-being and included only patients treated for MM. These findings were also comparable with those reported in a study by Pulgar et al. (2015) where reduced QoL was reported in the physical and emotional subscales except that the population consisted of a mix of patients with leukaemia, lymphoma and MM who were between one and two years' post-diagnosis.

As advancements in early detection and significant improvements in the treatment of haematological malignancies have increased the possibility of long-term survival; the quality of that survival has become an issue for health professionals, as well as for patients with cancer (Osoba et al. 1997; Zebrack 2000). Although growing numbers of studies have documented the considerable impact of cancer diagnosis and treatment on QoL in newly diagnosed cancer patients (Kang et al. 2017; Laghousi et al. 2019; Bachmann et al. 2018; Osoba et al. 1997), less attention has been focused on QoL in long-term survivors partly because of the recent improvements in the rates of survival (Gota et al. 2002; Hebdon et al. 2015; Kang et al. 2017).

Those affected by cancer have expressed the need for support in managing the consequences of cancer and the treatment effects on their lives (Corner et al. 2007). This is because they may not be prepared to face the consequences following treatment for cancer which can leave them vulnerable, in fear, experience loss of confidence and struggle to access care and support (Foster et al. 2015; Armes et al. 2009). Foster and colleagues (2018) have stressed the importance of identifying those cancer survivors who require support post treatment and the level of support and the timing of when and how this took take form.

In recent years there has been a significant focus on improving survival outcomes for those diagnosed with cancer in the UK (Foster et al. 2018). This has been demonstrated through the publication of the Cancer Reform Strategy (Department of Health, 2007); the establishment of the National Cancer Survivorship Initiative (2010, 2013); the Improving Outcomes Strategy for Cancer (Department of Health, 2011); and the establishment of a new Independent Cancer Taskforce in January 2015 (Cancer Research UK, 2015; NHS England, 2015), which shaped a five year cancer strategy for England (2015-2020) focusing on achieving world class cancer outcomes (Independent Cancer Taskforce, 2015; NHS, 2016).

The Independent Cancer Taskforce (2015) recommended reduced variations in treatment, outcomes and experience; and also, the implementation of the Recovery Package (Rowe et al. 2014). The

Recovery Package set out measures to improve the experiences of cancer and treatment including long term QoL. Against this background, it is important to provide context as to why research into the consequences of cancer and its treatment for patient with haematological malignancies is important.

The goal of survivorship research is to focus on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase (Aziz 2007). Survivorship research examines the causes of, and prevent and control the adverse effects associated with, cancer and its treatment, and optimise the physiologic, psychosocial, and functional outcomes for cancer survivors and their families (Aziz 2007). Cancer survivorship plays a strong focus on people's post-treatment lives in their communities and society (Takahashi 2016).

2.8 Unmet supportive care needs in cancer survivors

In the post-treatment phase for B-cell malignancies, many survivors continue to face challenges. Although some may continue to do well physically, emotionally, or socially, others experience continuing problems that may significantly affect their QoL (Moles et al. 2005; Aaronson et al. 2007). The issues or problems faced may depend on the type of treatment received. It is mainly following the completion of treatment when patients feel the lack of support measures in place (Lobb et al. 2009) as they move into long-term follow-up in an out-patient setting and lose interaction and continued connection with the health care providers. Patients may have many unmet supportive care needs that emerge in the post-treatment phase which can impact their QoL during this time.

The unique needs of these survivors have historically gone unrecognised (Holland and Reznik 2005). However, in recent years there has been a growing recognition in the acknowledgement of survivorship needs. For example, in January 2010, The National Cancer Survivorship Initiative (NCSI) was established in the UK, under the support of the Department of Health, Macmillan Cancer Support and other external stakeholders (Richards et al. 2011). This initiative aimed to understand the needs of those living with cancer and develop new models of care to enable them to live a healthy life as long as possible.

It has been argued that there has been more medical research into cancer survival reinforcing a biomedical model of illness in a fragmented way and removing subjectivity (Nettleton 1995) and relying heavily on questionnaire-based studies into quality of life (Doyle and Kelly 2005). Breaden (1997) and Thomas-Maclean (2004) suggested that 'needs' must not be universally defined but must take into consideration the social context, cultural background, support and/or interactions of those diagnosed with cancer and other illness.

Neil and colleagues (2017) and Breadon (1997) both described how 'cancer survivors' experience nightmares in similar ways to survivors of catastrophic events, such as earthquakes or fires, but with the additional burdens of fear of recurrence, physical compromise and isolation. It is thus important

to subjectively approach a topic such as survivorship taking into account the lived experiences of those who undergo intense treatments for a haematological malignancy and potentially experience long-term and late effects.

Previous studies have demonstrated that a substantial proportion of cancer survivors live with unmet needs that require help to deal with the malignancy and its consequences (Miller et al. 2016; Jefford et al. 2017). The most frequently reported unmet needs were found to be in the psychosocial domain with issues related to fear of cancer recurrence, uncertainty about the future and worry about family, friends, and colleagues (Harrison et al. 2009).

Supportive care is a vital component of healthcare (Fitch 2008) and entails the provision of necessary services to meet patients' needs. This may include physical, psychological, social, informational, and practical needs (Fitch 2008). Developing tailored programmes and services to best address the needs of cancer survivors should be a priority (Hall et al. 2015). Gaining insight from patients' experiences and information gathered from them is vital for developing and delivering appropriate supportive care services to cancer survivors (Hall et al. 2013).

The next chapter gives an overview of the QoL on survivors of a B-cell malignancy, discusses the changes to QoL over time, and explains the tools to measure QoL and the challenges associated with the same.

Chapter 3 Quality of Life: The Challenges

3.1 Setting the scene for QoL in survivors of haematological malignancies

QoL is an important aspect of a patient's cancer treatment and care. Although early detection advances in cancer treatment have offered better prognoses, cancer is still looked upon as a long-term illness (Lavdaniti and Tsitsis 2015). At the same time as being worried about the disease toxicities and other adverse effects of treatment can affect the QoL of the patients.

Many international professional societies have been established to advance research in health-related quality of life and thereby enhance the quality of patient care. One key organisation is the International Society for Quality-of-Life Research (ISOQOL) which was founded in 1994 (Grant and Rivera 1998). ISOQOL offers the opportunity for those involved in QoL research to connect and network. This international society now has over 820 members from over 40 countries who focus on advancing the science of high-quality research in health related QoL and patient-reported outcomes.

Over three decades ago the EORTC Quality of Life group was created to help develop the health-related quality of life measures for use in cancer clinical trials (Aaronson et al. 1993). This group was created to advise the EORTC headquarters in the design, implementation, and analysis of QoL studies within certain Phase 3 clinical studies (EORTC 2019). Phase 3 clinical studies refer to the main randomised controlled trial designed to evaluate a complex intervention in the MRC (Medical Research Council) Complex Interventions Framework (MRC 2000). This group is currently represented by fifteen European countries as well as Australia, Canada, and the United States of America (USA). Since its inception, there have been significant advancements in research to improve our understanding of the effects of cancer and its treatment on the QoL of diverse populations of patients. The group is now investigating the use of novel technologies in measuring patient-reported outcomes and QoL in clinical research and routine clinical practice.

3.2 Definition and overview of QoL

QoL has been defined in many ways and can be subjective. There is no universally accepted definition of QoL. The definitions range from emphasizing physical, emotional, and social wellbeing to those that describe the impact of a person's health on daily life (Carr and Higginson 2001; Pidala et al. 2010; Arndt et al. 2017). Although numerous authors have discussed the array of definitions of QoL, there has been no generally accepted definition (Lavdaniti and Tsitsis 2015).

Schumacher et al. defined it as "an individual's overall satisfaction with life and a general sense of personal well-being" (OECD 2004) and Cella referred to "quality of life as the patient's appraisal of and satisfaction with their current level of functioning compared with that, they perceive to be possible or ideal. The greater the gap between the actual and the ideal situation, the lower a person's quality of life will be" (OECD 2004). Dunn and colleagues (2013) defined QoL as a multi-

dimensional construct comprising an individual's physical, psychosocial, and emotional functioning. It is a concept that reflects many aspects of life.

The World Health Organization's Quality of Life (WHO QOL) Group (1998) has defined QoL. The WHO suggests that an individual's perception of their position in life in the context of the culture and value systems in which they are living concerning the person's goals, expectations standards, and concerns constitute their personal QoL. This broader definition includes domains such as physical and psychological health, level of independence, social relationships, and religious/personal beliefs. This MPhil study on the QoL of adult survivors of haematological malignancies mainly the B cell type, focuses on QoL and on different domains that can impact QoL. This study has used the WHO definition of QoL.

The last three decades have seen an increased interest in the measurement of QoL and its application as an outcome measure in patient-reported outcomes and clinical studies within disciplines related to health and social care. This appears to be a common feature measured in chronic diseases such as cancer and other life-limiting illnesses. In conditions such as haematological malignancies, QoL measurement can provide an insight into both the benefits and burden of the treatment.

Evaluation of treatment for haematological malignancies traditionally included measurement of overall survival, disease-free survival, and progression-free survival; however, there is now significant interest in assessing the QoL. Besides, there is also an increase in the number of journals that publish studies relating to QoL and some journals are even exclusively devoted to QoL research. Despite the challenges encountered in assessing the QoL from the perspective of the patient, there is an increase in interest in this field as it is commonly perceived to be a useful tool.

With the increase in adverse effects and toxicities (see **Section 2.4**) following completion of treatment for a haematological malignancy that may affect the QoL of these survivors, this has become an important parameter following treatment completion. It has gathered momentum and gained importance in nursing research.

QoL for cancer survivors can be influenced by their circumstances, levels of pain, attributions of self, their ability to function normally and their perceptions of themselves and their roles in the society they live in or the people around them (Zebrak 2000). The impact of cancer on the quality of life of an individual is likely to vary by cancer severity and site and type of treatment received (Gotay and Muraoka 1998; Esser et al. 2018).

3.3 Changes in QoL overtime

The debate around the conceptualisation and therefore the definition of QoL has been going on for some time now (Sprangers & Schwartz 1999). Within the ongoing debate, an important factor to consider is that the interpretation of QoL is not static, but changes over time. The significant aspects of QoL may change with everyone. Whilst levels of satisfaction with their life and QoL may also

change over time (Sprangers and Schwartz 1999). QoL can be influenced by individual, environmental, social, occupational, and biological factors (Lowy & Bernhard 2004).

Patients who have undergone treatment for a haematological malignancy may be in remission (biological); experience a change in working conditions or employment status which may occur following treatment (occupational/environmental); and/or there may be a change in the interpretation of QoL, something called a 'Response shift' (Sprangers and Schwartz 1999; Mechteld et al. 2005; Rohn et al. 2018). This 'Response shift model' describes changes in internal standards, values and conceptualisation of QoL of an individual can make the assessment of it more challenging over the entire cancer care continuum (Boucekine et al. 2015; Rohn et al. 2018).

There are changes and alterations observed in internal standards and values while adapting to a chronic illness (Hinz et al. 2017). For example, fatigue, acute pain, or insomnia may completely distort a healthy person's QoL while an individual who has undergone chemotherapy or radiotherapy for a B cell malignancy and has struggled with these symptoms may come to accept and learn to adapt and live with them by making relatively small lifestyle changes.

The values in respect to one's expectation of QoL may change over time such as the values, expectations and priorities of an adult and the factors that determine a person's own QoL may change as they become older (Carr et al. 2001; Carr and Higginson 2001). Measurement of QoL is further criticised as most studies in health research investigate the negative consequences of disease and treatment on an individual's QoL. Although exploration of negative consequences of cancer treatment is important as it offers valuable information and insight into a patient's experience, or how certain conditions and treatments influence the lives of individuals, it may not give a holistic idea about the other positive impact it can have on an individual's QoL (Moons et al. 2006). With the measurement of QoL focusing significantly on the limitations and negative impacts of the illness and treatment, very little attention has been paid to the positive elements that contribute to QoL (Hyland 1999).

Many studies on cancer patients and survivors have demonstrated the positive impacts the disease and treatment had on their quality of life. Cancer patients have perceived illness positively; have developed an increased sense of appreciation towards life, increased compassion, empathy, and self-assurance (Danoff et al. 1983; Fromm et al. 1996; Taylor et al. 1984; Tempelaar et al. 1989; Horgan et al. 2011). This has resulted in better QoL in cancer patients in comparison to healthy controls. Remaining positive may also enhance the positive experiences cancer survivors go through thus optimising their QoL. It is therefore important to include both the positive and negative factors when assessing QoL.

A qualitative study of osteosarcoma survivors revealed that most of them spoke about the positive consequences that cancer and the treatment had on their lives (Fauske et al. 2015). More than half of the participants stated how cancer had shaped their lives positively. Despite the challenges experienced, they overcame and worked to adapt to new challenges shaped them positively and their identity. Similar findings have been reported in other studies (Thornton 2002; Yonemoto et al. 2009).

Positive changes such as an experience of growth, a changed sense of oneself, a changed sense of relationship with others and a changed philosophy to life are termed as post-traumatic growth in the literature (Calhoun and Tedeschi 2006). Post-traumatic growth is also called benefit finding has been reported in a 'substantial proportion of cancer survivors linking positive changes to their life, relation to self with cancer, and relation to their experience with the illness in a review by Thornton (2002). Post-traumatic growth describes the positive psychological changes that can occur because of a struggle with highly challenging adverse events (Cormio et al. 2017). While negative consequences have been reported as a result of malignancy or its treatment, there is evidence to state that some survivors do experience positive consequences and appreciate the positive changes that may occur as a result of it which is reflected in the increasing number of publications that focus on the QoL in haematological cancer survivors (Allart-Vorelli et al. 2015).

3.4 Quality of life following treatment for a B cell malignancy

The majority of studies in cancer survivorship have focused on QoL in patients who have received treatment for breast, prostate and colorectal cancers (Ganz et al. 1998; Penson et al. 2003; Yost et al. 2008; Eton et al. 2019; Liao et al. 2019; Michael et al. 2019). Very little attention has been paid to survivors of leukaemias, lymphomas, myelomas and other haematological malignancies and even fewer studies in the post-treatment phase for patients of this disease group (Aziz 2007; Parry et al. 2011). Studies concerning survivorship are slowly increasing; however, most fail to include patients with haematological malignancy in their sample (Lobb et al. 2009; Oberoi et al. 2017).

QoL studies in patients with B-cell malignancies who have undergone chemotherapy, radiotherapy or stem cell transplantation are relatively few. Most studies measure the QoL during treatment (Ganz et al. 1998; Rezaei et al. 2012). Moreover, in patients with any kind of haematological malignancy, the greatest attention has been focused on adult survivors of childhood acute lymphoblastic leukaemia. For adult patients with a haematological malignancy, life following treatment is affected by physical, psychological, social, and spiritual needs (Aziz 2007; Ness et al. 2009; Raphael et al. 2019).

No effective cancer treatment appears to be without adverse effects. While many of these effects are temporary, others result in chronic health problems ranging from mildly annoying to life-threatening (Aziz and Rowland 2003). Aziz and Rowland (2003) and Langbecker and colleagues (2016) found

that late and long-term effects of cancer treatment include toxicities that are absent or subclinical at the end of therapy but manifest later and cause premature ageing of organs.

Chemotherapy agents used to treat haematological malignancies can cause damage to nerves and kidneys and result in social and psychological sequelae. Some of the consequences of this damage to nerves and kidneys include fatigue, sterility, loss of sexual function (Eakin et al. 2007), anxiety, uncertainty, social isolation (Doyle 2008; Garofalo et al. 2009), financial hardship and search for meaning in life (Beckford et al. 2008; Garofalo et al. 2009; Appleton et al. 2014; Wallace et al. 2015) can all impact survivorship.

The QoL of cancer survivors may be affected by various factors, including the type of haematological malignancy, physical activity, physical function, and social background (Heydarnejad et al. 2011; Charalambous 2016; Ramasubbu et al. 2021). In patients treated for haematological malignancies, exercise habits, anaemia, and psychosocial aspects are also reported to affect QoL, and physical function particularly in older survivors (Williams et al. 2019).

Patients with a B-cell malignancy in the post-treatment phase have many ongoing supportive care needs that are unmet which can considerably impact their QoL. Studies among patients with MM (Poulos et al. 2001; Gulbrandsen et al. 2004; Knob et al. 2007; Langbecker et al. 2016) found that, despite being in remission, many patients following treatment for MM continue to suffer from bone complications, chronic pain, impaired or reduced mobility or functioning and fatigue hugely affecting their QoL and well-being.

Another study conducted among survivors of aggressive NHL found that impairment in physical functioning reduced access to health care and resulted in experiencing more of an illness burden (Jensen et al. 2013). Similarly, studies among patients with chronic lymphocytic leukaemia (Holzner et al. 2004) and all haematological cancer patients (Das et al. 2011) reported that the QoL of these patients was fairly stable over one year of assessment, however, reported women to have a lower QoL in the areas of emotional and social functioning compared to male patients. Tao and colleagues (2015) argued that factors such as intensive and prolonged treatment modalities that often impose physical and psychological risks, long periods of hospital admissions, isolated caring environments for patients with haematological malignancies the quality of life of these individuals can be hugely affected.

In an Australian study of patients with haematological malignancies, 42% reported concerns about cancer recurrence, 33% expressed a need for a case manager or coordinator to approach about services needed and 31% of patients wanted their doctors to communicate better about their care (Dawson et al. 2016). This suggests that patients who have completed all treatment for a B-cell malignancy do have certain unmet supportive care needs. This study aims to identify these unmet needs and address them same. Therefore, along the cancer care continuum, concerns of these

survivors are an important part of cancer care and addressing these survivorship concerns optimises their QoL (Hewitt et al. 2006).

3.5 Summary

The evaluation of QoL in cancer survivors, particularly survivors treated for a haematological malignancy has become a growing interest in recent years. Although there is increasing debate around conceptualising QoL, there is a proliferation of interest in measuring QoL as an outcome measure in cancer survivors. There has been an increasing shift in the focus from the quantity of life to quality of life. The next question is of course: "What is the best way of measuring QoL?" Different types of QoL instruments measure QoL. It is evident that not all QoL instruments are appropriate for all populations. One of the main concerns is whether a particular QoL instrument is suitable for a particular patient population. A disease-specific QoL instrument captures QoL and any aspects associated with the particular disease and its treatment. Therefore, consideration of an appropriate measurement of QoL in survivors of a haematological malignancy mainly a B- cell malignancy is required.

The next chapter outlines the methodology of mixed-methods research and related issues in this thesis.

Chapter 4 The methodology of mixed-methods research

This study aimed to examine the QoL of adult haematological cancer survivors and identify any unmet supportive care needs that this group of people may experience. I aim to gain more knowledge on how a haematological malignancy mainly the diagnosis of a B cell malignancy and its treatments impacts an individual's QoL in the post-treatment phase. The objectives of this MPhil study as listed in **Section 2.1** were to enable the researcher to:

1. develop a deeper understanding of the QoL of survivors of adult haematological malignancies;
2. determine the impact of selected demographic variables on the QoL of survivors of haematological malignancies (e.g., age, gender, employment, education, living arrangements);
3. explore factors that influence that QoL;
4. Explore unmet supportive care needs in adult survivors of a haematological malignancy.

4.1 Introduction

There are many definitions of MMR but another commonly used one is the following:

'*Mixed methods research is a methodology for conducting research that involves collecting, analysing, and integrating (or mixing) quantitative and qualitative research (and data) in a single study or a longitudinal program of inquiry (Creswell 2003).'*

According to Johnson and colleagues (2007, p.123), MMR has been defined as:

…the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.

This chapter outlines the methodology of mixed methods research (MMR) employed to examine the QoL in adult survivors of haematological malignancies, B-cell malignancies in particular. It describes the background to pragmatism as a paradigm for undertaking this MPhil research and how it informs the study. The advantages of using pragmatism as a paradigm are discussed. The nature of the mixed-methods approach is discussed, the rationale for undertaking a mixed-methods study, advantages/disadvantages of undertaking a mixed methods study are described in this chapter.

The selection and definition of mixed-methods sequential explanatory design follow in this chapter. This chapter addresses the significance of this approach in detail and justifies its use in the data collection process. This chapter addresses the usefulness of a mixed-methods approach to study the QoL of those individuals who have completed primary treatment for a B-cell malignancy.

4.2 Theoretical framework: Pragmatism

The theoretical framework that has been adopted for this research is pragmatism. According to Shields (2004) and Hildebrand and David (2005), pragmatism is a philosophical movement that was derived from the Greek word 'pragma' meaning action. Early pragmatists believed that the real world could not be accessed solely by a singular scientific method (Conan and Eglen 2002: Gale 2005). According to Wolfe (1999), people's ordinary experiences and a desire for a better world are key to successfully understanding the world. Pragmatics "recognise that there are many different ways of interpreting the world and undertaking research, that no single point of view can ever give the entire picture and that there may be multiple realities" (Saunders et al. 2012). A theoretical framework such as pragmatism can be pivotal to the conduct of research as it focuses on the logical link between the two different paradigms of quantitative and qualitative research.

The pragmatism of mixed-methods approaches as a philosophical movement was formulated in the late 19th century (Johnson et al. 2007) when early pragmatists felt that taking a pragmatic and balanced approach would enhance communication amongst researchers from different paradigms and thereby improve knowledge (Maxcy 2003). Pragmatism according to Feilzer (2010) focuses on solving practical problems in the real world. However, both Rossman and Wilson (1994) and Morgan (1996) noted that pragmatism can present challenges for MMR and its researchers as there are claims that it can be wide-ranging. This is because pragmatism is believed to have a strong philosophical foothold amongst mixed-methods researchers and therefore, it is important to acknowledge these criticisms and defend with rigour the pragmatic choices made.

Pragmatism has also been identified in the research literature as an appropriate paradigm for conducting MMR (e.g., Howe 1988; Tashakkori and Teddlie 1998; Patton 2002; Maxcy 2003; Teddlie and Tashakkori 2003, 2006; 2009; Johnson and Onwuegbuzie 2004; Onwuegbuzie and Johnson 2006; Morgan, 2007; Denscombe 2008; Scott and Briggs 2009; Johnson and Gray 2010; Creswell and Plano Clark 2011). Many mixed-methods researchers, including (Johnson and Onwuegbuzie (2004); Maxcy (2003) and Morgan (2007) have advocated this paradigm and it has gained considerable support. Pragmatism as a paradigm can be pivotal to the conduct of research as it focuses on the logical link between two paradigms of enquiry: quantitative and qualitative encompassing both quantitative and qualitative research paradigms (Tashakkori and Teddlie 2003). MMR links the two paradigms of inquiry (Johnson and Onwuegbuzie 2004; Morgan 2007; Feilzer 2010).

Pragmatism is different from other world views. Unlike other paradigms, pragmatism as a worldview focus on the importance of the research question over the methods used, the consequences of the research, and those multiple data collection methods inform the study (Burt 2015; Creswell and Plana Clarke 2007). The nature of reality can be singular or multiple because the researcher can combine both deductive and inductive thinking to be able to present multiple perspectives of reality (Creswell

and Plana Clarke 2007; Pluye et al. 2018). Epistemologically the key to pragmatism is practicality. When addressing the research problem, the researcher collects data by 'what works', unlike post-positivism where distance and impartiality are underlying principles by which researchers collect data (Creswell and Plana Clarke 2007). According to Creswell and Plana Clarke (2007), in pragmatism, a multi stance approach allows the researcher to include both biased and unbiased perspectives and accepts that objective and subjective data are valuable to research. Both quantitative and qualitative data are collected and mixed and methodologically, this process not only enriches the research but also completes it (Tashakkori and Teddlie 2003; Kaur et al. 2019).

Distinguishing the various factors that may affect the quality of lives of adults who have completed treatment for haematological malignancy, a pragmatic approach is considered an appropriate means of inquiry for this study. The study aimed to examine the QoL of adults who have survived haematological malignancies and identify specific unmet supportive care needs that may persist following completion of primary treatment. To achieve this aim, the philosophical paradigm of pragmatism offered a means of thorough examination into the quality of lives of these haematological cancer survivors and enabled data to be collected and analysed. Using a sequential explanatory mixed-methods design within a pragmatic framework would be the best-suited means of examining the same.

In mixed-methods approaches health service researchers build knowledge on pragmatic grounds (Creswell 2003; Maxcy 2003) rather than being based on ideas, to engage with the variety of questions relevant to the complexity of health care (O 'Caithan et al. 2007). They choose approaches that are most appropriate for finding an answer to their research question (Tashakkori & Teddlie 1998). Pragmatism is based on the idea that quantitative and qualitative methods are compatible. Approaches are chosen which are most appropriate for finding an answer to the research question (Tashakkori and Teddlie 1998).

MMR enables a more detailed understanding of the phenomenon under study by combining quantitative and qualitative data collection techniques (Bryman 2006) which either approach on its own may not achieve. The concept of MMR was supported in this study in that it facilitated a rigorous approach to be undertaken to address a complex issue such as QoL in cancer survivors. Using a sequential explanatory mixed-methods design within a pragmatic framework would be the best-suited means of examining the same.

Data collected sequentially can facilitate a deeper understanding of a research problem. Researchers can use a range of data collection tools to study a problem comprehensively. This important consideration has been proposed in this study. MMR encourages the use of multiple worldviews and paradigms and focuses on the idea that problem-solving involve the use of numbers and words (Creswell and Plano-Clark 2007). Thus, both data collected sequentially or concurrently can enhance understanding of a given research problem. Aziz (2007) in her article "Cancer Survivorship

Research" stated that utilising a combination of qualitative and quantitative approaches, is also immensely useful.

According to Tashakkori and Teddlie (1998), MMR is considered a methodology. Creswell (2007) argues that as a methodology MMR emphasizes philosophical assumption/s or worldview/s, such as pragmatism. He further argues that any research has an underlying worldview or philosophical assumption that guides the researcher, and in this case of mixed methods research, it could be one worldview or multiple worldviews.

The next session outlines the background to the mixed-methods approach in practice.

4.3 Background to mixed-methods research

The notion of MMR has become popular in the last two decades predominantly in the field of education, management, sociology, and nursing (Creswell 2009). Although mixed methods approaches have become more popular over the past twenty years (Freshwater 2006; Giddings 2006; Creswell 2009), the argument that mixed methods are a 'new paradigm' is, in fact, new (Rapport and Braithwaite 2018).

"A mixed-methods way of thinking is an orientation toward social inquiry that actively invites us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished" (Greene, 2008, p. 20).

The term "mixed methods" refers to the methodology of research that progresses the systematic integration, or "mixing" of quantitative and qualitative data within a single investigation or programme of inquiry (Wisdom and Creswell 2013). MMR has become popular in the last decade predominantly in the field of education, management, sociology, and nursing (Creswell 2009). Although mixed methods approaches have become more popular over the past twenty years (Freshwater 2006; Giddings 2006; Creswell 2009), the argument that mixed methods are a 'new paradigm' is, in fact, new (Rapport and Braithwaite 2018). Some mixed methods researchers view it as an innovative approach to research whose exact nature can be undefined to some extent (Johnson et al. 2007).

Despite this, the past 15 years have seen a proliferation of mixed methods literature which also includes the publication of several new books (for example (Creswell and Plano Clarke 2011; Hesse-Biber 2010; Teddlie and Tashakkori 2009) and the publication of articles concerning MMR and its application in the *Journal of Mixed Methods Research*. This journal and the *International Journal of Multiple Research Approaches* are relatively new journals dedicated entirely to mixed methods research.

The Mixed Methods International Research Association (MMIRA) celebrated its fifth year as an organisation in August 2018 (MMIRA 2019). MMR involves the collection and analysis of both quantitative and qualitative data and integrating the two sets of results at some point in the research to draw inferences from the quantitative and qualitative results (Johnson and Onwuegbuzie 2004; Tashakkori and Creswell 2007). By integrating these methods, it is hoped to provide a better or deeper understanding of the research topic to give more detailed answers to research questions (Creswell and Plano Clark 2011; Guetermann et al. 2015) such as QoL in survivors of a haematological malignancy.

This approach has evolved to be increasingly attached to research practice and recognised as the third major research approach or research paradigm (Johnson et al. 2007). However, Creswell and Plano Clark (2007) and Tashakkori and Teddlie (2003) have argued that mixed-methods approaches involve the use of a research design whereby quantitative and qualitative aspects of research relate to each other and where equal weight is given to the quantitative and qualitative elements of data collection and analysis with pragmatism as a philosophical underpinning for the research.

According to Creswell, Fetters and Ivankova (2004), the core characteristics of a well-designed mixed-methods study include: collecting and analysing both quantitative (closed-ended) and qualitative (open-ended) data; integrating data during data collection, analysis, or discussion; using procedures to implement quantitative and qualitative components concurrently or sequentially. Although there does not exist a universally accepted definition of MMR, there is a wider agreement that the assured feature of MMR is the integration or “mixing” of quantitative and qualitative components (Johnson et al. 2007; Teddlie and Tashakkori 2009; 2012; Morse and Niehaus 2009).

Quantitative and qualitative data are intentionally integrated into mixed methods studies. Investigates believe that this integration maximises the strengths and minimises the weakness of each type of data (Creswell and Plano Clark 2017; Fetters, Curry and Creswell; 2013; Scammon et al 2013).

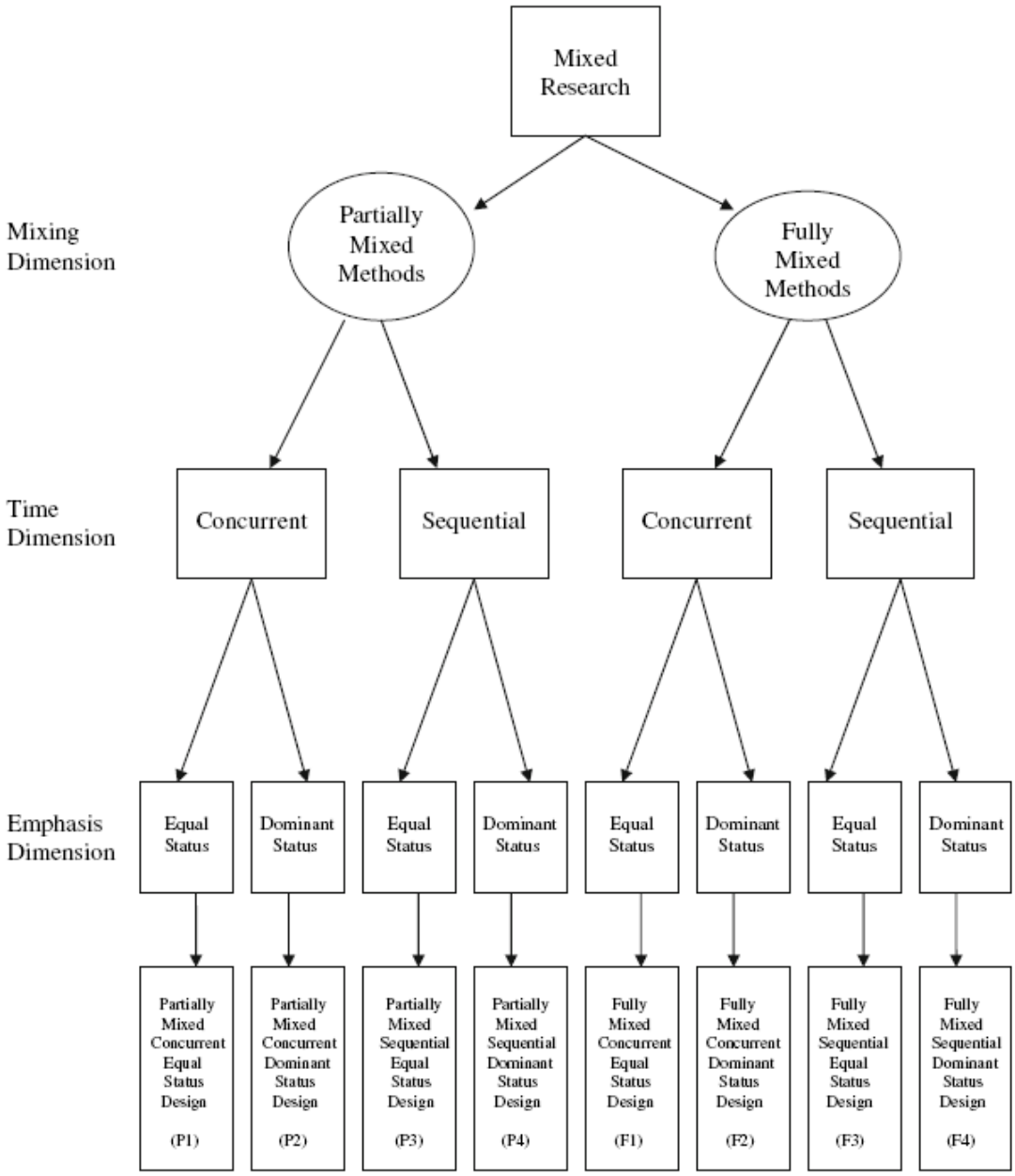


Figure 4-1: Typology of mixed methods

Source: Leech & Onwuegbuzie (2009)

4.4 Nature of mixed-methods research

One of the proposed advantages of conducting MMR is that it can overcome the disadvantages that are essential when adopting mono-method research (Greene and Caracelli 1997; Creswell et al. 2003; Johnson and Turner 2003; Onwuegbuzie and Johnson 2006; Teddlie and Tashakkori 2009). In this MPhil thesis it can be argued that by combining self-reported QoL questionnaires and semi-structured interviews in a single research study, the advantages of breadth and depth associated with these two respective methods are brought together. The effect of assimilating the results of these two methods possibly provides a more complete picture of a research topic that can address a range of

research questions and by doing so can provide a more complete picture that can enhance theory development and practice (Johnson and Onwuegbuzie 2004).

By employing MMR, researchers can use quantitative data to confirm and test the results of qualitative data, and qualitative data to confirm and add meaning to quantitative data (Johnson and Onwuegbuzie 2004). According to Johnson and Onwuegbuzie (2004), MMR was formalised as an approach to researching as it represents an attempt to legitimate the use of both quantitative and qualitative methods, rather than forcing the researchers to choose between one of the two methods.

4.5 The rationale for undertaking a mixed-methods study

No one method is sufficient in itself to capture the details of a complex situation such as the QoL of haematological cancer survivors. According to Doyle (2015), there have been significant advances in recent years in the field of MMR. This enables the capturing of multiple perspectives on the same problem. Holloway and Wheeler (2010) stated that MMR involves combining quantitative and qualitative approaches to research to strengthen the understanding of the clinical problem under investigation and develop new knowledge. When used in combination, quantitative and qualitative methods complement each other and allow for complete analysis (Green, Caracelli, & Graham 1989; Tashakkori & Teddlie 1998). To answer the research aims of this study, MMR was seen as the most suitable methodology.

The study aimed to measure and explore the QoL of those people who completed all treatment for haematological malignancies and identify the presence of unmet supportive care needs. To achieve this aim, the framework of pragmatism offers the MPhil researcher a means of thorough exploration of experiences and unmet supportive care needs cancer survivors may have that requires to be collected and interpreted. The most suitable means of exploring this within a pragmatic framework is through the use of a mixed-methods sequential explanatory design (see **Figure 4-1**).

Quantitative research approaches measure the QoL of adult survivors of haematological malignancies. Qualitative techniques facilitate explanations of the findings of quantitative phases. Employing quantitative methods (cross-sectional design) alone was considered but that in itself cannot effectively and adequately capture the reality of this situation. Hence, a sequential qualitative approach was required to explore survivors' experiences of living with haematological malignancy and the impact the disease and treatment had on their QoL. This method further facilitated the identifying of unmet supportive care needs in this group of survivors.

4.6 Advantages of conducting mixed-methods research

There are advantages and disadvantages of any method as well as MMR. The advantages of conducting MMR include: (1) allowing the researcher to gain a deeper and fuller understanding of the research problem under investigation by using both quantitative and qualitative data

(complementarity) (Giddings and Grant 2006; Andrew and Halcomb 2012) (2) the ability to complete a single research project more efficiently than conducting a series of interconnected projects (Morse and Niehaus 2011).

Understanding complex issues related to QoL and unmet supportive care needs in cancer survivors is achieved from different perspectives only by the use of mixed-methods research. The mixed-methods design is much stronger and the use of it enhances the validity and reduces bias as it uses more than one approach (Zhang 2014). Zhang (2014) argues that a mixed-methods approach offers a researcher more compelling evidence than with the use of a singular approach. The researcher can gain insight into the problem from different perspectives and gain a deeper understanding of complex issues (Bryers et al. 2014). However, with MMR being captured by post-positivism, it can still prove to be an effective approach for researchers from all paradigms (Giddings and Grant 2006).

4.7 Disadvantages of conducting mixed-methods research

As MMR involves the use of both quantitative and qualitative approaches, the time required for collection and analysis of both quantitative and qualitative data can be very time consuming and may result in financial implications too. With equal attention to be paid to two research methods and efficient management of resources, it can result in fewer questionnaires being collected or fewer interviews being conducted. Studies that involve a mixed-methods approach require people with expertise in both quantitative and qualitative research and also expertise in explaining findings generated by the two methods (Mahato et al. 2018).

4.8 Mixed-methods sequential explanatory design

Mixed methods research enables a detailed understanding of the phenomenon under study by combining quantitative and qualitative data collection techniques (Bryman 2006). Various typologies of MMR designs exist. For example, as outlined in Figure 4-1 mixed-methods designs may be sequential or concurrent (Creswell 2003; Hesse-Biber 2010). One phase of data collection occurs before the next in a sequential design: QUAN → QUAL or QUAL → QUAN. Sequential designs can be developed with the quantitative component first followed by the qualitative phase or vice versa. Capital letters are used to denote the dominance of the approach and small letters indicate the minor approach (for example QUAL and Quan). Explanatory studies are employed when the aim is to conduct a qualitative phase to help explain in further depth the quantitative results (Creswell 2003; Creswell and Plano Clark 2007; Hesse-Biber 2010). Creswell and others such as Plano Clark, Greene and Onwuegbuzie (2007) lay emphasis on the techniques or methods of data collection and analysis that are significant to mixed methods research.

Knowledge is developed based on cause and effect thinking, reduction to specific variables, hypotheses, and questions, use of measurement and observation, and the testing of theories (Creswell 1998). A researcher isolates variables and determines which to investigate and chooses instruments,

which will yield highly reliable and valid scores (Hesse-Biber 2010). In comparison, qualitative research is "an inquiry process of understanding" where the researcher develops a "complex, holistic picture, analyses words report detailed views of informants, and conducts the study in a natural setting" (Creswell 1998). In this approach, the researcher makes knowledge claims based on constructivist perspectives (Guba & Lincoln 1982). In qualitative research, data are collected from those immersed in the everyday life of the setting in which the study is framed. Ultimately, it "produces an understanding of the problem based on multiple contextual factors" (Miller 2000).

This study employed a sequential explanatory mixed methods design (Tashakkori & Teddlie 2003), for collecting, analysing and "mixing" both quantitative and qualitative data at some stage of the research process within a single study to understand the research problem more completely (Creswell 2002). In a sequential explanatory design (SED), qualitative data is used to enrich, explain, or elaborate upon, results gained from quantitative approaches (Creswell 2006). This method comprises two phases. Using this design, some researchers initially collect and analyse quantitative data during phase one of the study. The quantitative results are carefully scrutinised to identify areas that warrant further investigation with a qualitative phase. The second, qualitative phase clarifies and further explains/elaborates the quantitative results in detail (Creswell and Plano Clark 2007).

This design was selected over other competing designs (**refer to Section 4.2**) as it enables researchers to capture participants' experiences of living with a chronic illness further in a qualitative setting. In combining **both quantitative and qualitative data,** the research is methodologically rigorous (Gelling 2014). This is made evident whereby some researchers use mixed methods to improve the accuracy of the data, while a few others combine data to develop a complete picture. Mixed methods approaches have also been used to enable sampling in a study where questionnaires are used to identify participants to be included in an interview programme (Rocco et al. 2003; Bryman 2006; Collins et al. 2006).

For this study and to emphasise, Creswell's definition of mixed-method inquiry will be employed as it integrates a philosophical worldview, pragmatism and accommodates the idea of MMR as a methodology, while at the same time stressing the importance of method. MMR is fundamentally based on the principle that the combination of quantitative and qualitative approaches provides a better understanding of the problem or research question than either of the methods can achieve alone (Creswell and Plano Clarke 2007; Elliott 2005; Tashakkori and Teddlie 2003).

This concept of MMR has been supported in several areas throughout the study. First, MMR adds strength to the weaknesses of both quantitative and qualitative research. This was apt for this study as a rigorous approach to a complex issue as QoL in cancer survivors was ensured. Furthermore, researchers can allure on a wide range of data collection tools to study in detail a problem; an important reflection for a complex study as proposed. Mixed methods research also enables to answer questions that cannot be answered by just one approach. In this study, different analytical

skills were brought together. MMR encourages the use of multiple worldviews and paradigms and is viewed as a practical approach to research especially when addressing such a complex issue. This practical approach of MMR focuses on the notion that problems can be solved by using both numbers and words. This MPhil study used a pragmatic approach to answer the research question (Creswell and Plano Clarke 2007).

A diagrammatic representation of Creswell's Mixed-Methods Sequential Explanatory Design is illustrated in Figure 4.2 which illustrates the application of this model to the current study.

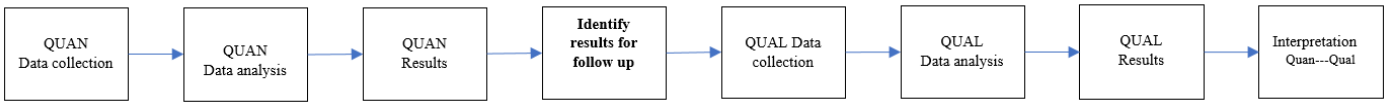


Figure 4-2: Diagrammatic representation Creswell's Mixed Methods Sequential Explanatory Design

(Creswell and Plano Clark 2007, p73)

Chapter 5 Methods used in this MPhil research

5.1 Introduction

Building on Chapter 4, the methodology of mixed-methods research (MMR), this chapter outlines the methods employed to explore and explain the phenomena of quality of lives of adult survivors with haematological malignancies living in one county in Southern England and treated at three hospitals. The chapter also addresses the use of an underlying conceptual framework of recovery of health and wellbeing in cancer survivorship by Foster and colleagues to situate the study (Foster et al. 2010). The methods used are a mixture of quantitative and qualitative starting with the quantitative methods in terms of a cross-sectional survey design followed by the qualitative in terms of semi-structured interviews.

Presented in this section are the identification and the recruitment of study participants in this study as well as the procedures and design of the study. Also included are an estimated sample size of the quantitative survey, an outline of the eligibility criteria, a description of quantitative and qualitative data collection methods and data analysis, ethical considerations, and limitations of conducting MMR.

5.2 Application of mixed-methods research in this MPhil

The nature of mixed-methods research is key to this research design. Some studies use both qualitative and quantitative research methods but report the results and discussion of the quantitative and qualitative elements separately. These are not considered integrated mixed-methods approaches. However, there is an increasing consensus that mixed-methods designs must aim to integrate quantitative and qualitative results to draw useful conclusions (Johnson et al. 2007).

The option in this thesis was either an explanatory or exploratory sequential design. Following the nature of the research aims, thorough reading and digesting of relevant literature and rigorous discussion with my MPhil supervisors, it was agreed that the explanatory sequential design was most suitable and relevant for this MPhil study. An explanatory sequential design with two phases- an initial quantitative phase followed by a qualitative phase was employed as illustrated in Figure 5.3. (Creswell 2003; Walsh et al. 2011).

Conducting a MPhil study can be a lonely existence (Bastalich 2017) and from my experience, this can be exacerbated by academic purists from either quantitative or qualitative paradigms. Due to the particularly restrictive timeframe and the need for the research to be conducted by a single researcher, it is rare for a mixed-methods doctoral study to move beyond a descriptive level. Bresson and colleagues (2016) in their review found that nursing studies that used MMR were explanatory in nature, often lacking explicitness. This may be appropriate if little is known about the research topic, but in areas such as cancer survivorship which has been highly studied in recent years, it can be a

challenge to undertake original research that can make a substantial contribution to the knowledge base.

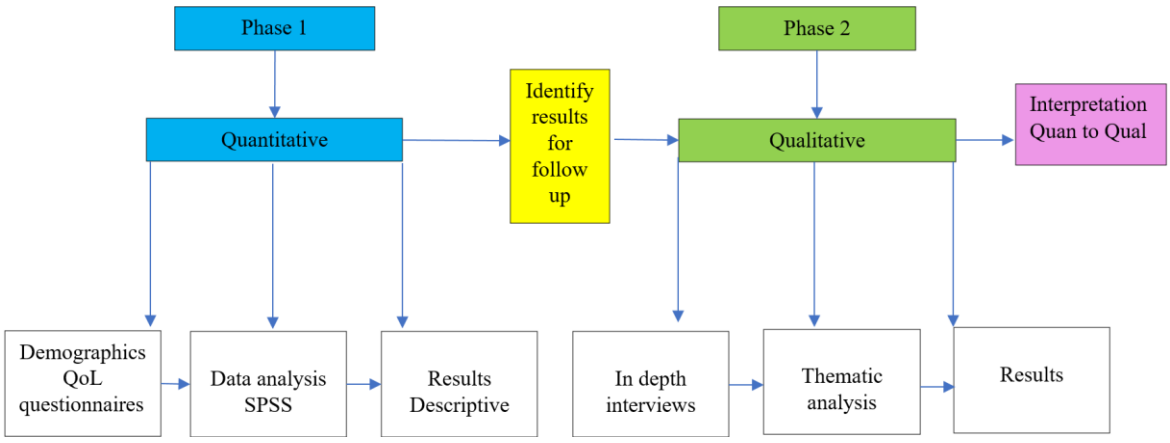


Figure 5-1: a mixed methods sequential explanatory design

Mixed-methods studies in their nature generate a large data set (Halcomb 2019). While a concurrent approach can be somewhat manageable, a sequential approach can lengthen the duration of data collection (Halcomb and Andrew 2009). This was evident from this MPhil study that the length of data collection for both the quantitative and qualitative phases was time consuming especially when the researcher had a full-time job alongside completing her doctoral study.

The framework (**Figure 5-2**) set out by Foster and colleagues (2010) draws in the wider domains of health and well-being coupled with Lent's model which has been applied to research with cancer survivors (Hoffman et al. 2013; Foster and Fenlon 2011). This model illustrates how problematic events and pre-existing socio-demographic factors may have an impact on how unsettling cancer and its treatment could be to the person reflected in the subjective health and well-being (Foster et al. 2010). Research also suggests that self-confidence is key to supporting and empowering people to manage problems following primary cancer treatment and that this is important for recovery of health and well-being (Foster and Fenlon 2011). An adapted version of the framework is illustrated in Chapter 8 and it reflects on the factors assessed in this study that are associated with optimising the QoL (Barlow et al. 2005; Lorig et al. 2001) of these haematological cancer survivors and those that enhance their recovery and well-being (Lev et al. 2001).

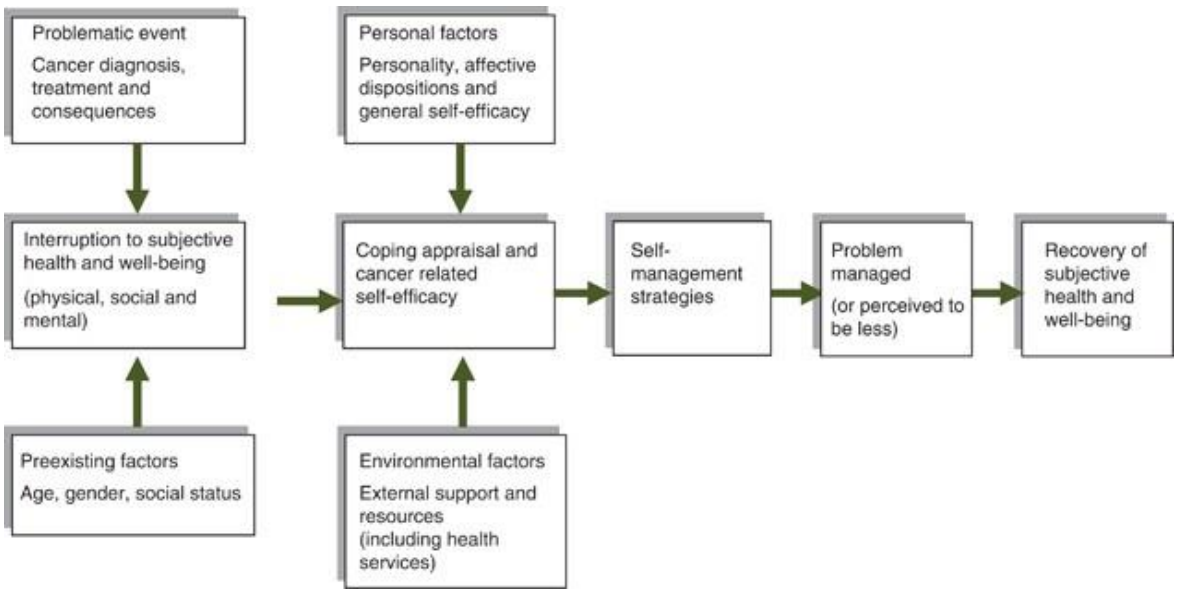


Figure 5-2: Recovery of health and well-being in cancer survivorship (adapted from Lent 2007; Foster et al. 2010).

5.3 Quantitative and qualitative sampling

5.3.1 Recruitment of study participants

In the first, quantitative phase of the study, there was a convenience sample of 131 participants recruited from three hospital sites in the South of England based on the eligibility criteria (**see Sections 5.4-5.5**). In the second, qualitative phase of the study, a subsample of eleven participants was purposively selected using maximum variation sampling (Polit and Beck 2012) for the in-depth semi-structured interviews. It was used to identify and recruit individuals who were able to reflect upon the phenomenon of interest (Smith and Osbourne 2003), i.e., the experience of living with a diagnosis of a haematological malignancy (specifically a B- cell malignancy) and thereafter.

Given the explanatory nature of the study, a maximum variation sampling strategy was employed to select the participants mainly adults diagnosed with a haematological malignancy, particularly the B cell type. To achieve this and based on the quantitative results, participants were selected from those who reported a good QoL with a very low level of unmet supportive care needs; those with moderate level and those with a poor QoL and high level of unmet supportive care needs as indicated from the QoL questionnaires.

Interviews were held in participants' homes or at their preferred location at a mutually convenient time and audio-recorded with their permission. Clarke (2006) suggested that research participants should be given a choice in the venue in which they are interviewed. Eleven of the interviews were conducted in participants' homes. One of the research participants preferred to be interviewed at their treatment hospital. This participant was interviewed in a private clinic room of the Haematology

outpatient department. For this purpose, a formal BU risk assessment was carried out. The BU risk assessment was to examine what likely cause may harm to individuals and to ensure enough precautions have been taken to prevent them from happening.

Participants were assured of confidentiality in their responses. The participant information sheet was mailed out to the participants before the interviews. Written informed consent was obtained from the participants before conducting interviews. The interviews ranged from 30 minutes to an hour each. The duration of each interview was ascribed to the nature of the malignancy and any problems the research participants were experiencing. The interviews were conducted by the researcher. Some of the participants provided elaborate answers, which lengthened the time of the interviews. The interview recordings were transcribed verbatim. Interview transcripts and recordings were only accessible to the researcher and the supervisory team. All the participants interviewed were between one- and five-years' post-treatment for a B-cell malignancy.

During the collection of qualitative data collection, the potential comorbidities of the participants were taken into consideration using a co-morbidity index as not all symptoms and problems experienced by these patients can, likely, be attributed to haematological malignancy or related treatment. It was imperative to identify comorbidities that may also influence the quality of life of these participants in addition to their disease and aggressive treatment.

At the time of collecting data, the participants were between one- and five-years following completion of all treatment or were in their post-treatment phase. The post-treatment phase refers to a period following completion of all treatment for a B cell malignancy.

5.4 Data collection methods

This method involved two phases: Phase 1 included the collection of objective, quantitative data. Survey research is defined as "the collection of information from a sample of individuals through their responses to questions" (Check & Schutt, 2012, p. 160). This type of research allows for a variety of methods to collect and analyse data and employ various instruments. This MPhil study used questionnaires with numerically rated items and according to Singleton and Straits (2009), surveys are often used in social and health care research. The Phase 2 part of the study employed a collection of subjective, qualitative data to further explain and elaborate on the results of the first, quantitative phase.

5.4.1 Phase 1: Quantitative approaches

This phase of the study involved a cross-sectional design (McMillan 2000; Chen et al. 2017) where data were collected at one point in time. It refers to collecting objective data at a single point in time in the form of a survey, as opposed to data collected over a longer period (CDC 2006). The aim of the first, quantitative phase of the study was to identify the factors that affect the QoL of survivors

of adult haematological malignancies and to determine the impact of selected demographic variables on the QoL of such survivors (e.g., employment, education, living arrangements, gender and age).

Questionnaire surveys have their merits and disadvantages. Questionnaires can be self-administered electronically or by post or administered by a researcher by telephone or in-person (Jones et al. 2013). Telephone and personal surveys can be very resource-consuming whereas postal surveys result in a better response rate and response bias (Edwards et al. 2009). Postal surveys were administered for this study to minimise the response bias and enhance response rates. A statistician was involved right from the beginning, and this helped to determine the sample size required to ensure this MPhil study has enough power.

An invitation letter was sent out to all participants of the research study which outlined the name of the study; the purpose of the research study and how the data would be collected and stored (refer to **Appendix 1, 2, 3** for a copy of the invitation letters). A reminder letter was sent two weeks later to the non-respondents (refer to **Appendix 4** for a copy of the letter). All the participants who completed the questionnaires were also invited to take part in Phase 2, the qualitative part of the study.

5.4.1.1 Tools to measure QoL

The relationship between objective and subjective dimensions concerning QoL measurement has been an ongoing discussion. Objective dimensions, traditionally refer to observable phenomena, such as the ability to walk, eat while subjective dimensions refer to an individual's perception such as overall happiness or satisfaction with life during or following completion of treatment (van Leeuwen et al. 2018).

Measurement, assessment, evaluation, and estimation of QoL using questionnaires have been used interchangeably in the literature. With data collected from validated QoL questionnaires predominantly being ordinal, it can be argued that QoL can be defined as 'measurement' only if the data is continuous. This is an important aspect to take into consideration when describing QoL data. Traditionally, the measurement of QoL for patients who have undergone chemotherapy, radiotherapy or a peripheral stem cell /bone marrow transplant for a haematological malignancy was to evaluate survival outcome. However, with advances in treatment modalities, recent times have seen an increasing trend in the measurements of the quality of that survival time of these patients.

Measurement of QoL in people with B-cell malignancies may be challenging due to prolonged and complex treatment regimens that may result in many of the very same symptoms that these diseases may cause (Efficace et al. 2007). Although there is increasing evidence for the added significance of measuring QoL, this poses a challenge when measuring it due to its subjective nature (Aaronson et al. 1993; Bowling 1995; Bottomley 2002; Hauken et al. 2015).

Despite the recognition of its importance and recommendations to include QoL outcome measures in cancer drug trials, few early phase studies included QoL as an outcome measure, especially from

patients' perspectives (e.g., patient-reported outcomes) (Efficace et al. 2007; Strasser-Weippl and Ludwig 2008). Treatment burden and overall survival are associated with patient-reported outcomes (Efficace et al. 2007; Esser et al. 2018). Additionally, very few later phases of randomised controlled trials in haematology include QoL as a primary outcome measure. However, there is a steady increase in the capture of QoL data as a secondary outcome measure in clinical trials.

In haematological malignancies, QoL measurement can offer insight into evaluating the benefits of the treatment and the burden the disease and treatment can place on an individual. QoL measurement can capture patients' experiences following treatment and the effects it has on them and this comprehensive measurement together with assessment of survival, capturing information about complications and disease recurrence can improve patient outcomes (Bottomley et al. 2005; Blazeby et al. 2006). This, in turn, can improve service provision in guiding decision making in oncology (Denis et al. 2017; Basch et al. 2017; Levato et al. 2013). Besides, the establishment of professional societies such as The International Society for QoL Research (ISOQOL) and the development of professional journals dedicated to QoL research has confirmed that there is an increased interest in the development of this concept.

5.4.1.1.1 ***Standardised questionnaires***

QoL in any malignancy can be measured using standardised HR-QoL questionnaires that may be generic, disease-specific, or domain-specific (Aaronson et al. 1993). Generic questionnaires measure general aspects that are common and noteworthy to everyone while, disease specific questionnaires are developed and used for a particular population such as cancer (Bowling 1995). A combination of HR-QoL instruments is generally employed in research to capture sensitive information and specific symptoms. The advantage of employing such instruments in QoL studies is that it is feasible to distribute them relatively easy to participants and can be completed at their convenience either in a hospital setting or in the comfort of their homes.

At the time of proposal writing, only two available QoL measures for cancer survivors were identified. This is despite the importance of issues experienced by long term survivors. One of the questionnaires is a modification of the other. The Quality of Life - Cancer Survivors Scale (QoL-CS) was developed by the City of Hope National Medical Centre. This questionnaire conceptualised QoL into four dimensions: physical, psychological, social, and spiritual (Ferrell et al. 1995). Items were based on a small number of survivors. Validation of the scale was based on survivors ranging from 4 months to 28 years after diagnosis (thus including newly diagnosed patients). There was not sufficient time and resources to pilot the QoL questionnaires employed in this MPhil study and hence this was not carried out.

5.4.1.1.2 *EORTC QLQ-C30 questionnaire*

EORTC QLQ-C30 is a standardised HR- QoL questionnaire developed by the European Organisation for Research and Treatment of Cancer (EORTC) Study Group to measure HR-QoL in patients undergoing treatment for cancer (Aaronson et al. 1993; Sprangers et al. 1993). This remains a frequently used generic instrument in research to capture the HR-QoL in cancer patients and was developed more than twenty-five years ago (Aaronson et al. 1993; Fayers and Bottomley 2002; Nolte et al. 2019). This core, generic questionnaire has been complemented with disease specific questionnaires, which capture components specific to each type of cancer (Kaasa et al. 1995; King 1996) and haematological malignancies in particular (Hjermstad et al. 1999; Zittoun et al. 1999). The same scoring systems applied to the disease specific questionnaires given to patients who were diagnosed with CLL (CLL 16) and MM (MY 20) along with the EORTC QLQ-C30 questionnaire. The modules describe aspects not included in the core questionnaire such as disease symptoms and treatment side effects. This was because they were primarily used in clinical trials to capture treatment side effects.

Several studies have investigated the validity, reliability, and other related measurement properties of the EORTC QLQ-C30 questionnaire (Aaronson et al. 1993; Niezgoda and Pater 1993; Aaronson et al. 1996; Kaasa et al. 1995; Groenvold et al.1997). These studies concluded that the questionnaire is generally an excellent instrument with good psychometric properties relevant to cancer-related populations (Aaronson et al. 1991; Aaronson et al. 1993; Niezgoda and Pater 1993; Aaronson et al. 1996; Bjordal and Kaasa 1992; Sieurdardottir et al. 1993; Ringdal and Ringdal 1993). Validity and reliability tests were not performed before use in this study as they had already been established.

5.4.1.1.3 *EQ-5D-3L questionnaire*

The EQ-5D-3L questionnaire has been in existence since 1987 and has been used to measure health outcomes (Euro QoL Group 2009) in a wide range of studies. The EQ-5D-3L, self-report includes mobility, self-care, usual activities, pain/discomfort and anxiety/depression. It also comprises a Visual Analogue Scale (VAS), which is a thermometer rated from 0-100 with 0 as the worst imaginable health state and 100 to be the best imaginable health state. The scores and differences between scores can be measured and thus easily quantified. This enables participants of research studies to self-rate their health status in a quantitative way (Rabin and Charro 2001; Chuang 2010). Validity and reliability tests were not performed before use in this study as they had already been established.

5.4.1.2 **Participant demographic data questionnaire**

Data on participants' demographic characteristics were collected using a demographic questionnaire. Demographic data collected included age at the time of data collection, gender, ethnic origin, marital, living, education and employment status. Demographic data is required to be collected to be able to analyse the associations between them and QoL. The collection of demographic data enables the description of the sample of people in the study (Connelly 2013). The variables to use were guided by the literature review. The hope is that the samples are representative of the larger population (Vogt and Johnson 2011).

The validity of collecting life history or biographical data has been well established. Clinical parameters collected included diagnosis and time since completion of treatment. Clinical information about the diagnosis, time of treatment completion was extracted from the medical records or hospital database and recorded on an excel spreadsheet and later transferred onto SPSS. The Statistical Package for the Social Sciences (SPSS) version 21.0 was used to analyse the quantitative results from the first phase of the study. Data were electronically stored securely on a hospital shared drive which was password protected.

5.4.1.3 **Quality of Life questionnaires**

The EORTC QLQ-C30, EQ-5D-3L and the relevant disease specific questionnaires (CLL 16 and MY 20) were used to collect data in the quantitative phase of the study to evaluate the different aspects of QoL. As outlined in **Sections 3.4.2 and 3.4.3,** the EORTC QLQ-C30 is one of the most widely used measures of QoL in cancer patients and assesses functional domains and symptoms that commonly occur in cancer patients. The EQ-5D-3L questionnaire measures the overall health status of an individual. The above-mentioned sections outline how widely these instruments are used and people's comments about their usefulness.

5.4.1.3.1 ***EORTC QLQ –C30 quality of life questionnaire***

Participants received the EORTC QLQ –C30 questionnaire (Aaronson et al. 1993 and Fayers et al. 2001). The validated 30-question EORTC QLQ-C30 questionnaire (Aaronson et al. 1993; Mustapa et al. 2007) assesses the health-related QoL and comprises fifteen scales which include: physical functioning, role functioning, cognitive functioning, emotional functioning, social functioning, fatigue, pain, nausea /vomiting, dyspnea, insomnia, appetite loss, constipation, diarrhea, financial difficulties, and global health status.

The questions were rated from 1 to 4 with scores corresponding to 'not at all', 'a little bit', 'quite a bit' and very much. Questions 29 and 30 were rated from 1 to 7 (very poor to excellent) (Aaronson et al. 1993). Each rated scale was used to compute a score ranging from 0 to 100 according to the

scoring manual of EORTC QLQ-C30 (2001). Higher scores for health status/QoL scale indicate better functioning whereas higher scores in symptom scales indicate the presence of more problems and difficulties (Sprangers et al. 1993). The validity and reliability of this questionnaire have been verified in several studies and reviews (Aaronson et al. 1993; Sprangers et al. 1993; Groenvold et al. 1997; Luckett et al. 2011), and the instrument is available in several languages (Fayers et al. 2001).

Descriptive statistics were first calculated. Numerical data were described using the median and interquartile range when skewed. Here, age was the only continuous variable that was considered skewed. The interquartile range is calculated by minusing the lower quartile from the upper quartile (Diamond and Jefferies 2006). Non-parametric Kendall's tau correlation coefficient was used to determine the associations between age and quality of life subscales with a two-tailed significance test ($p<0.05$). The Kendall's tau correlation was used as it measures the strength of the dependence of the two variables (Bland 2000).

In this study, the two variables whose strength of dependence was measured were age and quality of life subscales. The associations between socio-demographic, clinical factors and quality of life subscales were also determined using the Mann Whitney U test. This test is used when two independent random samples are compared and when the data are ordinal or dichotomous as in this sample (Bland 2000). The data collected from the quality-of-life questionnaires are considered ordinal as they range from 1-4 with 1 representing not at all, 2, a little bit, 3 quite a bit and 4 very much. Raw scores of this questionnaire are transformed into a linear scale ranging from 0-100. Higher scores represent higher functioning and quality of life and a higher level of symptoms. The scoring was undertaken using the directions from the EORTC scoring manual (Kaasa et al. 1995; Groenvold et al. 1997; Gulbrandsen et al. 2004). The data obtained from the demographic questionnaire is considered dichotomous.

5.4.1.3.2 *EQ-5D-3L quality of life questionnaire*

The EQ-5D-3L, a self-report questionnaire validated by the European QoL group and measures generic health related quality of life. The EQ-5D questionnaire has been in existence since 1987 and has been used to measure health outcomes (Euro QoL Group 2009). The questionnaire consists of 5 domains: Mobility, Self-care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. The participant was requested to choose from one of the three options which best describe how they feel ranging from 'no problems' to 'extreme problems.

The EQ-5D-3L VAS (visual analogue scale) ranges from 0-100 with 0 being the worst imaginable health state and 100 being the best imaginable health state. This enables participants to self-rate their health status (Rabin and Charro 2001). The participant is requested to mark their health status on the scale, and this is used as a quantitative measure to report health outcomes. Data from the questionnaires were analysed descriptively in accordance with the European Quality of Life Group

User Guide (Williams 1990). The three options (=levels) were combined into dichotomous variables in SPSS - option 1 (no problems) was relabelled as 'problems' and option 2 (some problems) and option 3 (extreme problems) as 'problems'.

The independent samples *t*-test was used to determine the associations between age and EQ-5D dimensions. This test was used as it tests the statistical differences between the means of two groups (Petrie and Sabin 2009). The independent sample *t*-test requires the assumption of homogeneity of variance. The test that is used for this assumption is Levene's test. If the null hypothesis of Levene's test is rejected, it suggests that the variances of both groups are not equal. This test was used to verify that assumption.

The associations between age and the EQ-5D VAS were determined using Spearman's rank correlation coefficient. This test is non-parametric and has been used to measure the strength and direction of two variables (Petrie and Sabin 2009). The associations between the socio-demographic variables and the dichotomised EQ-5D dimensions were determined using crosstabs. Row percentages were chosen as they were more useful and appropriate in answering the research question. If one cell had an expected count of less than 5, then Fisher's exact test was used (Foster et al. 2014).

5.4.1.3.3 *CLL16 and MY20 quality of life questionnaires*

These disease-specific questionnaires, also developed by the EORTC study group to measure QoL for patients undergoing cancer treatment, were used to collect data (e.g., CLL and Myeloma modules) for the first phase of the study (Holtzer-Goor et al. 2015). The same scoring systems applied to the disease specific questionnaires given to patients who were diagnosed with Chronic Lymphocytic Leukaemia (CLL 16) and Multiple Myeloma (MY 20) along with the other quality of life questionnaires. The EORTC QLQ-C30, EQ-5D-5L and the relevant disease specific questionnaires were used to evaluate the different aspects of health-related QoL. Two patients commented that they found the quality of life questionnaires difficult to read due to the smaller print. The EORTC quality of life group was contacted to find out if the same questionnaires were available in a bigger print. Unfortunately, the questionnaires were not available in bigger print.

This MPhil study aimed to examine and understand what quality of life means from a haematological cancer survivor's perspective. To achieve this, a researcher must be pragmatic and explore with an open mind to study various aspects that may affect the quality of lives of such survivors and identify unmet needs that may arise as a result. A semi-structured interview guide was used to help explore subjects of interest from the quantitative findings and those pertinent to the study (Patton 2002) (see **Appendix 15**). Questions were asked in a sequential manner as laid out in the interview guide. Interviewing as a method of data collection allows for the probing for more in-depth insights into a particular subject (Johnson and Turner 2003).

The second, qualitative phase aimed to explore more elaborately the results of findings of the first, quantitative phase of the study. Qualitative data were collected following analysis of data of the first phase of this research. Qualitative research methods facilitate understanding of the social phenomenon from the perspective of those involved and contextualise issues and understand the perspective from which the participants interpret so (Glesne 2006).

5.4.2 Phase 2: In-depth interviews

In qualitative research, the researcher captures the individual's observations or experiences as they have lived and/or felt it. It is usually a few participants who take part in qualitative research and the questions asked are in-depth, giving the individual the chance to answer personally and flexibly. In qualitative research, the interview with the participant might change and new questions will appear along the process. (Polit & Beck, 2012, 153-156).

The qualitative data will enhance and enrich the quantitative data and will give a fuller and comprehensive picture of the phenomenon under study (Creswell and Plano Clark 2007). In-depth face-to-face semi-structured interviews were employed to obtain qualitative data. In-depth semi-structured interviews were being conducted with the content and structure of the interviews envisaged to be grounded in the findings of the first, quantitative phase of the study. Semi-structured interviews are used when the topic being investigated is very personal to participants (Flick 1998). Semi-structured interviewing does not necessarily ask identical questions of each participant, and it uses mainly open-ended questions aiming to obtain specific information about the given situation (Flick 1998).

Semi-structured interviews are a simple, efficient and practical means of collecting important qualitative data (Creswell and Plano Clark 2007; Glesne 2006; Tashakkori and Teddlie 2003). They allow the researcher the opportunity to probe areas that are not easily observed such as feelings, emotions and, if necessary, discuss sensitive issues or topics in an appropriate manner (Creswell and Plano Clark 2007; Glesne 2006).

Semi-structured interviewing does not necessarily ask identical questions of each participant, and it uses mainly open-ended questions aiming to obtain specific information about the given situation (Flick 1998). A pre-determined set of questions is set for a semi-structured interview and other questions may emerge from dialogue with participants (Di Cicco-Bloom and Crabtree 2006). Hence, this interview technique was chosen over other techniques.

The validity and reliability of interviews are sometimes questioned. However, some researchers argue that semi-structured interviews have high validity because they allow the participants to talk in detail and can explain meanings behind actions with little or no input from the interviewer (Drever 1995; Glesne 2006; Tashakkori and Teddlie 2003; De Jonckheere and Vaughn 2019).

Johnson and Turner (2003) state that interview as a data collection method allows for the use of probing for more in-depth insights into a subject. A pre-determined set of questions is set for a semi-structured interview and other questions may emerge from dialogue with participants (Di Cicco-Bloom and Crabtree 2006). One-to-one interviews represent one of the best ways of gathering data on potentially sensitive subjects, such as the experiences of the individual with haematological malignancy (Miles and Huberman 1994). Hence this interview technique has been chosen over other techniques.

Interviews were conducted until data saturation was reached or the same material was heard across several interviews (Polit and Beck 2006). The response rate for agreeing to take part in the interviews was good and 93 participants had agreed to take part in the interviews. Out of those who had agreed to be interviewed, some of them were purposefully selected using a maximum variation sampling strategy (Patton 1990). This strategy enables understanding of a phenomenon like QoL in different people, in different settings and at different time points (Patton 1990).

Written informed consent was obtained from the participants before conducting interviews. The participant information sheet was being mailed out to the participants who sent back a reply slip expressing their willingness to take part in the interviews (see Appendix 6 and 7 for a copy of the participant information sheet and consent form). Interviews were held in participants' homes or at their preferred location at a mutually convenient time and audio-recorded with their permission. Clarke (2006) suggests that participants should be given the choice of venue. For this purpose, a BU (Bournemouth University) risk assessment was carried out. The purpose of the research was explained to the participants, and they were assured that all the information was completely confidential and anonymous. Each interview lasted for about an hour to an hour and a half and was recorded for later transcription. The interview recording was transcribed verbatim. The researcher's clinical skills of active listening and empathy were given primacy to remain participant-led as much as possible. All the audio files and transcripts were stored on password-protected computers and only the researcher had access to them.

Participants who completed the Phase 1 part of the study were approached to take part in the interview phase of the study to explore factors that affected their quality of life following completion of all treatment of a haematological malignancy (mainly a B-cell malignancy). The explanatory nature of the in-depth interviews provided added meaning and depth to the research problem and further enriched and explained the data collected in the quantitative phase of the study (Tashakkori and Teddlie 2003).

During the qualitative data collection, the co-morbidity of the participants was taken into consideration as not all symptoms and problems experienced by these patients can, likely, be attributed to haematological malignancy or related treatment. The Cumulative Illness Rating Scale (CIRS) was used as a tool (refer to **Appendix 14** for a copy of the CIRS scoring sheet) to measure

co-morbidity (Salvi et al. 2008). It is an index that takes the severity of the existing medical illnesses into account. Survivors with an increased number of associated diseases have reported lower QoL (De Souza et al. 2002; Slovacek et al. 2007). Therefore, it was imperative to identify co-morbidities that are likely to impact the QoL of these participants in addition to their disease and aggressive treatment. The second phase of the study captured such information from the participants' medical notes which was confirmed at the time of the interviews. It was not feasible to collect comorbidity data during the quantitative phase as most of the participants were sent the questionnaires by post. The topic guide for the qualitative phase was identified following analysis of the surveys. There was a gap between collecting quantitative data and the interviews as the quantitative data had to be analysed and a cohort was drawn to be invited for interviews.

5.5 Data Analysis

5.5.1 Quantitative data analysis

The Statistical Package for the Social Sciences (SPSS) version 21.0 was used to analyse the quantitative data. Descriptive statistics were first calculated. Numerical data were described using the median and interquartile range when skewed. Here, age was the only continuous variable that was considered skewed. The interquartile range is calculated by minusing the lower quartile from the upper quartile (Diamond and Jefferies 2006). Non-parametric Kendall's tau correlation coefficient was used to determine the associations between age and quality of life subscales with a two-tailed significance test ($p<0.05$). The Kendall's tau correlation was used as it measures the strength of the dependence of the two variables (Bland 2000). The two variables whose strength of dependence was measured were age and quality of life subscales. The associations between socio-demographic, clinical factors and quality of life subscales were also determined using the Mann-Whitney U test. This test is used when two independent random samples are compared and when the data are ordinal or dichotomous as in this sample (Bland 2000).

The data collected from the EORTC QLQ-C30 quality of life questionnaires were considered ordinal as they range from 1 to 4 with 1 representing not at all, 2, a little bit, 3 quite a bit and 4 very much. Raw scores of this questionnaire were transformed to a linear scale ranging from 0 to 100. Higher scores represent higher functioning and quality of life and a higher level of symptoms. The scoring was undertaken using the directions from the EORTC scoring manual (Kaasa et al. 1995; Groenvold et al. 1997; Gulbrandsen et al. 2004). The data obtained from the demographic questionnaire (refer to **Appendix 8**) was considered dichotomous.

The Independent samples *t*-test was used to determine the associations between age and EQ-5D dimensions. This test was used as it tests the statistical differences between the means of two groups (Petrie and Sabin 2009). The independent sample *t*-test requires the assumption of homogeneity of variance. The test that is used for this assumption is Levene's test. If the null hypothesis of Levene's

test is rejected, it suggests that the variances of both groups are not equal. This test was used to verify that assumption. The associations between age and the EQ-5D VAS were determined using Spearman's rank correlation coefficient. This test is non-parametric and has been used to measure the strength and direction of two variables (Petrie and Sabin 2009). The associations between the socio-demographic variables and the dichotomised EQ-5D dimensions were determined using crosstabs. Row percentages were chosen as they were more useful and appropriate in answering the research question. If one cell had an expected count of less than 5, then Fisher's exact test was used (Foster et al. 2014).

5.5.2 Qualitative data analysis

One of the most common methods of analysis and widely used in qualitative research is thematic analysis (Guest and Namey 2012). Thematic analysis is a process of identifying, analysing, and reporting themes or patterns within data (Braun and Clarke 2006). The choice of thematic analysis suits a pragmatic framework especially in nursing research with its ease of use, flexibility and acceptance academically (Braun and Clarke 2006). In nursing research, provides a rich description of data sets and allows for social and psychological interpretation of data sets and its ability to highlight similarities and differences (Nowell et al. 2017).

As detailed theoretical and technological knowledge is not required for thematic analysis as for other qualitative approaches, it is much more accessible as a form of analysis especially for those early in their research career (Guest et al. 2011). Braun and Clarke (2013) and King (2004) have argued that thematic analysis is a useful method for examining the perspectives of different participants. In this MPhil study, thematic analysis was used to identify factors that influenced the QoL of haematological cancer survivors and identify unmet supportive care needs that might be present. Thematic analysis conducted involved identifying, analysing and reporting themes in six phases: familiarising data; coding; searching for themes; reviewing themes; defining and naming themes and writing up (Braun and Clarke 2006; 2013; Keenan, van Teijlingen, & Pitchforth 2015).

The interviews followed a semi-structured approach, and the participants were given time to provide in-depth responses. The majority of interviews followed a fairly structured approach, with the majority of patient responses directly addressing the questions asked. For this reason, the interview guide was used as an initial coding structure, with any emerging themes noted as coding of the transcripts and hand notes progressed. All the interviews except one were held in participant homes and took up to an hour or an hour and a half each. One participant preferred to be interviewed at the hospital. From the coding of the interviews, similar themes that emerged were noted. A theme was highlighted in the analysis in cases whereby at least three of the twelve participants described a particular occurrence.

The interviews were audio-recorded and transcribed verbatim. Recording research interviews is a great way to capture qualitative data to ensure descriptive validity (Sutton and Austin 2015). Digital files do not get damaged with time and backup of files is easily managed without losing the integrity of files (Tessier 2012). Unlimited replay ability is possible in the digital recording of interviews (Al-yateem 2012) where the recording can be replayed many times, and this provides a basis for reliability and validity. Hand notes were taken when required and these were analysed together (Ritchie et al. 2013). Hand notes were taken to complement audio-taped interviews. These notes enable the researcher to make notes and comment upon impressions, environmental contexts and non-verbal cues that may not be adequately captured during the audio recording; the notes are taken at the same time as the recording of interviews (Sutton and Austin 2015).

The first stage in the analytical process was familiarising with the interview recordings and making notes. The second phase of analysis was the generation of codes across the qualitative dataset. This entailed complete coding of the entire data set. During this process, interesting and unique features were coded using a word or a short phrase. The same process was followed for all transcripts with data coded using the NVivo software package.

Individual transcripts were read and re-read several times, followed by a writing process which is a critical component of van Manen's (1990) hermeneutic process. As part of the writing process, meaning units were grouped together and subsequently organised into themes and sub-themes. Interview transcripts were initially de-identified once all transcripts were coded, they were categorised as clusters depending on how they relate to each other.

During the qualitative data analysis, regular meetings were held with all three supervisors. Emergent themes were discussed and agreed upon. Quotes from participant interviews were used to support the findings. The analytical approach was discussed with my academic supervisors, and we worked together to reach a consensus on the codes and themes to ensure the credibility and trustworthiness of the process (Minichiello et al. 2004; O'Reilly et al 2009; Cypress and Brigitte 2017).

5.5.2.1 **Rigour and trustworthiness**

Self-reflection of the researcher was enhanced by keeping a diary and a data analysis log and through regular meetings with the supervisory team to discuss themes as they emerged. Rigour was supported by the purposeful inclusion of participants who had experience with the phenomenon under investigation, an important consideration when the aim is to gain an in-depth understanding of the experience as in an interpretative study (Priest 2002).

Trustworthiness was enhanced by continuing with data collection until the same meanings were being relayed to the researcher and when the participants agreed with the sentiments, experiences, and opinions of other participants – 'the phenomenological nod'- and when asked what they meant, they indicated their agreement with the views of previous interviewees (Giddings et al. 2009.p.129).

An audit trail was also documented as the study progressed (Priest 2002). A full list of themes and subthemes are presented in **Table 7-2** in the results section.

5.5.3 Integration of findings

The term mixed methods refer to the process of collecting, analysing, and presenting both quantitative and qualitative data within the context of a single study (Tashakkori and Teddlie 2003). This approach provides a comprehensive way to address the objectives of this research. The analysis of mixed-methods design involves analysing both the quantitative and qualitative findings separately and then mixing the data. Inferences are drawn from both the quantitative and qualitative findings (Creswell and Plano Clark 2011). This study analysed data separately which is appropriate in explanatory mixed-methods designs (Creswell and Plano Clark 2011).

In this study, the quantitative data were collected first to inform the qualitative part of the study. The quantitative data served as a platform to inform the qualitative phase of the study. The quantitative data of this study navigated the qualitative phase which explained the numerical data from the quantitative phase. The advantage of this approach in this study was the ability to fully explore and gain a complete understanding of the phenomenon of QoL and identify certain unmet supportive care needs (Gueterman et al. 2015).

5.6 Recruiting sites

Eligible participants treated at three Dorset NHS hospitals within a single county in England-Royal Bournemouth Hospital, Poole General Hospital and Dorset County Hospital were invited to participate in the study. The treating haematologists at each hospital assumed responsibility for identifying potential participants who met the study eligibility criteria. The potential co-morbidity of older patients was taken into consideration using a co-morbidity index as not all symptoms and problems experienced by these patients can be attributed to a haematological malignancy or the related treatments. This was undertaken during the second, qualitative phase of the study. This was because the comorbidity index was not self-reported but had to be documented face to face. It, therefore, could not be captured during the first, quantitative phase of the study.

5.6.1 Sample size

Sampling plays a pivotal role in MMR design and is linked to the study design (Kemper et al. 2003; Creswell and Clark 2007; Onwuegbuzie and Collins 2017). The size of a quantitative sample, in general, would be larger than that of a qualitative sample (Creswell and Clark 2002; 2007; Tashakkori and Teddlie 2003). In mixed-methods sequential designs, data collection is dependent, with one form of data adding value to or building on another.

Sample size calculations were based upon detection of medium effect sizes (power = 0.8): a minimum sample size of 100 was required (Green 1991). Based on this calculation, for the First Phase of this study, around 200 eligible participants were identified. Only eligible participants were invited to take part in the first, quantitative phase of the study. Out of the 200 participants who were invited to participate in the first phase of the study, 131 of them returned completed questionnaires. The demographic and QoL questionnaires (refer to **Appendices 9-12**) were either handed over to the participants in the outpatient clinic or posted to their home address requesting them to return them within two weeks and also complete the reply slip (refer to **Appendix 5**) to be later contacted for an interview. Completed demographic and QoL questionnaires were returned to the haematology research office at Royal Bournemouth Hospital in postage-paid envelopes. Return of completed questionnaires implied consent.

In this mixed-methods sequential explanatory design, the qualitative data adds deeper meaning and provides more detail about the quantitative results. Creswell (2007) stresses the importance of using the same participants in both phases of the study. However, Creswell (2007) concludes that although maintaining the same participants is important, it is not necessary to maintain the same sample size for the qualitative phase.

Participants were recruited purposively for this thesis (**see Section 5.3.1**) that was determined by the richness of the individual cases. Purposive sampling is a standardised method to recruit participants since it is the most common sampling technique for gaining access to the most appropriate subjects known to provide rich information or experience (Gray 2014). It is important to purposively select participants for the qualitative phase that can best provide the detail required to expand on the quantitative results (Lebowski and Rubinstein 1995; Creswell and Clarke 2007; Johnson et al. 2007; Farrugia 2019).

Purposive sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases (Patton 2002). It involves the identification and selection of participants who are experienced with a particular phenomenon of interest (Creswell and Plano Clark 2011; 2017) and in this study, it refers to people who have completed all treatment for a B cell malignancy. Recent research has demonstrated the greater efficiency of purposive sampling compared to random sampling in qualitative research (van Rijnsoever 2017). The semi-structured interviews took place following the first phase of the study. There were twelve participants for the Second Phase of the study. The major purpose of the interviews was to develop an in-depth understanding of the results of the first phase of the study.

Semi-structured interviews were conducted until data saturation was achieved. Saturation is the most widely used principle for determining sample size and evaluating its sufficiency (Glaser and Strauss 1967; Kerr et al. 2010). Saturation being variously equated with ‘no new data’, ‘no new themes’, and ‘no new codes’ has emerged as the ‘gold standard’ in qualitative inquiry (Fusch and Ness 2015;

Guest, Bunce and Johnson 2006). Guest and colleagues (2006) analysed sixty interviews and found out that data saturation was reached at the twelfth interview. Data saturation in this MPhil thesis was reached at the twelfth interview. A copy of the semi-structured interview schedule can be found in **Appendix 15**.

5.6.2 Identification and recruitment of participants

Potential participants for the study were identified by treating clinicians at three hospital sites through a review of medical records, clinic lists and databases at each recruiting site. These participants were contacted by mail or in the outpatient clinics by their respective clinicians. Participants were also approached in outpatient clinics following confirmation of eligibility by the treating haematologists. The participants' age, diagnosis, time of diagnosis and time of treatment completion were extracted by the clinicians from the medical records or hospital databases.

Potential participants identified through the review of medical records were mailed an invitation letter detailing the purpose of the study, a demographic questionnaire, quality of life questionnaires, a reply slip and a postage-paid envelope. Those participants approached in outpatient clinics were given the same by hand. It was clearly stated that in the invitation letters that participation in the study was voluntary and the return of the completed questionnaire implied consent. This was stated to ensure that there was no coercion or undue influence of research participants to take part in the research study. Literature is abundant around voluntary consent for research studies (De Costa et al. 2004; Kass et al. 2005; Jegede 2009; Bull and Lindegger 2011). Due to limited resources, the researcher herself posted all the 200 questionnaire packs to patients.

A reply slip (refer to **Appendix 5**) requesting permission to be approached for the second qualitative phase of the study was enclosed for participants to complete with their contact details and to post with the completed questionnaires. Participants were requested to return the completed questionnaires in postage-paid envelopes.

5.6.3 Response rates

To enhance the response rate, a reminder letter and questionnaire pack were sent out after two weeks to all the participants who received the pack either by hand or by post initially. It is important to have high response rates in surveys as they reduce the risk of non-response bias (McColl et al. 2001). Participants receiving personalised invitation letters tend to respond better (Edwards et al. 2002). A strict exclusion criterion was set to help reduce the rates of refusal and non-completion rates (Boynton et al. 2004). For example, participants with mental disabilities, cognitive impairment, and those too unwell, and those who lacked basic proficiency in English which may interfere with the ability to complete questionnaires were excluded (see **Sections 4.7 and 4.8**).

Response rates are not important in qualitative research, but a range of participants must be included in the interviews, see **Table 7.1** for details of participants in the qualitative phase of this MPhil.

5.7 Inclusion criteria

The participants were all treated at the three hospital sites and resided in the region. The researcher worked in the three hospitals and had access to participants treated at those sites (please see sec 1.1) Participants were considered eligible in the study if: (1) they were men and women above 18 years of age. The United Nations Convention on the Rights of the Child 1989 defines a child as everyone under 18 unless, "under the law applicable to the child, the majority is attained earlier" (Office of the High Commissioner for Human Rights 1989). The UK has ratified this convention. Therefore, participants over the age of 18 years were included in the study as it aimed to examine the QoL of adults who have survived haematological malignancies; (2) they had no evidence of recurrent disease; (3) they had a basic proficiency in the English language. This attribute was expected from participants as there was no potential for translation. Hence, only English-speaking participants were included in the study. (4) They had completed induction and maintenance treatment (**see sec 2.2.1**) for a haematological malignancy mainly a B-cell malignancy 1-5 years before the commencement of the study; and (5) they were living within the catchment area/attending one of the selected hospital sites. We were careful in using purposive sampling to include the most appropriate people in the interviews (refer to **Table 7.1**).

5.8 Exclusion criteria

Participants with the following were excluded from the study: 1) cognitive impairment or a history of major psychiatric illness and lack capacity to provide informed consent, 2) too unwell to complete questionnaires or take part in interviews, 3) unwilling to give written informed consent to participate in the study, 4) living out of the study area and (5) not received treatment in any of the three hospital sites. The researcher did not have access to participants if they lived outside of the study area or were not treated at any of the three hospital sites. Ethical approval was only sought to include participants who lived /were treated at one of the three hospital sites.

5.9 Data

The diagnoses of participants in the study included people with haematological malignancies particularly B cell malignancies such as Chronic Lymphocytic Leukaemia (CLL), lymphomas and myelomas. In this study, quantitative methods are used firstly to identify specific issues or domains of QoL in people with these conditions like physical functioning, emotional functioning, cognitive functioning, social functioning, and other symptoms that may have a positive or negative impact on the lives of these survivors. The qualitative data are secondly used to enhance, complement, and

explain the quantitative findings in further detail. This sequencing also facilitates the understanding of unexplained results that may emerge from the first quantitative phase of the study. The qualitative methods help explore the lived-in experiences of survivors of B-cell malignancy in the post-treatment phase.

This study will use a sequential explanatory mixed methods design comprising of two distinct phases (Creswell 2002 and Creswell et al. 2003). In Phase 1(quantitative), numeric data will be collected using the EORTC QLQ-C30 questionnaires (Aaronson et al. 1993; Sprangers et al. 1993; Fayers et al. 2018). EORTC QLQ-C30 is a health-related quality of life questionnaire developed by the European Organization for Research and Treatment of Cancer (EORTC) Study Group (Aaronson et al. 1993; Sprangers et al. 1993; Fayers et al. 2012). The validity and reliability of the EORTC QLQ-C30 have been verified in several studies and reviews (Aaronson et al. 1993; Sprangers et al. 1996; Groenvold et al. 1997; Luckett et al. 2011), and the instrument is available in several languages (Fayers et al. 2016). Disease specific questionnaires also developed by the EORTC study group were used to collect data (e.g., CLL, NHL and Myeloma modules). These questionnaires captured data related to specific symptoms of haematological cancer. Data were collected in two phases. The aim of Phase 1 was to identify statistical differences amongst individuals who scored at extreme levels or gave extremes of responses and to explain the quantitative results in more depth with qualitative data (Creswell et al. 2003). This allowed for purposefully selecting participants for phase 2 (qualitative).

5.9.1 Data validation

To ensure the validity of data entered double-checking is recommended as data entry errors can have catastrophic effects on the results of the study (Barchard and Verenikina 2013). While entering quantitative data into SPSS, each set of data was double-checked for accuracy. 5% of data were randomly checked to do a quick comparison for the accuracy of data entered. There were no differences seen between the original data entered and the 5% that was randomly checked. This is only valid for the collection of quantitative data.

5.10 Ethical Considerations

Formal permission to conduct the study was obtained through the Integrated Research Administrative System (IRAS). The study was approved by the National Research Ethics Committee South Central –Southampton A (12/SC/0708). Local approval was also obtained from all the three hospital sites before approaching potential study participants. Approval from the NRES (National Research Ethics Service) committee and individual hospital sites were obtained as well as that of BU's Ethics Committee. A copy of the ethics approval letter is attached (**Appendix 16**).

Following on from the ethical principles of the Declaration of Helsinki which is based on protecting the rights, privacy, confidentiality, and well-being of study participants and assures that the study

protocol is followed (Martin and Thomson 2000, World Medical Association 2013). The study set forth to comply with these principles. The primary responsibility of the researcher was to safeguard participants and their data (Sutton and Austin 2015). The mechanisms to safeguard were clearly articulated to participants and was approved by the National Research Ethics Committee South Central –Southampton A.

There was no formal patient and public involvement in this research study except for a patient who was part of the ethics panel during study approval. I had numerous informal discussions with healthcare professionals around cancer survivorship, quality of life and the issues and problems around this significant topic. Of course, conducting semi-structured interviews allows the patients involved to contribute their views and experiences over and above the question I asked them. Being a researcher new to qualitative research, I sought advice from my supervisors who were very experienced in qualitative research before embarking on the project. All eligible patients were fully informed of what the study entailed as this is a fundamental principle of research ethics. For the first quantitative phase of the study, an invitation letter entailing the details of the study was enclosed with the relevant questionnaires and reply slip. It was made explicit in the invitation letters that participants could complete the relevant questionnaires but declined participation in the second phase of the study. A copy of the invitation letter, demographic data questionnaire, QoL questionnaires and reply slip is attached in the appendices.

Those participants who were invited to take part in the interviews were provided with written information about the study and given at least 24 hours to consider whether they wished to take part. The opportunity to clarify details of the study with participants was given either by phone or in-person before the interviews. Written consent was sought before data collection. As a researcher and nurse having received Good Clinical Practice and BU ethics training and working across the three locations where recruitment took place, information was presented in a manner that was free from coercion (ICN 1996) and ensured that the researcher's role as a nurse was not used to recruit participants unfairly.

Personal data was protected under the remit of the Data Protection Act (1998). The ethical nature of the study followed the Research Governance Framework (Department of Health 2005). All participants were informed that they were free to withdraw from the study at any time and the researcher answered any questions they had regarding the study. According to the ethical principles of beneficence, respect for human dignity and justice (Polit and Beck 2004), the participants were also informed that there will be no harm, prejudice or danger had they wished to decline to participate in the study and that this would have no impact on their medical care. The participants' general practitioner was informed of their participation in the study. In case of any concern or distress identified during interviewing, the participant's general practitioner will be informed. This may be expected while qualitative interviews are conducted.

5.11 Limitations of conducting mixed-methods research

The results of this study must be interpreted in the context of its limitations. In the quantitative phase of a research study, there is a potential risk of a non-response error, and this can affect the quality of the survey and potentially increase the total number of survey errors (Toepoel and Schonlau 2017). For example, problems caused by differences between those who respond and those who do not in the event of a low response rate have been noted (Dillman et al. 2014).

Being both a researcher and a research nurse, in this case, may have had the potential to bias results in the qualitative phase of the study. It may not be possible to understand the quality of life issues of those who did not respond or refused to participate in the study. For those participating in the study, the treatment regimens may be different as treatments may have changed in five years and some participants may have taken part in clinical trials receiving experimental drugs. Hence the treatment-related toxicities may differ between these patients.

5.12 Summary

Pragmatism as a paradigm has been outlined in this chapter and why it is best suited to this study. The use of a mixed-methods sequential explanatory design is detailed in this chapter and how it enhanced the outcome of this study. The use and choice of both the quantitative and qualitative methods have been detailed in this chapter.

The inclusion/exclusion criteria for this study have been clearly outlined with the recruitment process for both the quantitative and qualitative phases also defined. A detailed outline of the ethical considerations has been given which includes the national and local hospital and university guidelines. The sample size, study population, the different data collection techniques, and tools for both the quantitative and qualitative phases related to the study has been addressed. Data analysis which includes both quantitative and qualitative has been clearly outlined with reference to the use of mixed methods design. The limitations of conducting an MMR were also discussed finally. The next chapter will discuss the findings of the quality of life questionnaires.

Chapter 6 Findings of QoL survey

6.1 Introduction

This chapter presents the findings from the analysis of the cross-sectional survey. The study had four aims as stated in **Section 1.2**. This chapter attempts to develop a theoretical understanding of the QoL of survivors of adult haematological malignancies and to determine the impact of the selected demographic variables of the QoL. It starts by providing an overview of the participants' demographic and clinical characteristics.

6.2 Participants' demographic and clinical characteristics

Table 6.1 summarises the descriptive demographic and clinical characteristics of participants. For this phase of the study, it was calculated that a total sample size of 100 participants would provide 80% power to detect differences in mean QoL subscale scores of seven or more between groups of patients (assuming a standard deviation of 12 and 2-sided significance of 0.05). Two hundred participants were invited to take part in the quantitative phase of the study resulting in 131 completed questionnaires with a response rate of 66%. The population from which the participants were recruited were those who received treatment from the three hospital sites in the south of England. To ensure that appropriate participants took part local clinicians were involved in screening these participants using the eligibility criteria set by the MPhil student.

Demographic data collected included age at the time of data collection, gender, ethnic origin, marital, living, education and employment status. The above data were significant and pertinent to the study as there is a known association between financial status, living status, having children and QoL (Connolly 2013). Clinical parameters collected included diagnosis and time since completion of treatment. The Statistical Package for the Social Sciences (SPSS) version 21.0 was used to analyse the quantitative results from the first phase of the study. Descriptive statistics were first calculated. Most of the participants were aged 60 or over. The median (interquartile range) age of participants was 66.0 years (21.0-95.0) which reflects the incidence of these types of haematological malignancies in an older population.

The proportion of men (59.5 %) was greater than women in the sample enrolled in the study. More than two thirds (70%) of the sample were married or cohabitating but nearly one-third (29.8%) of participants were living alone at the time of data collection; the majority (79.4%) had children. Almost two-thirds (61.8%) of the sample had been educated up to the college level and nearly two-thirds (60%) of the enrolled participants were not in employment. All the participants were white Caucasians. The main disease type represented in the sample enrolled was lymphoma (78%); over 11% of the respondents reported having been treated for myeloma and a tenth of them were treated for CLL (10%). The spread of the diseases was as expected with the number of participants treated

for lymphoma encompassing more than two-thirds of the involved 131 participants. The non-Hodgkin's lymphomas are the most prevalent haematological malignancies in the UK, followed by leukaemias and other lymphomas (Cancer Research UK 2015). More than half of the people enrolled (58%) had completed treatment for B- cell malignancy more than two and a half years previously. Just under two-thirds (59.6 %) and almost a third (30%) of the respondents rated their general health status as very good and average respectively. Just over a tenth (12.2%) of participants rated their general health status as poor. All the enrolled participants were in remission from their disease at the time of data collection. It's positive that only around 10% of the participants reported poor health in this MPhil study. One of the main reasons for that could be that this cohort of participants in the study was disease-free at the time of recruitment and there was a range of participants between one and five years post-primary treatment; hence the likelihood of a lower rate reporting poor health.

Table 6-1: Demographic and Clinical Characteristics of survivors of a B-cell malignancy collected between July 2013 and May 2014 in Dorset, UK

Characteristics	**N (%)**
Median age in years (interquartile range)	66 (21-95)
Gender	
Female	53 (40.5)
Male	78 (59.5)
Marital Status	
Single/divorced/separated	27 (20.6)
Married/cohabitating	92 (70.2)
Widowed	12 (9.2)
Children	
Have children	104 (79.4)
Don't have children	27 (20.6)
Educational status	
Up to college	81 (61.8)
Graduate and above	44 (33.6
Employment status	
Employed	39 (29.8)
Not employed	80 (61.1)
Living status	
Living alone	39 (29.8)
Not living alone	92 (70.2)
Ethnic origin (White)	131 (100)
Diagnosis	
Leukaemia	14 (10.7)
Lymphoma	102 (77.9)
Myeloma	14 (10.7)
Time since completion of treatment	
<= 2.5 years	55 (41.9)
> 2.5 years	76 (58.1)
Health status	
Good	74 (59.6)
Average	35 (28.2)
Poor	15 (12.2)

6.3 Associations between quality-of-life domains and socio-demographic characteristics

The correlation between the QoL domains in the EORTC QLQ-C30 questionnaire and the socio-demographic characteristics are presented in **Table 6.2.**

Age showed a significant negative correlation with global QoL, physical functioning, and role functioning. Significant QoL differences were observed in gender with men reporting better physical functioning (P=0.041) when compared to women. In addition, men reported fewer symptoms of pain (P=0.000) and less sleep loss (P=0.001) compared with women. Employed participants experienced better physical functioning (P=0.000), role functioning (P=0.000) and cognitive functioning (P=0.000) compared to those who were not employed (as above). Unemployed participants experienced more fatigue (P=0.000), more symptoms of pain (P=0.000), dyspnoea (P=0.003), sleep loss (P=0.001), appetite (P=0.031) and constipation (P=0.031) compared with those that were employed. Other parameters such as 'time since completion of treatment', 'living arrangements' and 'educational statuses' did not have a significant impact on the QoL of these survivors.

Numerical data were described using the median and interquartile range when skewed. Here, age was the only continuous variable that was considered skewed. The interquartile range is calculated by minusing the lower quartile from the upper quartile (Diamond and Jefferies 2006). Non-parametric Kendall's tau correlation coefficient was used to determine the associations between age and quality of life subscales with a 2-tailed significance test ($p<0.05$). The Kendall's tau correlation was used as it measures the strength of the dependence of the two variables (Bland 2000).

In this research study, the two variables whose strength of dependence was measured were age and quality of life subscales. The associations between socio-demographic, clinical factors and QoL subscales were also determined using the Mann Whitney U test. This test is used when two independent random samples are compared and when the data are ordinal or dichotomous as in this MPhil study sample (Bland 2000). This was important for my research study because the data collected from the QoL questionnaires are considered ordinal as they range from 1-4 with 1 representing not at all, 2, a little bit, 3 quite a bit and 4 very much. Raw scores of this questionnaire were transformed into a linear scale ranging from 0-100. Higher scores represent higher functioning and QoL and a higher level of symptoms. The scoring was undertaken using the directions from the EORTC scoring manual (Kaasa et al. 1995; Groenvold et al. 1997; Gulbrandsen et al. 2004). The data obtained from the demographic questionnaire are considered dichotomous. The variables were dichotomised due to the distinct group of individuals who participated and also to simplify the presentation of results. Furthermore, these decisions were guided by the statisticians who helped guide the analyses in this MPhil thesis.

Table 6-2: Associations between Quality of Life domains and sociodemographic characteristics of survivors of a B-cell malignancy in Dorset, UK using the European Organisation for Research and Treatment for Cancer QoL (EORTC QLQ C-30) questionnaire

Factor	QoL	Physical Functioning	Role Functioning	Emotional Functioning	Cognitive Functioning	Social Functioning	Fatigue	Financial Difficulties	Pain	Dyspnoea	Sleep Loss	Appetite	Constipation	Diarrhoea
Age*														
Z	-0.139	-0.277	-0.218	0.136	-0.048	-0.065	0.105	-0.163	0.150	0.188	0.020	-0.025	0.093	-0.119
P value	0.032	0.000	0.002	0.039	0.489	0.341	0.108	0.023	0.030	0.007	0.741	0.727	0.188	0.102
Gender														
Male	65.94	52.67	61.99	64.01	67.11	62.80	62.65	63.57	55.80	65.51	57.61	63.19	65.20	62.32
Female	61.20	41.29	59.59	62.75	59.52	64.53	64.75	64.52	74.80	66.72	76.96	68.86	65.93	66.51
Z	-0.724	-2.039	-0.408	-0.195	-1.213	-0.286	-0.324	-0.209	-3.210	-0.202	-3.190	-1.228	-0.135	-1.065
P value	0.469	0.041	0.683	0.846	0.225	0.777	0.746	0.834	0.000	0.840	0.001	0.219	0.893	0.287
Living arrangements														
living alone	60.64	53.34	64.96	62.68	70.28	71.84	60.23	65.46	60.70	63.85	69.85	70.62	59.32	60.76
not living alone	65.38	45.65	59.19	63.84	61.42	60.03	64.86	63.40	64.60	66.91	63.64	63.31	68.15	65.33
Z	-0.671	-1.291	-0.925	-0.168	-1.310	-1.808	-0.659	-0.382	-0.620	-0.480	-0.950	-1.476	-1.512	-1.078
P value	0.502	0.197	0.355	0.866	0.190	0.071	0.510	0.703	0.540	0.631	0.340	0.140	0.131	0.281
Education														
Upto college level	61.29	44.62	58.19	61.32	59.75	62.68	60.36	61.46	59.90	65.14	65.24	63.35	61.51	61.54
Graduate and above	60.48	47.18	57.63	60.42	63.27	56.59	60.76	60.17	61.70	59.07	57.52	60.95	64.30	61.42

Z	-0.124	-0.456	-0.094	-0.139	-0.562	0.999	-0.062	-0.261	-0.300	-1.017	-1.270	-0.525	-0.510	-0.031
P value	0.901	0.649	0.925	0.889	0.574	0.318	0.951	0.794	0.760	0.309	0.205	0.600	0.610	0.975
Employment														
employed	73.61	58.88	73.10	63.21	71.38	69.03	40.34	56.05	43.30	48.32	46.38	51.84	51.54	58.07
not employed	51.14	33.86	46.08	55.43	52.22	52.56	66.38	59.69	65.30	65.69	65.73	63.14	63.28	58.71
Z	0.732	-4.591	-4.590	-1.214	-3.055	-2.714	-3.979	-0.732	-3.670	-2.941	-3.190	-2.157	-2.157	-0.162
P value	0.464	0.000	0.000	0.225	0.000	0.007	0.000	0.464	0.000	0.003	0.001	0.031	0.031	0.464
Time since completion of treatment														
<=2.5 years	55.85	45.46	52.08	56.13	54.84	52.20	59.68	52.83	58.20	61.37	61.86	60.68	58.93	58.92
>2.5 years	56.98	47.23	63.36	56.78	57.74	58.79	53.20	59.25	54.30	56.33	55.03	55.94	57.28	55.58
Z	-0.186	-0.323	-1.977	-0.109	-0.498	-1.184	-1.069	-1.368	-0.710	-0.904	-1.220	-1.104	-0.323	-0.907
P value	0.853	0.747	0.048	0.913	0.619	0.236	0.285	0.171	0.480	0.366	0.224	0.270	0.747	0.364

*Kendall's Tau Correlation Coefficient used for age and Mann-Whitney U test used for other variables.

For functioning scales: higher the scores, better the functioning

For symptom scales: higher the scores, higher the magnitude of the symptoms

Associations between the QoL domains and the sociodemographic characteristics are presented in **Table 6.3.** Among the five identified dimensions, the fewest problems were reported for self-care (10.1%) and the most for pain/discomfort (38.5%), followed by usual activity (35.9%). Interestingly, almost two-thirds (61.5%) of participants reported being problem-free.

Table 6-3: Proportion of survivors treated for a B-cell malignancy who reported any problems in EQ-5D dimensions in Dorset, the UK between July 2013 and May 2014.

Dimension	No problems		Problems	
	Number	Percentage	Number	Percentage
Mobility	84	64.6	46	35.4
Self-care	116	89.9	13	10.1
Usual activity	82	64.1	46	35.9
Pain/discomfort	80	61.5	50	38.5
Anxiety/depression	96	73.8	34	26.2

The proportion of participants reporting any/no problems in the five dimensions of the EQ-5D descriptive system is shown in **Table 6.4**.

The socio-demographic variables were the age in years, gender, living status, employment status, educational status, health status at the time of completing questionnaires and time since completion of treatment in years. The dependent variables were the dimensions of the EQ-5D-3L (Williams 1990) questionnaire and the EQ-5D VAS (visual analogue scale). The EQ-5D questionnaire measures generic health related quality of life. The questionnaire consists of 5 domains: Mobility, Self-care, Usual activities, Pain/Discomfort and Anxiety/depression. The participants were requested to choose from one of the three options which best describe how they feel ranging from ‘no problems’ to ‘extreme problems’. The EQ-5D VAS ranges from 0-100 with 0 being the worst imaginable health state and 100 being the best imaginable health state. They were requested to mark their health status on the scale, and this is used as a quantitative measure to report health outcomes. Data from the questionnaires were evaluated using descriptive analysis in accordance with the European Quality of Life Group User Guide (Williams 1990). The three options were combined into dichotomous variables in SPSS - option 1 (no problems) was re-labelled as ‘no problems, option 2 (some problems) and option 3 (extreme problems) re-labelled as ‘problems’.

Table 6-4: Associations between the sociodemographic characteristics and EQ-5D-3L dimensions and visual analogue scale of survivors of a B-cell malignancy collected between July 2013 and May 2014 in Dorset, UK

	Mobility				Self-care				Usual Activities				Pain/Discomfort				Anxiety/Depression			
	No problem% [n]	Problem % [n]	Total % [n]	*P* value	No problem % [n]	Problem % [n]	Total % [n]	*P* value	No problem % [n]	Problem % [n]	Total % [n]	*P* value	No problem % [n]	Problem % [n]	Total % [n]	*P* value	No problem %[n]	Problem % [n]	Total % [n]	*P* value
Gender	66.2 [51]	33.8 [26]	100.0 [77]	0.642	90.8 [69]	9.2 [7]	100.0 [76]	0.695	68.0 [51]	32.0 [24]	100.0 [75]	0.269	70.1 [54]	29.9 [23]	100.0 [77]	0.015[3]	76.6 [59]	23.4 [18]	100.0 [77]	0.385
Male	62.3 [33]	37.7 [20]	100.0 [53]		88.7 [47]	11.3 [6]	100.0 [53]		58.5 [31]	41.5 [22]	100.0 [53]		49.1 [26]	50.9 [27]	100.0 [53]		69.8 [37]	30.2 [16]	100.0 [53]	
Female																				
Treatment Compl[1]	56.0 [28]	44.0 [22]	100.0 [50]	0.690	86.0 [43]	14.0 [7]	100.0 [50]	0.102[2]	58.0 [29]	42.0 [21]	100.0 [50]	0.154	62.0 [31]	38.0 [19]	100.0 [50]	0.906	72.0 [36]	28.0 [14]	100.0[50]	0.547
<=2.5 yrs.	72.3 [47]	27.7 [18]	100.0 [65]		95.3 [61]	4.7 [3]	100.0 [64]		70.8 [46]	29.2 [19]	100.0 [65]		63.1 [41]	36.9 [24]	100.0 [65]		76.9 [50]	23.1 [15]	100.0 [65]	
>2.5 yrs.																				
Living	69.2 [27]	30.8 [12]	100.0 [39]	0.471	92.3 [36]	7.7 [3]	100.0 [39]	0.753[2]	69.2 [27]	30.8 [12]	100.0 [39]	0.420	69.2 [27]	30.8 [12]	100.0 [39]	0.238	74.4 [29]	25.6 [10]	100.0 [39]	0.931
Living alone	62.6 [57]	37.4 [34]	100.0 [91]		88.9 [80]	11.1 [10]	100.0 [90]		61.8 [55]	38.2 [34]	100.0 [89]		58.2 [53]	41.8 [38]	100.0 [91]		73.6 [67]	26.4 [24]	100.0 [91]	
Not living alone																				
Children	60.0 [63]	40.0 [42]	100.0 [105]	0.024[3]	88.5 [92]	11.5 [12]	100.0 [104]	0.461[2]	59.2 [61]	40.8 [42]	100.0 [103]	0.021[3]	58.1 [61]	41.9 [44]	100.0 [105]	0.098	71.4 [75]	28.6 [30]	100.0 [105]	0.199
Yes	84.0 [21]	16.0 [4]	100.0 [25]		96.0 [24]	4.0 [1]	100.0 [25]		84.0 [21]	16.0 [4]	100.0 [25]		76.0 [19]	24.0 [6]	100.0 [25]		84.0 [21]	16.0 [4]	100.0 [25]	
No																				
Education Up to College	62.5 [50]	37.5 [30]	100.0 [80]	0.373	91.1 [72]	8.9 [7]	100.0 [79]	0.754[2]	64.1 [50]	35.9 [28]	100.0 [78]	0.841	60.0 [48]	40.0 [32]	100.0 [80]	0.516	75.0 [60]	25.0 [20]	100.0 [80]	1.000
	70.5 [31]	29.5 [13]	100.0 [44]		88.6 [39]	11.4 [5]	100.0 [44]		65.9 [29]	34.1 [15]	100.0 [44]		65.9 [29]	34.1 [15]	100.0 [44]		75.0 [33]	25.0 [11]	100.0 [44]	
Graduate and above																				
Employment	89.5 [34]	10.5 [4]	100.0 [38]	<0.001	100.0 [38]	0.0 [0]	100.0 [38]	0.009[2]	92.1 [35]	7.9 [3]	100.0 [38]	<0.001[3]	78.9 [30]	21.1 [8]	100.0 [38]	0.004[3]	86.8 [33]	13.2 [5]	100.0 [38]	0.035[3]
Employed	50.0 [40]	50.0 [40]	100.0 [80]		84.8 [67]	15.2 [12]	100.0 [79]		48.7 [38]	51.3 [40]	100.0 [78]		51.3 [41]	48.8 [39]	100.0 [80]		68.8 [55]	31.3 [25]	100.0 [80]	

Not employed																			
Health	100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.0 [0]	100.0 [25]		100.0 [25]	0.0 [0]	100.0 [25]		100.0 [25]	0.0 [0]	100.0 [25]		96.0 [24]	4.0 [1]	1002[5]	
Good	100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	
Average	100.0 [25]	0.00 [0]	100.0 [25]	<0.001	100.0 [25]	0.00 [0]	100.0 [25]	<0.001	100.0 [25]	0.00 [0]	100.0 [25]	<0.001	100.0 [25]	0.00 [0]	100.0 [25]	<0.001	100.0 [25]	0.00 [0]	100.0 [25]	<0.001
Poor																				

1 Duration of completion of treatment

2 Fisher's Exact Test

3 Statistically significant

According to the results of the EQ-5D-3L questionnaire, most participants did not report any problems with self-care or anxiety/depression. However, a high proportion of participants reported problems with mobility (35.4%), usual activities (35.9%) and pain/discomfort (38.5%) (**Refer to Table 6-4**).

Age

The independent samples *t*-test was used to determine the associations between age and EQ-5D dimensions. This test was used to examine the statistical differences between the means of the two groups (Petrie and Sabin 2009). The independent sample *t*-test requires the assumption of homogeneity of variance. The test that is used for this assumption is Levene's test. If the null hypothesis of Levene's test is rejected, it suggests that the variances of both groups are not equal. This test was used to verify that assumption.

The associations between age and the EQ-5D VAS were determined using Spearman's rank correlation coefficient. This test is non-parametric and has been used to measure the strength and direction of two variables (Petrie and Sabin 2009). The associations between the socio-demographic variables and the dichotomised EQ-5D dimensions were determined using crosstabs. Row percentages were chosen as they were more useful and appropriate in answering the research question. If one cell had an expected count of less than 5, then Fisher's exact test was used (Foster et al. 2014).

Gender

There was little difference by gender in mobility, self-care, usual activities, and anxiety/depression; however, two-thirds (66.2%) of men and just under two-thirds (62.3%) of women reported no problems with mobility. Most (90.8% of men/88.7% of women) reported no problems with self-care activities, and over two thirds (68%) of men and over half (58.5%) of women had no problems in sustaining usual activities. However, there were significant gender differences when reporting pain/discomfort. The proportion of men who reported no problems with pain or discomfort (70.1%) was considerably higher than the proportion of women (49.1%) who reported any problems with pain. This difference was statistically significant with a p-value of 0.015. The lowest proportion of problems was reported in the self-care dimension (10%) by all participants.

Having children

Participants with children were more likely to report problems with mobility (40.0%) than those without children (16.0%). A statistically significant difference was observed here with a p-value of 0.024. Those participants with children were less likely to report any problems with usual activities (59.2%) than those without children (84.0%) with a p-value of 0.021. Having children in this MPhil

study refers to having adult daughters and sons. See **Section 8.2** for a detailed discussion of this issue.

Employment status

The variable that was significant for all dimensions was employment. Employed participants reported no problems with mobility (p-value <0.001) when compared to unemployed /or retired participants. All employed participants reported no problems with self-care. Most (92.1%) employed participants reported no problems with carrying out usual activities with the differences being statistically significant (p-value <0.001). Most (78.9%) employed participants did not report any pain/ or discomfort (P=0.004). Anxiety and/ or depression was not a problem reported in most (86.8%) participants who were employed (P=0.035). The variable related to participants who reported no problems with anxiety and/or depression as associated with all dimensions also reported very good health status with the difference being statistically significant.

Time since completion of treatment

Participants in this MPhil study who lived beyond two and a half years following completion of treatment for a haematological malignancy reported better role functioning than those who had completed treatment less than 2.5 years previously (P= <0.048). The variables were dichotomised to simplify the presentation of results. Again this was carried out with the help of a statistician from Bournemouth University.

Other domains

Other variables such as 'living arrangements' and 'educational status' did not have a significant impact on other QoL domains.

CLL16 and MY20 quality of life questionnaires

Based on the sample of 131 in total, the number of participants with a diagnosis of MM and CLL was relatively small, hence it did not allow for comparison of the QoL among the groups. The number of participants with MM and CLL was 15 each. Those with a diagnosis of any type of lymphoma were predominant in this population, which may not be representative of the quality of life assessment of the smaller groups (CLL and MM). Hence, analysis of the disease specific measure was not included here.

Although the sample was sufficient to detect the impact a B- cell malignancy and its treatments may have on the QoL of a person, the sample comprised of people who had received treatment at one of the three hospitals in the south of England. Furthermore, the sample consisted completely of people who were of White British ethnicity. Therefore, generalisation of the results to a broader British population and other ethnic groups must proceed with caution.

6.4 Summary

Chapter six has presented an analysis of cross-sectional surveys of the study. The data also showed the impact of socio-demographic variables on the QoL of adults who survived a B cell malignancy. Men and those in employment who have completed treatment for haematological malignancy reported better QoL in this study. Women reported lower physical functioning, more pain and less sleep when compared to men. Age had a significant negative correlation with global QoL, physical and role functioning. This chapter has been published as an article in a peer-reviewed journal.

In line with the mixed-methods sequential explanatory design, the results of the quantitative data were used to inform the qualitative results of the study. The qualitative findings of the study are presented in chapter seven.

Chapter 7 Findings: Qualitative insights into wellbeing of people surviving haematological malignancies

7.1 Introduction: Semi-structured interviews

This chapter reports on findings from the second qualitative phase of the study, to help interpret findings from the first quantitative phase of this research. The collection of the qualitative data had a clear aim, namely to help explain the quantitative data in greater depth. This phase allowed for the development of key themes that explored factors that may influence the quality of life and identify any unmet supportive care needs. This chapter presents the main themes and subthemes, which arose, from the qualitative interviews and the data analysis.

The qualitative phase is set to address the following aims:

1. Explore factors that influence that QoL:
2. Explore unmet supportive care needs in adult survivors of haematological malignancy.

Although the number of participants in the qualitative phase was relatively small (n=12), this is not unusual for in-depth qualitative studies. This data not only explained the quantitative findings but added depth and richness to the data. Of more importance was that it gave the participants a voice about their lived experiences. This chapter aims to represent the voice of the participants, add strength to the quantitative data and ensure the rigorous exploration of the phenomenon of QoL and unmet supportive care needs.

Overall, twenty sub-themes were identified, which on reading and re-reading fitted into four overarching themes, which are: (1) Physical well-being; (2) Psychosocial-wellbeing; (3) Independence; and (4) Unmet supportive care needs. The first theme explores the physical changes that take place in the post-treatment phase and how that impacts one's QoL. The second theme focuses on participants' experiences of living with a haematological malignancy on a societal level and coping strategies they adopted. The third theme examines the level of independence gained by participants both physically and financially in the post-treatment phase. The final theme discusses the long term unmet supportive care needs that remain to be met in these participants. After the presentation of the key characteristics of the interviewees in **Table 7.1** this chapter introduces and offers insight into those four major themes.

The key characteristics of each interview participant are presented in **Table 7.1**.

7.2 Participant interviews

7.2.1 Participants

The second stage of the study (Phase 2) aimed to explore more fully the findings of the first, quantitative phase of the study. In-depth semi-structured interviews were conducted with the content and structure of the interviews grounded in the findings of the first, quantitative phase of the study. Semi-structured interviews are used when the topic being investigated is very personal to participants (Flick 1998). In this study, the quantitative data helped the researcher to identify the questions to ask in Phase 2.

All participants who completed the demographic and relevant quality of life questionnaires were invited to take part in the second, qualitative phase of the study. The main purpose of the semi-structured interviews was to gain greater insight and a deeper understanding of the participants' experience of living with haematological malignancy and the factors that affect their quality of life and help explain the results of the quantitative phase of the study. Identification of any unmet supportive care needs was also explored. All participants were encouraged to be open, honest and as detailed as possible.

The data gathered from the interviews were varied in depth; some participants talked openly about their experiences, while others were reserved about some specific issues. A number of participants were comfortable talking with me about their personal experiences and found it very useful to express their emotions. However, it was noted that most of them did not feel comfortable being explicit about their sexual functioning and wellbeing. Some of them tend to give socially pleasing answers. Socially desirable responding (SDR) is typically defined as the tendency to give positive self-descriptions (Paulhos 1991, p 49). This type of response was noted mostly when they describe their position as cancer survivors. Therefore, further follow-up questions and asking for examples were used to elicit deeper understanding.

Purposive sampling and in-depth interviewing were undertaken to develop a rich description of the experience. It also helped to identify important common patterns that emerged across the variations. The response rate for agreeing to take part in the interviews was good and 93 participants had agreed to take part in the interviews. After interviewing twelve who volunteered, and hearing the same stories repeated, with no new theme or subthemes emerging, it was decided that data saturation (Polit et al 2006; Streiner and Norman 2003) has been reached and therefore no further interviews were conducted. After every five interviews, transcripts were analysed to check for saturation point. The new themes and subthemes were emerging until the tenth participant. To confirm the saturation, further interviews were continued until the twelfth interview when the decision was taken with my supervisors to stop interviewing.

The second phase of the study also captured information on any co-morbidities from the participants' medical notes, which was confirmed at the time of the interviews. This was undertaken using the CIRS-G rating scale **(see Appendix 14).** Out of the twelve participants interviewed, three of them presented with one comorbidity, one had two comorbidities and one presented with three comorbid conditions. All the transcribed qualitative data were coded for issues/ subthemes which were gradually combined into broader overarching themes.

A total of twelve interviews were conducted between October 2015 and May 2016. This number of interviews is not unusual for qualitative studies. The sample did not reach a gender balance as nine of the participants were male and three were female. The age of the participants ranged from 55 to 97 years. Six of the twelve participants were within two-and-a-half years of completing treatment for a B-cell malignancy. Prior to the interviews being conducted, it was ensured that all participants were in remission from their malignancy as for some there had been at least one year from the time of completing the QoL questionnaires to interviews. The researcher travelled to rural and remote places in Dorset to interview the participants in their homes. Interviews were conducted until data saturation was achieved. The qualitative data not only explained the quantitative findings but added richness and deeper meaning to the data. It also adds strength to the quantitative findings. The characteristics of participants who took part in phase two of this mixed-methods study are detailed in **Table 7.1.**

Figure 7-1: Characteristics of interview participants

Participant identification number	**Age in years**	**Gender**	**Time since treatment completion in years**
54	63	Male	< 2.5
66	74	Male	< 2.5
140	97	Male	< 2.5
152	90	Male	>2.5
87	61	Male	< 2.5
162	72	Male	>2.5
153	82	Male	>2.5
26	55	Female	>2.5
12	61	Female	>2.5
99	55	Male	>2.5
113	86	Male	< 2.5

66	74	Male	< 2.5

Participant's reactions (verbal and non-verbal) during the interview and the uncovered issues were captured by the use of reflective field notes. The interviews were audio-recorded and transcribed verbatim by the researcher. There were listened to multiple times before entering into NVivo (Phillips and Lu 2018). The audio recording has listened to multiple times and data was analysed manually. This facilitated familiarity with the transcripts' content and participants' stories (Alloh et al. 2018). This helped to organise, categorise the data efficiently, and help identify clearly what participants were describing (Klopper 2008). The responses were analysed thematically to identify themes using an inductive approach (Bradley et al. 2007; Keenan, van Teijlingen, & Pitchforth 2015).

7.3 Themes

Some twenty subthemes were generated and reviewed from the qualitative data analysis. This was quite a lengthy and time-consuming iterative process. Many factors were revealed during the analysis of the interviews. During various rounds of discussion with my supervisors these sub-themes or factors were reorganised into four themes: (1) Physical wellbeing; (2) Psychological wellbeing; (3) Independence; and (4) Unmet supportive care needs. The themes do not appear individually, and often sub-themes overlap and often they fit into more than one overarching theme. This section highlights the factors that influence the quality of life of those participants who survived a B cell malignancy. A full list of themes and sub-themes is presented in **Table 7-2.**

7.3.1 Physical well-being

The theme of physical well-being highlights the subthemes that may contribute to the physical well-being of the participants and the ones, which may inhibit the physical functioning thus influencing survivors of B-cell malignancies' QoL. This theme integrates four subthemes; (i) Keeping fit; (ii) Healthy lifestyle; (iii) Limitation; and (iv) Exacerbation of comorbidities. Physical activity is associated with numerous benefits such as improved cardiovascular fitness, decreased fatigue and improved overall quality of life in cancer survivors (Volakhlis et al. 2013; Lemanne et al. 2013; Rogers et al. 2009; Denlinger and Engstrom 2011). Tailored physical activity may the physical well-being of cancer survivors and improve overall health.

7.3.1.1 Keeping fit

Most of the interviewees shared positive experiences of keeping fit by doing certain activities such as walking, cycling, gardening, horse riding and gentle tasks around the house, all of which were perceived to have a positive influence on their physical well-being. They described the physical

benefits of keeping fit and physically healthy. Participants viewed physical activity as having a positive impact on their quality of life. Leading an active life enabled them to keep fit. This is depicted by one participant who said: *On the days I don't work, I cycle quite a lot; about 150 miles/week. Generally busy. It's difficult from keeping fit and healthy to having chemotherapy and the run-up to being fit again and it took me 6-9 months again (Pt. ID: 4).*

And by another who commented specifically commented on: Hard physical work, still do odd jobs, plumbing and woodwork… (Pt. ID: 2)

A third interviewee suggested having a rich and busy lifestyle:

The rest of the time, I spend looking after horses and grandchildren. There is always stuff too from chickens and horses. Painting and decorating. I have just started doing this course; a muscle management course, very interesting. I have already done a Reiki 1 and 2 courses. Planning to do a Reiki course. Always really busy. Everything is fabulous … (Pt. ID: 7).

Other participants similarly reflected this sub-theme as another further commented:

I am very active. I enjoy running, walking and cycling which I very often do when I can .... (Pt. ID: 11).

Others framed this very much as a preventative measure:

Try to eat healthily, exercise. I do not want to go there again (Pt. ID: 8).

Two of the participants described their reduced ability to perform any activity following chemotherapy. Although they were functional physically, they still experienced certain limitations to their mobility and thus their abilities to keep fit. For some, even simple activities like getting in and out of the bath or bed were challenging. Some of the participants also pointed out that the limitations experienced and not being fit enough could be due to their age and not exclusively the treatment for a B-cell malignancy. These points are exemplified by two participants who said:

I get more tired now than before. The ability level has reduced. But I can still go for shorter rides. I accept that (Pt. ID: 4).

Sometimes the limitation was a single bodily function, for example, one's joints:

I find it difficult getting in and out of the bath; the bodily functions, I can cope with. My sight is good, my hearing is OK; except for my knees, I am happy with my body (Pt. ID: 2).

7.3.1.2 **Healthy lifestyle**

Participants described how the benefits of leading a healthy lifestyle had a positive impact on their physical well-being. Living a healthy lifestyle improved their energy levels and enabled them to function effortlessly throughout the day. Walking, cycling and gardening were perceived to be the main activities for participants to enable them to lead a family active healthy life. This is depicted by one participant who said:

My dog and I would go for a walk in the forest, go and visit some clients from Macmillan. In general, I am able to live a normal and happy life … (Pt. ID: 8).

These points are exemplified by one participant who said:

Chopping up logs. Cleaning after horses (Pt. ID: 7)...

And by another who commented: 'The rest of the time I spend looking after horses and grandchildren. There is always stuff to do from chickens and horses. Painting and decorating' (Pt. ID: 7)

The reference to looking after horses and the following quote on being the owner of a lake, suggests that participants had the financial resources to stay healthy (see further Section 7.4.3.4):

I have a lake. If I want to go fishing I still go fishing. Shoot pheasants. That's life for me and I enjoy every minute of it … (Pt. ID: 6).

Participants often linked their current lifestyle to health living in the past:

I have had a good lifestyle; I cycle a lot and keep fit. We follow a healthy diet. I do running and circuit training. I've always raced. Historically I've had a very good life … (Pt. ID: 4).

7.3.1.3 **Exacerbation of comorbidities**

Exacerbation of comorbidities may diminish physical activity thereby diminishing physical wellbeing. Three of the participants struggled with their comorbidities, which had an impact on their physical wellbeing. Exacerbation of comorbidities may be negatively associated with an individual's QoL. This is depicted by one participant who said:

I am the only man in the gym with Mantel cell lymphoma in a wheelchair (Pt. ID: 1).

One of the participants during the interview stated that he had a colostomy bag in place and how it had a negative impact on his QoL significantly. He stated how he learned to live with a stoma and still went swimming and cycling to keep fit.

The trouble is I have a stoma and that is the annoying thing. I am living with it and have lived with it since 2009. Did come as a shock to me as I thought I had got away with it but...woke up and looked down and thought...oh God! (Pt ID: 3).

One of the participants suffered from side effects of treatment and developed osteopenia, which had a negative influence on his physical wellbeing.

My bones and joints since I had chemo are painful at times. I had a bone density test and I now have osteopenia. Getting older with it. Apart from that, I seem to be fine (Pt ID: 8).

7.3.1.4 **Limitation**

Four out of twelve survivors reported limitations in their physical activities following treatment for a B cell malignancy. One of the participants experienced mild peripheral neuropathy because of the chemotherapy, which affected his ability to do work in the garden or anything else that required fine grasping. Normal activities like getting in and out of the bath and doing little chores around the house were slightly difficult for a few of them. These points are exemplified by other participants who said:

I love going out fishing. I would love to go probably more often. I'd like to go out more (Pt ID: 1).

Interviewees also listed the kind of things they could no longer do, or could no longer do easily:

I used to do DIY things and in the garden. I cannot do all these things now. My hands are getting bad. Fingers rather (Pt ID: 10)

Find it difficult getting in and out of the bath; the bodily functions (Pt ID: 2).

My bones and joints since I had chemo are painful at times. I had a bone density test and I now have osteopenia. Getting older with it. Apart from that, I seem to be fine (Pt ID: 8).

7.3.2 Psycho-social well being

Physical health directly influences psycho-social well-being in cancer survivors. This can have an overall impact on the quality of life. Unlike physical symptoms, mental symptoms may not be easily diagnosed and treated. Some of them may face challenges that may be exacerbated during the treatment period. This theme comprised of ten subthemes that enhanced the psychological well-being of the survivors. Patients who have undergone treatment for a haematological malignancy also undergo many changes concerning the diagnosis of malignancy and treatment.

7.3.2.1 **Maintaining a positive outlook**

Most participants expressed a positive outlook on life following their treatment. Besides, trying to remain positive enabled them to eliminate any negative thoughts or feelings. The significance of remaining positive throughout and mainly post-treatment emerged often during the interviews. Remaining positive enhanced their well-being which was depicted by one of the participants as follows:

I have always had a very positive outlook. I feel that I am the sort of person who looks at my glass as being half full rather than half empty. So, I am very positive. I want to live a long and healthy life if I can and spend some of the pension I have been working hard for (laughs). All things are good (Pt ID: 11).

In addition to not viewing themselves as being typical cancer patients, some of the participants strived to maintain a positive outlook by staying fit and enjoying a nice social life. For pt. 3, this was seen to be positive:

I stay fit. I walk a lot and swim. Have a nice social life. Things are going well. My life is what I would expect as a pensioner. What I was looking forward to. That's important, I think. The other thing is I am comfortable off with the money. And that's very important as pensioners if you haven't saved and have been spending all your money over the years on expensive holidays etc it will be difficult. We are very comfortable (Pt ID: 3).

7.3.2.2 **Coping**

Patients respond differently to a diagnosis of malignancy and/or its treatment. Most of them live with fear and anxiety of living with a diagnosis of cancer and adopt different coping strategies. Being diagnosed with a malignancy not just affects their physical wellbeing but also how they cope living with a diagnosis of malignancy and the side effects of treatment. It changes their outlook towards life too. How they cope with diagnosis and treatment impacts highly on their quality of life. For some participants, having a positive attitude enabled them to cope better. This is depicted by two participants who said:

I am coping very well. Something I have been told I will cope with throughout illness; from the first stages of diagnosis through the treatment of chemotherapy. I have always had a very positive outlook. I feel that I am the sort of person who looks at my glass as half-full, rather than half empty. So, I am very positive. I want to live a long and healthy life (Pt ID: 11)

Another survivor simple does no equate having cancer as being ill:

It does not even enter my head the fact that I had been ill. Not even a little bit. In fact, when I am ill; say I get a headache; my friends say to me if I worry that cancer may come back. I do not even think of that. I do not even worry about my cancer (Pt ID: 7)

Some survivors used different mechanisms to cope with the disease, treatment, and its after-effects. One of them *(Pt ID: 8*) described her as looking like a boiled egg and stated that using such a sense of humour was how she coped with being in that situation. She had to sustain this sense of humour during and after treatment for the malignancy. However, some of them struggled to come to terms with living with a certain type of haematological malignancy that has no cure. Hence there was always this fear of recurrence and coping in such a situation was challenging.

With a chronic condition, it to be on your mind quite a lot. It is there hanging above you especially when it is malignant as it stands now no cure. So, it is hard to know and cope with (Pt ID: 9).

Most survivors mentioned that the support they received from family was significant but some of them stated that close family members struggled to cope with a family being diagnosed and treated for malignancy.

However, somebody else saw me like that. You could see it on their face. They could not handle it. Therefore, I do not blame them (Pt ID: 8).

7.3.2.3 **Determination**

From interviewing these survivors, it was evident that they were determined to not let the malignancy, or the effects of treatment consume their moments. Their determination and innate ability to live their lives and was inspiring and these are depicted by one participant who said:

They want to help you and do everything but in my past life I've been, get up and go, Do it yourself. Get on with it. Of course, I find that difficult. Hmm. I like to go to, maybe physically it's not possible but I have to do things people don't normally do I suppose. It's just the way I am (Pt ID: 1).

Another participant similarly reflected this sub-theme as a further comment:

I will be very pleased. I've always been determined. Whichever path I set out on, that's what I am going to do (Pt. ID: 6).

7.3.2.4 **Sense of gratitude**

A sense of gratitude was seen in those participants who underwent treatment. They were able to re-evaluate their lives and be grateful for all the privileges they had. They were grateful for the days they slept well and walked without pain. They will live the thought of their disease for the rest of their lives yet were grateful for all they had.

It does make you evaluate your life. Material things are not important. What is important is your health, love and having a roof over your head. Material things can go, and you can get them anytime but the other things are priceless (Pt ID: 8).

7.3.2.5 **Act of kindness**

Some participants stated how random acts of kindness enabled them to be grateful for the life they had and how useful they could prove to be to people around them. Volunteering activities appeared to be a fulfilling experience for cancer survivors. They felt that wanted to give something back to society in return for what they received from family and friends during and after their treatment.

Quite Ok and work as a volunteer for Macmillan caring locally. I go out into the community and help people with anxieties with their cancer and generally help where I can give back (Pt ID: 8).

Another participant further commented: 'I go to FAB which is a physically handicapped able buddy group. I help them do their quarterly magazine, putting all events what's going on and if people have achieved things, things like that. I do all the birthday cards for FAB. If there are 80 members, I get the cards anyway. Every month if there are 6 or 7 people, say, I send the cards and they tell me, "No one else does it". I say, "No", I do it' (Pt ID: 1).

As part of their survivorship experience, many survivors felt it would benefit others if they contributed to society (Tsuchiya et al. 2013).

7.3.2.6 **Changed habits post-treatment**

Surviving a haematological malignancy caused changes in habits or brought about lifestyle changes for many survivors following completion of treatment. These survivors were inclined to make conscious changes in their dietary, exercise patterns, and overall lifestyle. One of the participants depicted:

When you get diagnosed with an illness like that it is shocking. It was an awful lot to digest in. Then you go through stages. I felt angry, sad, upset, and thought why me? And then you think that you have to battle this and make the best of it and fight this. You get your strength (Pt ID: 8).

And another further commented: 'Just activities. I find I can't do as much as I used to do as it may be because of age or post-treatment. I don't have the same energy levels. Post-treatment you are not strong enough to build muscle. Now I am doing everything. I am in the gym and on the bike. I think energy levels will get better' (Pt ID: 4).

7.3.2.7 **Frustration**

For some, the challenging part of their malignancy, treatment, and life after was accepting the consequences of the disease and treatment.

For some it was the inability to continue doing the things they did before the diagnosis of the malignancy and its treatment. The side effects of the treatment caused a negative influence on his life.

I can't do what I used to do. It's frustrating really. I used to do DIY things and in the garden. I cannot do all these things now. My hands are getting bad. Fingers rather. (Pt ID: 10).

I find I can't do as much as I used to do as it may be because of age or post-treatment. I don't have the same energy levels. Post-treatment you are not strong enough to build muscle (Pt ID: 4).

For one individual, it was unfortunate that his wife was diagnosed with the same haematological malignancy. His frustration revolved around the fact that they both spent a significant amount of time at the hospital for treatment and follow up visits.

Every 6 months. Wouldn't want to go anymore. In those 6 months, 3 or 4 things happening then, and my wife has got the same thing. We spend our life evolving around hospitals and doctors and fetching tablets (Pt ID: 5).

7.3.2.8 **Helplessness**

Fear of disease recurrence made most participants feel helpless. They stated that they went through emotions of fear, anger, and helplessness during diagnosis to post-treatment. Some of them felt helpless due to frailty, the disease and the treatment that had caused them. Having to depend on family and friends increased the feelings of helplessness and frustration amongst them.

I feel helpless. My son comes and does my shopping every two weeks and takes me to the hospital (Pt ID: 10).

Other participants reflected this sub-theme as two of them further commented:

When you get diagnosed with an illness like that it is shocking. It was an awful lot to digest in. Then you go through stages. I felt angry, sad, upset and thought why me (Pt ID: 8).

In those 6 months, 3 or 4 things happening than me and my wife have got the same thing (Pt ID: 5).

7.3.2.9 **Emotional challenges**

Some participants reported emotional challenges that arose in the post-treatment phase. Fear of second malignancies and the stress related to it can be overwhelming. Separation from frequent contact with health care professionals can cause increased emotional distress. This is depicted by one participant who said:

When you get diagnosed with an illness like that it is shocking. It was an awful lot to digest in. Then you go through stages. I felt angry, sad, upset, and thought why me? And then you think that you must battle this and make the best of it and fight this (Pt ID: 8).

One of the participants expressed how tired he was most times and became confined to his house more and limited his interactions with others:

‘My wife tells me I get quite depressed, and she is probably right. I get very introverted and lazy. I think its mental fatigue sometimes. You can’t be bothered to talk to anyone. You can become a bit irritable’ (Pt ID: 9).

7.3.3 Independence

For survivors of haematological malignancy and its treatment, resuming daily activities and being able to enjoy simple pleasures of life was perceived to be like winning the road to independence following treatment completion.

7.3.3.1 Family support

Most participants reiterated how well looked after they were and amidst all challenges, their family members helped them stay positive and offered tremendous encouragement and support. This was depicted by a participant who said:

I am well looked after (Pt ID: 10).

7.3.3.2 Family involvement in decisions

Outcomes can be improved and thus the quality of life of survivors of a haematological malignancy when family members or caregivers are involved in the decision-making process or patients’ care. Participants felt that the meaningful engagement of family members in important decisions brings benefits in many ways.

The ambulance turns up and picks me up and takes me on my own. But I’m coming with you, so I’ve got to be fair, You’ve got to involve your family, haven’t you? I’ve always been independent in the past and I am terrible. I am so domineering; I suppose (Pt ID: 1)

One of the participants was grateful for the support he received from his family: ‘*My son does the shopping every two weeks and takes me to the hospital’ (Pt ID: 10)*

7.3.3.3 Support from friends

Most participants commented on how well friends supported them during and after their treatment. One of the participants, however, expressed that some friends of her distanced themselves from her as they found it challenging to deal with what the participant was experiencing during her intensive treatment for a haematological malignancy; although she stated that few of her close friends stood by and offered tremendous support during and after treatment. These points were exemplified by two participants who said:

Its support from your neighbours and friends as much as the medical people I think (Pt ID: 2).

To be totally honest with you, it certainly shows who your true friends are. There were a lot of people I classed as friends that I don't see now. As soon as I mentioned that I was ill with a certain illness that was it. They made their excuses. We just grew apart. And then there were my dear friends who stood with me right through and still with me today (Pt ID: 8).

7.3.3.4 Economic independence

None of the participants quoted financial concerns as one of the major factors affecting their quality of life. Most were retired and perceived themselves to be financially independent. They reflected this sub-theme as they commented:

Finances are good (Pt ID: 11)

The other thing is I am comfortable off with the money. And that's very important as pensioners if you haven't saved and have been spending all your money over the years on expensive holidays etc. it will be difficult. We are very comfortable (Pt ID: 3)

One of them started having minor issues during treatment which was then resolved with the help of the specialist nurse.

When we had financial issues, the specialist nurse sorted them out for us (Pt ID: 4).

7.3.4 Unmet supportive care needs

Those treated for a haematological malignancy can experience unmet supportive care needs that may be present not just during diagnosis and treatment but in the survivorship phase. Improved information support and continuity of care in the post-treatment phase was a major unmet need in this cohort of participants. Fear of recurrence, causing distress also influenced their quality of life negatively.

7.3.4.1 Continuing connection with health care providers

The frequency of medical and nursing support lessens as patients' complete active treatment and transition into the survivorship phase. Most of the participants stated that they felt lost following the completion of treatment and that caused some anxiety in them. This is depicted by what one participant said:

When we come out of the hospital, we feel very vulnerable, you feel disconnected. When you come out, you wonder if you are ready to come out, what happens now. You are in a protected environment until then. It's good to have that contact; it is a bit of a void you experience during that post-treatment period soon after discharge (Pt ID: 4).

And another who shared this sense of frustration of losing that continued connection with health care professionals: 'Just having that connection once, a year is important. Losing that in the end would

worry me because I would just be scared and wouldn't know if it would come back and would not have a specialist to talk to. I find that very important. It's the only thing that worries me. The thing I would honestly say is that there is a need for that contact' (Pt ID: 8).

7.3.4.2 **Fear of recurrence**

One of the main concerns described by cancer survivors is fear of recurrence (Simard et al. 2010; Mehnert et al. 2009). It appears to be one of the topmost concerns amongst cancer survivors. It is also a commonly reported problem amongst cancer survivors. This fear of recurrence can have a huge impact negatively on the quality of life of these survivors.

That cancer has been in the background with early signs of it coming back, how I will manage, how it will affect me and my life. What treatment will I have to go through in the future? (Pt ID: 11).

Other participants talked about how they tried to avoid thinking about their illness focus less on their experience. Despite this lack of focus on these experiences, the experiences of their cancer were such, that even if their health was threatened in a minor way, their initial reaction was often that cancer may have come back. This was depicted by two participants who said:

I guess it's going to come back again is the biggest concern (Pt ID: 4).

I think over time with me being longer in remission. The longer I am in remission the more I have to come to terms with the fact that it may not come back but it is at the back of your mind all the time whereas before it was more in the forefront of my mind. I push it back (Pt ID: 8).

Many of the survivors discussed in general cancer recurrence. Some of them were generally worried about the impact of cancer relapse in terms of leaving loved ones behind. Some of the B-cell malignancies may remain in remission for a while and relapse with symptoms of pain, fatigue, lumps and upcoming hospital follow up visits can trigger bouts of anxiety in survivors. The occurrence of a secondary malignancy can have a tremendous influence on the quality of life of these survivors.

7.3.4.3 **Uncertainty about the future**

Living with uncertainty following the completion of treatment for a haematological malignancy can be very upsetting in cancer survivors. Although the disease may be in remission, a sudden lifestyle change, changed habits post-treatment, change in relationships, finance and unsure of how their lives may change following treatment can influence their quality of life. This is depicted by one participant who commented:

I have always been one for saving for the future. Looking further ahead instead of just looking for tomorrow if you like (Pt ID: 11).

And by another who commented: 'Yes. It has. You think you can manage and control life. You have a plan for the future. Illness makes you realise you can't control your life if you have a major illness (Pt ID: 4).

Other participants similarly reflected this sub-theme as a further comment: *'You tend not to plan long term' (Pt ID: 4).*

Table 5 the meaning of QoL and identification of unmet supportive care needs

Physical wellbeing	**Psychological wellbeing**
❖ Keeping fit ❖ Healthy lifestyle ❖ Exacerbation of co-morbidities ❖ Limitation	❖ Maintaining a positive outlook ❖ Coping ❖ Determination ❖ Sense of gratitude ❖ Act of kindness ❖ Changed habits post-treatment ❖ Frustration ❖ Helplessness ❖ Emotional challenges
Independence	**Unmet supportive care needs**
❖ Family support ❖ Family involvement in decisions ❖ Support from friends ❖ Economic independence	❖ Continuing connection with health care providers ❖ Fear of recurrence ❖ Uncertainty about the future

7.4 Summary

This chapter presented the qualitative findings of the study. Semi-structured interviews were conducted to collect data from twelve survivors of a haematological malignancy. The aim was to provide greater insight and a deeper understanding of a complex phenomenon as the quality of life. The data were analysed thematically, and the qualitative phase enabled to explain the quantitative phase in further detail. Combined, the quantitative and qualitative findings provide a deeper

understanding and insight into the QoL of people who had completed all treatment for a B-cell malignancy.

The findings from the qualitative phase reinforce the findings of previous research. It offers an expansion of what is already known. Considerable changes in physical well-being, psychosocial wellbeing were evident from the interviews. As this method of this inquiry was open-ended qualitative interviews, it enabled the participants to talk freely about what they felt was important to them and what needs remain unmet in the post-treatment phase. This method adds detail and insight to the EORTC and EQ-5D QoL questionnaires, which only gave participants the chance to answer pre-set questions. The questionnaires did not provide for any further opportunity to further explain their QoL and any specific areas of their QoL (see **Section 5.4.1.1**). It was clear from the results that the EORTC QLQ-C30, EQ-5D and disease specific QoL questionnaires were not designed to capture all issues of QoL in the post-treatment phase and it was not entirely relevant to this patient group (see also **Section 8.7.3**). These measures do not address the issues of survivorship or post cancer changes. The qualitative enquiry offered greater insight into the subjective experiences of participants.

The following chapter discusses the key findings of the study and integrates the quantitative and qualitative findings from both phases of the study.

Chapter 8 Discussion: Drawing quantitative and qualitative threads together

8.1 Introduction

This chapter brings together quantitative and qualitative findings from both phases of this mixed-methods research study which were reported in **Chapters six and seven**. The study is an explanatory mixed-methods study. In this type of design, the researcher first gathers and analyses the quantitative data which is followed by a qualitative phase undertaken to help explain the quantitative results (Creswell & Plano Clark 2011). In this MPhil study the follow-up qualitative phase helped to explain the findings from measures administered in the initial quantitative phase. The mixing of both sets of data strengthens the overall outcome of the study by offering a more comprehensive integration of results (Creswell & Plano Clark 2011).

The primary purpose of the research was to better understand the lived experiences of adult patients who were treated for a B-cell malignancy. This chapter presents key findings and discusses how the results inform the aforementioned aim of the study and identify any unmet supportive care needs. The themes that emerged from the qualitative phase of the study help further our knowledge and understanding of the quantitative results captured from the QoL questionnaires. The findings of the study present some of the unique challenges faced by survivors of haematological malignancies. This chapter presents the interpretation of the questionnaire data sets and how these are explained with the associated qualitative findings. Next, it discusses overall /key findings from both the quantitative and qualitative phases of the study, implications for clinical practice and, future research.

With substantial progress made in early detection and treatment modalities, survival rates have significantly improved leading to the increased number of long-term survivors of haematological malignancies (De Angelis et al. 2014). However, with the intensity and complexity of therapeutic regimens, which include chemotherapy, immunotherapy and radiotherapy, adverse effects of treatments, most of these patients may experience a reduced QoL in the post-treatment phase.

The purpose of this mixed-methods sequential explanatory study was to examine in greater detail the impact of treatments on the QoL of patients who have survived a haematological malignancy and were between one- and five-years post-treatment. Findings from the first quantitative phase of this mixed-methods study and the themes that emerged relating to QoL from the participant interviews were described in the previous two chapters. This chapter reflects on how the results inform the main aim of the study, which was to examine the QoL of survivors of a haematological malignancy (mainly a B cell malignancy) and identify any unmet supportive care needs. The research study analysed in detail the impact of chemotherapy and its residual effects had on the QoL of such survivors.

The themes that emerged from the qualitative phase of the study help further our understanding of the quantitative results captured from the QoL questionnaires and explain in depth the quantitative results or offer insight into the findings from the questionnaires concerning the QoL of haematological malignancy survivors. Phases one and two were connected as the questions from the Phase two, qualitative, was guided from the results of the Phase one, quantitative. The qualitative data subject to thematic analysis complemented the findings from the quantitative phase by enabling an understanding of the quality of life issues following completion of treatment for a haematological malignancy and identifying unmet supportive care needs. This chapter presents the integration of data and discusses key findings from both the quantitative and qualitative phases of the study.

It has been recognised that individuals face particular challenges when primary treatment for a haematological malignancy comes to an end. Haematological cancer survivors may face a range of physical and psychological, emotional, and social issues including fatigue, concerns about disease recurrence, expectation of life returning to normality, expectations on adjusting to physical ability and concerns about leaving the hospital system (Jefford et al. 2008), in addition to concerns relating to friends and family and unmet supportive care needs (Armes et al. 2009).

8.2 Interpreting the EORTC-QLQ C30 QoL questionnaire

Participants of the research outlined in this thesis experienced changes to their physical functioning, role functioning, psychological functioning and social wellbeing following treatment completion. Some of them experienced effects of treatment and the illness, which persisted in varying degrees in the post-treatment phase. The results show that the illness and its treatment may have profound and lasting effects on the individuals physically and emotionally. Previous studies by Mounier and colleagues (2015), Takahashi (2016) and van de Poll-Franse and colleagues (2018) have shown similar findings (See **Section 2.4)**

Generally, demographic characteristics such as age, gender, marital status, employment, income and social support from family or friends can affect QoL. Whilst QoL in turn can influence the patient's ability to function physically, psychologically, and also have an adverse effect on cognitive function and social wellbeing (Smith et al. 2013; Wong et al. 2013; Bucholz et al. 2014; Juul et al. 2014; Osann et al. 2014; Patterson et al. 2018; Ho et al. 2018). QoL has become a significant outcome parameter in clinical practice and increasingly in clinical trials (Trask et al. 2009). A decrease in QoL can have a negative impact on a patient's survival (Efficace et al. 2011; 2013; Gotay et al. 2008). Previous studies have demonstrated that demographic characteristics such as age, gender, and marital status, and educational level, employment, having children and living status have an impact on the QoL of survivors of any malignancy (Jordhoy et al. 2001; Ramadas et al. 2015; Moro-Valdezate et al. 2014). The key findings of the importance of gender for pain; having children for mobility and usual activities; employment status and health status for all dimensions were presented from this MPhil thesis (see **Table 6.2**). In a study by Kiebert and colleagues, survivors did a rate that having

children as somewhat important in decision making (Kiebert et al. 1994). In this MPhil thesis, children played vital roles in influencing treatment choices and offering continued care in the post-treatment phase.

This thesis explored key issues that were predominant among the survivors, including the impact of selected socio-demographic variables on the QoL of survivors of B-cell malignancies. Increasing age was associated with lower QoL (see **Table 6.2**). Das and colleagues (2011) who reported reduced QoL with impaired physical and role functioning in older patients support these findings in a study. A similar trend between physical activity and QoL in the post-treatment phase is evident in a study conducted by Slovacek and colleagues (2007); Speck et al. (2010) and Knobf et al. (2014).

A large population-based study by Arndt and colleagues (2017) also demonstrated that prominent deficits were in QoL amongst younger cancer survivors. The aggravated QoL deficits were observed in the domains of cognitive functioning, social functioning, and role functioning and overall health/QoL amongst younger cancer survivors in comparison with the older ones. This study also reported less severity of certain symptoms such as fatigue, pain, insomnia in comparison to the younger cohorts.

The overall burden of cancer may increase with age, but younger age groups may struggle to cope with the diagnosis, treatment, and after-effects of treatment. The younger cohort may consider the diagnosis life-threatening whereas the older cohort may accept it better in terms of their physical health and comparison to their aged peers (Wenzel et al. 1999). Alternatively, older patients may receive less aggressive therapy resulting in fewer side effects, which can explain the differences in findings between the two cohorts. This could be due to the fact that treatment decisions in older patients are not only influenced by disease characteristics, such as stage, histology, cytogenetics, and molecular markers, but also patient-related factors, such as fitness, frailty, and patient preference. Besides, fitness and frailty are dynamic factors that can improve or deteriorate over time in the course of a disease and its treatment (Cordoba et al. 2021).

The results from the EORTC QLQ-C30 questionnaire and the socio-demographic characteristics **(Table 6.2)** in this thesis showed that age had a significant negative correlation with global QoL, physical functioning, and role functioning. In other words, the older the person gets, the lower was the global QoL, physical and role functioning. A previous study by Bantemma-Joppe et al. (2015), demonstrated that younger breast cancer survivors struggled in the domains of physical functioning and role functioning in the first year following radiotherapy. The literature shows that younger breast cancer survivors showed better global health in contrast to the older group who had worse global health. Findings similar to the MPhil study were shown in a study of breast cancer survivors were women under the age of 65 years demonstrated a better quality of life than those who were over 65. The presence of comorbidities resulted in a lower QoL in older survivors (Dialla et al. 2015). However, studies have also reported that older age has predicted higher QoL in patients with a range

of different clinical conditions (Brown and Roose 2011; Mc Naughton et al. 2001) and also in cancer patients (Pashos et al. 2013; Roland et al. 2013; Wong et al. 2013; Zimmermann et al. 2011).

Significant QoL differences were observed in gender with men reporting better physical functioning (P=0.041) than women. In addition, men reported fewer symptoms of pain (P=0.000) and less sleep loss (P=0.001) compared with women. Men also reported lower pain scores and less loss of sleep than women (see **Table 6.2 and** S**ection 6.3**). Studies by Mellon et al (2000) and Matthews et al (2012) add support to these findings where women reported lower QoL than men. However, these findings were not specific to survivors of a haematological malignancy but encompassed all cancer survivors.

A significant difference was seen in the domain of physical functioning with men reporting higher levels (P<0.05) (see **Table 6.2)**. Four of the 131 participants who completed the QoL questionnaires in this MPhil study made a note against the question about pain stating that their pain was due to either arthritis, pelvic surgery but not due to the malignancy or its treatment. For those participants who confirmed the presence of pain/discomfort in the QoL questionnaires, the cause of the same could not be differentiated. It was most likely due to the malignancy or the side effects of treatment itself. The qualitative phase provided a detailed gender explanation of the reasons behind the pain, which may otherwise not have been captured in the QoL questionnaires. Similar results have been reported in patients with haematological malignancies (Leunis et al. 2014; Stauder et al. 2018).

Several studies across different disciplines have reported gender differences in QoL with women generally reporting a lower QoL than their male counterparts. The lower QoL was reported in at least one of the domains assessed (Dodd et al. 2011; Zimmermann et al. 2011; Smith et al. 2013; Bushnell et al. 2014; Osann et al. 2014). Although the exact reason for gender differences in QoL is not known or completely understood, it can be related to characteristics of the disease, response to treatment and the differences in the way men and women report symptoms and perceive problems that may arise due to the effects of the disease and treatment, differences in societal expectations and roles (Izadnegahdar et al. 2014; Zimmermann et al. 2011).

In a study by West and colleagues (2015), women reported lower QoL than men in most of the domains that assessed QoL which were consistent with the findings of this MPhil study. The result of several other studies was consistent with those of this MPhil study (Laghousi et al. 2019). These characteristics may predict QoL differently in men and women. Holzner and colleagues (2004) also showed comparable gender differences in their results as reported in this MPhil study. They assessed QoL using the EORTCQLQ-C-30 questionnaire to 76 CLL patients (41% were women) at Innsbruck University which was very similar to the proportion of women in this doctoral study. It was found that women with CLL reported significantly lower QoL in the domains of physical functioning, emotional and cognitive functioning than men with CLL. It is therefore important to explore the factors that mediate these differences between the genders with women mostly reporting high levels

of fatigue, pain, anxiety, and depression. The similarities and differences in QoL based on gender can enable health care providers to inform appropriate supportive care strategies (Shanafelt and Kay 2007; Laghousi et al. 2019).

Employed participants experienced better physical functioning (P=0.000), role functioning (P=0.000) and cognitive functioning (P=0.000) compared to those who were not employed or were retired. Unemployed participants experienced more fatigue (P=0.000), more symptoms of pain (P=0.000), dyspnoea (P=0.003), sleep loss (P=0.001), appetite (P=0.031) and constipation (P=0.031) than those in employment (refer **Table 6.2)**. Previous studies on employment and illness report the impact malignancy and its treatment can have on an individual's return to work. Pryce and colleagues (2007) found that the presence of more physical symptoms and higher levels of fatigue were associated with cancer survivors who returned to work following completion of treatment. Survivors returning to work struggled to manage fatigue, physical changes associated with cancer and manage the stress associated with cancer and its treatments. Survivors who were employed reported significantly better physical functioning and social functioning and fewer role limitations and symptoms than those who were not in employment. In general, employed participants, therefore, reported a much better QoL than those who are not employed. To add, most of the participants in this MPhil study with more symptoms of fatigue, pain, sleep loss, appetite loss, and constipation were not in paid employment or were already retired (**Table 4.2**).

Several studies have examined associations between employment and QoL of cancer survivors (Carlson et al. 2008; de Boer et al. 2009; Syse et al. 2008). With the advancements in cancer treatments and subsequent improvements in five-year survival rates, there has been a proportionate increase in the number of cancer survivors (Mols et al. 2009; Jennings et al. 2014; Jung et al. 2011). With the recent advancements in treatment, there has also been a considerable increase in cancer survivors being able to or willing to return to work following treatment (Taskila and Lindbohm 2007).

Cancer survivors, in general, are at an increased risk of not being reemployed (Park et al. 2009) if they were unemployed at the time of treatment and therefore more likely to be out of employment (Carlson et al. 2008; Syse et al. 2008; Vayr et al. 2019). Risk factors such as depression, poor health, presence of comorbidities, long term effects of illness and treatment have been identified as reasons for unemployment (Carlson et al. 2008; Ahn et al. 2009; Hoffman 2016) and previous studies have reported patients to lose or quit jobs within the first year of their diagnosis and treatment (Short et al. 2005; Park et al. 2005; Yoo et al. 2013; Carlson et al. 2014). Tailored rehabilitation programmes can be developed to enable survivors to return to employment, which may enhance their QoL. Less than a third (30%) of the participants in this MPhil study was employed. It was not possible to assess the reason for unemployment in these participants. With the median age of participants in this study being 66 years, it could be assumed that many participants were of retirement age. During the interviews, some participants mentioned that they had taken early retirement.

Participants in this MPhil study who lived beyond two and a half years following completion of treatment for a haematological malignancy reported better role functioning than those who had completed treatment less than 2.5 years previously (P= <0.048). Other QoL dimensions did not show significant associations concerning time since the completion of treatment. No significant associations were found between the QoL dimensions and the marital status and /or living arrangements of participants in this study. Similar results have been reported in a recent cross-sectional study of breast cancer patients (Zhang et al. 2018). Two previous studies (focusing on 116 Hodgkin lymphoma survivors and 294 non-Hodgkin lymphoma survivors) reported similar findings with the group of patients closer to diagnosis reported worse levels of physical, psychological and social functioning (Mols et al. 2006; Mole et al. 2007). Immediately post-treatment these patients reported higher levels of pain, anxiety, depression and fear of their health and anger. However, this was overcome by the positive effects of post-traumatic growth, increased confidence, and reduced the fear of survival or recurrence of the disease (Casellas-Grau et al. 2017).

Other variables such as 'time since completion of treatment', 'living arrangements' and 'educational status' did not have a significant impact on the other QoL domains. Overall younger participants, men and those in employment reported better quality of life. Following the completion of treatment in this MPhil study, survivors experienced a limitation in their physical functioning because of the side effects of the treatment, exacerbation of their comorbidities, which influenced negatively their quality of life. The qualitative data supports and enhances a deeper understanding of the quantitative findings as the reason behind the limitation in physical functioning was explained and elaborated in further detail in the qualitative phase. This point may be highlighted as a recommendation for future survivorship programmes in this age group to proactively prepare the health care providers to factor in this understanding of limitation to physical functioning due to age-related factors, increase and exacerbation of comorbidities. However, ten of the survivors interviewed adopted lifestyle modifications such as trying to keep fit by walking and doing mild exercises, leading a healthy lifestyle, which led to improving their fitness, life and health post-treatment.

These MPhil results are reflected in the literature with epidemiological and interventional studies evaluating the engagement of healthy eating and physical activity suggesting that lifestyle behaviours are important in reducing the effects of treatment and improving overall QoL outcomes (Pekmezi and Demark-Wahnefried 2011; Vijayvergia and Denlinger 2015; Irwin et al. 2015). Previous studies have shown that increased physical activity shows improved cardiovascular fitness, decreases fatigue, and improve overall QoL in cancer survivors (Ferrer et al. 2011; Lemanne et al. 2013; Rogers et al. 2009). Unhealthy lifestyle habits such as smoking, excessive drinking, an unbalanced diet and lack of exercise can lead to disease relapse, cardiovascular disorders, secondary cancers, diabetes, osteoporosis, depression, and functional decline (Demark-Wahnefried and Jones 2008; Takahashi 2016). Therefore, cancer patients and survivors must be educated to follow a healthy lifestyle to prevent disease relapse and optimise outcomes.

Shin-Hye and colleagues (2017) found that in a group of cervical cancer survivors, the higher the level of physical activity, the lower the levels of fatigue and pain which resonate with the findings of this MPhil thesis. Other studies also demonstrated similar results (Sagen et al. 2009; Valenti et al. 2008; Rogers et al. 2009; Lashbrook et al. 2018; Wang et al. 2019). It is also quite evident that tailored exercise therapy is linked to better physical functioning, decreased pain, fatigue, and an overall improvement in QoL in cancer survivors.

8.3 Interpreting the EQ-5D questionnaire

It is common for patients to experience emotional side effects during treatment for a malignancy. For some of them, these effects continue and last for a considerable period following the completion of treatment (Mitchell et al. 2013). Depression and anxiety are very common symptoms experienced by cancer survivors. These feelings are exacerbated at times. Survivors do express that the threshold to withstand such emotions becomes very less. Less than 30% of participants reported in the EQ-5D, problems with self-care and anxiety/depression (see **Table 6.3**). The present findings seem to be consistent with other studies among lymphoma patients who were receiving chemotherapy (Cull et al. 1996) and acute leukaemia patients with anxiety and depression showing an improvement towards the end of treatment and after (Zittoun et al. 1999). Heinonen and colleagues (2001) suggested that the level of anxiety and depression was lower in the post-treatment follow-up phase than in the active treatment phase for peripheral stem cell transplant recipients. Similar results were seen in other studies (Burgess et al. 2005; Korfage et al. 2006; Nayak et al. 2017). However, it is to be noted that the above studies were conducted in breast and colorectal cancer survivors.

Fear of recurrence and the constant thought of the disease coming back also can trigger emotions of anxiety and depression amongst these survivors. Nayak and colleagues (2017) identified similar findings in a study. During the interviews, patients expressed feeling negative at times, grateful, and privileged for having survived the malignancy and its treatment when many of them may have not.

Research into exploring the emotional experience of cancer survivors is yet to receive greater attention. There has been a considerable amount of work undertaken in this area that has focussed on patients receiving active treatment or in the earlier course of the malignancy (Mitchell et al. 2013). The shift has been to cancer is considered a chronic condition rather than an acute disease. Therefore, there has been heightened interest in exploring the emotional effects of the illness and the treatment in cancer survivors. Longitudinal studies undertaken in assessing anxiety and depression in cancer survivors have shown that fluctuations in the mood do tend to decrease over time but remain higher than in healthy controls (Korfage et al. 2006; Burgess et al. 2005; Yi and Syrjala 2017). Anxiety and depression may be due to feelings of uncertainty, health related worries, fears surrounding the reason for the malignancy and possible prevention of secondary malignancies and lack of education and awareness around them. Most of the participants in this MPhil study expressed anxiety towards the end of treatment due to losing continued connection with dedicated health professionals. They

articulated the need for a key worker or dedicated health care professionals to remain as a point of contact to address any concerns raised in the post-treatment phase.

There has been some work undertaken around the emotional experiences amongst cancer survivors many months following treatment that can lead to post-traumatic stress disorder (Chan et al.2017; Smith et al. 1999). Although post-traumatic stress disorder (PTSD) commonly occurs, in patients who have experienced severe trauma and is used commonly concerning war, it may also occur in cancer patients. A study by Chan and colleagues (2017) showed that the incidence of PTSD at six-month follow up in cancer patients was 21.7% dropping down to 6.1% at four-year follow-up. PTSD can include feelings of anxiety, depression, fear of recurrence, emotional distress which may be caused due to the triggering of memories of the past cancer experience.

Not all emotional experiences described by cancer survivors can be attributed to being negative. Participants also expressed positive emotions because of experiencing a traumatic journey of cancer diagnosis and intensive chemotherapy treatment. For many of them, surviving a haematological malignancy and enduring a challenging journey of intense treatment and its side effects enabled them to be more understanding of others. Being compassionate and empathetic were attributes survivors described themselves to have acquired through this journey of cancer and treatment.

Post-traumatic growth has been explored in the literature and demonstrates that survivors not only experience the negative impact of cancer and treatment but also positive changes that can impact the way they viewed their relationships and feelings for others (Calhoun and Tedeschi 2006; Morris et al. 2011). In this compassion for others, they desire to give back or help other people (Hefferson et al. 2009). Participants in this MPhil study engaged in volunteering and working for charitable sources in talking to patients undergoing a similar journey in their respective diagnosis of cancer and treatment. Some of them even helped friends and neighbours by taking them to hospital appointments for their cancer treatments.

The risk of becoming unwell and deterioration enabled participants to frame the malignancy as a positive experience and hence cope better. Survivors were able to prioritise and make plans effectively in many situations. They were able to build and sustain meaningful relationships. Being still considered an integral part of the family, upholding that role in the family and preserving that normality helped enhance their quality of life (Potrata et al. 2011; Boland et al. 2013). The experience of being diagnosed with a haematological malignancy can be immensely distressing for the patient, their family and wider circle. Patients with conditions such as myeloma and certain kinds of lymphoma may never be cured. Their disease can just be kept at bay. They may be left with life-altering changes and effects of the malignancy and treatment that leave them in chronic pain and fatigue. Therefore, it is just not the physical challenges associated with the malignancy and treatment, but also the emotional trauma of experiencing the same. Previous work by Tom and Helgeson (2002) suggests that the search for positive meaning and outcomes following a malignancy may be an

important step in survivors' adjustment to the malignancy and its treatment-associated effects. With the focus on positive outcomes, participants in the MPhil study were able to reframe their experiences and therefore help them deal with the challenges much more effectively.

More than 35% of participants in this MPhil study reported having problems with mobility, usual activity, and pain or discomfort (see **Table 6.3**). They indicated mild/moderate, severe problems in mobility, usual activity, and pain/discomfort dimensions. A study of survivors of cervical cancer has shown comparable results (Chuang et al. 2010) for the self-care dimension; however, less than 10% of participants in the study had problems with mobility. Pain or discomfort was the most frequently reported symptom amongst all the other dimensions in this group of survivors of haematological malignancy with 38.5% of survivors reporting moderate or severe pain or discomfort. Studies of cancer patients and survivors using the EQ-5D-5L have reported higher rates in the pain/discomfort category (Tran et al. 2020; Zhu et al. 2021; Borchert et al. 2020). Similar results have been reported in patients with haematological malignancies (Osaki et al. 2022; Stauder et al. 2018).

Women reported more pain or discomfort when compared to men with more than 50% of women reporting moderate or severe levels of pain/discomfort whereas less than 30% of men reported moderate/severe problems with pain/discomfort. These findings were consistent with the results of previous studies (Baker et al. 2003; Matalqah et al. 2011; Oh et al. 2014). Oh, and colleagues (2014) assessed the QoL of cancer survivors demonstrating the highest proportion of problems in the pain/discomfort dimension. More than 43.7% of cancer survivors in this study reported moderate/severe pain/discomfort. This MPhil study shows comparable results.

Except for encompassing all cancer survivors, this study also employed the EQ-5D-3L QoL questionnaire to assess the QoL of cancer survivors. The qualitative findings further elaborate on the quantitative results. Interviewees reported pain because of side effects of certain chemotherapeutic agents such as peripheral neuropathy in the second, qualitative phase of the study. Fatigue was also a concern following treatment which limited their role functioning but most of the participants during the interviews believed that it may also be due to increasing age. Similar findings were reported in previous studies (Gulbrandsen et al. 2001; Uyl-de Groot et al. 2005; Matias et al. 2019; Salome et al. 2019). These two studies examined the QoL in patients with multiple myeloma pre, 12-months and 36-months post autologous stem cell transplant. Fatigue and pain were the two most frequently reported symptoms that influenced the QoL in these patients. Any new symptoms of pain, lumps, feelings of weakness, and fatigue can inculcate the fear of potential disease recurrence in survivors (Gill et al. 2004; Lebel et al. 2014). The qualitative method provides a deeper understanding of symptoms such as pain/discomfort and fatigue reported in the quantitative phase. The quantitative phase-only captures the fact of pain/discomfort or fatigue whereas the qualitative phase explains the details and possible causes of pain/discomfort experienced by the survivors.

In this doctoral study, survivors who reported pain or neuropathy associated pain had predominantly been treated for MM. This may be because MM is characterised by bone pain, recurrent infections and neuropathic pain related to the treatment administered (Nielson et al. 2017). Regular assessment for pain in the survivorship phase, developing interventions aimed to alleviate them will optimise the QoL in cancer survivors. In both the QoL questionnaires (EORTC QLQ-C30 and EQ-5D-3L), performing usual activity was the second most frequently reported problem in this group of survivors (35.9%) followed by mobility dimension which was the next frequently reported dimension where participants reported moderate or severe problems (35.4%). A study by Oh and colleagues (2014) also showed similar results with self-care being the lowest reported dimension with moderate to severe problems. These symptoms may also be attributed to a predominantly older population. This indicates that even if the survivors are disease-free, they may experience debilitating symptoms of pain/discomfort and other issues such as mobility and performing the usual activity to a certain degree, which can have a significant impact on their quality of life.

Due to the specific characteristics of this population, there are comorbid conditions with exacerbated symptoms and symptoms because of the haematological malignancy or its treatment. It is challenging to disentangle if the reported symptoms and their severity are due to the malignancy, its treatment, or any other medical condition. The presence of one or more comorbidities along with haematological malignancy and the resulting treatment can affect the QoL of these individuals. Mao and colleagues (2007) examined the effect of comorbidity and age on self-reported symptom burden such as pain, psychological distress and insomnia on patients who had received chemotherapy for cancer. They concluded that the overall symptom burden increased significantly with age and an increase in the number of comorbid conditions. These factors can also be attributed to an ageing population such as in this MPhil study in Dorset. It is therefore very important for health care providers to pay attention to and manage these needs. This supports the case strongly for a mixed-methods approach.

8.4 Impact of comorbid conditions on QoL

Comorbidities can further negatively influence the QoL of an individual independent of a cancer diagnosis or its related treatments. Many of the participants in this study had an increased likelihood of having a comorbid condition in addition to cancer (Extermann 2006). This increased likelihood of the presence of comorbidities in participants may have influenced the different QoL domains. Had most of the participants in this study been younger; there may have been differences in the physical QoL. Internationally, research has shown that older cancer survivors experience lower levels of physical QoL, increased fatigue than younger ones (Extermann 2007). Comorbidities such as hypertension, diabetes mellitus, cardiovascular diseases and musculoskeletal diseases were quite common amongst cancer survivors based on data collected for the qualitative phase of this study.

Cancer survivors with comorbidities may have different clinical and healthcare needs (Guralnik et al. 1989; Schellevis et al. 1993; Eytan et al. 2019).

In this MPhil study, during the qualitative data collection, it was found that three of them presented with one comorbidity; one of the interviewees had two comorbidities and one, with three comorbid conditions. Therefore, to optimise the QoL of these survivors, it is important to address these comorbid conditions. It is vital to implement programmes that address the overall issues rather than just taking only cancer into context.

8.5 Unmet supportive care needs in cancer survivorship

In the sequential, qualitative Phase two, the unmet supportive care needs of these survivors were explored. Cancer survivorship has become an increasingly specialised area of research and gathered significance in recent years: around 2 million people were said to be surviving cancer at the end of 2008 (Maher and McConnell 2011) with these figures estimated to rise by 3 % each year (Maddams et al. 2009) and this rate of increase is also anticipated to increase due to improved detection of cancer and survival.

Knowledge of unmet supportive care needs is essential to inform appropriate interventions in the future to improve patient outcomes and the QoL of survivors. Although studies are focussing on the QoL of patients with haematological malignancies (Allart et al. 2013; Tzelepis et al. 2018; Oberoi et al. 2017), very few studies focus on the assessment of supportive care needs in survivors. QoL in these survivors can be optimised mainly when their concerns in the post-treatment are addressed (Campbell et al. 2011: Hall et al. 2014; So et al. 2019).

Unmet supportive care needs have been defined as “those needs, which lack the level of service, or support an individual perceives is necessary to achieve optimal well-being’’ (Sanson-Fisher et al. 2000: p.123). It is effectively a gap between the desire to have a need met and the reality in a patient or cancer survivor. This typically happens during the time of transition from active treatment to follow-up and has been associated with distress due to the loss of frequent medical monitoring and support, and the shift in the responsibility of the individual which may result in feelings of abandonment, vulnerability, and the loss of a ‘safety net’ (Ward et al. 1992). Cancer survivors report problems with physical well-being, finance, emotional problems, relationship problems, and problems with the uncertainty of the future, fear of disease recurrence and loss of connection with health professionals in the hospital in the post-treatment phase. It is important to address these unmet supportive care needs to optimise their quality of life in the survivorship phase. The most frequently identified unmet supportive care needs in cancer survivors are predominantly psychosocial (Lisy et al. 2019).

Focus on survivorship issues has heightened interest among healthcare providers and initiatives such as The National Cancer Survivorship Initiative (NCSI) “Taking action to Improve Outcomes” in

2013 published a toolkit which identified how key interventions such as Recovery Package would improve outcomes for this population of patients (NCSI 2013). The report recommended the commissioning of a number of initiatives such as the Recovery Package (see **Figure 8-1**). The Recovery Package and associated elements were seen as key interventions that would support people and carers to live well with their cancer post active treatment.

Figure 8-1 Recovery Package Elements (NCSI 2013)

Holistic Needs Assessment Treatment Summaries Cancer Care Reviews Education and Support events.

For cancer patients to return to living a life as active as possible following treatment completion, further research is warranted to ensure strategies are in place to achieve these outcomes. This was highlighted in the Improving Outcomes Strategy for Cancer document (Department of Health 2011). In a report published by the Department of Health (2012) that explored the quality of life of cancer survivors, patients with non-Hodgkin's lymphoma (NHL) reported poorer outcomes when compared to breast, colorectal and prostate cancer survivors.

Unmet supportive care needs are increasingly becoming a major concern for cancer survivors. The following qualitative themes discussed in this chapter were not identified through quantitative enquiry. The qualitative results complemented the quantitative findings and enabled a deeper understanding of survivors' needs that were required to be addressed in areas such as physical, psychological, and health care information domains. All the participants interviewed in the qualitative phase reported at least one unmet supportive care need. A study by Hall and colleagues confirmed that 25% of haematological cancer survivors were found to have had a high/very high level of unmet need (Hall et al. 2014).

A Canadian study that included a mix of breast, gastrointestinal, genitourinary, and other types of cancer found out that 93% of the participants reported having at least one unmet need, which was more psychological, and 64% reported at least one unmet need relating to inadequate follow-up services (Siu et al. 2013). Edib and colleagues (2016) undertook a cross-sectional study in breast cancer patients at a surgery and oncology clinic in Malaysia reported similar results. This study found out that the most prevalent unmet supportive care need in this cohort was uncertainty about the future (78.6%). Around 76.1% of participants reported fear of cancer recurrence as a common unmet need. Only 45.3% of participants reported health information as an unmet need. This may be because the Malaysian Health care system has a robust pathway for breast cancer patients and survivors in enabling them to have regular access to health care professionals (Dahlui et al. 2011) which explains a low level of unmet need in the healthcare information domain. Swash and colleagues (2017)

revealed similar findings in a study. In line with the above three studies, uncertainty about the future, fear of cancer recurrence and loss of connection with health care professionals in the post-treatment phase emerged as major unmet supportive care needs in the current study. Some unmet needs may be more common amongst cancer survivors of one country while the others may serve to minimise them. It is also to be acknowledged that there may be potential differences that may exist in the different countries and in the way; the healthcare system works (E.g., National Health Service for the UK and privatised medical care in other countries).

A systematic review conducted by Ralph and colleagues (2017) discovered a lack of studies focussing on psychosocial issues amongst survivors of haematological malignancies. The qualitative results of this thesis illustrated the theme of fear of recurrence as a major unmet supportive care needs in the post-treatment phase and how participants in the current study expressed constant worry around the probabilities of the disease relapsing or spreading. Nine of the twelve interviewees in this MPhil study talked about the fear of recurrence of their malignancy. It was explicit that most of the participants experienced emotional effects, which negatively influenced their quality of life. They still experienced challenging and negative emotions because of their treatment and the ongoing cancer journey with regular visits to the hospital for follow up. The results of this thesis both confirm and extends the previous work of Glaser and colleagues (2013), Ream, and colleagues (2008). Previous studies have reported that 31-52% of cancer patients experienced the fear of cancer recurrence, with 24-40% of patients having experienced moderate to high levels of need for help to cope with it (Hartl et al. 2003; Hodgkinson et al. 2007; Lebel et al. 2016).

The majority of studies examining the emotional experience of patients have been mainly during the early stages of diagnosis and treatment. There is still very little attention focussed on exploring the emotional experience of long-term cancer survivors (Mitchell et al. 2013). However, in a study by Kang and colleagues (2017), fear of relapse of cancer and occurrence of a second malignancy was reported as the most distressing problem amongst a group of long-term survivors of non-Hodgkin lymphoma. A review by Cris and Grunfeld (2013) was consistent with the above findings with fear of recurrence being the primary concern for cancer survivors regardless of the type of cancer, stage at diagnosis and length of survivorship. However, fear of recurrence of the malignancy was reported less within a year of completion of treatment in a large qualitative study of more than 9000 cancer survivors. This Australian study included patients from fourteen different states and six different cancer diagnoses (Burg et al. 2015). The theme of fear of recurrence as a key unmet need in this thesis would not have been arrived at with a single methodology or a non-explanatory mixed methods study.

Once diagnosed with a malignancy, the individuals live with this lingering uncertainty of the possibility of the disease returning at any point in the future. This can instil fear and exert an emotional toll on their lives in coming to terms with this feeling of uncertainty. A feeling of uncertainty about the future emerged as another key unmet supportive care need in this MPhil study

amongst the survivors that were interviewed. Similar results were seen in a study conducted by Edib and colleagues (2016) amongst breast cancer patients in a tertiary hospital in Malaysia where more than 78% of patients expressed uncertainty of the future as a prevalent unmet need. A literature review undertaken by Lisey and colleagues (2019) of fifteen cross-sectional studies and two longitudinal ones conducted in Australia showed that up to 26% of participants reported unmet needs and help to cope with uncertainty about the future. This resulted in them not being able to set future goals and make long-term plans.

Unmet psychological needs have previously predominantly been identified in previous studies undertaken in the western countries (Mehnert and Koch 2008; Knobf et al. 2012; Bredart et al. 2013; Burg et al. 2015) such as the current MPhil study whereas needs related to health care information system of cancer survivors were high in studies undertaken in developing countries (Chan et al. 2012; So et al. 2013; So et al. 2014; Singh-Carlson et al. 2013). Congruent with this study, feeling uncertain about the future was reported as a high-unmet need in more than 20% of the participants (Boyes et al. 2015). Although this study was undertaken in participants with a haematological malignancy, it is not clear, if all those participants had completed treatment for a haematological malignancy or if some were still receiving treatment. Details of whether the participants were in watchful waiting or receiving treatment were not captured. Feelings of uncertainty about the future may result from persistent adverse effects of treatment and the feeling that they will always remain and be a source of discomfort which may cause concern amongst some survivors.

Although the expectation of cancer patients on completion of treatment for any malignancy is happiness or a feeling of having conquered; this is not always the case. Some people tend not to focus on them and attempt to move on while others may worry about the future, about the fear of cancer recurrence and these thoughts may be overwhelming (Lebel et al. 2016). These feelings of sadness and anxiety about the future may be related to the fear of cancer coming back and other times it may just be something that may not be related to cancer at all. Some survivors may take it up as a challenge and become encouraged (Sun et al. 2019). A study by Molassiotis and colleagues (2011) adds support to the findings of this thesis by demonstrating that patients living with multiple myeloma experience psychological problems such as anxiety and depression. These psychological and social issues in haematological cancer survivors may cause distress and poorer QoL (Korzun et al. 2014).

Although these thoughts may not be entirely preventable learning to live with uncertainty and accepting this fact may benefit and improve overall QoL. Understanding the reasons behind such feelings of uncertainty and discussions with a health professional may help address this need in survivorship. These uncertainties persist even beyond treatment completion. Survivors need to know that they can approach a dedicated therapist when having to raise such concerns. Motivating them to adopt healthy lifestyle changes, encouraging them to eat healthily, exercise as much they can enable them to deal with this feeling of uncertainty about the future. They should be encouraged to look at

life positively and think of the times they courageously endured a diagnosis of cancer and its intensive treatment. This feeling of taking charge of your life and adopting healthy lifestyle changes may pose less of a challenge when thinking about living with uncertainty. Peer support programmes amongst cancer survivors have been found to address informational, social and emotional needs in previous studies (Dunn et al. 2003; Klemm et al. 2003; Campbell et al. 2014).

It is not uncommon that patients who receive excellent treatment or more personalised care during their active phase of receiving chemotherapy, feel abandoned once all active treatment is completed (Winnie et al. 2017). Lack of care coordination between healthcare providers and across various healthcare settings can lead to issues in the survivorship phase. Unclear communication between cancer survivors and healthcare providers can raise a concern and result in an inferior QoL. Lack of connection with health care professionals in the post-treatment phase emerged as another key unmet supportive care need in the current study. Some participants feel neglected following the completion of active treatment.

Previous studies have demonstrated the importance of information and continuing contact with healthcare providers (Winnie et al. 2017; So et al. 2013; Li et al. 2013). Echoing the findings of other studies (Henry et al. 2016; Wells et al. 2015), this study contributes to the emerging body of evidence relating to major unmet supportive care needs pertinent to the population of cancer survivors. Similar results were shown in other studies where participants continue to desire to be in contact with a member of the health care to approach for any concerns and overall post-treatment planning (Winnie et al. 2017; Lam et al. 2011; So et al. 2014). However, the participants were predominantly head and neck and breast cancer survivors, but the unmet needs appear to be similar across most disease groups. In a study of mixed haematological cancer survivors, lack of care coordination post-treatment emerged as one of the top unmet needs (Lobb et al. 2009).

Lack of sufficient information in the survivorship phase can be associated with the lack of continuous connection with the healthcare providers following treatment completion. This was also cited as one of the major unmet needs in the survivorship phase. These findings were echoes in previous studies undertaken on cancer patients in Hong Kong where information needs were consistently emphasised (So et al. 2013; Li et al. 2013). A previous study by Hall and colleagues (2013) in a population of American and Canadian haematological cancer survivors indicated that lack of information was a major unmet need. The main advantage of the qualitative phase is to explain and expand quantitative findings. Where the quantitative phase did not provide a detailed insight into the needs of the survivors, the qualitative phase specifically provided a specific understanding of the needs. These unmet needs reflect the lack in limitation of resources or importance shown in the continuing care of these patients. Based on these results, it is recommended to streamline supportive care services to optimise outcomes and QoL by addressing the unmet needs of these survivors mainly due to the vulnerability of the subgroup.

Studies just adding a quantitative or qualitative component to a study do not qualify or expect to meet the criteria for a mixed-methods study. To qualify for a mixed-methods study, a clear rationale for combining quantitative and qualitative data must be provided. The strategies for integrating the data throughout the study must be identified early on and must be made explicit during the research process. This explicit explanation is important to achieve the status of a mixed-methods study (Woodley 2009). This study included both types of data, which was driven by the need to examine a complex phenomenon such as quality of life in survivors of a haematological malignancy. Each phase of the study complemented the other. Importantly, the study not only combined quantitative and qualitative data but also provided a rationale to integrate the data to study such a complex phenomenon and demonstrate a deeper understanding. The collection and analysis of both quantitative and qualitative data enriched and enhanced the study outcomes (Andrew and Halcomb 2008). This mixed-methods study helped to identify that combining both methods help overcome the weakness that may occur when a single methodology is used (Giddings and Grant 2006) such as the inability to understand in depth the meaning of QoL in a quantitative study or to generalise findings in a qualitative study (Creswell and Plano-Clark 2011).

8.6 A cancer survivor's role in supported self-management

One of the key National Cancer Survivorship Initiative's shifts in cancer survivorship is supported self-management. This lays emphasis on patients to actively participate in their recovery, rehabilitation, or on-going survivorship care. Part of supported self-management involves initiatives to assist cancer survivors to overcome challenges associated with treatment related physical and psychosocial symptoms (NCSI 2013). This NCSI model encourages patients to participate and take ownership of their survivorship care. Examination of the literature regarding supported self-management informs that psycho-educational strategies, for example, may reduce fatigue and increase energy in cancer survivors (McCorkle et al. 2011).

An adapted version of the Foster and Fenlon's framework (2011) earlier mentioned in Chapter 5 is illustrated here and it reflects on the factors assessed in this study that are associated with optimising the QoL (Barlow et al. 2005; Lorig et al. 2001) of these haematological cancer survivors and those that enhance their recovery and well-being (Lev et al. 2001).

In this MPhil study, the problematic events such as the cancer diagnosis and its treatment and pre-existing factors such as the indivisual's age, gender, socio-economic status, employment status and living with children etc did influence how disruptive the cancer and its treatment were on the subjective health and well being and in optimising their QoL. How each individual is able to appraise their situation and manage it confidently is reliant on certain personal (e.g. personality, general confidence) and environmental factors such as health and social care support, family and friends and support from the community. This may enable and empower cancer survivors to manage their problems and challenges elated to the cancer and its treatment. This in turn is likely to influence the

types of self management strategies used and may further influence how the problem is managed. All the above ultimately influences the perceived health ad well being of the cancer survivors.

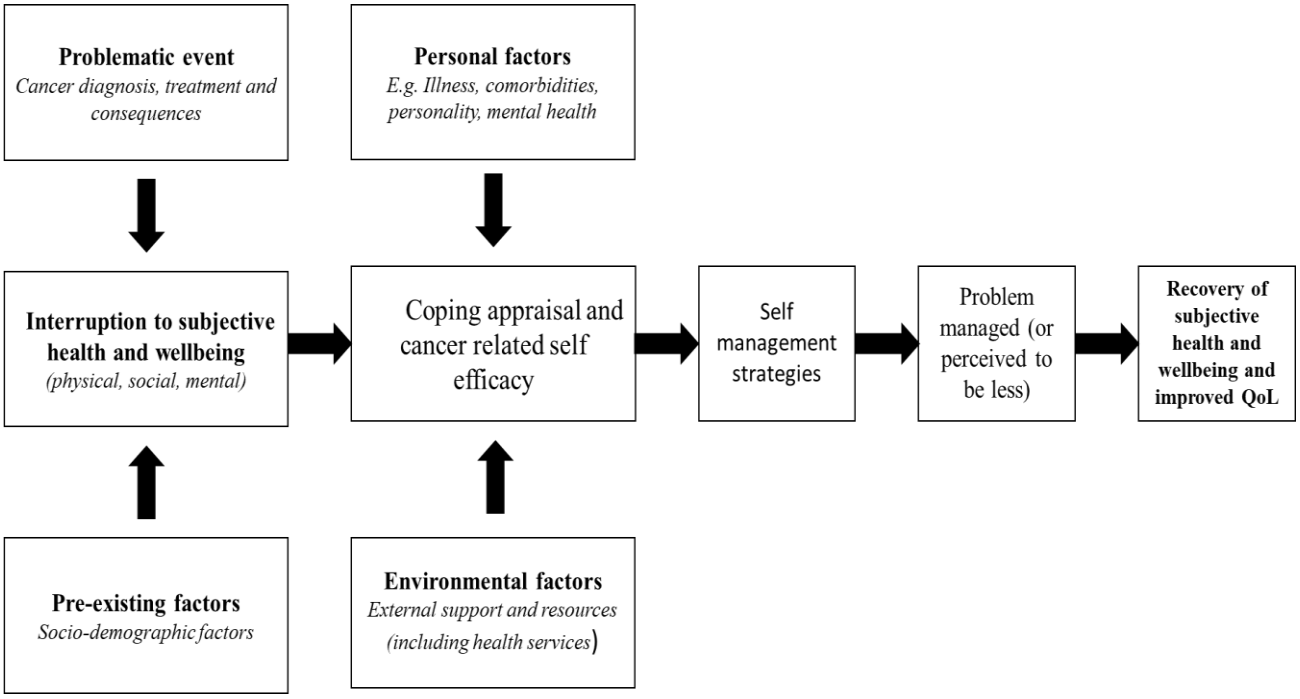


Figure 8-2: Recovery of health and well-being in cancer survivorship (adapted from Foster et al. 2011)

Several self-management programmes have been introduced with some focusing on cancer survivors. For example, the Macmillan "Living with Cancer" programme delivered by a trained oncology nurse rehabilitates cancer survivors by supporting them to adjust to their cancer, treatment, and its consequences. They are encouraged to engage in physical activity and healthy nutrition. Additionally, the cancer survivors receive support for their emotional and financial needs (Davies 2009).

8.7 COVID-19 and cancer survivorship

The COVID-19 pandemic has profoundly changed the management of cancer patients (Archer et al. 2020; Tsamakis et al. 2020). The quarantine and lockdown measures have hindered access to clinical care (Neal et al. 2020) and most importantly access to supportive care including psychosocial care in cancer survivors (Archer et al. 2020). Although the clinical centres were able to swiftly switch to telehealth (Archer et al. 2020), remote monitoring via video conferencing and phone calls, this would not have effectively and sufficiently met the needs of most of the survivors (Neal et al. 2020) which is likely to have adverse effects on patient outcomes.

A cross-sectional study by Hulbert-Williams and colleagues (2021) compared the psychosocial impact of COVID-19 in cancer patients and those in their informal networks. The study demonstrated that the pandemic had led to a readjustment of unmet needs across the different domains of psychosocial well-being in this cohort of patients.

This section has been added to bring into perspective the impact of COVID-19 in cancer survivors and those individuals who might have just transitioned from completion of treatment to the post treatment phase. Potentially, the pandemic might have resulted in poorer QoL in some survivors (Hulbert-Williams et al 2021). However, this MPhil study was conducted and initially submitted prior to the COVID-19 pandemic.

8.8 Strengths of the study

The combination of quantitative and qualitative data in this mixed-methods approach was an important strength of this study. This approach adds strength to the research outcomes as each phase complements the other (Creswell and Clark 2011). One of the other main strengths of the study was that it was representative of an ageing population with haematological malignancies of the whole of the UK. A high completion and return rate of the questionnaires was also an important strength of this study. The use of validated generic and disease specific questionnaires enabled capturing of data in detail. Participants were drawn from three different treating hospitals covering the whole county. This study was the first of its kind to be undertaken in a population of people who had completed treatments for haematological malignancy in Dorset. This study contributes and adds value to the methodological advancements of MMR. The research study has created a better understanding of both MMR and QoL research.

Understanding complex issues related to QoL in the post-treatment phase and identifying specific unmet supportive care needs required combining methods, which were achieved by the use of mixed-methods research. It provided better results as the findings were supported by different methods (Bryers et al. 2014). The qualitative data subject to thematic analysis complemented the findings from the quantitative phase by enabling a deeper understanding of the quality of life issues following completion of primary treatment for a haematological malignancy and identifying unmet supportive care needs. Without the qualitative phase, these unmet supportive care needs would not have been captured or highlighted in this MPhil study.

In Phase 2 of the study, the qualitative interviews with the survivors strengthened the overall study outcome as the data from interviews helped unfold some of the findings of the quantitative data and enabled a clearer understanding of these findings. It led to a detailed understanding of the survivors' unmet supportive care needs. Where the quantitative phase did not provide a detailed insight into the needs of the survivors, the qualitative phase specifically provided a specific understanding of these needs. The high response rate in the study and the employment of mixed methods research enriched

our understanding of the meaning of quality of life providing an in-depth understanding of the unmet supportive care needs. This of course should be the outcome of a mixed-methods approach.

Subjective experiences of survivors in this study interpreted differently could be a limitation (mentioned below); however, this was addressed and clarified during the interviews. For example, bowel issues were not a commonly occurring symptom in most participants in the current study and questions relating to pain were relevant only to certain types of malignancies like myeloma. Where some participants had stated pain as a predominant symptom, it was later made clear at the time of interviews that the pain was due to a co-existing medical condition rather than the haematological malignancy or its corresponding treatment itself. Although some participants expressed physical concerns, many of them expressed coming to terms with the cancer and their experiences following treatment. Strategies such as maintaining a positive outlook, adopting healthy lifestyle changes enabled them to reframe their lives and cope better. Capturing such vital information relating to their life post-treatment and adapting to significant changes to optimise their QoL would not have been possible only from the quantitative findings.

Furthermore, the results of this MPhil study have strengthened existing knowledge in line with *The NHS Long Term Plan* (Alderwick and Dixon 2019) published in January 2019. As QoL is a subjective experience, there is no 'one size fits all' approach to definition and measurement. This plan aims to empower people to manage their care and the impact of their cancer and the plan is to have every patient with cancer access to the recovery package which includes the holistic needs assessment (HNA) checklist of concerns that covers physical, emotional, practical, spiritual and financial issues ensuring each area is addressed and a care plan created for those identified as needing specific support; treatment summary (TS) which is a document produced by the doctor at the end of treatment, cancer care review is carried out by the primary care providers and is based on the HNA and TS and health and wellbeing interventions which include any support in terms of education and programmes that help the patient to transition seamlessly from cancer patient to survivor. This was precisely what the participants in this MPhil study experienced and identified as supportive care needs that needed to be met.

8.9 Study limitations

It is important to address some limitations of this study, which should be considered when interpreting the findings here.

8.9.1 Representativeness of the sample

One of the main limitations of this study is the representativeness of the sample. The sociodemographic characteristics of the participants was not representative of the wider cohort of cancer survivors' living with and beyond cancer. The study is limited by the fact that all the participants were white British and from a single regional area. This means that the findings are not

necessarily inclusive of those from other cultures (Foster 2010). It has been recognised for a long time that despite a greater burden of disease, people from ethnic minority groups are underrepresented in clinical and health research (Redwood and Gill 2013; Gill et al. 2007). If the same study had to take place in a different region in the UK, it is possible to have a more diverse ethnic group covered. This often-unintended exclusion may have implications for clinical practice and research by limiting validity and generalisability.

Participants were recruited from one geographical region. Participants from different geographical regions may have different experiences and thus different unmet supportive care needs. Dorset, in general, is an affluent region. The participants in this MPhil study achieved a higher level of education than expected from a wider population of cancer survivors (ONS 2018; Foster et al. 2015). None of the participants interviewed expressed major financial concerns, which could be partly due to Dorset having a higher proportion of well-off elderly than the national average (ONS 2018; Dorset LEP Strategic Economic Plan 2018). This may not have been the case if another geographical location was sought. However, this study was funded to examine the QoL of survivors treated for a B cell malignancy in Dorset. It was a great idea to do an MMR study.

Furthermore, the method of recruitment means there may have been different perspectives in the community of patients that may have not been included. QoL and unmet supportive care needs may be wide-ranging, which means that the experience of the disease, its treatment and adverse effects may differ across the various B-cell malignancies. This issue must be given due consideration when reviewing the findings of the study.

One important issue is the potential for selection bias among patients who decided to participate in the study. A number of patients - 69 out of 200 approached had refused to participate. Therefore, the response rate for this study was relatively high but still only reached two-thirds (66%) of those invited to participate. Due to time constraints and potential to cause distress, comparison between respondents and non-respondents was not possible. It is possible that non-respondents experience different levels of quality of life, such as lower HRQOL, and this may have influenced the results of the present study. Moreover, one of the problems common in any investigation of QoL in cancer patients, is the inherent sampling bias, in those only patients who have survived their treatment and who are well enough to participate are included in such studies. This may result in conclusions being made on the basis of unrepresentative samples.

Another main limitation related to the sample size in Phase one of the study. The sample size of the participants with myeloma and Chronic lymphocytic leukaemia was too small to draw on some statistical interpretations. It was not possible to make any comparison between the QoL of these groups due to the small numbers of participants.

8.9.2 The study design

Due to the cross-sectional nature of the study, it had not been possible to explore the changes in QoL over time as in longitudinal studies and this study design did not allow for causal inferences. This type of design does not provide a baseline measure from which to evaluate subsequent assessments. This made it challenging to accurately assess the extent to which impairments to QoL had resulted from patients' cancer or resulting treatment rather than from other extraneous factors such as another illness or life event. For instance, if a patient suffered heart disease or arthritis, it would not be possible to detect the extent to which this might have affected his/her QoL independently of his/her cancer or cancer treatment. It is possible that the participants' mental status at the time of completion of questionnaires may have influenced their answers and the EQ-VAS scores. For example, if participants had trouble sleeping at night, or experienced fatigue or pain at the time of completion of questionnaires, this could have hugely influenced the answers. These symptoms may not entirely be related to the illness and its treatment.

Based on the sample of 131participants in the quantitative phase of this research, the number of participants with MM and CLL was relatively small, not allowing for statistically significant comparisons of the QoL among the groups. Those with a diagnosis of any type of lymphoma were predominant in this study population, which may not be representative of the quality of life assessment of the smaller groups (CLL and MM).

In addition, for the qualitative phase of the research, the interview participants included unequal numbers of men and women. The qualitative phase-only consisted of three women. It would have been beneficial if there were a gender balance in the cohort that was interviewed. The results from the qualitative phase may not entirely apply or are generalisable to women too due to the low number of women interviewed. The quantitative phase, however, comprised 60% men. It was interesting, especially that the number of men who volunteered to take part in the study was disproportionate to women. As the qualitative phase of this study only had a small sample of participants, representativeness and generalisability to other populations are not intended. Finally, this being a cross-sectional study, data was only collected at a one-time point.

8.9.3 The study instruments

The QoL questionnaires by the EORTC and the European Quality of Life Group focus predominantly on the symptoms of cancer overall and the side effects of its treatments. Although a set of QoL dimensions may occur in most survivors, the significance of each dimension may vary according to each individual and can change over time (Felce 1997). These questionnaires do not entirely address issues or concerns of survivorship. The questionnaires only gave patients a chance to answer pre-set questions and did not offer an opportunity to offer further explanation or areas they may have felt was missing which could influence their quality of life. From the MPhil thesis, it is clear that the

QoL questionnaires employed were designed to measure short-term QoL and mainly in patients on treatment and the qualitative enquiry, in addition, provided greater insight into the subjective experiences of the participants.

Although these QoL questionnaires provide an overview of QoL in general, they do not provide a great understanding of the different aspects of QoL that may affect patients who have completed treatment for haematological malignancy. As the questionnaires capture the subjective experiences of patients, about their symptoms and functions, they may be interpreted in various ways; pain may be due to malignant disease or another co-morbid condition. Limitations in physical functioning can be attributed to age.

Experiences of living following treatment for haematological malignancy, adjusting to a new way of life, enduring long-term changes and side effects of the malignancy and treatment could not be captured from these questionnaires. It was evident that these questionnaires did not carry relevance to this population of survivors. Alternatively, the EORTC-QLQ-C30 questionnaire does not necessarily differentiate between different cancers. They are highly specific for patients who have completed treatment for haematological malignancy. A validated questionnaire that explores in detail specific issues pertinent to survivors may have been immensely useful, but none was available at the start of the study. These issues warrant further investigation. Another consideration is the multiple significance tests and that differences have been found by chance.

Co-morbidities of the interview participants were captured from their medical notes. It was not feasible to capture the co-morbidities of all participants in the first quantitative phase although that would have been helpful to have that information. Some of the responses to the questions may have been due to the presence of a co-morbidity rather than the illness or treatment side effects. Future studies must collect comorbidities to examine their association with cancer and QoL. However, the validity of self-reported comorbidities may be questionable (Katz et al. 1996; Sridharan et al. 2014).

8.9.4 Patient involvement

Patient and Public Involvement (PPI) has the potential to bring many benefits to research (REF). People affected by cancer may help improve the design and conduct of research work by understanding the realities of cancer and by offering new ideas and perspectives. At the time of writing the MPhil proposal, PPI had not come to the forefront in the way it has in the past decade.

Despite missing out on PPI, this MPhil study has qualitative individual interviews-based element, hence the participants had clear opportunities to put forward their ideas, views, feelings, and perceptions on the topic of survival and anything else they believed to be relevant in this context. In addition, there was a patient representative on the ethics committee when the proposal was being reviewed and approved. On reflection, if I were doing a similar study starting now, I would include

a patient involvement (PPI) early into the design and in the analysis to improve the quality and relevance of my work.

8.10 Validity of the study

In a mixed-methods study it is critical that each approach, - quantitative and qualitative, - meet the validity criteria specific to each data set. I have addressed this within each phase of the study in the thesis. However, Onwuegbuzie and Johnson (2006) argued that mixed methods studies require more than the usual validity check and claim legitimating checks should occur at each stage of the mixed methods process. They list a number of legitimating checks that should occur across the study. I have used this framework for mixed-methods validity, and the results of my appraisal, included in Table 8-2, indicate that the validity has been appropriately addressed ad thought fully considered in the current MPhil study.

Table 8-2 Typology of mixed-methods legitimation- (adapted Onwuegbuzie & Johnson 2006)

Legitimation type	**Description (Onwuegbuzie and Johnson (2006)**	**Description (A mixed methods sequential explanatory study to examine the QoL of haematological cancer survivors)**
Sample integration	The extent to which the relationship between the quantitative and qualitative sampling designs yields quality inferences.	Qualitative sample was drawn from the Phase 1 quantitative sample. The qualitative interview questions were devised from information gathered in quantitative phase.
Weakness minimisation	The extent to which the weakness from one approach is compensated by the strengths from the other approach.	The inherent weaknesses of quantitative data in Phase 1 were counter-balanced by qualitative data in Phase 2. The qualitative data added depth of understanding to quantitative data and helped offset the limitations of analysis due to a relatively small quantitative sample.
Sequential	Extent to which one has minimised the potential problem wherein the inferences could be affected by reversing the sequence of the quantitative and qualitative phases.	The sequential explanatory design in this study was the best approach for exploring this phenomenon. The quantitative phase was used to direct and inform the selection of participants and devise suitable questions to explore in Phase 2.
Paradigmatic mixing	The extent to which researcher's epistemological, ontological, methodological and rhetorical beliefs that underlie the quantitative and qualitative approaches are successfully combined or blended into a usable package.	To fully explore phenomena (QoL in cancer survivors), it is difficult to adopt a singular approach in isolating the quantitative and qualitative data and attempting to assign meaning. It was rather viewed as a continuum and trusted the pragmatic approach applied and the interaction between the quantitative and qualitative approaches to bring out the strengths of each method and hence the overall MPhil study outcomes.
Multiple validities	The extent to which addressing legitimation of the quantitative and qualitative components of the study result from the use of quantitative, qualitative and mixed validity types, resulting in high quality inferences.	In both quantitative and qualitative phases, relevant validity was addressed and achieved. Drawing the quantitative and qualitative threads together allowed for stronger inferences and added to the overall findings. The importance of the individual elements of the study was recognised, however, drawing them together has a synergetic effect.

8.11 Summary

This chapter has discussed findings from this study. The thesis demonstrated the significance of mixing both quantitative and qualitative data within a study to achieve greater meaning and effectiveness in the findings. The sequential, explanation of findings is important as it resulted in a deeper understanding of the QoL of adults who have completed treatment for haematological malignancy, mainly a B cell malignancy. This approach also enabled the identification of unmet supportive care needs in detail by interviewing some of the participants. The findings have been presented in light of current literature and landmark research dating back a few decades when warranted. This sequential, explanatory model has proved vital in the conduct of a mixed-methods study. The qualitative approach providing a comprehensive understanding of the quantitative findings has significantly contributed to an enhanced outcome.

To summarise, this is the first study to examine the QoL of survivors of haematological malignancies, and specifically of B cell malignancies, in England. This study makes it explicit that despite facing many challenges after completing treatment for a B cell malignancy, most people lead a relatively normal life and learn to accept limitations associated with age, their disease, and the effects treatment poses. The following chapter addresses the main strengths and limitations of the study, relevance of the findings to improve practice, implication of the findings for research and shaping healthcare practice.

Despite the limitations imposed by the cross-sectional design, the specific characteristics of the sample and the specific study instruments, important research and practical clinical implications arise from this study. These are further discussed in Chapter 10 Recommendations.

Chapter 9 Conclusion

The thesis aimed to explore the QoL of haematological cancer survivors and identify specific unmet supportive care needs that are relevant to haematological cancer patients via a series of research questions:

1. What is the meaning QoL of survivors of adult haematological malignancies?
2. What is the impact of selected demographic variables on the QoL of survivors of haematological malignancies (e.g., employment, education, living arrangements, gender, and age)?
3. What are the factors that influence that QoL?
4. What are the unmet supportive care needs in adult survivors of a haematological malignancy?

With a growing number of people surviving cancer, there is an increasing need to understand the issues of survivorship. This chapter draws the key conclusions from both the quantitative and qualitative and integration the findings of this thesis. It addresses the strengths and limitations of the study. It also proposes recommendations for future research, education, and clinical practice. This chapter has also provided an opportunity to reflect on the role of the researcher in ensuring good quality research, the positive aspects and challenges encountered while undertaking the research and what worked well and didn't work well. As this MPhil study was conducted in the south of England, this in itself was a limitation (see **Section 8.7**). This particular part of the UK has a relatively high proportion of older people and at the same time it is one of the more prosperous regions in the country.

The quantitative findings showed that men and those in employment who have completed treatment for a haematological malignancy reported better QoL than women in this study. Women reported lower physical functioning, more pain and, less sleep when compared to men. Age had a significant negative correlation with global QoL, physical and role functioning so that the older the participant the greater the impact. Issues such as this need to be addressed when planning long-term survivorship care as it must be tailored to suit individual needs and gender differences. With the gender differences in QoL identified, different clinical approaches are warranted in male and female survivors. These different approaches may enable healthcare providers to provide tailored patient-centred treatment modalities to optimise outcomes and improve QoL.

To provide ongoing support and set up robust systems in the cancer care pathway, it is very important to understand the experiences of these survivors and the possible long-term effects, the malignancy and its treatments entail. Assessment at an early stage will prepare healthcare providers to determine the level of support each patient may require in the survivorship phase. To optimise QoL for these survivors, healthcare services must focus and target the disease and treatment associated sequelae

that may influence a patient in the survivorship phase. Structured survivorship care models can be implemented to further enhance the quality of life of these survivors.

Patients' needs and concerns may change along their cancer spectrum. It is important to utilise assessment tools that report the concerns of survivors and enable conversations with healthcare providers with "care planning," continued communication between primary care physicians and haematologists, access to health and well-being services are recommended as the optimal approach in delivering personalised survivor care. A further validated questionnaire that specifically addresses needs pertinent to survivors of a haematological malignancy is required. These questionnaires will facilitate the capturing of such needs and may enable the development of care models. This study warrants the investigation of a systematic long-term follow-up care model in larger studies. Specific exercise programmes may be developed to improve physical functioning and other related interventions or measures to enhance better sleep and reduce pain. Structured survivorship care models can be implemented to further enhance the quality of life of such survivors. A further validated questionnaire that specifically addresses needs pertinent to survivors of a haematological malignancy is warranted. These questionnaires will facilitate the capturing of such needs and may enable the development of survivorship care models. This study warrants the investigation of a systematic long-term follow-up care model in larger studies.

Health care providers must identify unmet supportive care needs in patients receiving or having completed chemotherapy for haematological malignancies to enhance their quality of life post-treatment. Health Education England (2018) recognises the cancer specialist workforce to grow. Supporting people to live with and beyond cancer is one of their Cancer Taskforce Strategy's four key goals to be delivered by 2021. Health Education England (2018) is committed to improving working practices and introducing new skills and productivity measures. This, in turn, will certainly improve patient outcomes (Oberoi et al. 2017).

9.1 A personal reflexive account

Reflexivity relates to thoughtful, self-awareness of the researcher's experiences, reasoning and overall impact throughout the research process. The qualitative methodology gives primacy to openness, closeness and distance, construction and situating of knowledge, trustworthiness and integrity and ethical dilemmas (Dahlbery et al. 2008; Kvale and Brinkmann 2009). It is the process of conscious self-reflection of social and cultural background, personal and professional experience and assumptions and values that might impact the research process (Hennink et al. 2010). In this thesis, reflexivity is an important element of where the researcher is located from her study and whether this location could have affected the data collection, analysis, or reporting. Apart from the process of self-reflection described in this thesis the researcher was assisted in her reflection through discussions with her three supervisors who has a professional background in (1) nursing, (2)

medicine/haematology, and (3) social sciences/sociology. The supervisions meetings facilitated and supported my reflective approach.

Following the completion of my nursing degree from India, I was employed as a nurse in the field of haemato-oncology in India and pursued a career in clinical research in haematology. I have worked in a few hospitals in the UK. During this time spanning over two decades, I have gained a considerable amount of experience in studying the different haematological malignancies and experiences patients go through. There have been particularly challenging and distressing times when patients have gone through intensive treatment and are experiencing awful side effects. I had developed expertise in a highly specialised field such as haematology oncology nursing and was intrigued to explore the quality of life of these patients' following completion of treatment.

Prior to embarking on a MPhil, I was working as a senior clinical research nurse in the field of haemato-oncology for almost four years. I had completed my master's in advanced nursing and wished to pursue my education further. I was always intrigued to explore the lives of patients who were treated for a haematological malignancy and wondered about their lives following treatment. I have seen many patients in the clinic during this time, many of whom were still alive and some sadly no more. Of the ones who were alive, some of them were cancer-free but with physical limitations, which resulted patients mobilising in wheelchairs most of the time or not being able to function effectively.

It was during this time that I saw an advertisement at Royal Bournemouth Hospital for a haematology research nurse to pursue a MPhil in parallel. I was successful in securing this position and since then worked on my MPhil one day a week for many years. The idea behind this role developed following discussions between the specialists in the cancer services with a concern that there was a huge gap in the service for those patients who were diagnosed and treated for haematological malignancy in the post-treatment phase.

My role as a senior research nurse at the time of the MPhil study entailed working across all three hospitals across Dorset that treated patients with haematological malignancies. Working as a research nurse and having submitted numerous research applications to the institutional review boards enabled the process of submitting my MPhil research application for ethics approval slightly less challenging.

The practice of self-reflection is a key aspect of ensuring quality and rigour in qualitative research (Richardson 2000; Tracey 2010). This attribute contributes to transparency in practice and enables the researcher to further develop their skills and reflect on areas that need improvement.

The researcher plays an active role in the research process. We, the researchers, ask the questions, set the tone of the interview and address questions or issues raised by participants during the interview. To a certain extent, the personal and professional experiences of the researcher and beliefs

would have a certain impact on the interview. It is not possible to remain completely objective throughout the process. Knowledge and interpretation of data are jointly produced through the research-participant dialogue and not just through the collection and analysis of data (Manderson et al. 2006).

Reflexivity suggested that the researcher had a dual role, as both an 'insider' and an 'outsider', during data collection (Roulston 2010). My insider knowledge of issues affecting individuals' undergoing treatment for a malignancy was gained from personal experiences of friends and close family being diagnosed and treated for the same. As a practising nurse, I was deeply aware of the personal struggles and challenges they face while trying to adjust to a diagnosis, treatment and subsequently living with cancer.

As an outsider, being a cancer nurse and having spent many years caring for patients with haematological malignancies, I was able to understand the impact of treatment on the individual and the families and this helped me to deal with, and support, patients in a sensitive manner. As a researcher, it enables an interpretive outlook that aids the exploration of the meaning cancer survivorship. In addition, I had not known any of the research participants prior as I had just started a new role in the three Dorset hospitals and all participants recruited to the study were following treatment completion. Although none of my participants had experience in being interviewed for research before, they agreed to have the interviews recorded.

I am now committed to the importance of reflexivity and reflection as a crucial component of the researcher role (Attia and Edge 2017). Reflexivity is a continual process that assists the researcher to raise their awareness of their role in the research process and vice versa (Mann 2016). To be reflective requires the researcher assume a stance of ongoing questioning or inquisitiveness throughout the entire research process which leads to a greater sense of self-awareness (Usher, Kim & Holmes, Colin 2014) and a deeper level of meaning-making throughout the research process (Haynes 2012).

9.1.1 The dual role of researcher and registered health professional: professional boundaries

I think it is important to be open and honest about my experiences to be reflexive about my role as a practitioner and researcher. Ryan and colleagues (2015) in their paper ask midwifery practitioners engaged in research about ethical dilemmas that may arise. It is important that I acknowledge it as that would be me being honest and true to my work. Although nurses are governed by their professional code of conduct (NMC 2008), their role as a nurse must override their role as a researcher and their duty of care must come first (Rogers 2008; Henry and Chan 2010).

The interview process can be impacted by the beliefs, understanding and views of the researcher. These experiences and views may arise solely from a theoretical or work standpoint. This was not

entirely the case with me. I had two friends and a member of the family affected by cancer before and during my research study.

Firstly, a close friend of mine was diagnosed with acute lymphoblastic leukaemia and sadly died within a year of being diagnosed. There were numerous occasions when I nursed him during his treatment. That was quite a challenging journey and had left a void that cannot be filled. Secondly, an aunt of mine was diagnosed with breast cancer; however, her experiences of cancer and treatment were very different. She is alive with minimal late and long-term effects of the disease and treatments as of this day.

During the latter phase of this study as I was writing up, another close friend of mine was diagnosed with metastatic breast cancer with a very poor prognosis. To this day, she struggles with the side effects of the illness and treatment. She is a young widow with a child. Despite living through life as a widow in a society where a vast majority still view it as a stigma coupled with cancer which was not disclosed too many around her (Harding et al 2019). It was indeed traumatising to watch her go through this.

The above-mentioned experiences undoubtedly had a huge impact on my thoughts and feelings. What I, bring to this research work and the lens through which I view it, are forever bound to my own experiences, thoughts, and feelings. To be fully reflexive, and to be honest about my role as a researcher, it is crucial to acknowledge and be open and honest about my own experience of cancer. To ignore, or disregard this would be, I believe, untrue to my work.

It enabled me to take a completely different perspective and reflect on what the participants had said during the interviews. The above experiences helped me to be more empathetic. It also enabled me to be a good listener and pay attention to the narratives of the interviewees. Some of the participants were very positive and considered their experience of cancer and treatments very positively. I was able to resonate with this, as my friend remained extremely and consistently positive too. She wanted to overcome this hurdle for the sake of her son, as she was his only living parent. I was also able to reflect on some of the feelings that the participants talked about; unfairness, fear, the uncertainty of the future, developing a positive outlook towards life, gratitude and related this to my friend's situation.

9.1.2 Interviewer – participant relationship

The participants were generally very positive and willing to take part in the study. I was able to forge positive relationships with them. In qualitative research, it is important to forge relationships with participants and this was the case in my fieldwork in this study. The resilience experienced by the survivors was a true inspiration to me during the interview process. In a study by Derrett and Colhoun (2011), interviewers were able to enhance positive relationships and share positive aspects of conducting interviews with their patients on a longitudinal study. I was able to establish a similarly

good rapport sooner and therefore there was a connection made by the time the interviews ended. The quality of this connectivity depends on the researcher's ability to pay close attention to signals exhibited in terms of thoughts, actions, feelings, and words. Words alone are not completely capable of describing patients' experiences (Ronsholdt et al. 2013).

Qualitative research has long recognised the significance of the relationship between an interviewer and participants in a study (Broom et al. 2009; Derrett and Colhoun 2011) and this was the case in this fieldwork. The nature of relationships between an interviewer and participant is pivotal in the whole process of conducting qualitative interviews. The interviewer is hugely responsible for the outcome of the data collection (Simon et al. 2006; O'Brien et al. 2006; Derrett and Colhoun 2011).

The effectiveness of an interview dialogue results from the ability of the researcher to achieve connectivity. This is characterised by insight, compassion and understanding of a participant's experience of their situation, intentions and statements and the researcher's reflections of the dialogue, approach to the topic and participant (Jacobs et al. 2017).

9.1.3 Discussing sex

The gender dynamic between interviewer and interviewee is pertinent when it comes to discussions around sex. One of the biggest challenges for interviewers when discussing sex is to create a favourable environment that enables participants to have frank disclosures about their sex life (Maleki et al. 2021). The topic of sex is not something most people would feel comfortable doing or will do spontaneously in an interview setting. Disclosing of highly intimate and sensitive information can be challenging. It could be argued that this is particularly true to this study cohort, given their age. Conversations about sex from a young age with the current generation may be normal and accepted. For older adults, their view on sex, sex education and access to sexual stimuli may be very different.

Although I have had discussions around sex with my patients as part of my work, it was usually initiated by the patients in a particular context. This was the first time, I had to voluntarily bring about the topic of sex with my participants. Although I was slightly uncomfortable raising this in my last question section of the interviews, I was aware that I must approach it the right way so as not to make them feel uncomfortable or become embarrassed. Most of the participants were able to laugh and make a joke about their sex life, with some commenting that they don't even remember what that was. This somewhat eased and minimised any tension in the room.

Although it is important in qualitative work to build rapport and trust with a participant, it is equally important, I believe as a researcher to push beyond the surface conversation and explore issues which may not be easier to talk about or discuss in a casual manner. However, with practice making perfect, I gathered that with the third interview, I was learning to tackle the situation better and able to have discussions with ease which also made the participants comfortable. I feel further probing into sexual

function could have been done. This could have offered further insights into identity changes as a result of cancer and its treatment, and perhaps the relationship between port traumatic growth, identity shift and QoL.

9.1.4 Dealing exclusively with the participant during interviews

This posed a slight challenge while undertaking some of the interviews. On some occasions, the partner or spouse would sit in with the participant and add to the answers. This, I had observed made some participants slightly uncomfortable. It also made me reflect on the authenticity of the data collected as the answers may have been influenced by the family member seated beside them, even when they sat quietly beside the participant and did not actively participate in the interviews. Participants could have given mixed responses to the researcher in the presence of a family member. This is also found in the literature (Derrett and Colhoun 2011; O'Brien et al. 2006) whereby the participants would have been uncomfortable in talking about some of their experiences especially if the information disclosed was sensitive.

9.1.5 What I might have done differently

Comorbidities: They may have a significant impact on the QoL in long term cancer survivors. Studies in colorectal cancer survivors (Cummings et al. 2018) and breast cancer survivors (Scoormans et al. 2015) have found that comorbidities were correlated with a decrease in QoL. QoL was found to decrease overtime despite the comorbidities remaining constant. It was not possible to capture the comorbidity data on all participants during Phase 1 of this MPhil study. If I were to repeat this study, I would endeavour to streamline a process of capturing comorbidities for those who participate in the quantitative phase and also on those who decline to participate in the study. The reasons for non-participation are informative for future research.

Gender distribution: This MPhil study had recruited more male than female participants. If I were to conduct a similar study again, I would try to ensure that there is a more equal representation of both genders in the study cohort. I would try get PPI involvement early on to get patients' views on how to appeal to and recruit more female participants.

Long-term cancer survivorship*:* It is evident that QoL continues to be significantly impacted in long term cancer survivorship (Firkins et al. 2020; Thong et al. 2019). If I was to repeat this study, I would endeavour to spend time exploring the QoL and the impact of treatments on the different haematological malignancies over a period of time. To improve the QoL and experience of patients with cancer, a deeper understanding of the long-term impact of cancer on these survivors is vital (Firkins et al. 2020).

9.2 Key contributions

The study findings add an important consideration to research into haematological cancer survivors. This research is original for the following reasons:

- The study was representative of an ageing population with haematological malignancies of the whole of the UK.
- This study was the first of its kind to be undertaken in a population of people who had completed treatments for haematological malignancies in Dorset.
- This study contributes and adds value to the methodological advancements of MMR. The research study has created a better understanding of both MMR and QoL research.
- The data from the qualitative phase provides a detailed description of the reasons behind participants' symptoms and lived experiences with haematological cancer survivorship.

In light of these key contributions, the next chapter offers recommendations for clinical practice, research and education.

9.3 Conclusions in the context of living with and beyond cancer

Living with and beyond cancer has become a key topic of interest in cancer experience research (Cavers et al. 2020). It is evident that the rise in survival rates is largely due to the increase in improved treatment modalities and improvement of targeted treatments such as immunotherapy which has resulted in increased life expectancy of cancer patients (Foster et al. 2018). This coupled with early detection and varied treatment options will result in the number of long-term cancer survivors world-wide (Firkins et al. 2020). Cancer survival is embedded in the context of an ageing society, with the number of UK residents over 65 predicted to rise to 26% of the total population by 2041, compared with 15.8% in 1991. Therefore, more people are living with and beyond cancer (ONS 2018). These people experience a range of health and social care needs which are often complicated by comorbid conditions (Harrison et al. 2011: Corner et al. 2013). As a result, this poses challenges to the already stretched healthcare system in the UK. As the number of cancer survivors continues to grow, QOL will continue to be a key concern in understanding the long-term impact of cancer and its treatment on survivors.

A growing body of research is being developed around the psychosocial needs of those living with and beyond cancer (Harrison et al. 2011; Adams et al. 2012; Watson et al. 2011; O'Brien et al. 2011). The findings of this MPhil study clearly align with the top ten priorities of the NCRI (National Cancer Research Institute) Living With and Beyond Cancer Research Initiative (https://www.ncri.org.uk/lwbc/#lwbc_questions) and the James Lind Alliance (www.jameslindalliance.co.uk) who have taken significant efforts in setting research priorities in these areas. Improved coordination of care for people with complex health needs was identified as

priority number three of the initiative. This was one of the major findings of this MPhil study where cancer survivors expressed the need for better care coordination in the post treatment phase.

Throughout my time as a MPhil candidate, I have attended and presented at many conferences within the UK and abroad. I was a recipient of the Winston Churchill Travel Fellowship, which enabled me to study survivorship care models in well-established cancer centres in Australia and Canada. A fellowship received through Santander Bank also enabled me to carry out the same observation at the Yale Cancer Survivorship Clinic. I have also submitted and published the following with my supervisors (**see Appendices 17 and 18**).

Publication:

Table 9-1: Declaration by candidate

Thesis	Article	Impact factor	Publication details	Author contributions
Findings: Quantitative results	Quality of life of survivors of adult haematological malignancy	2.421	Published European Journal of Cancer Care	Dr J Hunt Prof E van Teijlingen Dr H McCarthy Dr Z Sheppard

Chapter 10 Recommendations

This thesis aimed to explore the QoL and identify specific unmet supportive care needs that are most pertinent to patients who have been treated for haematological malignancies. This final chapter will bring together these findings, explore how they may add value to national initiatives, and affect clinical practice, future research, and education.

When some of the participants who did not return the QoL questionnaires were contacted by phone, they stated that they were either unwell or were not interested. It was not possible to contact some of the others over the phone to clarify reasons for non-participation in the study. Valuable information could have been gathered from the non-respondents as they may have had other underlying causes that stopped them from participating in the study. Some participants who provided valuable information on the questionnaires refused to take part in the qualitative interviews as they were not mentally prepared or physically able to sit through an interview. It would have been beneficial to explore the QoL of these non-participating survivors to identify and address any unmet supportive care needs. However, there was no time available nor were there resources to add this aspect to the MPhil study.

Another limitation was that the sample size in the qualitative phase was small. This may limit the generalisability of the study but the aim of qualitative research is not to seek representativeness of data but to highlight any phenomena or issue that the survivors may express relating to the quality of lives post treatment. The participants were interviewed only once. Repeated interviews at specific time points in the survivorship phase would have better highlighted issues and unmet needs over a period of time. Again, there was no time nor were there resources available to add such longer-term aspect to the qualitative phase of the study.

10.1 Implications for clinical practice

The findings of this study, from a clinical perspective, provide valuable information for both healthcare providers and future patients who have survived haematological malignancies. With advances in treatment and improved survival rates, it is evident that patients are living longer than in the recent past, and this increase in these figures is only predicted to rise (Maddams et al. 2012). Consequently, cancer overall is being increasingly recognised, especially in high-income countries such as the UK, as a long-term condition rather than an acute one. Therefore, it is pivotal that the supportive care needs of these cancer survivors are addressed over a period prospectively rather than just in the acute treatment and recovery phase.

As discussed in **Section 7. 3**, this MPhil study has shown that survivors of a haematological malignancy experience problems with their physical well-being; psychological well-being and long-term supportive care needs that are challenging to deal with in the post-treatment phase. Whilst QoL questionnaires such as the EORTC-QLQ-C30 and EQ-5D-3L capture vital information during and

immediately after treatment, the contents of these questionnaires are not entirely suitable or relevant for survivors. They do not provide valuable and relevant information on the long-term needs of cancer survivors. In my role as a nurse researcher, I am aware that there is yet to be a validated survivorship questionnaire to be developed for patients who have completed treatment for haematological malignancies. It is recommended that we have one to precisely capture issues related to survivors and their QoL.

The key findings from the quantitative phase of this study (see Section 6.3) found that increasing age, unemployment, being a woman and reduced physical activity were associated with reduced QoL. A high proportion of participants in this MPhil study reported problems with mobility (35.4%), usual activities (35.9%) and pain/discomfort (38.5%). This, in turn, may cause emotional and psychological distress with some undergoing significant personal and cognitive changes following completion of all treatments for a B cell malignancy.

To address the above problems, it is important to provide ongoing appropriate support and set up robust systems in the cancer care continuum. It is pertinent that health care providers understand the experiences of these survivors, the possible long-term effects of the malignancy, and what its treatment entails. Educating healthcare professionals in their undergraduate degrees to identify and address late effects, much earlier on in the treatment phase, will enable them to make better clinical decisions, provide optimal support and offer help appropriately in the post-treatment phase. This help and support could then be tailored to suit individual patients' needs.

Tailoring self-management to individual needs will enhance engagement of patients in achieving their goals. This, in turn, will enable patients to be prepared from the early stages of their survivorship journey at the outset of treatment, alleviate a lot of their anxieties and distress, and address many of the uncertainties. Tailored self- management programmes would benefit the survivors and the health care system in reducing the burden in terms of cost and other resources. Assessment of potential supportive care needs at an early stage will prepare health care providers to tailor the individual the level of support each patient may require in the survivorship phase. Enhanced and continued communication between the clinicians and general practitioners may make the transition from being an active patient to a survivor seamless for patients.

It is important to understand where patients' expectations of needs to be addressed lie and where improvement to service provision can make that difference and meet the need to optimise outcomes and QoL. This MPhil study identified three major unmet supportive care needs: (1) a strong desire for participants to maintain contact with health care providers, (2) fear of disease recurrence and, (3) uncertainty about the future (**Section 7.3.4**). Understanding these unmet needs of cancer survivors is essential to inform health service planning and optimise cancer survivorship care. One of the important messages from these results was mental framing. Many of the participants were able to cope with the distressing side effects of the malignancy and its treatment by keeping a positive

outlook and attitude and adapting to its long-term impacts. The above findings provide vital information for areas of improvement in the supportive care services and tailored survivorship care for this heterogeneous group of cancer survivors. Providing targeted education and tailored cancer survivorship services to survivors is crucial to optimise their quality of life. The tailored follow-up care will enable the identification of patients who need frequent contact from healthcare providers and this pathway may make the transition from an active treatment phase to the survivorship phase seamless.

Service providers can generate local information by routinely assessing the unmet needs of their patients. This can result in the development of recommendations regarding optimising the allocation and delivery of health care resources (Asadi-Lari et al. 2004). It is advisable to encourage healthcare providers to routinely assess supportive care needs and QoL comprehensively for patients during and after treatment to provide a timely response to their needs and enhance their QoL.

This study offers a strong base for the development of interventions to address individuals' specific unmet supportive care needs. This study demonstrates the importance of timely rendering of support services to enhance the physical and psychological wellbeing of the survivors, which will help them in adjusting to a new phase in their life. The definition of cancer survivorship has been extended from the time of diagnosis and now predominantly emphasises the post-treatment phase (Hewitt et al. 2006). This is because cancer survivors may experience a range of late and long-term side effects of the illness and treatment, which may have a huge impact on their QoL (McCabe et al. 2013; Ness et al. 2013). Therefore, support services could be initiated towards the end of the treatment phase to make the transition to the post-treatment phase seamless. The reported QOL was better in the results of this thesis for patients beyond two-and-half-years post-treatment. There is now a move nationally for early discharge from follow up at two years for example for high-grade lymphomas.

Certain issues may arise when patients have been treated intensively in an outpatient unit to then going onto three monthly routine clinical follow up. This long-term adjustment process will certainly ensure a better QoL. There are several resources in Dorset-Dorset Community Transport and nationally Maggie's cancer services could link in with the cancer charities to optimise available support. This difference may enable health care providers to tailor interventions according to individual patients to enhance their QoL.

To address the above, a workable survivorship care pathway could be defined to enable patients to transition from the haematology service to the survivorship service. A survivorship clinic embedded within the oncology services could be set up to address the late and lingering effects of the illness and treatment. This could be achieved by an individualised survivorship care plan to optimise the health and wellbeing of survivors through health education, integrative therapies etc. Such a programme can be run successfully only when there is institutional support, strong leadership and a model that would suit the population the hospital serves. It is important to have a dedicated team of

haematologists, primary care physicians, specialist nurses, coordinators, psychologists, integrative therapists to enable the smooth running of the programme. For such a programme to be successful, it is important to instil confidence in patients that it could be easily accessible and for haematologists to transfer patients to this programme seamlessly. Haematologists also should be assured of the quality of the programme whereby patients will be under strict surveillance and have access to integrative therapies to minimise symptom burden.

The findings from this study could also add value to initiatives such as the Living with and beyond cancer programme run in collaboration between NHS England and Macmillan Cancer Support (2014). These findings would certainly complement and provide evidence for the ongoing needs of cancer survivors alongside the above-mentioned initiatives.

10.2 Implications for research

Findings from this study suggest that further research is required. Research into how individuals and families adapt successfully to the diagnosis and treatment of a haematological malignancy is crucial. Further research is required to be undertaken to determine effective strategies to optimise QoL in such survivors.

First, enhancing the sample size would prove beneficial to be undertaken as the sample size was representative of three haematology cancer treatment centres in Dorset, UK. Secondly, service providers may vary between centres in other locations and other parts of the country. The larger sample size for the quantitative phase would have been more beneficial to produce statistically significant results between participants with different haematological malignancies. The larger sample size would have enabled to accommodate other acute haematological malignancies and patients who have undergone peripheral stem cell transplantations, as patient outcomes may be different for these different groups hence resulting in the assessment of different unmet supportive care needs too.

Treatment modalities may have a significant impact on long-term QOL in cancer survivorship and should be further studied (Firkins et al. 2020). It is important to consider the impact of treatment modalities on long-term QoL in cancer survivors and these individuals are living longer due to the availability of more treatment options. It would be immensely useful to undertake a longitudinal study with the same sample that was collected for this MPhil study. Being able to compare results over time would allow us to have a more definitive idea about the impact of haematological malignancies and their treatments on these adults. Particularly taking into account the demographics of the population, it would be useful to explore the changes in health and attitudes over time for older adults using longitudinal studies.

As discussed in **Section 2.4**, patients treated for B-cell malignancies may experience late and long-term effects of the illness and its treatments (Moore 2014; Hess et al. 2011). Over a period as people

get older, some of the effects of treatment may become more distressing and affect their ability to cope with daily living. Being able to compare results over the years would allow a comparison overtime that could give a more definitive idea of the impact cancer has on older adults, particularly as health and attitudes change over time, along with the outcomes of cancer.

This study has identified and highlighted specific unmet supportive care needs in survivors of B cell malignancies such as loss of continued contact with health care providers, fear of disease recurrence and uncertainty about the future. Further research is needed to determine the prevalence of unmet supportive care needs, which are specific to this group of survivors. Survivors of haematological malignancies have common, ongoing unmet supportive care needs that are yet to be addressed. While unmet supportive care needs relating to physical matters or the burden of disease may decrease over time or following treatment completion, the emotional burden of the disease and the uncertainty of the future and fear of disease recurrence remain.

Currently, not all survivors of haematological malignancies receive continuous support that is appropriate to address their supportive care needs from the hospital they have received treatment from. However, not all patients would desire to receive ongoing support, but for those who require them or express a need to receive such support, it would be beneficial to formalise post-treatment care and receive input from experienced healthcare providers.

In order to understand differences in QoL and associated factors, it is important to undertake a similar study with a large quantitative sample to undertake further analysis especially to explore the differences in QoL and the factors that contribute to a better/poorer QoL amongst the different groups such as MM, CLL and lymphomas. Very few mixed methods studies have been conducted in the field of QoL in haematological cancer survivors. Further mixed methods study on a larger scale in a diverse population will be highly recommended in the area of QoL in haematological cancer survivors. Studying some of the less common haematological malignancies and the cancer-related events on an international collaboration would facilitate increased power (Rowland et al. 2013).

This study identified positive life changes that were common among participants that included trying to keep fit, adopting healthy lifestyles, having a positive outlook towards life, developing a sense of gratitude, demonstrating an act of kindness, enhanced relationships with family and friends. Participants tried to exercise and perform small chores around the house and garden to keep themselves fit. Enhanced physical functioning is also known to improve psychosocial outcomes in cancer survivors by relieving stress/anxiety symptoms (Ilie et al. 2019). Royal Bournemouth Hospital has established a tailored exercise programme for cancer survivors following completion of treatment called BACSUP (Bournemouth after cancer survivorship exercise programme) which has demonstrated positive outcomes for patients who took part in it. Such a tailored exercise programme could be rolled out to the rest of Dorset to optimise outcomes and improve QoL.

Integrative oncology, a combination of conventional oncology along with evidenced-based complementary treatment approaches, is an emerging field (Cramer et al. 2013; Dobos et al. 2013; Dobos et al. 2012). Mind-Body Medicine, an important category of complementary and alternative medicine interventions, is defined as "practices that focus on the interactions among the brain, mind, body, and behaviour, with the intent to use the mind to affect physical functioning and promote health" (NCCAM 2019). This includes lifestyle topics to enhance a person's capacity for self-care, such as exercise, nutrition, relaxation, and self-help strategies (NCCAM 2019). Previous work has demonstrated that mindfulness-based interventions in cancer survivors have improved QoL, mental health and cancer-related symptoms (Dobos et al. 2015; Bussing et al. 2009). Such interventions could be incorporated into the survivorship programme for cancer survivors.

It is vital that funding is streamlined nationally into cancer survivorship research. This is of particular importance due to the growing number of cancer survivors, the increase in the developments of treatments and the lack of QoL measures for surviving cancer patients. It is important to research a collaborative partnership with the involvement of key stakeholders to establish robust pathways and also undertake population-based observational studies in an unselected group of patients (Lagergren et al. 2019).

Further longitudinal studies are needed to clarify how patients treated with chemo and chemo immunotherapy for haematological malignancies experience impact on their sexuality, body image and HRQoL. More knowledge is also needed to explore how these concepts relate to and influence on each other. Multicentre studies are needed in order to obtain a sufficient number of patients. Studies focusing on sexual relationship are needed from both patients' and partners' perspective in order to identify the need for support. More research is needed in order to explore the impact and potential moderators of long-term cancer survivorship on QOL. It is crucial in implementing a collaborative, multidisciplinary methods approach in exploring long term survivorship care.

10.3 Implications for education

The National Health Service (NHS) is paving the way in recognising QoL outcomes in cancer care as important to that of survival (NHS England 2019). Given the current context of healthcare in the National Health Service in England, the development of novel approaches and pathways to focus on the care of cancer patients in the post-treatment phase may optimise outcomes. This will certainly improve the QoL of the survivors ensuring quality and cost-effectiveness for the future. There is a massive trend for early discharge from oncology/haematology clinics- but that aligns well with a strategy to optimise "living well with cancer". Rather than follow up patients with haematology consultants, patients could go into a "cancer survivorship pathway which includes a tailored exercise programme, mindfulness, support group meetings and late effects clinics. This strategy links in with the tailored cancer survivorship programme embedded within the oncology/haematology clinical service proposed in **Section 10.1**.

Major themes around physical wellbeing, psychological wellbeing and maintaining independence emerged from the qualitative findings. Loss of continuing connection with health care professionals in the post-treatment phase, fear of disease recurrence and uncertainty about the future emerged as major unmet supportive needs in this phase of the study.

Finally, the study demonstrated the effectiveness of choosing a mixed-methods approach in studying a complex phenomenon such as QoL and identifying unmet supportive care needs in a cohort of patients who have completed treatment for a B cell malignancy. This study overall has provided useful and significant information on the QoL of haematological cancer survivors and unmet supportive care needs that persist in the post-treatment phase. It has brought to our attention the importance of enhancing the QoL of those diagnosed and treated for haematological malignancy. It has highlighted the implications a haematological malignancy and its treatment can have on an individual. The study findings add to the growing literature on Quality of life and survivorship and unmet supportive care needs in a haematological malignancy setting. Intervention studies evaluating education and training in communication for nurses are needed to develop their skills in communicating sensitive issues.

10.4 Summary of thesis

Cancer survivorship is a complex and multi-faceted experience that one study cannot hope but simply touch upon the challenges that cancer survivor's experience. The study aimed to examine the QoL of people who had completed treatment for a B cell malignancy and identify unmet supportive care needs. The thesis presented a review of the literature with historical data, which is important as it highlights the paucity of literature in survivorship research and how survivorship care and research has gained significant importance.

A detailed account of the methodology of the study has been presented including the specifics of the quantitative and qualitative phases of the study. To maximise the data collected and to provide a complete picture of the experience of the QoL of survivors of a B cell malignancy and identify unmet supportive care needs, the mixed-methods sequential explanatory design was selected as it deemed to be the most appropriate way to conduct the study.

The qualitative phase of the study helped answer questions that arose from the quantitative phase. The findings from the quantitative phase enabled us to disentangle some of the questions and issues around unmet supportive care needs following treatment completion for a B cell malignancy. Most importantly, the study demonstrated that although patients with haematological malignancies undergo treatments and are left with debilitating symptoms, which may disrupt their day-to-day life, there was a lot of positivity found in those patients. Despite negative experiences, they were able to find strength and positivity in overcoming these experiences.

With the continued increase in early detection and cancer treatment modalities, the number of long-term cancer survivors will continue to increase worldwide. With this steady rise in the number of cancer survivors, QoL will continue to be a key concern in understanding the long-term impact of cancer and its treatment on survivors. More research is needed in order to explore the impact and potential arbitrators of long-term cancer survivorship on QoL.

This study, in conclusion, has demonstrated that the survivors of a haematological malignancy have a broad range of experiences and challenges. These individuals, despite presenting with certain unmet supportive care needs, coping with the symptoms and illness, remaining positive, developing coping strategies remain far more significant. As QoL is a subjective experience, not a single approach would suit all. With this in mind, it is pertinent that healthcare providers, researchers and policymakers understand the varied meaning and be clear about the purpose of QoL measures in survivors. In addition, effective collaboration with cancer survivors for developing efficient support systems related to survivorship will be of greater importance (Takahashi 2016).

References

Aaronson, N.K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A. and Duez, N.J., 1993.The European Organisation for Research and Treatment of Cancer QLQC30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute,* 85, 365-376.

Aaronson, N.K., Cull, A., Kaasa, S., Sprangers, M.A.,1996. The European Organization for Research and Treatment of Cancer (EORTC) modular approach to quality of life assessment in oncology: an update.Spilker B.Quality of Life and Pharmacoeconomics in Clinical Trials.Lippincott Williams & Wilkins Philadelphia:

Aaronson, N.K., Ahmedzai, S., Bullinger, M., et. al. 1991.The EORTC Core Quality-of-Life Questionnaire: interim results of an international field study.Osoba D.Effect of Cancer on Quality of Life.CRC Press, Inc.Boca Raton, FL:

Abratt, R.P., Morgan, G.W., Silvestri, G., Willcox, P., 2004. Pulmonary complications of radiation therapy. *Clinics in Chest Medicine,* 25 (1), 167-177.

Adam, S., van de Poll-Franse, L. V., Mols, F., Ezendam, N. P. M., de Hingh, I. H. J. T., Arndt, V. and Thong, M. S. Y., 2019. The association of cancer-related fatigue with all-cause mortality of colorectal and endometrial cancer survivors: Results from the population-based PROFILES registry. *Cancer Medicine,* 8(6), 3227-3236.

Adams, E., Boulton, M., Rose, P.W., Lund, S., Richardson, A., Wilson, S., 2012. A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. *Supportive Care in Cancer,* 20 (11), 2785–94.

Ahn, E., Cho, J. and Shin, D.W., 2009. Impact of breast cancer diagnosis and treatment on work-related life and factors affecting them. *Breast Cancer Research and Treatment,* 116 (3), 609–616.

Alderwick, H. and Dixon, J., 2019. The NHS long term plan. *British Medical Journal*, 364, l84. doi:10.1136/bmj.l84.

Aleman, B. M. and van Leeuwen, F. E., 2007. Are we improving the long-term burden of Hodgkin's lymphoma patients with modern treatment? Haematology/Oncology Clinics of North America, 21(5), 961–975.

Al-Janabi, H., Flynn, T, N. and Coast, J., 2012. Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Quality of Life Research*, 21:167–176. doi: 10.1007/s11136-011-9927-2.

Allart-Vorelli, P., Porro, B., Baguet, F., Michel, A. and Cousson-Gélie, F., 2015. Haematological cancer and quality of life: a systematic literature review. *Blood Cancer Journal*, 305.

Albini, A., Pennesi, G., Donatelli, F., Cammarota, R., De Flora, S. and Noonan, D. M., 2010. Cardiotoxicity of anticancer drugs: the need for cardio-oncology and cardio-oncological prevention. *Journal Of The National Cancer Institute* [online], 102 (1), 14-25.

American Cancer Society. Cancer Facts and Figures 2012. Atlanta, Georgia: American Cancer Society Inc.

Andrew, S. and Halcombe, E., 2008. Mixed method research. In S, Borbasi, D, Jackson and R, Langford(Eds), Navigating the maze of nursing research: An interactive learning adventure (2nd ed.).Chatswood: Elsevier.

Anon., 2005. Research Governance Framework for Health and Social Care. *Therapy Today*, 16 (8), 44-44.

Anon., 2006. Cancer Control. [electronic resource] : knowledge into action : WHO guide for effective programmes [Bibliographies Non-fiction Computer File]. World Health Organization.

Anon., 2011. Review: Paperbacks: Non-fiction: The Emperor of All Maladies, by Siddhartha Mukherjee. [Book review]. Available from: https://search-ebscohost-com.libezproxy.bournemouth.ac.uk/login.aspx?direct=true&db=edsgin&AN=edsgcl.269029705&site=eds-live&scope=site [Accessed 1 July 2019]

Appleton, L. and Flynn, M., 2014. Searching for the new normal: Exploring the role of language and metaphors in becoming a cancer survivor. *European Journal of Oncology Nursing* [online], 18 (4), 378-384.

Archer, S., Holch, P., Armes, J., Calman, L., Foster, C., Gelcich, S., MacLennan, S. J., & Absolom, K. (2020). "No turning back" Psycho-oncology in the time of COVID-19: Insights from a survey of UK professionals. *Psycho-Oncology*, 29, 1430–1435. https://doi.org/10.1002/pon.5486

Armes, J., Crowe, M., Colbourne, L., Morhan, H., Murrells, T., Oakley, C., Palmer, N., Ream, E., Young, A. and Richardson, A., 2009. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172 – 6179.

Arndt, V., Koch-Gallenkamp, L., Jansen, L., Bertram, H., Eberle, A., Holleczek, B., Schmid-Höpfner, S., Waldmann, A., Zeissig, S.R. and Brenner, H., 2017. Quality of life in long-term and very long-term cancer survivors versus population controls in Germany. *Acta Oncologica*, 56 (2), 190-197.

Asadi-Lari, M., Marcello Tamburini, M. and Gray, D., 2004. Patients' needs, satisfaction and health related quality of life: Towards a comprehensive model. *Health and Quality of Life Outcomes*, (2), 32.

Aziz, N. M., 2007. Cancer survivorship research: State of knowledge, challenges and opportunities, 417.

Aziz, N.M. and Rowland, J. H., 2003.Trends and advances in cancer survivorship research: challenge and opportunity. *Seminars in Radiation Oncology*,13, 248 –66.

Balducci, L. and Extermann, M., 2000. Management of the frail person with advanced cancer. *Critical Reviews in Oncology/Hematology* [online], 33 (2), 143-148.

Bantema-Joppe, E. J., de Bock, G. H., Woltman-van Iersel, M., Busz, D. M., Ranchor, A. V., Langendijk, J. A., Maduro, J. H. and van den Heuvel, E. R., 2015. The impact of age on changes in quality of life among breast cancer survivors treated with breast-conserving surgery and radiotherapy, *British Journal of Cancer*, 112 (4),636-643.

Barchard, K. A. and Verenikina, Y., 2013. Improving data accuracy: Selecting the best data checking technique. *Computers in Human Behaviour*, 29 (5), 1917–1922.

Barlow, J., Bancroft, G. and Turner, A., 2005. Self-management training for people with chronic disease: a shared learning experience. *Journal of Health Psychology*, 10(6), 863–72.

Basch, E., Deal, A.M. and Dueck, A.C., 2017. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *The Journal of the American Medical Association*, 318,197-198.

Bastalich, W., 2017. Content and context in knowledge production: A critical review of doctoral supervision literature. *Studies in Higher Education*, 42(7), 1145–1157.

Beckjord, E. B., Arora, N. K., McLaughlin, W., Oakley-Girvan, I., Hamilton, A. S. and Hesse, B. W., 2008. Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *Journal of Cancer Survivorship*, 2 (3), 179-189.

Behringer,K.,Breuer,K.,Reineke,T.,May,M.,Nogova,L.andKlimm,B.,2005. Secondaryamenorrhea after Hodgkin's lymphoma is influenced by age at treatment, stage of disease, chemotherapy regimen, and the use of oral contraceptives during therapy:a report from the German Hodgkin's lymphoma study group. *Journal of Clinical Oncology*, 23, 7555-7564.

Bhakta, N., Liu, Q., Yeo, F., Baassiri, M., Ehrhard,t M.J., Srivastava, D.K. 2016. Cumulativeburden of cardiovascular morbidity in paediatric, adolescent, and young adultsurvivors of Hodgkin's lymphoma: an analysis from the St Jude lifetime CohortStudy. *Lancet Oncology*,17,1325-1334.

Bjordal, K. and Kaasa, S.,1992. Psychometric validation of the EORTC Core Quality of Life Questionnaire, 30-item version and a diagnosis-specific module for head and neck cancer patients. *Acta Oncolgica*, 31, 311-321.

Bloomfield, C. D., Marcucci, G., Dohner, K. and Dohner, H., 2008. Introduction: Acute Myeloid Leukemia, 324.

Boland, E., Eiser, C., Ezaydi, Y., Greenfield, D. M., Ahmedzai, S. H. and Snowden, J. A., 2013. Living with advanced but stable multiple myeloma: a study of the symptom burden and cumulative effects of disease and intensive (hematopoietic stem cell transplant-based) treatment on health-related quality of life. *Journal Of Pain And Symptom Management*, 46 (5), 671-680.

Borchert, K., Jacob, C., Wetzel, N., Jänicke, M., Eggers, E., Sauer, A., Marschner, N., Altevers, .J, Mittendorf, T. and Greiner, W., 2020. Application study of the EQ-5D-5L in oncology: linking self-reported quality of life of patients with advanced or metastatic colorectal cancer to clinical data from a German tumor registry. *Health Economics Reviews*, 10(1),40. https://doi.org/10.1186/s13561-020-00297-6

Bottomley, A., 2002. The cancer patient and quality of life. *The Oncologist*,7(2):120-125.

Boynton, P.M., Wood, G.W. and Greenhalgh, T., 2004. A hands-on guide to questionnaire research: reaching beyond the white middle classes. *British Medical Journal*, 328, 1433.

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.

Braun, V. and Clarke, V., 2013. *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage.

Brazier, J, Ratcliffe J., Salomon, J. and Tsuchiya, A., 2007. Measuring and Valuing Health Benefits for Economic Evaluation (ed) Oxford: Oxford University Press.

Breadon, K., 1997. Cancer and beyond: the question of survivorship. *Journal of Advanced Nursing*, 26 (5), 978-984.

Brenner, H., Bouvier, A. M., Foschi, R., Hackl, M., Larsen, I. K., Lemmens, V., Mangone, L. and Francisci, S., 2012. Progress in colorectal cancer survival in Europe from the late 1980s to the early 21st century: the EUROCARE study. *International Journal Of Cancer* [online], 131(7), 1649-1658.

Bressan, V., Bagnasco, A., Aleo, G., Timmins, F., Barisone, M., Bianchi, M., Pellegrini, R., and Sasso, L., 2016. Mixed-methods research in nursing – A critical review. *Journal of Clinical Nursing*, 26, 2878–2890.

Brown, P.J. and Roose, S.P., 2011. Age and anxiety and depressive symptoms: The effect on domains of quality of life. *International Journal of Geriatric Psychiatry*, 26,1260–1266.

Broom, A., Hand, K. and Tovey, P., 2009. The role of gender, environment and individual biography in shaping qualitative interview data. *International Journal of Social Research Methodology*, 12(1), 51-65.

Bryers, M.H., van Teijlingen, E. and Pitchforth, E., 2014. Advocating mixed-methods approaches in health research. *Nepal Journal of Epidemiology*, 4(5), 417- 422.

Bucholz, E.M., Strait, K.M, Dreyer, R.P., Geda, M., Spatz, E.S., Bueno, H. and Krumholz, H.M., 2014. Effect of low perceived social support on health outcomes in young patients with acute myocardial infarction: Results from the VIRGO (Variation in Recovery: Role of Gender on Outcomes of Young AMI Patients) Study. *Journal of American Heart Association*, 3 DOI: 10.1161/JAHA114.001252. e00 1252.

Bull, S. and Lindegger, G.C., 2011. Ensuring consent to research is voluntary: how far do we need to go? *American Journal of Bioethics*, 11(8), 27–29.

Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M. and Ramirez, A., 2005. Depression and anxiety in women with early breast cancer: a five-year observational cohort study, *British Medical Journal*, 330 (7493), 702. doi: 10.1136/bmj.38343.670868702.

Burt, J., 2015. Following the mixed methods trail: some travel advice. *British Journal of General Practice, 65*(634), 264–265. doi:10.3399/bjgp15X685045

Bushnell, C.D., Reeves, M.J., Zhao, X., Pan, W., Prvu-Bettger, J., Zimmer, L. and Peterson, E., 2014. Sex differences in quality of life after ischemic stroke. *Neurology*, 82 (11), 922–931.

Bussing, A., Fischer, J., Haller, A., Heusser, P., Ostermann, T., Matthiessen, P.F., 2009.Validation of the brief multidimensional life satisfaction scale in patients with chronic diseases. *European Journal of Medical Research*, 14(4),171–177.

Busson, R., van der Kaaij, M., Mounier, N., Aleman, B.M.P., Thiéblemont, C., Stamatoullas, A., Ribrag, V., Tilly, H., Haioun, C., Casasnovas, R-O., Kluin-Nelemans, H.C., Henry-Amar, M., 2019. Fatigue level changes with time in long-term Hodgkin and non-Hodgkin lymphoma survivors: a joint EORTC-LYSA cross-sectional study, *Health and Quality of Life Outcomes*,17,115.

Campbell, H. S., Phaneuf, M. R. and Deane, K., 2004. Cancer peer support programs-do they work? 3.

Cancer Research UK, 2014. https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/age (Accessed 2 May 2019).

Cancer Research UK, 2014. Cancer survival statistics. http://info.cancerresearchuk.org/cancerstats/survival/ (Accessed 2 May 2019).

Cancer Research UK, 2015. Cancer Statistics for the UK. http://www.cancerresearchuk.org/health-professional/cancer-statistics accessed Jan 2021.

Cancer Research UK, 2017. Non-Hodgkin Lymphoma. Available at: http://publications.cancerresearchuk.org/downloads/Product/CS_REPORT_NHL.pdf. Last accessed on 30/11/2017.

CancerResearch. Cancer incidence for common cancers, http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero (2015, 01 September 2021)

Cancer Research UK, 2017. Hodgkin lymphoma. Available at http://www.cancerresearchuk.org/about cancer/hodgkin-lymphoma/survival. Accessed on 30/11/2017.

Cancer Research UK, https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero, Accessed September 2019.

Cancer Research UK, 2017. https://www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll (Accessed October 2019)

Cancer Research UK, 2022. Available from: https://www.cancerresearchuk.org/ health-professional/cancer-statistics/incidence (Accessed February 2022)

Caracelli, V. J. and Greene, J. C., 1997. Crafting Mixed-Method Evaluation Designs. Available online https://onlinelibrary.wiley.com/doi/pdf/10.1002/ev.1069 [Accessed 2 October 2019].

Carlsen, K., Dalton, S.O., Diderichsen, F. and Johansen, C., 2008. The risk for unemployment of cancer survivors: A Danish cohort study. *European Journal of Cancer*, 44 (13), 1866–1874.

Carlsen, K., Ewertz, M., Dalton, S. O., Badsberg, J. H. and Osler, M., 2014. Unemployment among breast cancer survivors, *Scandinavian Journal of Public Health*, 42 (3), 319-328.

Carr, A. J. and Higginson, I. J., 2001. Is the quality of life measures patient-centred? *British Medical Journal* (Clinical research ed.), 322 (7298), 1357–1360. doi:10.1136/BMJ.322.7298.1357.

Casellas-Grau, A., Ochoa, C. and Ruini, C., 2017. Psychological and clinical correlates of posttraumatic growth in cancer: A systematic and critical review. *Psycho-Oncology*, 26 (12), 2007–18.

Cavers, D., Cunningham-Burley, S., Watson, E., Banks , E. and Campbell, C., 2020. Setting the research agenda for living with and beyond cancer with comorbid illness: reflections on a research prioritisation exercise. *Research Involvement and Engagemt*, 6, 17. https://doi.org/10.1186/s40900-020-00191-9.

Chan, C. M. H., Ng, C. G., Taib, N. A., Wee, L. H., Krupat, E. and Meyer, F., 2018. Course and predictors of post-traumatic stress disorder in a cohort of psychologically distressed patients with cancer: A 4-year follow-up study. *Cancer* [online], 124 (2), 406.

Charalambous, A. and Kouta, C ., 2016. Cancer related fatigue and quality of life in patients with advanced prostate cancer undergoing chemotherapy. *Biomedical Research International*, 3989286.

Check, J., and Schutt, R. K., 2012. Survey research. In: J. Check, R. K. Schutt., editors. *Research methods in education*. Thousand Oaks, CA: Sage Publications; 159–185.

Chen, S. Q., Liu, J. E., Zhang, Z. X. and Li, Z., 2017. Self-acceptance and associated factors among Chinese women with breast cancer. *Journal of Clinical Nursing* [online], 26 (11-12), 1516.

Cherepanov, D., Palta, M., Fryback, D.G. and Robert, S.A., 2010. Gender differences in health-related quality-of-life are partly explained by sociodemographic and socioeconomic variation between adult men and women in the US: Evidence from four US nationally representative data sets. *Quality of Life Research*, 19, 1115–1124.

Chuang, L., Shun, S. C., Hsieh, C. L., Lan, C. F. and Lang, H. C., 2010. Validation of EQ-5D in patients with cervical cancer in Taiwan. *Supportive Care in Cancer* [online], 18 (10), 1279-1286.

Clarke, A., 2006. Qualitative interviewing: encountering ethical issues and challenges. *Nurse Researcher* [online], 13 (4), 19-29.

Coast, J., Smith, R. and Lorgelly, P., 2008. Should the capability approach be applied in health economics? *Health Economics*,17:667–670. doi: 10.1002/hec.1359.

Coast, J., Flynn, T., Sutton, E., Al-Janabi, H., Vosper, J., Lavender, S., Louviere, J. and Peters, T.,2008. Investigating choice experiments for preferences of older people (ICEPOP): Evaluative spaces in health economics. *Journal of health services research and policy*,13(Suppl 3):31–37. doi: 10.1258/jhsrp.2008.008024.

Cohen, J. M., Harvey, J., Gaspar, H. B., Cathy, C., Jones, A., Davies, E. G., Sebire, N. J., Rao, K., Amrolia, P. J., Veys, P. and Cubitt, D., 2007. Successful treatment of lymphoproliferative disease complicating primary immunodeficiency/immunodysregulatory disorders with reduced-intensity allogeneic stem-cell transplantation. *Blood* [online], 110 (6), 2209-2214.

Collins, K. M. T., Onwuegbuzie, A. J. and Sutton, I. L., 2006. A Model Incorporating the Rationale and Purpose for Conducting Mixed-Methods Research in Special Education and Beyond. Learning Disabilities *A Contemporary Journal* [online], 4 (1), 67-100.

Conant, J. and Eglen, U., (Eds) 2002. *Pragmatism and realism*. London: Routledge.

Connelly, L.M., 2013. "Demographic data in research studies." *Medical-Surgical Nursing*, 269. Gale Academic One file, [Accessed 24 Sept. 2019].

Conroy, T. and Blazeby, J. M., 2003. Health-related quality of life in colorectal cancer patients. *Expert Review Of Anticancer Therapy* [online], 3 (4), 493-504.

Cordoba, R., Eyre, T.A., Klepin, H.D., Wildes, T.M. and Goede,V., 2021. A comprehensive approach to therapy of haematological malignancies in older patients. *Lancet Haematology*, 8(11):e840-e852. doi: 10.1016/S2352-3026(21)00241-6. Epub 2021 Oct 5. PMID: 34624238.

Cormio, C., Muzzatti, B., Romito, F., Mattioli, V., & Annunziata, M. A., 2017. Posttraumatic growth and cancer: a study 5 years after treatment ends. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer, 25*(4),1087–1096. DOI:10.1007/s00520-016-3496-4.

Corner, J., Wright, D., Hopkinson, J., Gunaratnam, Y., McDonald, J.W. and Foster, C., 2007. The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *British Journal of Cancer, 96* (6), 875-881.

Corner, J., Wagland, R., Glaser, A. and Richards, M., 2013. Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England. *British Medical Journal Open*,3(4) no pagination:e002316.

Cramer, H., Cohen, L., Dobos, G., Witt, C.M., 2013. Integrative oncology: best of both worlds-theoretical, practical, and research issues. *Evidence-Based Complementary Alternative Medicine: eCAM 2013:383142*.

Creswell, J. W., Goodchild, L. F. and Turner, P. P., 1996. Integrated Qualitative and Quantitative Research: Epistemology, History, and Designs, 90.

Creswell, J.W., 2002. Educational research: Planning, conducting, and evaluating quantitative and qualitative approaches to research. Upper Saddle River, NJ: Merrill/Pearson Education.

Creswell, J. W., Plano Clark, V. L., Guttmann, M., Hanson, W., 2003. Advanced mixed methods research designs. In: A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in the behavioural and social sciences*, 209-240, Thousand Oaks, CA: Sage Publications.

Creswell, J.W., Plano Clark, V., Gutmann, M. and Hanson, W.,2003. 'Advanced mixed methods research designs', in Tashakkori, A., Teddlie, C. (Eds): Handbook of Mixed Methods in Social and Behavioral Research, Sage: Thousand Oaks, CA.

Creswell, J.W., Fetters, M.D. and Ivankova, N.Y., 2004. Designing a mixed-methods study in primary care. *Annals of Family Medicine*, 2(1),7–12.

Creswell, J. W. and Plano Clark, V., 2007. Designing and Conducting Mixed Methods Research. CA: Sage.

Creswell, J., 2009. *Research design: Qualitative, quantitative, and mixed methods approach (3rd ed.).* Thousand Oaks, CA: Sage.

Creswell, J. W., 2010. Designing and conducting mixed methods research / John W. Creswell [Non-fiction]. London: SAGE.

Creswell, J. W. and Plano Clark, V., 2011. Designing and Conducting Mixed Methods Research (2nd ed) Thousand Oaks. Sage Publications Inc.

Creswell, J.W. and Plano Clark, V.L., 2017. *Designing and conducting mixed methods research* (3rd ed.). Thousand Oaks, CA: Sage

Cullen, M., 2001. 'Best supportive care' has had its day. *The Lancet Oncology*,2(3),173-5.

Cummings, A., Grimmett, C., Calman, L., Patel, M., Permyakova, N.V., Winter, J., Corner, J., Din, A., Fenlon, D., Richardson,A. and Smith, P.W., 2018. Comorbidities are associated with poorer quality of life and functioning and worse symptoms in the 5 years following colorectal cancer surgery: results from the ColoREctal Well-being (CREW) cohort study. *Psycho-oncology*, 27(10),2427–35.

Cutler, T., 2012. Lymphoma: pathophysiology, care and management. In: Brown M, Cutler TJ, editors. *Haematology nursing*. Chichester, West Sussex: Wiley-Blackwell; p. 217–231.

Cypress, B.S., 2017. Rigor or Reliability and Validity in Qualitative Research: Perspectives, Strategies, Reconceptualization, and Recommendations. *Dimensions in Critical Care Nursing*, 36(4),253-263. doi: 10.1097/DCC.0000000000000253. PMID: 28570380.

Dahlberg, K., Dahlberg, H. and Nyström, M., 2008. Reflective lifeworld research.Lund: Studentlitteratur.

Damlaj, M., El Fakih, R. and Hashmi, S.K., 2019. Evolution of survivorship in lymphoma, myeloma and leukemia: metamorphosis of the field into long term follow-up care. *Blood Reviews*, 33, 63-73.

Daniels, L. A., Oerlemans, S., Krol, A. D., Creutzberg, C.L., van de Poll-Franse, L.V., 2014. Chronicfatigue in Hodgkin lymphoma survivors and associations with anxiety, depression and comorbidity. *British Journal of Cancer*, 4, 110, 868-874.

Davies, N. J., 2009. Cancer survivorship: living with or beyond cancer. *Cancer Nursing Practice* [online], 8 (7), 29.

Davies, A. N., Patel, S.D. and Gregory, A., *2017.* An observational study of sleep disturbances in advanced cancer. *British Medical Journal of Supportive & Palliative Care,* 7,435-440.

Dawson, G., Madsen, L. T. and Dains, J. E., 2016. Interventions to Manage Uncertainty and Fear of Recurrence in Female Breast Cancer Survivors: A Review of the Literature. *Clinical Journal of Oncology Nursing* [online], 20 (6), E155-E161.

De Angelis, R., Sant, M., and Coleman, M. P., 2014. Cancer survival in Europe 1999–2007 by country and age: Results of EUROCARE-5 - A population-based study. *Lancet Oncology*, 2014 (15), 23–34.

de Boer, A.G., Taskila, T., Ojajärvi, A., van Dijk, F.J. and Verbeek, J.H., 2009. Cancer survivors and unemployment: a meta-analysis and meta-regression. *The Journal of the American Medical Association*, 301(7), 753–762.

De Costa, A., D'Souza, N., Krishnan, S., Chhabra, M.S., Shihaam, I. and Goswami, K., Community based trials and informed consent in rural north India. *Journal of Medical Ethics*, 30,318–323.

Department of Health, Macmillan Cancer Support, NHS Improvement 2010The National Cancer Survivorship Initiative Vision.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230

Department of Health, Macmillan Cancer Support, & NHS Improvement., 2013. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision) (1st ed.). Retrieved from http://www.ncsi.org.uk/wpcontent/uploads/Living-with-and-beyond-2013.pdf

Deimling, G. T., Kahana, B., Bowman, K. F. and Schaefer, M. L., 2002. Cancer survivorship and psychological distress in later life. *Psycho-Oncology* [online], 11 (6), 479-494.

Deimling, G.T., Bowman, K.F. and Wagner, L.J., 2007. Cancer survivorship and identity among long-term survivors. *Cancer Investigation*, 25,758-765.

DeMarinis, V., Barsky, A. J., Antin, J. H. and Chang, G., 2009. Health psychology and distress after haematopoietic stem cell transplantation. *European Journal of Cancer Care* [online], 18 (1), 57-63.

Demark-Wahnefried, W., Aziz, N.M., Rowland, J.H. and Pinto, B.M., 2005. Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *Journal of Clinical Oncology*, 23,5814-5830.

Demark-Wahnefried, W. and Jones, L. W., 2008. Promoting a healthy lifestyle among cancer survivors. *Hematology/Oncology Clinics Of North America* [online], 22 (2), 319.

Denis, F., Lethrosne, C., Pourel, N., Molinier, O., Pointreau, Y., Domont, J., Bourgeois, H., Senellart, H., Trémolières, P., Lizée, T., Bennouna, J., Urban, T., El Khouri, C., Charron, A., Septans, A, L., Balavoine, M., Landry, S., Solal-Céligny, P. and Letellie,R, C., 2017. A randomised trial comparing a web-mediated follow-up with routine surveillance in lung cancer patients. *Journal of National Cancer Institute*, 109 (9). DOI: 10.1093/jnci/djx029.

Denscombe, M., 2008. 'Communities of practice: a research paradigm for the mixed methods approach. *Journal of Mixed Methods Research*, 2(3), 270-283.

Denzin, N. K., 1999. Qualitative Inquiry and Research Design: Choosing Among Five Traditions by John W. Creswell Introduction to Qualitative Research Methods (3rd ed.) by Steven J. Taylor and Robert Bogdan, 97.

Department of Health, 2005a. Research governance framework for health and social care.

Department of Health, 2005b. Research governance framework for health and social care. Department of Health.

Department of Health, 200). Cancer Reform Strategy (1st ed.). Retrieved from http://www.nhs.uk/NHSEngland/NSF/Documents/Cancer%20Reform%20Strategy.pdf

Department of Health , 2008. Cancer Reform Strategy: Maintaining Momentum, Building for the Future – First Annual Report. DH, London.

Department of Health, Macmillan Cancer Support & NHS Improvement, 2010. National Cancer Survivorship Initiative vision. Department of Health, Crown Copyright, London, UK.

Derrett, S. & Colhoun, S., 2011. Being a quantitative interviewer: qualitatively exploring interviewers' experiences in a longitudinal cohort study. *BMC medical research methodology*, *11*, 165. doi:10.1186/1471-2288-11-165.

De Jonckheere, M. and Vaughn, L. M., 2019. Semi-structured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health,* **7.**

Drever, E., 1995. Using semi-structured interviews in small-scale research: a teacher's guide Edinburgh: Scottish Council for Research in Education.

Dialla, P. O., Chu, W. O., Roignot, P., Bone-Lepinoy, M. C., Poillot, M. L., Coutant, C., Arveux, P. and Dabakuyo-Yonli, T. S., 2015. Impact of age-related socio-economic and clinical determinants of quality of life among long-term breast cancer survivors, 362.

Diamond, J., 1999. *C:* Because Cowards Get Cancer Too..., Vermilion: UK.

DiCicco-Bloom, B. and Crabtree, B. F., 2006. The qualitative research interview. *Medical Education* [online], 40 (4), 314-321.

Dillman, D. A., Smyth, J. D. and Christian, L. M., 2014. Internet, phone, mail, and mixed-mode surveys: The tailored design method, 4th ed. Hoboken, NJ: John Wiley & Sons Inc.

Dobos, G., Cramer, H., Anant, S., Witt, C.M., Cohen, L., 2013. Integrative oncology. *Evidence Based Complement and Alternative Medicine*: eCAM 2013: 124032. doi:10.1155/2013/124032

Dobos, G.J., Voiss, P., Schwidde, I., Choi, K.E., Paul, A., Kirschbaum, B., Saha, F.J., Kuemmel, S.,2012. Integrative oncology for breast cancer patients: introduction of an expert-based model. *BMC Cancer* 12: 539.

Dobos, G., Overhamm, T., Büssing, A., Ostermann, T., Langhorst, J., Kümmel, S., Cramer, H., 2015. Integrating mindfulness in supportive cancer care: a cohort study on a mindfulness-based day care clinic for cancer survivors. *Supportive Care in Cancer*, 23,10, 2945–2955. https://doi-org.libezproxy.bournemouth.ac.uk/10.1007/s00520-015-2660-6.

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E.S., Humphries, J., Lee, K., Miaskowski, C., Puntillo, K., Rankin, S. and Taylor, D., 2001. Advancing the science of symptom management. *Journal of Advanced Nursing*, 33(5), 668–676.

Dolan, P., Layard, R. and Metcalfe, R., 2011. Measuring subjective wellbeing for public policy: Recommendations on measures.

Dombret, H., Raffoux, E. and Gardin, C., 2008. Acute Myeloid Leukemia in the Elderly. *Seminars in Oncology* (ScienceDirect) [online], 35,4,430.

Dorset LEP Strategic Economic Plan, Dorset County and Unitary Local Economic Assessments, and other local strategic and delivery reports, including local statistical benchmarks and databases.2018.https://www.dorsetlep.co.uk/userfiles/files/Dorset-LEP-Economic_Ambition%20final.pdf

Doyle, N. and Kelly, D., 2005. 'So what happens now?' Issues in Cancer survival and rehabilitation. *Clinical Effectiveness in Nursing, 9,* 147-153.

Doyle, C., Kushi, L. H., Byers, T., Courneya, K. S., Demark-Wahnefried, W., Grant, B., McTiernan, A., Rock, C. L., Thompson, C., Gansler, T. and Andrews, K. S., 2006. Nutrition and physical activity during and after cancer treatment: an American Cancer Society guide for informed choices. *CA: A Cancer Journal For Clinicians* [online], 56 (6), 323-353.

Doyle, N., 2008. Cancer survivorship: evolutionary concept analysis, *Journal of Advanced Nursing,* 62 (4),499-509.

Doyle, L., 2015. Mixed methods. In: Henly SJ (ed.) Routledge International Handbook of Advanced Quantitative Methods in Nursing Research. Abingdon: Routledge, 411–422.

Dunleavy, K. and Wilson, W.H., 2013. Diagnosis and treatment of diffuse large B-cell lymphoma and Burkitt lymphoma. In R. Hoffman (Ed.) (6th ed.). Haematology: basic principles and practice (pp. 1236-1244). Philadelphia: Saunders/Elsevier.

Dunn, J., Ng, S. K., Breitbart, W., Aitken, J., Youl, P., Baade, P. D. and Chambers, S. K., 2013. Health-related quality of life and life satisfaction in colorectal cancer survivors: trajectories of adjustment. *Health And Quality Of Life Outcomes* [online], 11 (1), 46-46.

Dunn, J., Steginga, S. K., Rosoman, N. and Millichap, D., 2003. A Review of Peer Support in the Context of Cancer. *Journal of Psychosocial Oncology* [online], 21 (2), 55.

Dunkel, B., 2017. Disorders of the hematopoietic system in *Equine Internal Medicine (4th edition),* Elsevier.

Eakin, E. G., Youlden, D. R., Baade, P. D., Lawler, S. P., Reeves, M. M., Heyworth, J. S. and Fritschi, L., 2006. Health status of long-term cancer survivors: results from an Australian population-based sample. Cancer Epidemiology, Biomarkers & Prevention: A Publication Of The American Association For Cancer Research, Cosponsored By *The American Society Of Preventive Oncology [*online], 15 (10), 1969-1976.

Eakin, E. G., Youlden, D. R., Baade, P. D., Lawler, S. P., Reeves, M. M., Heyworth, J. S. and Fritschi, L., 2007. Health behaviours of cancer survivors: data from an Australian population-based survey, *Cancer Causes and Control*,18(8),881-894.

Eckerblad, J., Theander, K., Ekdahl, A., Unosson, M., Wirehn, A.B., Milberg, A., Krevers, B. and Jaarsma, T., 2015. Symptom burden in community-dwelling older people with multimorbidity: a cross-sectional study. *BMC Geriatrics*,15,1.https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4292813/

Edwards, P., Roberts, I., Clarke, M., Di Guiseppi, C., Pratap, S., Wentz, R., Kwan, I., Cooper, R., Felix, L, M., Pratap, S., 2002. Increasing response rates to postal questionnaires: a systematic review. *British Medical Journal*, 324, 1183.

Edwards, P.J, Roberts I, Clarke, M. J., Diguiseppi, C., Wentz, R., Kwan, I., Cooper, R., Felix, L.M. and Pratap, S., 2009. Methods to increase response to postal and electronic questionnaires. *Cochrane Database Systematic Review*, 3.

Eton, D. T., Anderson, R. T., Cohn, W. F., Kennedy, E. M., St. Sauver, J. L., Bucknell, B. J. and Ruddy, K. J., 2019. Risk factors for poor health-related quality of life in cancer survivors with multiple chronic conditions: exploring the role of treatment burden as a mediator. *Patient-Related Outcome Measures*, 89.

Efficace, F., Baccarani, M., Breccia, M., Cottone, F., Alimena, G., Deliliers, G. L., Baratè, C., Specchia, G., Di Lorenzo, R., Luciano, L., Turri, D., Martino, B., Stagno, F., Dabusti, M., Bergamaschi, M., Leoni, P., Simula, M. P., Levato, L., Fava, C., Veneri, D., Sica, S., Rambaldi, A., Rosti, G., Vignetti, M. and Mandelli, F., 2013. Chronic fatigue is the most important factor limiting the health-related quality of life of chronic myeloid leukaemia patients treated with Imatinib. *Leukemia* [online], 27 (7), 1511-1519.

Efficace, F., Novik, A., Vignetti, M., Mandelli, F. and Cleeland, C. S., 2007a. Health-related quality of life and symptom assessment in clinical research of patients with hematologic malignancies: where are we now and where do we go from here? *Haematologica* [online], 1596.

Efficace, F., Novik, A., Vignetti, M., Mandelli, F. and Cleeland, C. S., 2007b. Health-related quality of life and symptom assessment in clinical research of patients with hematologic malignancies: where are we now and where do we go from here? *Haematologica* [online], 92(12), 1596-1598.

Egon, G. G. and Yvonna, S. L., 1982. Epistemological and Methodological Bases of Naturalistic Inquiry. *Educational Communication and Technology* [online], 30(4),233.

Emanuel, P.D.,2007. Introduction to leukocyte neoplasms. In: Rodak BF, Fritsma GA, Doig K (eds) Hematology: clinical principles and applications, 3rd eds. Saunders Elsevier, St Louis Missouri, 389– 397.

Esser, P., Kuba, K., Mehnert A., Johansen, C., Hinz, a., Lordick, F. and Gotze, H., 2018. Quality of life in survivors of haematological malignancies stratified by cancer type, time since diagnosis and stem cell transplantation. *European Journal of Haematology*, 101, 340–348.

Extermann, M., 2007. Interaction Between Comorbidity and Cancer, *Cancer Control*,14 (1),13-22.

Eytan, D. F., Blackford, A. L., Eisele, D. W. and Fakhry, C., 2019. Prevalence of Comorbidities among Older Head and Neck Cancer Survivors in the United States, 85.

Fayers, P., Aaronson, N., Bjordal, K., Groenvold, M., Curran, D. and Bottomley, A., 2001. *EORTC QLQ-C30 Scoring Manual. Third.* Brussels, Belgium: EORTC.

Fazio, V. W., Fletcher, J. and Montague, D., 1980. A prospective study of the effect of resection of the rectum on male sexual function. *World Journal of Surgery* [online], 4(2), 149-152.

Feinstein, A. R., 1970. The Pre-therapeutic Classification of Co-morbidity in Chronic Disease. *Journal Of Chronic Diseases* [online], 23(7), 455-468.

Fetters, M.D., Curry, L.A. and Creswell, J.W., 2013. Achieving integration in mixed methods designs: Principles and practices. *Health Services Research*, 48, 2134- 2156.

Felce, D., 1997. Defining and applying the concept of quality of life. *Journal Of Intellectual Disability Research: JIDR* [online], 41(2), 126-135.

Ferrell, B.R, Hassey Dow K, Grant M. Measurement of the quality of life in cancer survivors. *Qual ity of Life Research*, 1995, 4, 523–531.

Firkins, J., Hansen, L., Driessnack, M. and Dieckmann, N., 2020. Quality of life in "chronic" cancer survivors: a meta-analysis. *Journal of Cancer Survivorship,14,* 504–517.

Fitch, M.I., 2008. Supportive care framework. *Can Oncology Nursing Journal*(Revue Canadienne de Nursing Oncologique),8(1),6–14. doi: 10.5737/1181912x181614.

Flick, U., 1998. An introduction to qualitative research. Thousand oak, CA: SAGE publications.

Florczak, K. L., 2014. Purists need not apply the case for pragmatism in mixed methods research. *Nursing Science Quarterly* [online], 27 (4), 278-282.

Forman, D., Stockton, D., Møller, H., Quinn, M., Babb, P., De Angelis, R. and Micheli, A., 2003. Cancer prevalence in the UK: results from the EUROPREVAL study. Annals Of Oncology: Official Journal of *The European Society for Medical Oncology* / ESMO [online], 14 (4), 648-654.

Fortner, B., Baldwin, S., Schwartzberg, L. and Houts, A. C., 2006. Validation of the Cancer Care Monitor Items for Physical Symptoms and Treatment Side Effects Using Expert Oncology Nurse Evaluation, 207.

Fortner, B. V., Tauer, K. W., Okon, T., Houts, A. C. and Schwartzberg, L. S., 2005. Experiencing neutropenia: Quality of life interviews with adult cancer patients. *Biomedical Medical Central Nursing* [online], 4, 4-8.

Foster, C,. Roffe, L., Scott, I. and Cotterell, P., 2010. Self-Management of Problems Experienced Following Primary Cancer Treatment: An Exploratory Study. Report for Macmillan Cancer Support: London.

Foster, K., 2010. 'You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness. *Journal of Clinical Nursing,* 19 (21), 3143-3151.

Foster, C. and Fenlon, D., 2011. Recovery and self-management support following primary cancer treatment. *British Journal of Cancer*, 105,Suppl 1, S21–8.

Foster, I., Jefferies, J. and Foster, L., 2014. Beginning statistics: an introduction for social scientists [Non-fiction]. Los Angeles: SAGE.

Foster, C., Breckons, M., Cotterell, P., Barbosa, D., Calman, L., Corner, J., Fenlon, D., Foster, R., Grimmett, C., Richardson, A. and Smith, P.W., 2015. Cancer survivors' self-efficacy to self-manage in the year following primary treatment. *Journal of Cancer Survivorship, 9* (1),11-19.

Foster, C., Calman, L., Richardson,A., Pimperton, H. and Nash, R., 2018.
Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice, *Journal of Cancer Policy*, 15, 92-95.

Friedman, D. R., Coan, A. D., Smith, S. K., Herndon, J. E., 2nd and Abernethy, A. P., 2010. Informational needs assessment of non-Hodgkin lymphoma survivors and their physicians. *American Journal Of Hematology* [online], 85 (7), 528-532.

Fusch, P. I. and Ness, L. R., 2015. Are We There Yet? Data Saturation in Qualitative Research [Article]. *Qualitative Report*, 10520147.

Gale, M., 2005. *The philosophy of William James: An introduction.* Cambridge: Cambridge University Press.

Galper, S.L., Yu, J.B., Mauch, P.M., Strasser, J.F., Silver, B., Lacasce A., Marcus, K. J., stevenson, M. A., Chen, M. H. and Ng, A.K., 2011. Clinically significant cardiac disease in patients with Hodgkin lymphoma treated with mediastinal irradiation. *Blood*, 117, 412-418.

Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T. and Esparza, A., 2010. Evolving Information Priorities of Hematologic Cancer Survivors, Caregivers, and Other Relatives, *Journal of Cancer Education*, 25(3),302-311.

Ganz, P. A., 2001. Late effects of cancer and its treatment. *Seminars in Oncology Nursing* [online], 17 (4), 241.

Ganz, P. A., 2009. Survivorship: adult cancer survivors. *Primary Care*, 36 (4), 721-741.

Ganz, P. A., Rowland, J. H., Desmond, K., Meyerowitz, B. E. and Wyatt, G. E., 1998. Life after breast cancer: understanding women's health-related quality of life and sexual functioning. *Journal Of Clinical Oncology* [online], 16 (2), 501-514.

Gapstur, R.L., 2007. Symptom Burden: a concept analysis and implications for oncology nurses Oncology Nursing Forum, 34, 3, 673-680.

Garofalo, J. P., Choppala, S., Hamann, H. A. and Gjerde, J., 2009a. Uncertainty during the transition from cancer patient to survivor. *Cancer Nursing* [online], 32 (4), E8-14.

Garofalo, J. P., Choppala, S., Hamann, H. A. and Gjerde, J., 2009b. Uncertainty during the transition from cancer patient to survivor. *Cancer Nursing* [online], 32 (4), E8-E14.

Gelling, L., 2014. When to use mixed methods. *Nurse Researcher* [online], 21 (4), 6-7.

Giddings, L. S. and Grant, B. M., 2006. Mixed methods research for the novice researcher. *Contemporary Nurse* [online], 23 (1), 3-11.

Giddings, L. S. and Grant, B. M., 2009. From rigour to trustworthiness; Validating mixed methods, In S. Andrew and E, Halcombe (Eds), Research for nursing and health sciences, Oxford,UK :Wiley-Blackwell.

Giddings, L., 2006. Mixed-methods research: Positivism dressed in drag? *Journal of Research in Nursing*,11(3), 195–203.

Giesinger, J. M., Kieffer, J. M., Fayers, P. M., Groenvold, M., Petersen, M. A., Scott, N. W., Sprangers, M. A. G., Velikova, G. and Aaronson, N. K., 2016. Replication and validation of higher-order models demonstrated that a summary score for the EORTC QLQ-C30 is robust. *Journal Of Clinical Epidemiology* [online], 69, 79-88.

Gijsen, R., Hoeymans, N., Schellevis, F. G., Ruwaard, D., Satariano, W. A. and van den Bos, G. A., 2001. Causes and consequences of comorbidity: a review. *Journal Of Clinical Epidemiology* [online], 54 (7), 661-674.

Gill PS, Kai J, Bhopal RS, and Wild S. 2007. Health care needs assessment: black and minority ethnic groups. In: Raftery J, Stevens A, Mant J, editors. Health care needs assessment. The epidemiologically based needs assessment reviews. Abingdon: Radcliffe Publishing Ltd; pp. 227–399. Third Series.

Glaser, A., 2011. A new approach. *Health Service Journal*, Cancer Survivorship supplements, 1.

Glaser, A.W., Fraser, L.K., Corner, J.,2013. Patient-reported outcomes of cancer survivors in England 1–5 years after diagnosis: a cross-sectional survey. *British Medical Journal Open*, 3.

Glesne, C., 2006. Becoming qualitative researchers an introduction (3rd ed). Boston: Pearson Education Inc.

Glogowska, M., 2011. Paradigms, pragmatism and possibilities: mixed-methods research in speech and language therapy. *International Journal Of Language & Communication Disorders* / Royal College Of Speech & Language Therapists (online), 46 (3), 251-260.

Gotay, C. C. and Muraoka, M. K., 1998. Quality of Life in Long-Term Survivors of Adult-Onset Cancers, *Journal- National Cancer Institute,* 90 (9),656-667.

Gotay, C. C., Holup, J. L. and Pagano, I., 2002. Ethnic differences in quality of life among early breast and prostate cancer survivors, *Psycho Oncology,*11(2),103-113.

Gotay, C.C., Kawamoto, C.T., Bottomley, A. and Efficace, F., 2008. The prognostic significance of patient-reported outcomes in cancer clinical trials. *Journal of Clinical Oncology*, 26 (8), 1355–1363.

Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., Wendel, C. S., Baldwin, C. M. and Krouse, R. S., 2011. Gender Differences in Quality of Life Among Long-Term Colorectal Cancer Survivors With Ostomies, *Oncology nursing forum*, 38 (5), 587-600.

Grant, M.M. and Rivera, L.M., 1998. Quality of life: From nursing and patient perspectives. Theory-Research–Practice. *Evolution of quality of life in oncology and oncology nursing*, Jones and Bartlett Publishers, Sudbury, Massachusetts.

Gratwohl, A., Baldomero, H., Horisberger, B., Schmid, C., Passweg, J., Urbano-Ispizua, A. and Accreditation Committee of the European Group for Blood and Marrow, T., 2002. Current trends in hematopoietic stem cell transplantation in Europe, *Blood,* 100 (7),2374-2386.

Gratwohl, A., Baldomero, H. and Passweg, J., 2013. Hematopoietic stem cell transplantation activity in Europe. *Current Opinion In Hematology* [online], 20 (6), 485-493.

Gray, D., 2014. Doing research in the real world, 2 nd ed., California: Sage

Greene, J. C., Caracelli, V. J. and Graham, W. F., 1989. Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation & Policy Analysis*, 11, 255-274.

Green, S.B., 1991. How many subjects does it take to do a regression analysis? *Multivariate Behavioural Research,* 26,499-510.

Greene, J.C. and Caracelli, V.J., 1997. 'Defining and describing the paradigm issue in mixed-method evaluation', in Greene, J.C., Caracelli, V.J. (Eds): New Directions for Evaluation: Number 74. Advances in Mixed-Method Evaluation: The Challenges and Benefits of Integrating Diverse Paradigms, Jossey Bass, San Francisco.

Groeneveld, L., Mein, G., Garrod, R., Jewell, A. P., Van Someren, K., Stephens, R., D'Sa, S. P. and Yong, K. L., 2013. A mixed exercise training programme is feasible and safe and may improve the quality of life and muscle strength in multiple myeloma survivors. *BioMedical Central Cancer* [online], 13, 31-31.

Groenvold, M., Klee, M. C., Sprangers, M. A. and Aaronson, N. K., 1997. Validation of the EORTC QLQ-C30 quality of life questionnaire through combined qualitative and quantitative assessment of the patient-observer agreement. *Journal Of Clinical Epidemiology*, 50 (4), 441-450.

Group, W., 1993a. Study Protocol for the World Health Organization Project to Develop a Quality of Life Assessment Instrument (WHOQOL), *Quality of Life Research,*153.

Group, W., 1993b. Study Protocol for the World Health Organization Project to Develop a Quality of Life Assessment Instrument (WHOQOL). *Quality of Life Research*, 2 (2), 153.

Guba, E. G. and Lincoln, Y. S., 1982. Epistemological and methodological bases of naturalistic inquiry. *Educational Communication & Technology Journal* [online], 30 (4), 233-252.

Guetterman, T.C., Fetters, M.D. and Creswell, J.W., 2015. Integrating quantitative and qualitative results in health science mixed methods research through joint displays. *Annals of Family Medicine,* 13, 554–61.

Guest, G., Mac Queen, K. M. and Namey, E. E., 2011. Applied thematic analysis. Thousand Oaks, CA: Sage.

Gulbrandsen, N., Hjermstad, M.J. and Wisloff, F., 2004. Nordic Myeloma Study Group Interpretation of quality of life scores in multiple myeloma by comparison with a reference population and assessment of the clinical importance of score differences. *European Journal of Haematology,* 72,172– 180.

Guralnik, J, M., La Croix, A.Z., Everett, D.F. and Kovar, M., 1989. Ageing in the Eighties: The Prevalence of Co-morbidity and Its Association with Disability. Hyattsville, Md: National Center for Health Statistics; Advance Data from Vital and Health Statistics, No. 170. Hyattsville, MD: National Centre for Health Statistics.

Guzzinati S, Virdone S, De Angelis R, Panato C, Buzzoni C, Capocaccia R, Francisci S, Gigli A, Zorzi M, Tagliabue G *et al* (2018) Characteristics of people living in Italy after a cancer diagnosis in 2010 and projections to 2020. *Bio Medical Central Cancer*, 18, 169.

Hall, A., Campbell, H. S., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R. and Carey, M., 2013. Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology* [online], 22 (9), 2032-2038.

Halcomb, E.J. 2019. Mixed methods research: The issues beyond combining methods. *Journal of Advanced Nursing*. 75(3):499-501. doi: 10.1111/jan.13877. Epub 2018 Dec 21. PMID: 30375033.

Halcomb, Elizabeth & Andrews, Sharon. (2009). Mixed methods research for nursing and the health sciences.

Haynes, K., 2012. Reflexivity in qualitative research. Qualitative Organizational Research: Core Methods and Current Challenges, 72-89.

Halcomb, E.J. and Andrews, S., 2009. Practical considerations for higher degree research students undertaking mixed methods projects, *International Journal of Multiple Research Approaches*, 3(2), 153-162, DOI: 10.5172/mra.3.2.153.

Hall, A., Lynagh, M., Bryant, J. and Sanson-Fisher, R., 2013. Supportive care needs of haematological cancer survivors: a critical review of the literature. *Critical Reviews in Oncol/Hematol,* 88,102–116. doi: 10.1016/j.critrevonc.2013.03.008

Hameed, A., Brady, J. J., Dowling, P., Clynes, M. and O'Gorman, P., 2014. Bone disease in multiple myeloma: pathophysiology and management, *Cancer Growth and Metastasis*,7,33–42. doi:10.4137/CGM.S16817

Harding, R., Nair, S. and Ekstrand, M., 2014. A multilevel model of stigma and barriers to cancer palliative care in India: a qualitative study, *British Medical Journal Open,* 9.

Harrison, S.E., Watson, E.K., Ward, A.M., Khan, N.F., Turner, D., Adams, E., Forman, D., Roche, M.F. and Rose, P.W., 2011. Primary health and supportive care needs of long-term cancer survivors: a questionnaire survey. *Journal of Clinical Oncology,* 29(15), 2091–8.

Hartl, K., Janni, W. and Kästner, R., 2003. Impact of medical and demographic factors on long-term quality of life and body image of breast cancer patients. *Annals of Oncology*, 14 (7), 1064–1071.

Hartlapp, I., Pallasch, C., Weibert, G., Kemkers, A., Hummel, M. and Re D., 2009. "Depsipeptide induces cell death in Hodgkin lymphoma-derived cell lines". *Leukaemia Research, 33 (7), 929–36.*

Hassan, M. and Abdi-Valugerdi, M., 2014. Hematologic malignancies in elderly patients. *Haematologica*, 99 (7), 1124–1127.

Health Education England, 2018. https://www.hee.nhs.uk/sites/default/files/documents/HEE%20Business%20Plan%202018-19.pdf (accessed 5 October 2019).

Hebdon, M., Foli, K. and McComb, S., 2015. Survivor in the cancer context: a concept analysis. *Journal of Advanced Nursing* [online], 71 (8), 1774-1786.

Hegney,D. and Chan,T.W., 2010. Ethical challenges in the conduct of qualitative research, Nurse Researcher,18 (1), 4-7.

Hemminki, K., Lenner, P., Sundquist, J. and Bermejo, J.L., 2008. Risk of subsequent solid tumorsafter non-Hodgkin's lymphoma: effect of diagnostic age and time since diagnosis. *Journal of Clinical Oncology*, 26, 1850-1857.

Henry-Amar, M. and Somers, R., 1990. Survival outcome after Hodgkin's disease: a report from the international data base on Hodgkin's disease. *Seminars in Oncology*, 17, 758-768.

Hennink, M., Hutter, I. and Bailey, A., 2010. Qualitative Research Methods, London, the UK: Sage.

Hess, S. L., Johannsdottir, I. M., Hamre, H., Kiserud, C. E., Loge, J. H. & Fossa, S. D., 2011. Adult survivors of childhood malignant lymphoma are not aware of their risk of late effects. *Acta Oncologica*, 50 (5), 653–659.

Herce Lopez, J., Rollon Mayordomo, A., Lozano Rosado, R., Salazar Fernandez, C. I. and Gallana, S., 2009. Quality of life in long-term oral cancer survivors: a comparison with Spanish general population norms. *Journal of Oral & Maxillofacial Surgery* (02782391) [online], 67 (8), 1607-1614.

Hewitt, M., Greenfield, S. and Stovall, E., 2006. *From Cancer Patient to Cancer Survivor-Lost in Transition*. Washington, DC: National Academies Press.

Heydarnejad, M.S., Hassanpour, D.A. and Solati, D.K., 2011. Factors afecting quality of life in cancer patients undergoing chemotherapy. *African Health Science*s, 11(2), 266–270.

Hewitt, M. E., Ganz, P. A., Institute of, M. and American Society of Clinical, O., 2006. From Cancer Patient to Cancer Survivor: Lost in Transition [Book]. Washington, D.C.: National Academies Press.

HMRN (2014). Incidence. Available at: ⟨https://www.hmrn.org/Statistics/incidence⟩. [accessed on 29 November 2017].

Hinz, A., Mehnert, A., Dégi, C., Reissmann, D.R., Schotte, D. and Schulte, T., 2017. The relationship between global and specific components of quality of life, assessed with the EORTC QLQ-C30 in a sample of 2019 cancer patients. *European Journal of Cancer Care*, 26,12416.

Hodgkinson, K., Butow, P., Hunt, G., 2007. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CASUN (Cancer Survivors' Unmet Needs measure), *Psych oncology*, 16 (9), 796–804. doi:10.1002/pon.1137.

Hodgson, D. C., Grunfeld, E., Gunraj, N. & Del Giudice, L., 2010. A population-based study of follow-up care for Hodgkin lymphoma survivors: Opportunities to improve surveillance for relapse and late effects. *Cancer*, 116 (14), 3417–3425.

Hoffman, M., Lent, R. and Raque-Bogdan, T., 2013. A social cognitive perspective on coping with cancer: theory, research, and intervention. *The Counselling Psychologist*, 41(2), 240–267.

Hoffman, B., 2016. Upstream Advocacy: Addressing Cancer Survivors' Employment Problems through Medical-Legal Partnerships. Washington Law Review Online, (Issue 1), 1.

Holzner, B., Kemmler, G., Kopp, M., Nguyen-Van-Tam, D., Sperner-Unterweger, B. and Greil, R., 2004. Quality of life of patients with chronic lymphocytic leukaemia: results of a longitudinal investigation over 1 yr. *European Journal of Haematology* [online], 72 (6), 381-389.

Hooper, G. and Gerber, E., 2014. Measuring the Quality of Life In Men with Prostate Cancer. *Urologic Nursing* [online], 34 (4), 177-184.

Hughes, M. and Duffy, C., 2018: A Concept analysis of public involvement in health and social care research. *Health Expectations*. https://rdcu.be/5uin

Hulbert-Williams, N.J., Leslie, M., Hulbert-Williams, L., Smith, E., Howells, L. and Pinato, D.J., 2021. Evaluating the impact of COVID-19 on supportive care needs, psychological distress and quality of life in UK cancer survivors and their support network. *European Journal of Cancer Care* (Engl), Sep; 30 (5), e13442. doi: 10.1111/ecc.13442. Epub 2021 Mar 25. PMID: 33764611; PMCID: PMC8250124.

Ibrahim, N. M., Merav, B., Bipin, N. S., Elihu, H. E. and Shahrukh, K. H., 2020. *Blood Reviews*, 44, Article 100674.

ICN (International Council of Nurses), 1996. Ethical guidelines for nursing research. Geneva: ICN.

Ilie, G., Mason, R., Bell, D., Bailly, G., Rendon, R.A., Mann, R., Lawen, J.G., Bowes, D., Wilke, D., Patil, N., Rutledge, R.D.H., 2019. Development and Initial Evaluation of a Multifaceted Intervention to Improve Mental Health and Quality of Life Among Prostate Cancer Survivors. International Journal of Mental Health Addiction,1-14.

Independent Cancer Taskforce, 2015. Achieving World-Class Cancer Outcomes. A Strategy for England 2015–2020.
Available from: http://www.cancerresearchuk.org/about-us/cancer-strategy-in-england

Ivankova, N. V., Creswell, J. W. and Stick, S. L., 2006. Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice, 3.

Izadnegahdar, M., Norris, C., Kaul, P., Pilote, L. and Humphries, K.H., 2014. The basis for sex-dependent outcomes in acute coronary syndrome. *Canadian Journal of Cardiology*, 30 (7), 713–720.

Jacobs, G., Lieshout, F., Borg, M. and Ness, O., 2017. Being a person-centred researcher: principles and methods for doing research in a person-centred way. Chp 4 in McCormack, B., van Dulmen, S., Eide, H., Skovdahl, K. and Eide, T., 2017. (Eds.) Person-centred Healthcare Research. Chichester, UK: Wiley-Blackwell. pp 51-60.

Jefford, M., Karahalios, E., Pollard, A., Baravelli, C., Carey, M., Franklin, J., Aranda, S. and Schofield, P., 2008. Survivorship issues following treatment completion – results from focus groups with Australian cancer survivors and health professionals. *Journal of Cancer Survivorship*, 2 (1), 20 – 32.

Jefford, M., Lotfi-Jam, K., Baravelli, C., Grogan, S., Rogers, M., Krishnasamy, M., Pezaro, C., Milne, D., Aranda, S., King, D., Shaw, B. and Schofield, P., 2011. Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. *Cancer Nursing* [online], 34 (3), E1-E10.

Jefford, M., Ward, A.C., Lisy, K., Lacey, K., Emery, J.D., Glaser, A.W., Cross, H., Krishnaswamy, M., McLachlan S.A. and Bishop, J., 2017. Patient-reported outcomes in cancer survivors: a population-wide cross-sectional study, *Supportive Care in Cancer*, 25(10), 3171–3179.

Jegede, A.S., 2009. Understanding informed consent for participation in international health research. *Developing World Bioethics*, 9 (2), 81–87.

Jennings, S., Philip, E. J., Nelson, C., Schuler, T., Starr, T., Jandorf, L., Temple, L., Garcia, E., Carter, J. and DuHamel, K., 2014. Barriers to recruitment in psycho-oncology: unique challenges in conducting research focusing on sexual health in female survivorship. *Psycho-Oncology* [online], 23 (10), 1192-1195.

Jensen, R. E., Arora, N. K., Bellizzi, K. M., Rowland, J. H., Hamilton, A. S., Aziz, N. M. and Potosky, A. L., 2013. Health-related quality of life among survivors of aggressive non-Hodgkin lymphoma. *Cancer* [online], 119 (3), 672-680.

Joakim, Ö., 2010. Review: Janice M. Morse & Linda Niehaus (2009). Mixed-Method Design: Principles and Procedures. Forum: Qualitative Social Research, (1).

Johnson, B. and Turner, L.A., 2003. Data Collection Strategies in Mixed Methods Research. In: Tashakkori, A.M. and Teddlie, C.B., Eds., Handbook of Mixed Methods in Social and Behavioural Research, SAGE Publications, Thousand Oaks, 297-319.

Johnson, R.B. and Turner, L. A., 2003. 'Data collection strategies in mixed methods research', in Tashakkori, A., Teddlie, C. (Eds): Handbook of Mixed Methods in Social and Behavioral Research, Sage, Thousand Oaks, CA.

Johnson, R. B. and Onwuegbuzie, A. J., 2004. Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher* [online], 33 (7), 14-26.

Johnson, R. B., Onwuegbuzie, A. J. and Turner, L. A., 2007a. Toward a Definition of Mixed Methods Research. *Journal, of Mixed Methods Research* [online], 1 (2), 112-133.

Johnson, R. B., Onwuegbuzie, A. J. and Turner, L. A., 2007b. Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1 (2), 112.

Johnson, R., Onwuegbuzie, A.J. and Turner, L. A., 2007.Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1, 112–33.

Johnsen, A. T., Tholstrup, D., Petersen, M. A., Pedersen, L. and Groenvold, M., 2009a. Health related quality of life in a nationally representative sample of haematological patients. *European Journal of Haematology* [online], 83 (2), 139-148.

Johnsen, A. T., Tholstrup, D., Petersen, M. A., Pedersen, L. and Groenvold, M., 2009b. Health related quality of life in a nationally representative sample of haematological patients. *European Journal Of Haematology* [online], 83 (2), 139-148

Johnson, B. and Gray, R. (2010) 'A history of philosophical and theoretical issues for mixed methods research, in Tashakkori, A., Teddlie, C. (Eds): SAGE Handbook of Mixed Methods in Social and Behavioral Research, 2nd edition, Sage, Thousand Oaks, CA.

Jones, T.L., Baxter, M, A, J. and Khanduja, V., 2013. A quick guide to survey research, *Annals Royal College of Surgeons of Englan*, 95(1),5-7.

Kaasa, S., Kvikstad, A., Bjordal, K., Aaronson, N., Moum, T., Wist, E. and Hagen, S., 1995. The EORTC Core Quality of Life questionnaire (QLQ-C30): validity and reliability when analysed with patients treated with palliative radiotherapy. *European Journal of Cancer* [online], 31 (13-14), 2260-2263.

Kang, D., Cho, J., Kim, I., Kim, M. K., Kim, W. S. and Kim, S. J., 2018. Health-Related Quality of Life in Non-Hodgkin Lymphoma Survivors: A Prospective Cohort Study. *Cancer Research And Treatment*, 50 (4), 1051-1063.

Kang, D., Kim, I.-R., Choi, E.-K., Yoon, J. H., Lee, S.-K., Lee, J. E., Nam, S. J., Han, W., Noh, D.-Y. and Cho, J., 2017b. Who are happy survivors? Physical, psychosocial, and spiritual factors are associated with the happiness of breast cancer survivors during the transition from cancer patient to survivor. *Psycho-Oncology*, 26 (11), 1922-1928.

Katz, J.N., Chang, L.C., Sangha, O., Fossel, A.H. and Bates, D.W., 1996. Can comorbidity be measured by questionnaire rather than medical record review? *Medical Care*, 34, 73–84.

Kazanjian, A., Smillie, K., Howard, A. F., Ward, A. and Doll, R., 2012. A structured approach to knowledge exchange: Understanding the implementation of a cancer survivor program. *European Journal of Oncology Nursing*, 16 (4), 399-405.

Kiebert, G.M., Stiggelbout, A.M., Kievit, J., Leer, J.W., van de Velde, C.J. and de Haes, H.J., 1994. Choices in oncology: factors that influence patients' treatment preference. *Quality of Life Research*, 3(3),175-182.

Kelly, M. and Dowling, M., 2011. Patients' lived experience of myeloma. *Nursing Standard* (Royal College Of Nursing (Great Britain): 1987) [online], 25 (28), 38-44.

Kim, S. H., Kim, I.-R., Kim, S. H., Lee, S., Ok, O., Kim, W. S., Suh, C. and Lee, M. H., 2014. Health-related quality of life in Korean lymphoma survivors compared with the general population. *Annals of Hematology* [online], 93 (9), 1531-1540.

Kim, Y., Schulz, R. and Carver, C.S., 2007. Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine*,69 (3), 83–291. doi: 10.1097/PSY.0b013e3180417cf4.

Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P. and Holecek, A., 2003. Online cancer support groups: a review of the research literature. Computers, Informatics, Nursing: CIN, 21 (3), 136-142.

Knobf, M.T., Thompson, A.S., Fennie, K. and Erdos, D., 2014. The effect of a community-based exercise intervention on symptoms and quality of life. *Cancer Nursing*, 37,43–50.

Korfage, I. J., Essink-Bot, M. L., Janssens, A. C., Schroder, F. H. and de Koning, H. J., 2006. Anxiety and depression after prostate cancer diagnosis and treatment: 5-year follow-up. *British Journal of Cancer*,94 (8), 1093-1098.

Korszun, A., Sarker, S.-J., Chowdhury, K., Clark, C., Greaves, P., Johnson, R., Kingston, J., Levitt, G., Matthews, J., White, P., Lister, A. and Gribben, J., 2014. Psychosocial factors associated with the impact of cancer in long-term haematological cancer survivors. *British Journal of Haematology* [online], 164 (6), 790.

Kriegsman, D. M. W., Deeg, D. J. H. and Stalman, W. A. B., 2004. Comorbidity of somatic chronic diseases and decline in physical functioning; the Longitudinal Aging Study Amsterdam. *Journal Of Clinical Epidemiology*, 57 (1), 55-65.

Krouse, R. S., Herrinton, L. J., Grant, M., Wendel, C. S., Green, S. B., Mohler, M. J., Baldwin, C. M., McMullen, C. K., Rawl, S. M., Matayoshi, E., Coons, S. J. and Hornbrook, M. C., 2009. Health-related quality of life among long-term rectal cancer survivors with an ostomy: manifestations by sex. *Journal Of Clinical Oncology*: The American Society Of Clinical Oncology, 27 (28), 4664-4670.

Kvale S, Brinkmann S. InterViews: Learning the craft of qualitative interviewing. Los Angeles, CA: Sage; 2009.

Kyle, R.A. and Rajkumar, S.V., 2009. Criteria for diagnosis, staging, risk stratification and response assessment of multiple myeloma, *Leukemia*, 23(1),3–9.

Lagergren, P., Schandl, A., Aaronson, N. K., Adami, H. O., de Lorenzo, F., Denis, L., Faithfull, S., Liu, L., Meunier,F. and Urich, C., 2019. Cancer survivorship: an integral part of Europe's research agenda. *Molecular Oncology*, *13* (3), 624–635.

Langbecker, D., Ekberg, S., Yates, P., Chan, A., Chan, R. and Chan, R. J., 2016. What are the barriers to quality survivorship care for haematology cancer patients? Qualitative insights from cancer nurses. *Journal of Cancer Survivorship*, 10 (1), 122-130.

Lashbrook, M., Bernardes, C. M., Kirshbaum, M. N. and Valery, P. C., 2018. Physical functioning and psychological morbidity among regional and rural cancer survivors: A report from a regional cancer centre. *Australian Journal of Rural Health*, 26 (3), 211-219.

Lavdaniti, M. and Tsitsis, N., 2015. Definitions and conceptual models of quality of life in cancer patients. *Health Science Journal*, 9.

Lebel, S., Ozakinci, G. and Humphris, G., 2016. From the normal response to the clinical problem: definition and clinical features of fear of cancer recurrence, *Supportive Care in Cancer*, 24 (8), 3265–3268. DOI: 10.1007/s00520-016-3272-5

Leigh, S., 1992. Myths, Monsters, and Magic: Personal Perspectives and Professional Challenges of Survival (10. pp. 1475). United States: Oncology Nursing Society.

Lent, R.W., 2007. Restoring emotional well-being: a theoretical model. In *Handbook of Cancer Survivorship*, Feuerstein M (ed), pp 231–248. Springer: New York

Lev, E., Daley, K.,, Connor, N., Reith, M., Fernandez, C. and Owen, S., 2001. An intervention to increase quality of life and self-care self-efficacy and decrease symptoms in breast cancer patients. *Research and Theory for Nuring Practice*, 5(3),277–94.

Levato, L., Cantaffa, R., Kropp, M. G., Magro, D., Piro, E. and Molica, S., 2013. Progressive peripheral arterial occlusive disease and other vascular events during nilotinib therapy in chronic myeloid leukaemia: a single-institution study. *European Journal Of Haematology*, 90 (6), 531-532.

Leunis, A., Redekop, W. K., Uyl-de Groot, C.A. and Löwenberg, B., 2014. Impaired health-related quality of life in acute myeloid leukemia survivors: a single-center study. *European Journal of Haematology*, 93(3),198–206. https://doi.org/10.1111/ejh.12324

Li, W. W. Y., Lam, W. W. T., Au, A. H. Y., Ye, M., Law, W. L., Poon, J., Kwong, A., Suen, D., Tsang, J., Girgis, A. and Fielding, R., 2013. Interpreting differences in patterns of supportive care needs between patients with breast cancer and patients with colorectal cancer. *Psycho-Oncology*, 22 (4), 792-798.

Liao, L -J., Hsu, W.-L., Lo, W.-C., Cheng, P.-W., Sheung, P.-W. and Hsieh, C.-H., 2019. Health-related quality of life and utility in head and neck cancer survivors. *Biomedical Central Cancer*, 19 (1), 425-425.

Linendoll, N., Saunders, T., Burns, T., Nyce, J.D., Wendell, K.B., Evens, A.B. and Parsons, S.K., 2016. Health-related quality of life in Hodgkin lymphoma: a systematic review, *Health and Quality of Life Outcomes,* 14,114.

Leigh, S., 2004. Defining our destiny. In B Hoffman (Ed), A cancer survivor's almanack: Charting your journey, Hoboken, NJ: John Wiley.

Lobb, E. A., Joske, D., Butow, P., Kristjanson, L. J., Cannell, P., Cull, G. and Augustson, B., 2009. When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Education and Counseling*, 77 (1), 103-108.

Londonhttps://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2015.

Lorig, K., Sobel, D., Ritter, P., Laurent, D. and Hobbs, M., 2001. Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice*, 4(6), 256–62.

Lowy, A. and Bernhard, J., 2004. Quantitative assessment of changes in patients' constructs of quality of life An application of multilevel models. *Qualitative of Life Research*, 13 (7),1177-1185.

Luckett, T., King, M. T., Butow, P. N., Oguchi, M., Rankin, N., Price, M. A., Hackl, N. A. and Heading, G., 2011a. Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: issues, evidence and recommendations. *Annals Of Oncology*, 22 (10), 2179-2190.

Luckett, T., King, M. T., Butow, P. N., Oguchi, M., Rankin, N., Price, M. A., Hackl, N. A. and Heading, G., 2011b. Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: issues, evidence and recommendations. *Annals Of Oncology*: Official Journal Of The European Society For Medical Oncology, 22 (10), 2179-2190.

Lund, M.B., Kongerud, J., Nome, O., Abrahamsen, A.F., Bjortuft, O., Forfang K. and Boe, J., 1995. Lung function impairment in long-term survivors of Hodgkin's disease. *Annals of oncology*, 6, 495-501.

Macmillan Cancer Support, 2011. Living After Diagnosis: Median Survival Times. https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf[Accessed May 2019].

Macmillan Cancer Support, 2013. Throwing light on the consequences of cancer and its treatment http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Throwinglightontheconsequencesofcanceranditstreatment.pdf accessed 2021

Macmillan Cancer Support, National Cancer Intelligence Network, & Monitor Deloitte. (2014). Routes from Diagnosis (1st ed.). Retrieved from http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/routes-from-diagnosis-report.pdf

Macmillan Cancer Support, 2015. The Changing Story of Cancer http://www.macmillan.org.uk/Documents/AboutUs/Research/TheChangingStoryofCancer.pdf accessed 2021

https://www.macmillan.org.uk/information-and-support/lymphoma/lymphoma-non-hodgkin#163217 [Accessed May 2019].

https://www.macmillan.org.uk/information-and-support/leukaemia/chronic-lymphocytic/understanding-cancer/about-cll.html#270531[Accessed May 2019].

https://www.macmillan.org.uk/information-and-support/lymphoma/lymphoma-non-hodgkin/treating/overview.html [Accessed May 2019].

Maddams, J., Brewster, D., Gavin, A., Steward, J., Elliott, J., Utley, M. and Moller, H., 2009. Cancer prevalence in the United Kingdom: estimates for 2008, 541.

Maddams, J., Utley, M. and Møller, H., 2012. Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal Of Cancer*, 107 (7), 1195-1202.

Mahato, P., Angell, C., van Teijlingen, E. and Simkhada, P., 2018. Using mixed-methods research in health and education in Nepal. *Journal of Health Promotion*, 6, 45-48.

Maher, J. and McConnell, H., 2011. New pathways of care for cancer survivors: adding the numbers. *British Journal of Cancer*,8,105, S5.

Maleki, M., Mardani, A., Ghafourifard, M. and Vaismoradi,M., 2021.. Qualitative exploration of sexual life among breast cancer survivors at reproductive age. *BMC Women's Health,* 21**,** 56.

Malvezzi, M., Bertuccio, P., Rosso, T., Rota, M., Levi, F., La Vecchia, C. and Negri, E ., 2015. European cancer mortality predictions for the year 2015: does lung cancer have the highest death rate in EU women? *Annals of Oncology*, 26, 779–786.

Manderson, L., Bennett, E. and Andajani-Sutjahjo, S., 2006. The Social Dynamics of the Interview: Age, Class, and Gender. *Qualitative Health Research*, 16 (10), 1317-1334.

Mann, S., 2016. *The research interview: Reflective practice and reflexivity in research processes*. London: Palgrave Macmillan.

Margarida, M., Giulia, B., Mohamed, N., Antonio Di, M., Stefan, M., Ann, H. P., Marc Karim, B., Karim, F., Michel, D., Fabrice, A. and Ines, V. L., 2019. Fatigue and physical activity in cancer survivors: A cross-sectional population-based study. *Cancer Medicine*, (5), 2535.

Martin, C. R. and Thompson, D. R., 2000. Design and analysis of clinical nursing research studies [Non-fiction]. Routledge.

Attia, M., Edge, J. 2017. Becoming a reflexive researcher: a developmental approach to research methodology, *Open Review of Educational Research*, 4:1, 33-4., DOI: 10.1080/23265507.2017.1300068

Mason, B., Nanton, V., Epiphaniou, E., Murray, S.A., Donaldson, A., Shipman, C., Daveson, B. A., Harding, R., Higginson, I. R., Munday, D., Barclay, S., Dale, J., Kendall, M., Worth, A. and Boyd, K., 2014. 'My body's falling apart.' understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers. *BMJ Supportive Palliative Care*, 6, 60–65.

Matalqah, L. M., Yusoff, Z. M., Awais, A. and Radaideh, K. M., 2011. Health-related quality of life using EQ-5D among breast cancer survivors in comparison with age-matched peers from the general population in the state of Penang, Malaysia. *Journal of Public Health* [online], 19 (5), 475-480.

Matthews, A. K., Tejeda, S., Johnson, T. P., Berbaum, M. L. and Manfredi, C., 2012. Correlates of Quality of Life Among African American and White Cancer Survivors. *Cancer Nursing* [online], 35 (5), 355-364.

Maxcy, S. J.,2003. Pragmatic threads in mixed methods research in the social sciences: The search for multiple modes of inquiry and the end of the philosophy of 79 formalism. In: A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in the behavioural and social sciences*, pp. 51-89. Thousand Oaks, CA: Sage Publications.

McCabe, M. S., Bhatia, S., Oeffinger, K. C., Reaman, G. H., Tyne, C., Collins, D. S. and Hudson, M. M., 2013. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. *Journal Of Clinical Oncology [*online], 31 (5), 631-640.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K. and Wagner, E.H.,2011. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer Journal for Clinicians*, 61(1),50-62. doi: 10.3322/caac.20093. Epub 2011 Jan 4. PMID: 21205833; PMCID: PMC3058905.

McDonald, H. N., Dietrich, T., Townsend, A., Li, L. C., Cox, S. and Backman, C. L., 2012. Exploring occupational disruption among women after the onset of rheumatoid arthritis. *Arthritis Care & Research* [online], 64 (2), 197-205.

McGrath, P. and Phillips, E., 2008. "It is very hard": treatment for childhood lymphoma from the parents' perspective. *Issues in Comprehensive Pediatric Nursing*, 31 (1), 37-54.

McIntosh, C. N., 2012. Improving the evaluation of model fit in confirmatory factor analysis: A commentary on Gundy, C. M., Fayers, P. M., Groenvold, M., Petersen, M. A., Scott, N.W., Sprangers, M A J., Aelikov, G, Aaronson, N K., 2011. Comparing higher-order models for the EORTC QLQ-C30 Quality of Life Research. Quality of Life Research: *An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 21 (9), 1619-1621.

McLaughlin, H., 2009. Keeping service user involvement in research honest. *British Journal of Social Work*, 40, 1591-1608.

McMillan, J. H., 2000. *Educational research: fundamentals for the consumer* (3rd ed.). New York, NY: Addison Wesley Longman.

McNaughton Collins, M., Pontari, M. A., O'Leary, M. P., Calhoun, E. A., Santanna, J., Landis, J. R., Kusek, J. W. and Litwin, M. S., 2001. Quality of life is impaired in men with chronic prostatitis: the Chronic Prostatitis Collaborative Research Network. *Journal Of General Internal Medicine*, 16 (10), 656-662.

Mechteld, V., Frans, O., Jan van, L., Jacobus van der, V., Jaap, K., Dirk, G. and Mirjam, S., 2005. P-236/1180/Testing the Response Shift Model of Sprangers and Schwarz Empirically. *Quality of Life Research* [online], 14 (9), 2109.

Mellon, S., Northouse, L. L. and Weiss, L. K., 2006. A Population-Based Study of the Quality of Life of Cancer Survivors and Their Family Caregivers. *Cancer Nursing*, 29 (2), 120-131.

Merli, F., Bertini, M., Luminari, S., Mozzana, R., Bertè, R., Trottini, M., Stelitano, C., Botto, B., Pizzuti, M., Quintana, G., De Paoli, A. and Federico, M., 2004. Quality of life assessment in elderly patients with aggressive non-Hodgkin's Lymphoma treated with anthracycline-containing regimens. Report of a prospective study by the Intergruppo Italiano Linfomi. *Haematologica* [online], 89 (8), 973-978.

Michael, C. R., Elizabeth, J. L., Jaejoong, S., Matthew, C.-M., Yisheng, L., Charles, E. G., Bernardine, M. P., Cindy, L. C., Carol, H., George, B. and Karen, M. B.-E., 2019. Change in physical activity and quality of life in endometrial cancer survivors receiving a physical activity intervention. *Health and Quality of Life Outcomes*, (1), 1.

Miles, M. & Huberman, M., 1994. *Qualitative data analysis: an expanded sourcebook*. (2nd ed.) Thousand Oaks: Sage Publications.

Miller, M. D., Paradis, C. F., Houck, P. R., Mazumdar, S., Stack, J. A., Rifai, A. H., Mulsant, B. and Reynolds, C. F., 3rd, 1992. Rating chronic medical illness burden in geropsychiatric practise and research: application of the Cumulative Illness Rating Scale. *Psychiatry Research* [online], 41 (3), 237-248.

Miller, D., 2000. *Qualitative Research Course Packet.* University of Nebraska – Lincoln.
Miller, K., 2009. Medical and Psychosocial Care of the Cancer Patient, Sudbury, MA; Jones and Bartlett.

Miller, K.D., Siegel, R.L., Lin, C.C., Mariotto, A.B., Kramer, J.L, Rowland, J.H., Stein, K.D., Slteri, R. and Jemal, A., 2016. Cancer treatment and survivorship statistics, 2016. *CA Cancer Journal for Clinician*s,66 (4),271-289.

Miltenyi, Z., Magyari, F., Simon, Z. and Illes, A.2010. Quality of life and fatigue in Hodgkin's lymphoma patients, *Tumori*, 96,594–600.

Minichiello, Victor & Sullivan, Gerard & Greenwood, Ken & Axford, Rita. (2004). Research Methods for Nursing and Health Science. (2nd ed), Sydney: Pearson.

Miranda, M.B., Lauseker, M., Kraus, M.P., Proete,l U., Hanfstein, B., Fabarius, A., Baerlocher, G.M., Heim, D., Hossfeld, D.K., Kolb, H-J., Krause, S.W., Nerl, C., Brummendof, T.H., Verbeel, W., Fauser, A. A., Prummer, o., Neben, K., Hess.U., Mahlberg, R., Ploger,C., Flasshove., Rendenbach, B., Muller, M.C., Hasford, J., Hehlmann, R. and Saudbele,S., 2016. Secondary malignancies in chronic myeloid leukemia patients after imatinib-basedtreatment: long-term observation in CML Study IV. *Leukemia,* 30, pp. 1255-1262.

Mitchell, A. J., Ferguson, D. W., Gill, J., Paul, J. and Symonds, P., 2013. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncology*, 14 (8),721-732.

Mixed Methods International Research Association. http://mmira. wildapricot.org/page-1859605. Accessed September 10, 2019.

Molassiotis, A., Wilson, B., Blair, S., Howe, T. and Cavet, J., 2011. Unmet supportive care needs, psychological well being and quality of life in patients living with multiple myeloma and their partners, *Psychooncology*,20(1),88-97.

Mols, F., Aaronson, N. K., Vingerhoets, A. J. J. M., Coebergh, J.-W. W., Vreugdenhil, G., Lybbert, M. L. M. and van de Poll-Franse, L. V., 2007. Quality of life among long-term non-Hodgkin lymphoma survivors: a population-based study. *Cancer*, 109 (8), 1659-1667.

Mols, F., Thong, M. S., Vreugdenhil, G. and van de Poll-Franse, L. V., 2009. Long-term cancer survivors experience work changes after diagnosis: results of a population-based study, *Psychooncology*,18(12),1252-1260.

Mols, F., Vingerhoets, A. J. J. M., Coebergh, J. W., Vreugdenhil, G., Aaronson, N. K., Lybeert, M. L. M. and van de Poll-Franse, L. V., 2006. Better quality of life among 10-15 year survivors of Hodgkin's lymphoma compared to 5-9 year survivors: a population-based study. *European Journal Of Cancer* (Oxford, England: 1990) [online], 42 (16), 2794-2801.

Mols, F., Oerlemans, S., Vos, A.H., Koster, A., Verelst, S., Sonneveld, P., 2012. et. al.: Health-related quality of life and disease-specific complaints among multiple myeloma patients up to 10 yr after diagnosis: results from a population-based study using the PROFILES registry. *European Journal of Haematology*, 89, 311-319.

Montgomery, C., Pocock, M., Titley, K. and Lloyd, K., 2002. Individual quality of life in patients with leukaemia and lymphoma. Psycho-Oncology [online], 11 (3), 239-243.

Moore, H. C. F., 2014. An overview of chemotherapy-related cognitive dysfunction, or 'chemobrain'. *Oncology* (Williston Park, N.Y.) [online], 28 (9), 797-804.

Mortensen, G.L. Salomo, M., 2016. Quality of Life in Patients with Multiple Myeloma: A Qualitative Study. *Journal of Cancer Science and Therapy*, 8, 289-293.

Morgan, D. L., 2007. Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. *Journal of Mixed Methods Research* [online],1 (1), 48-76.

Morris, B. A., Shakespeare-Finch, J. and Scott, J. L., 2012. Posttraumatic growth after cancer: the importance of health-related benefits and newfound compassion for others, *Supportive Care in Cancer,* 20 (4),749-756.

Morse, J.M. and Niehaus, L., 2009. *Mixed Methods Design: Principles and Procedures*. 1st ed. Walnut Creek, CA: Left Coast Press.

Moscaritolo, L. M., 2009. Interventional strategies to decrease nursing student anxiety in the clinical learning environment. *Journal of Nursing Education*, 48 (1), 17-23..

Moser, E.C., Noordijk, E.M., van Leeuwen, F.E., le Cessie, S., Baars, J.W., Thomas, J., Carde, P., Meerwaldt, J.H., van Glabbeke, M. and Kluin- Nelemans, H. C., 2006. Long-term risk of cardiovascular disease after treatment for aggressive non-Hodgkin lymphoma. *Blood*, 107, 2912-2919.

Moser, E. C. & Meunier, F., 2014. Cancer survivorship: A positive side-effect of more successful cancer treatment. *European Journal of Cancer Supplements*, 12, 1-4.

Mounier, M., Bossard, N., Remontet, L., Belot, A., Minicozzi, P., De Angelis, R., Capocaccia, R., Iwaz, J., Monnereau, A., Troussard, X., Sant, M., Maynadié, M. and Giorgi, R., 2015. Changes in dynamics of excess mortality rates and net survival after diagnosis of follicular lymphoma or diffuse large B-cell lymphoma: comparison between European population-based data (EUROCARE-5). *The Lancet*. *Haematology*, 2 (11), e481-e491.

Mounier,N., Anthony,R., Busson,R., Thieblemont,C., Ribrag,V., Tilly,H., Haioun, C., Casasnovas, R-O., Morschhauser,F., Feugier,P., Delarue,R., Ysebaert,L., Sebban, C., Broussais-Guillaumot, F., Damaj,G., Nerich, V., Jais, J-p., Laborde,L., Salles,G.and Henry-Amar, M., 2019. Long-Term Fatigue in Survivors of Non-Hodgkin Lymphoma: The Lymphoma Study Association SIMONAL Cross-Sectional Study. *Cancer*,125, 2291-2299.

MRC 2000 https://mrc.ukri.org/documents/pdf/rcts-for-complex-interventions-to-improve-health/

Mustapa, N. and Yian, L. G., 2007a. Pilot-testing the Malay version of the EORTC questionnaire. *Singapore Nursing Journal*, 34 (2), 16-20.

Mustapa, N. and Yian, L. G., 2007b. Pilot-testing the Malay Version of the EORTC Questionnaire, 16.

https://www.myeloma.org.uk/documents/high-dose-therapy-and-autologous-stem-cell-transplantation-infoguide/ [Accessed May 2019].

Myrehaug, S., Pintilie, M., Tsang, R., Mackenzie, R., Crump, M., Chen, Z., Sun, A. and Hodgson, D.C., 2008. Cardiacmorbidity following modern treatment for Hodgkin lymphoma: supra-additive cardiotoxicity of doxorubicin and radiation therapy. *Leukemia and Lymphoma*, 49, 1486-1493.

Namrata, V. and Crystal, S. D., 2015. Lifestyle Factors in Cancer Survivorship: Where We Are and Where We Are Headed. *Journal of Personalized Medicine*, (3), 243.

National Cancer Survivorship Initiative, 2010. Priorities for research on cancer survivorship. Retrieved from http://www.ncsi.org.uk/wp-content/uploads/NCSI-Research-Priorities-Report.pdf

National Cancer Survivorship Initiative, 2013. Living with and beyond cancer: taking action to improve outcomes.

National Cancer Research Institute, The NCRI Living With and Beyond Cancer research initiative (http://www.ncri.org.uk/accelerating-cancer-research/lwbc/living-with-and-beyond-cancer-research-initiative/)

National Institute for Health and Care Excellence. Haematological cancers: improving outcomes (guidance update) [Internet]; 2016 May 25 [cited 2019 March 26]. Available from: https://www.nice.org.uk/guidance/ng47/resources/haematologicalcancers-improving-outcomes-1837457868229

National Coalition for Cancer Survivorship (NCCS), 2013. About us. Retrieved 30th September 2018 from http://canceradvocacy.org/about-us/

National Coalition for Cancer Survivorship (2015). NCCS Mission http://www.canceradvocacy.org/about-us/our-mission/ accessed 2021

National Institute for Clinical Excellence NICE, 2003.Health care services for haematological cancers. London: National Health Service.

National Institute of Clinical Excellence, 2016. *Haematological cancers: improving outcomes.* NICE Guideline NG47. Available from: www. nice. org.uk [last accessed 04 December 2018].

National Institute for Clinical Excellence (NICE) (2003) Guidance on cancer services improving outcomes in haematological cancers: the manual. National Health Service.

Neal, R. D., Nekhlyudov, L., Wheatstone, P., & Koczwara, B., 2020. Cancer care during and after the pandemic. British Medical Journal, 370, m2622. https://doi.org/10.1136/bmj.m2622

Ness, K. K., Hudson, M. M., Ginsberg, J. P., Nagarajan, R., Kaste, S. C., Marina, N., Whitton, J., Robison, L. L. and Gurney, J. G., 2009. Physical performance limitations in the Childhood Cancer Survivor Study cohort. *Journal Of Clinical Oncology*: Official Journal Of The American Society Of Clinical Oncology, 27 (14), 2382-2389.

Ng, A.K., Lacasce, A. and Travis, L.B., 2011. Long-term complications of lymphoma and its treatment. *Journal of Clinical Oncology*, 29,1885-1892.

Ng, A.K., 2011. Review of the cardiac long-term effects of therapy for Hodgkin lymphoma. *British Journal of Haematology*, 154,23-31.

Nowell, L.S., Norris, J.M., White, D.E. and Moules, N.J., 2017. Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods,* 16, 1-13.

McCabe, M.S., Bhatia, S., Oeffinger, K.C., Reaman, G.H., Tyne, C., Collins, D.S., Hudson, M.M., 2013. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. *Journal of Clinical Oncology*, 31(5),631–640.

National Center for Complementary and Alternative Medicine (NCCAM). http://nccam.nih.gov/. [Accessed June 2019].

Nettleton, S., 1997. Governing the risky self in *Foucault: Health and Medicine* (Petersen A and Bunton R, eds) Routledge, London: the UK, 207-222.

NHS England, 2019. https://www.england.nhs.uk/cancer/living/#quality-of-life [Accessed October 2019].

The NHS Long term plan, 2019. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf (accessed November 2021).

NMC, 2008. The code: Standards of conduct, performance, and ethics for nurses and midwives. Nursing and Midwifery Council: London.

Nolte, S., Liegl, G., Petersen, M. A., Aaronson, N. K., Costantini, A., Fayers, P. M., Groenvold, M., Holzner, B., Johnson, C. D., Kemmler, G., Tomaszewski, K. A., Waldmann, A., Young, T. E. and Rose, M., 2019. General population normative data for the EORTC QLQ-C30 health-related quality of life questionnaire based on 15,386 persons across 13 European countries, Canada and the United States. *European Journal of Cancer* [online], 107, 153-163.

Ntetu Antoine, L., Vanasse, A., Hudon, C., Lapointe, L., Fortin, M. and Maltais, D., 2004. Multimorbidity and quality of life in primary care: a systematic review. *Health and Quality of Life Outcomes*, 1, 51.

O'Brien, E.M., Black, M.C., Carley-Baxter, L.R. and Simon, T.R.,2006. Sensitive Topics, Survey Nonresponse, and Considerations for Interviewer Training. *American Journal of Preventive Medicine*,31(5), 419-426.

O'Brien, R., Wyke, S., Guthrie, B., Watt, G., Mercer, S., 2011. An 'endless struggle': a qualitative study of general practitioners' and practice nurses' experiences of managing multimorbidity in socio-economically deprived areas of Scotland. *Chronic Illness*, 7(1):45–59.

O Cathain, A., Murphy, E. and Nicholl, J., 2008. The quality of mixed methods studies in health services research, *Journal of Health Services Research and Policy*,13(2), 92 - 98.

O'Cathain, A., Murphy, E. and Nicholl, J., 2007. Why, and how, mixed methods research is undertaken in health services research in England: a mixed-methods study. *BMC Health Services Research [*online], 7, 85-85.

Oberoi, D. V., White, V. M., Seymour, J. F., Prince, H. M., Harrison, S., Jefford, M., Winship, I., Hill, D. J., Bolton, D., Millar, J., Wong Doo, N., Kay, A. and Giles, G., 2017. Distress and unmet needs during treatment and quality of life in early cancer survivorship: A longitudinal study of haematological cancer patients. *European Journal of Haematology*, 99 (5), 423-430.

O'Brien, E.M., Black, M.C., Carley-Baxter, L.R. and Simon, T.R..2006. Sensitive Topics, Survey Nonresponse, and Considerations for Interviewer Training. *American Journal of Preventive Medicine*, 31(5):419–426. doi: 10.1016/j.amepre.2006.07.010.

OECD, 2004. Social Expenditure Database (SOCX), 1980–2001. Organisation for Economic Co-operation and Development, Paris.

Office of National Statistics, 2014. Cancer Survival in England: Adults Diagnosed 2008 to 2012, followed up to 2013. London.

Office of National Statistics, 2010. 2009 and 1999 Mid-Year Population Estimates. London.

Office for National Statistics [ONS] (2018). Cancer Survival Statistics: England Statistical Bulletins. [Accessed December 2018].

Office for National Statistics [ONS] (2018). https://www.ons.gov.uk/economy/grossvalueaddedgva/bulletins/regionalgrossvalueaddedbalanceduk/1998to2017#interactive-map-gross-value-added-gva-per-head-for-nuts3-local-areas-1998-to-2017

Office for National Statistics. Living longer: how our population is changing and why it matters. London: Office for National Statistics; 2018.

Oh, M. G., Han, M. A., Park, C.-Y., Park, S.-G. and Chung, C. H., 2014. Health-related quality of life among cancer survivors in Korea: the Korea National Health and Nutrition Examination Survey. *Japanese Journal Of Clinical Oncology* [online], 44 (2), 153-158.

www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016#-cancer- survival in - England - patients - diagnosed - between-2011-and-2015-and-followed-up-to-2016-national-statistics

Oliver, S., Rees, R., Clarke-Jones, L., Milne, R., Oakley, A.R., Gabbay, J., Stein, K., Buchanan, P. and Gyte,G., 2008. A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations*,11(1):72-84.

Onwuegbuzie, A. and Burke Johnson, R., 2006. The validity issue in mixed reesarch. *Research in the schools,*13 (1), 48-63.

O'Reilly, R., Peters, K., Beale, B. and Jackson, D., 2009. Women's experiences of recovery from childbirth: focus on pelvis problems that extend beyond the puerperium. *Journal of Clinical Nursing*, 18(14):2013-9.

Osoba, D., Aaronson, N. K., Muller, M., Sneeuw, K., Hsu, M. A., Yung, W. K. A., Brada, M. and Newlands, E., 1997. Effect of neurological dysfunction of health-related quality of life in patients with high-grade glioma, *Journal of Neuro-oncology*, 34 (3), 263-278.

Osaki, K., Morishita, S., Takami, S., Sakai,Y., Kamimura, A. and Shindo, A., 2022. Quality of life of patients with hematological malignancies and factors affecting health state utility values. *Supportive Care in Cancer*,DOI: 10.1007/s00520-022-06958-y. PMID: 35278136.

Padilla, G. and Ropka, M. E., 2005. Quality of life and chemotherapy-induced neutropenia. *Cancer Nursing* [online], 28 (3), 167-171.

Palumbo, A., Bringhen, S., Kumar, S.K., Lupparelli, G., Usmani, S., Waage, A., Larocca,A., Musto, P., Offidani, m., Petrucci, M.T., Evangelista, A., Zweegman, S., Nooka, A.K., Spencer, A., Hajek, R., Cavo, M., Richardson, P., Lonial, S., Ciccone, G., Boccadoro, M., Anderson K., Barlogie, B., Sonneveld, P. and mccarthy, P.L., 2014. Second primary malignancies with lenalidomide therapy for newly diagnosed myeloma: a metaanalysis of individual patient data. *Lancet Oncology*, 15, 333-342.

Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M. and Rowland, J. H., 2011. Cancer Survivors: A Booming Population. [online], *Epidemiological Biomarkers and Prevention*, 20(10), 1996-2005.

Paterson, C., Robertson, A., Smith, A. and Nabi, G.,2015. Identifying the unmet supportive care needs of men living with and beyond prostate cancer: a systematic review. European Journal of Oncology Nursing, 19 (4), 405-418.

Patton, M. Q., 1990. Qualitative evaluation and research methods / Michael Quinn Patton [Non-fiction]. Newbury Park, Calif. ; London: Sage, 1990. 2nd ed.

Patton, M. Q., 2002. *Qualitative Research & Evaluation Methods*. (3 ed.) California: Sage Publications.

Paulhos, D. L., 1991.
https://www2.psych.ubc.ca/~dpaulhus/research/CIRCUMPLEX/ETS%20chapter.pdf

Penson, D. F., Feng, Z., Kuniyuki, A., McClellan, D., Albertsen, P. C., Deapen, D., Gilliland, F., Hoffman, R., Stephenson, R. A., Potosky, A. L. and Stanford, J. L., 2003. The general quality of life 2 years following treatment for prostate cancer: what influences outcomes? Results from the prostate cancer outcomes study. *Journal Of Clinical Oncology*, 21(6), 1147-1154.

Petrie, A. and Sabin, C., 2009. Medical statistics at a glance [Non-fiction]. Oxford: Wiley-Blackwell, 2009. 3rd ed.

Petrisor, B. A. and Bhandari, M., 2006. Principles of teaching evidence-based medicine. Injury [online], 37(4), 335-339.

Pham, M.T., Rajić, A., Greig, J.D., Sargeant, J.M., Papadopoulos, A., McEwen, S.A., 2014. A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research Synthesis Methods*, 4, 3, 71-85. doi: 10.1002/jrsm.1123. Epub 2014 Jul 24. PMID: 26052958; PMCID: PMC4491356.

Piccirillo, J. F., 2000. Importance of comorbidity in head and neck cancer. *The Laryngoscope* [online], 110 (4), 593-602.

Piccirillo, J. F., Tierney, R. M., Costas, I., Grove, L. and Spitznagel, J. E. L., Prognostic Importance of Comorbidity in a Hospital-Based Cancer Registry. JAMA: *Journal of the American Medical Association*, 291 (20), 2441-2447.

Pickard, A. S., Wilke, C. T., Lin, H.-W. and Lloyd, A., 2007. Health utilities using the EQ-5D in studies of cancer. *Pharmacoeconomics* [online], 25 (5), 365-384.

Pidala, J., Anasetti, C. and Jim, H., 2010. Health-related quality of life following haematopoietic cell transplantation: patient education, evaluation and intervention. *British Journal of Haematology*, 148,373–85.

Pluye, P., Bengoechea, E.G., Granikov, V., Kaur, N. and Tang, D., 2018. A world of possibilities in mixed methods: a review of the combinations of strategies used to integrate the phases, results and quantitative and qualitative data (Invited paper). *International Journal of Multiple Research Approaches*, 10 (1), 41–56.

Polit, D. F. and Beck, C. T., 2004. Nursing research: principles and methods / Denise F. Polit, Cheryl Tatano Beck [Non-fiction]. Philadelphia; London: Lippincott Williams & Wilkins,
7th ed.

Polit, D. F. and Beck, C. T., (Eds)2006. Essentials of nursing research: Methods,appraisal and utilization. Philadelphia:Lippincott Williams and Wilkins.

Polit, D. and Beck, C. T., 2012. Nursing Research: Generating and Assessing Evidence for Nursing Practice. (9th ed). Wolters Kluwer Health. P.153-156, 658.

Poulos, A. R., Gertz, M. A., Pankratz, V. S. and Post-White, J., 2001. Pain, mood disturbance, and quality of life in patients with multiple myeloma. *Oncology Nursing Forum*, 28 (7), 1163-1171.

Priest.H., 2002. An approach to the phenomenological analysis of data. *Nurse Researcher*, 10(2),50-63.

Priscilla, D., Salmiah, M. S., Hamidin, A., Azhar, M. Z., Noorjan, K. and Bahariah, K., 2011. The socio-demographic and clinical factors associated with quality of life among patients with haematological cancer in a large government hospital in Malaysia. *Malaysian Journal of Medical Sciences* [online], 18 (3), 49-56.

Pryce, J., Munir, F. and Haslam, C., 2007. Cancer survivorship and work: Symptoms, supervisor response, co-worker disclosure and work adjustment. *Journal of Occupational Rehabilitation* [online], 17 (1), 83-92.

Quinn, G. P., Gonçalves, V., Sehovic, I., Bowman, M. L. and Reed, D. R., 2015. Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient-Related Outcome Measures* [online], 6, 19-51.

Rabin, R. and Charro, F. d., 2001. EQ-SD: a measure of health status from the EuroQol Group. *Annals of Medicine* [online], 33 (5), 337.

Raphael, D., Frey, R. and Gott, M., 2019. Maintaining psychosocial wellbeing for post-treatment haematological cancer survivors: Strategies and potential barriers. *European Journal of Oncology Nursing*, 38, 36-41.

Ramasubbu, S.K., Pasricha, R.K., Nath, U.K., Rawat, V.S. and Das, B., 2021. Quality of life and factors afecting it in adult cancer patients undergoing cancer chemotherapy in a tertiary care hospital. *Cancer Reports* (Hoboken) 4 (2):e1312. https://doi.org/10.1002/cnr2.1

Rapport, F. and Braithwaite, J., 2018. Are we on the cusp of a fourth research paradigm? Predicting the future for a new approach to methods-use in medical and health services research. *BMC Medical Research Methodology*,18,131.

Ream, E., Quennel,l A., Fincham, L.,2008. Supportive care needs of men living with prostate cancer in England: a survey. *Britsh Journal of Cancer*, 98,1903–9.

Redwood, S., and Gill, P. S., 2013. Under-representation of minority ethnic groups in research--call for action. *The British journal of general practice: the journal of the Royal College of General Practitioners*, 63(612), 342–343. doi:10.3399/bjgp13X668456

Rencz, F., Gulácsi, L., Drummond, M., Golicki, D., Prevolnik Rupel, V., Simon, J., Stolk, E., Brodszky, V., Baji, P., Závada, J., Petrova, G., Rotar, A. and Péntek, M., 2016. EQ-5D in Central and Eastern Europe: 2000-2015. *Quality of Life Research* [online], 25 (11), 2693-2710.

Rezaei, O., Sharifian, R.-A., Soleimani, M. and Jahanian, A., 2012. The Quality of Life of Haematological Malignancy Patients with Major Depressive Disorder or Subsyndromal Depression. *International Journal of Psychiatry in Medicine* [online], 44 (2), 149-163.

Ringdal, G.I. and Ringdal, K., 1993. Testing the EORTC Quality of Life Questionnaire on cancer patients with heterogeneous diagnoses. *Quality of Life Research*,2, 129-140.

Richardson, Laurel (2000), "Writing: A Method of Inquiry," in Norman K. Denzin and Yvonna S. Lincoln (eds.), Handbook of Qualitative Research (2nd ed.). Thousand Oaks, CA: Sage Publications, 923-948.

Ritchie, J., Lewis, J., Nicholls, C. M. & Ormston, R., (Eds.). (2013). *Qualitative research practises A guide for social science students and researchers.* Thousand Oaks, CA: Sage

Rocco, T. S., Bliss, L. A., Gallagher, S. and Pérez-Prado, A., 2003. Taking the next step: Mixed Methods Research in Organisational Systems. *Information Technology, Learning & Performance Journal* [online], 21 (1), 19-29.

Rohn, E. J., Tate, D. G., Forchheimer, M. and DiPonio, L., 2018. Contextualizing the lived experience of the quality of life for persons with spinal cord injury: A mixed-methods application of the response shift model. *The Journal Of Spinal Cord Medicine* [online], 1-9.

Rogers, K., 2008. Ethics and qualitative research: Issues for midwifery researchers, *British Journal of Midwifery*, 16 (3),179-182.

Roulston, K., 2010. Reflective interviewing: a guide to theory and practice, London, the UK: Sage

Rowe, J., Young, N. and Rowlands, S., 2014. The recovery package. *We are Macmillan Cancer Support, Spring*, 1-20.

Rønsholdt, J., Groot, A., Godrim, F. and Bech, E. (2013) Relationspsykologi I Praksis (Relationship Psychology in Practice). Fredrikshavn, Denmark: Dafolo.

Round, J., Sampson, E.L. and Jones, L. A., 2014. A framework for understanding quality of life in individuals without capacity. *Quality of Life Research*, 23(2), 477–484. doi:10.1007/s11136-013-0500-z

Rowland, J. H., Kent, E. E., Forsythe, L. P., Loge, J. H., Hjorth, L., Glaser, A., Mattioli, V. and Foss, S. D., 2013. Cancer survivorship research in Europe and the United States: Where have we been, where are we going, and what can we learn from each other? 2094.

Rubin, R., 2015. Improving the quality of life at the end of life. *JAMA* [online], 313 (21), 2110-2112.

Salas, M., Henderson, M., Sundararajan, M., Tu, N., Islam, Z. and Ebeid. M., 2021. Use of comorbidity indices in patients with any cancer, breast cancer, and human epidermal growth factor receptor-2-positive breast cancer: A systematic review. *PLoS ONE*,16(6): e0252925. https://doi.org/10.1371/journal.pone.0252925

Salvi, F., Miller, M. D., Grilli, A., Giorgi, R., Towers, A. L., Morichi, V., Spazzafumo, L., Mancinelli, L., Espinosa, E., Rappelli, A. and Dessì-Fulgheri, P., 2008. A Manual of Guidelines to Score the Modified Cumulative Illness Rating Scale and Its Validation in Acute Hospitalized Elderly Patients. *Journal of the American Geriatrics Society* [online], 56 (10), 1926-1931.

Sanna, G., Lorizzo, K., Rotmensz, N., Bagnardi, V., Cinieri S., Colleoni M.,Nole,F. and Goldhirsch, A., 2007. Breast cancer in Hodgkin's disease and non-Hodgkin's lymphoma survivors. *Annals of Oncology*,18, 288-292.

Saunders, M., Lewis, P. & Thornhill, A., 2012. "Research Methods for Business Students" 6th edition, Pearson Education Limited.

Scammon D.L., Tomoaia-Cotisel, A., Day, R., Day, J., Kim, J., Waitzman, N., Farrell, T. and Magill, M.,2013. Connecting the dots and merging meaning: Using mixed methods to study primary care delivery transformation. *Health Services Research*, 48, 2181-2207.

Schaapveld, M., Aleman, B.M., van Eggermond, A.M., Janus, C.P., Krol A.D., van der Maazen R.W., Roedink, J., Raemaekers, J. M. M.,de Boer, J. P., Petersen, E.J., Poortmans, P.M.P., Beijert, M., Lybeert, M.L., Mulder, I., Viser, O., Louwman, M. J., krul, I. M., Lugtenburg, P. L. and van Leeuwen, F.E., 2015. Second cancer risk up to 40 years after treatment for Hodgkin'slymphoma. *New England Journal of Medicine*, 373, 2499-2511.

Schellevis, F.G., van der Velden, J., van de Lisdonk, E., van Eijk, J.T. and van Weel, C., 1993.Comorbidity of chronic diseases in general practice. *Journal of Clinical Epidemiology*, 46,469–473.

Sherman, R. S., Cooke, E. and Grant, M., 2005. Dialogue among survivors of hematopoietic cell transplantation: support-group themes. *Journal of Psychosocial Oncology* [online], 23 (1), 1-24.

Shin-Hye, Y., Young Ho, Y., Sangmin, P., Young-Ae, K., Sang-Yoon, P., Duk-Soo, B., Joo Hyun, N., Chong Taik, P., Chi-Heum, C. and Jong-Min, L., 2013. The correlates of unemployment and its association with quality of life in cervical cancer survivors. *Journal of Gynecologic Onco*logy, 24 (4), 367-375.

Sieniawski, M., Reineke, T., Nogova, L., Josting, A., Pfistner, B., Diehl, V. and Engert, A., 2008. Fertility inmale patients with advanced Hodgkin lymphoma treated with BEACOPP: a report of the German Hodgkin Study Group (GHSG). *Blood*, 111, 71-76.

Sieurdardottir, V., Bolund, C., Brandbere, Y. and Sullivan, M., 1993.The impact of generalized malignant melanoma on quality of life evaluated by the EORTC questionnaire technique. *Quality of Life Research*, 2, 193-203.

Simard, S. B., Savard, J. E. and Ivers, H., 2010. Fear of cancer recurrence: specific profiles and nature of intrusive thoughts, *Journal of Cancer Survivorship Research and Practice*, 4 (4),361-371.

Simon, T.R., Mercy, J.A. and Barker, L., 2006. Can We Talk?: Importance of Random-DigitDial Surveys for Injury Prevention Research. *American Journal of Preventive Medicine*, 31(5),406-410.

Singh, B., Bhaya, M., Stern, J., Roland, J. T., Zimbler, M., Rosenfeld, R. M., Har-El, G. and Lucente, F. E., 1997. Validation of the Charlson Comorbidity Index in Patients With Head and Neck Cancer: A Multi-institutional Study, *Laryngoscope*, 107(11),1469-1475.

Singleton R. A. and Straits B. C., 2009. *Approaches to social research*. New York: Oxford University Press.

Singh-Carlson, S., Wong, F., Martin, L. and Nguyen, S. K. A., 2013. Breast cancer survivorship and South Asian women: understanding about the follow-up care plan and perspectives and preferences for information post-treatment. *Current Oncology* (Toronto, Ont.) [online], 20 (2), e63-e79.

Slovacek, L., Slovackova, B., Pavlik, V. and Jebavy, L., 2007. Original Paper: Health-related quality of life in acute myeloid leukaemia and multiple myeloma survivors undergoing autologous progenitor stem cell transplantation: a retrospective analysis. *Reports of Practical Oncology & Radiotherapy* [online], 12, 231-238.

Smith, A.W., Reeve, B.B., Bellizzi, K.M., Harlan, L.C., Klabunde, C.N., Amsellem, M., Bierman, A.S. and Hays, R.D., 2008. Cancer, comorbidities, and health-related quality of life of older adults. *Health Care Financ Review*, 29(4):41–56.

Smith, A., Howell, D., Patmore, R., Jack, A. and Roman, E., 2011. Incidence of haematological malignancy by sub-type: a report from the Haematological Malignancy Research Network. *British Journal Of Cancer* [online], 105 (11), 1684-1692.

Smith, M. Y., Redd, W. H., Peyser, C. and Vogl, D., 1999. Post-Traumatic Stress Disorder in Cancer: A Review, *Psycho-Oncology*,8(6),521-537.

So, W. K. W., Chow, K. M., Chan, H. Y. L., Choi, K. C., Wan, R. W. M., Mak, S. S. S., Chair, S. Y. and Chan, C. W. H., 2014. Quality of life and most prevalent unmet needs of Chinese breast cancer survivors at one year after cancer treatment. *European Journal Of Oncology Nursing*: [online], 18 (3), 323-328.

So, W. K. W., Wong, C.-L., Choi, K.-C., Chan, C. W. H., Chan, J. C. Y., Law, B. M. H., Wan, R. W. M., Mak, S. S. S., Ling, W.-M., Ng, W.-T. and Yu, B. W. L., 2019a. A Mixed-Methods Study of Unmet Supportive Care Needs Among Head and Neck Cancer Survivors. *Cancer Nursing*, 42 (1), 67-78.

So, W. K. W., Wong, C.-L., Choi, K.-C., Chan, C. W. H., Chan, J. C. Y., Law, B. M. H., Wan, R. W. M., Mak, S. S. S., Ling, W.-M., Ng, W.-T. and Yu, B. W. L., 2019b. A Mixed-Methods Study of Unmet Supportive Care Needs Among Head and Neck Cancer Survivors (1. pp. 67). United States: Lippincott Williams and Wilkins.

Sprangers, M. A. G., Cull, A., Bjordal, K., Groenvold, M. and Aaronson, N. K., 1993. The European Organization for Research and Treatment of Cancer Approach to Quality of Life Assessment: Guidelines for Developing Questionnaire Modules, 287.

Sprangers, M. A. G., Cull, A., Groenvold, M., Bjordal, K., Blazeby, J. and Aaronson, N. K., 1998. The European Organization for Research and Treatment of Cancer Approach to Developing Questionnaire Modules: An Update and Overview. *Quality of Life Research* [online], 7 (4), 291-300.

Sprangers, M. A. G., Groenvold, M., Arraras, J. I., Franklin, J., Te Velde, A., Muller, M., Franzini, L., Williams, A., De Haes, H. C. J. M. and Hopwood, P., 1996. The European Organization for Research and Treatment of Cancer Breast Cancer-Specific Quality-of-Life Questionnaire Module: First Results From a Three-Country Field Study, 2756. https://doi.org/10.1200/jco.1996.14.10.2756

Speck, R. M., Courneya, K. S., Mâsse, L. C., Duval, S. and Schmitz, K. H., 2010. An update of controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *Journal of Cancer Survivorship*, 4 ,87–100.

Sridharan, S., Berdeprado, J., Vilar, E., Roberts, J. and Farrington, K. A., 2014. Self-report comorbidity questionnaire for haemodialysis patients. *BioMedical Central Nephrology*, 15,134.

Stecker, T., 2004. Well-being in an academic environment. *Medical Education*, 38 (5), 465-478 414p.

Stein, K. D., Syrjala, K. L. and Andrykowski, M. A., 2008. Physical and psychological long-term and late effects of cancer, *Cancer*,112 (supp/11), 2577-2592.

Stergiou-Kita1, M., Pritlove, C. and Kirsh, B., 2016. The Big C^—stigma, cancer, and workplace discrimination. *Journal of Cancer Survivorship*, 10, 1035–1050.

Stiglitz, J., Sen, A. and Fitoussi, J, P., 2009. Report by the Commission on the Measurement of Economic Performance and Social Progress. https://ec.europa.eu/eurostat/documents/8131721/8131772/Stiglitz-Sen-Fitoussi-Commission-report.pdf

Stauder, R., Yu, G., Koinig, K. A., Bagguley, T., Fenaux, P., Symeonidis, A., Sanz, G., Cermak, J., Mittelman, M., Hellström-Lindberg, E., Langemeijer, S., Holm, M.S., Mądry, K., Malcovati, L., Tatic, A., Germing, U., Savic, A., van Marrewijk, C., Guerci-Bresler, A., Luño, E., Droste, J., Efcace, F., Smith, A., Bowen, D. and de Witte, T., 2018. Health-related quality of life in lower-risk MDS patients compared with age- and sex-matched reference populations: a European Leukemia Net study, *Leukemia*, 32(6), 1380–1392. https://doi.org/ 10.1038/s41375-018-0089-x

Streiner, D.L. and Norman, G. R., 2003. Health measurement scales a practical guide to their development and use. Oxford: Oxford University Press, 12-28.

Subramaniam, S., Sidik, S. M., Rampal, L., Fadhilah, S. I. and Periasamy, U., 2019. Quality Of Life among Cancer Patients Undergoing Chemotherapy in Government Hospitals in Peninsular Malaysia. *Malaysian Journal of Medicine & Health Sciences* [online], 15 (1), 5-15.

Sun, H., Yang, Y., Zhang, J., Liu, T., Wang, H., Garg, S., & Zhang, B. (2019). Fear of cancer recurrence, anxiety and depressive symptoms in adolescent and young adult cancer patients. *Neuropsychiatric Disease and Treatment, 15*, 857–865. doi:10.2147/NDT.S202432.

Sutton, J. & Austin, Z., 2015.Qualitative Research: Data Collection, Analysis, and Management. *The Canadian Journal of Hospital Pharmacy*, 68(3), 226–231. doi:10.4212/cjhp.v68i3.1456.

Swash, B., Bramwell, R. and Hulbert-Williams, N. J., 2017. Unmet psychosocial supportive care needs and psychological distress in haematological cancer survivors: The moderating role of psychological flexibility. *Journal of Contextual Behavioral Science*, 6 (2), 187-194.

Tao, J. J., Visvanathan, K. and Wolff, A. C., 2015. Long term side effects of adjuvant chemotherapy in patients with early breast cancer. *The Breast* [online], 24 (Supplement 2), S149-S153.

Tashakkori, A. and Teddlie, C., 1998. *Mixed methodology: combining qualitative and quantitative approaches* Thousand Oaks, Calif. : Sage, c1998.

Tashakkori, A. and Teddlie, C., 2003. *Handbook of Mixed Methods in Social and Behavioural Research.* Thousand Oaks, CA: Sage

Teddlie, C., Tashakkori, A., eds, 2009. *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences*. 1st ed. Thousand Oaks, CA: Sage Publications, Inc.

Tashakkori, A. and Teddlie, C., 2010. *Sage handbook of mixed methods in social & behavioural research*. 2nd ed. edition. Los Angeles; London: SAGE.

Taylor, S. E., Lichtman, R. R. and Wood, J.V., 1984. Attributions, beliefs about control, and adjustment to breast cancer. *Journal of Personality and Social Psychology* [online], 46 (3), 489-502.

Taylor, K., Chan, R.J. and Monterosso, L., 2015. Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review. *Supportive Care in Cancer*, 23, 1447–1458.

Taylor, J., Xiao, W. and Abdel-Wahab, O., 2017.Diagnosis and classification of hematologic malignancies on the basis of genetics. *Blood,* 130,410-423.

Teddlie, C. and Tashakkori, A., 2006. A general typology of research designs featuring mixed methods. *Research in the Schools* [online], 13 (1), 12-28.

Teddlie, C. and Tashakkori, A., 2012. Common "core" characteristics of mixed methods research: a review of critical issues and call for greater convergence. *American Behavioural Scientist,*56 (6),774-788.

Tempelaar, R., de Haes, J. C. J. M., de Ruiter, J. H., Bakker, D., van den Heuvel, W. J. A. and van Nieuwenhuijzen, M.G., 1989. The social experiences of cancer patients under treatment: A comparative study. *Social Science & Medicine* [online], 29 (5), 635-642.

The WHO QoL Group, 1998. The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine*, 46 (12), 1569-1585.

Thong, M.S.Y, Koch-Gallenkamp, L., Jansen, L., Bertram, H., Eberle, A., Holleczek, B., 2019. Age-specific health-related quality of life in long-term and very long-term colorectal cancer survivors versus population controls–a population-based study. *Acta Oncologica*, 58 (5), 801–10.

Thorne SE, Oliffe JL, Oglov V, and Gelmon K. 2013. Communication challenges for chronic metastatic cancer in an era of novel therapeutics. *Qualitative Health Research*, 7(23), 863–875. doi: 10.1177/1049732313483926.

Thornton, A. A., 2002. Perceiving Benefits in the Cancer Experience, *Journal of Clinical Psychology in Medical Settings*, 9 (2),153-165.

Toepoel, V. and Schonlau, M. 2017. Dealing with nonresponse: Strategies to increase participation and methods for post-survey adjustments, *Mathematical Population Studies*, 24:2, 79-83, DOI: 10.1080/08898480.2017.1299988.

Tomich, P. L. and Helgeson, V. S., 2002a. Five years later: a cross-sectional comparison of breast cancer survivors with healthy women, *Psycho-Oncology*, 154.

Tomich, P. L. and Helgeson, V. S., 2002b. Five years later: a cross-sectional comparison of breast cancer survivors with healthy women. *Psycho-Oncology*, 11 (2), 154-169.

Tracey, S.J. (2010). Qualitative quality: Eight "Big-Tent" criteria for excellent qualitative research, *Qualitative enquiry*, 16(10): 837-851.

Tran, B.T., Pham, N.H., Nguyen, T.X., Choi, K.S., Sohn, D.K., Kim, S.Y., Suh, J.K., Nguyen, T.D., Phan, V.S., Tran, D.T., Nguyen, T.T., Nguyen, T.T.B., Nguyen, M.T. and Oh, J.K., 2020. Measurement of health-related quality of life among colorectal cancer patients using the Vietnamese value set of the EQ-5D-5L. Patient Prefer Adherence 14:2427–2437. https://doi.org/10.2147/PPA.S281500

Tsamakis, K., Gavriatopoulou, M., Schizas, D., Stravodimou, A., Mougkou, A., Tsiptsios, D., Sioulas, V., Spartalis, E., Sioulas, A. D., Tsamakis, C., Charalampakis, N., Mueller, C., Arya, D., Zarogoulidis, P., Spandidos, D. A., Dimopoulos, M. A., Papageorgiou, C., & Rizos, E. (2020). Oncology during the COVID-19 pandemic: Challenges, dilemmas and the psychosocial impact on cancer patients. *Oncology Letters*, 20 (1), 441–447. https://doi.org/10.3892/ol.2020.11599.

Tsuchiya, M., Horn, S. and Ingham, R., 2013. Positive changes in Japanese breast cancer survivors: A qualitative study. *Psychologyl Health Medicine*, 18 (1),107-116.

Tuinstra, J., Hagedoorn, M., Van Sonderen, E., Ranchor, A. V., Van den Bos, G. A. M., Nijboer, C. and Sanderman, R., 2004. Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence, *British Journal of Health Psychology*, 9 (4), 465-478. http://dx.doi.org/10.1348/1359107042304588.

Tward, J.D., Wendland, M.M., Shrieve, D.C., Szabo, A. and Gaffney, D.K., 2006. The risk of secondary malignancies over 30 years after the treatment of non-Hodgkin lymphoma. *Cancer*, 107, 108-115.

Twombly, R., 2004. What's in a name: who is a cancer survivor? *Journal of National Cancer Institute*,96 (19):1414–1415. doi: 10.1093/jnci/96.19.1414.

Tzelepis, F., Paul, C. L., Sanson-Fisher, R. W., Campbell, H. S., Bradstock, K., Carey, M. L. and Williamson, A., 2018. Unmet supportive care needs of haematological cancer survivors: rural versus urban residents. *Annals Of Hematology*, 97 (7), 1283-1292.

Usher, Kim & Holmes, Colin., 2014. Reflective practice: what, why and how. https://researchonline.jcu.edu.au/cgi/users/login?target=https%3A%2F%2Fresearchonline.jcu.edu.au%2F30464%2F1%2F30464%2520Usher%2520and%2520Holmes%25202014.pdf

Valenti, M., Porzio, G., Aielli, F., Verna, L., Cannita, K., Manno, R., Masedu, F., Marchetti, P., Ficorella, C.,2008. Physical Exercise and Quality of Life in Breast Cancer Survivors. *International Journal of Medical Sciences*,5,1,24-28. doi:10.7150/ijms.5.24. Available from http://www.medsci.org/v05p0024.htm

van Griensven, H., Moore, A. P. and Hall, V., 2014. Masterclass: Mixed methods research – The best of both worlds? *Manual Therapy*, 19, 367-371.

Vayr, F., Savall, F., Bigay-Game, L., Soulat, J.-M., Chouaid, C. and Herin, F., 2019. Lung cancer survivors and employment: A systematic review (pp. 31). Netherlands: Elsevier Science B.V., Amsterdam.

Vogt, W. P., & Johnson, R. B., 2011. Dictionary of statistics and methodology: *A nontechnical guide for the social sciences*. Los Angeles, CA: Sage.

Volaklis, K. A., Halle, M. and Tokmakidis, S. P., 2013. Exercise in the prevention and rehabilitation of breast cancer, *Wiener Klinische Wochenschrift*, 125 (11/12),297-301.

Walker, M. S., Pohl, G. M., Houts, A. C., Peltz, G., Miller, P. J. E., Schwartzberg, L. S., Stepanski, E. J. and Marciniak, M., 2017. Analysis of the psychological impact of cancer-related symptoms in patients with non-small cell lung cancer. *Psycho-Oncology*, 26 (6), 755.

Wallace, A., Downs, E., Gates, P., Thomas, A., Yates, P. and Chan, R. J., 2015. Provision of survivorship care for patients with haematological malignancy at the completion of treatment: A cancer nursing practice survey study. *European Journal of Oncology Nursing*, 19 (5), 516-522.

Wang, J. H.-y., Gomez, S. L., Brown, R. L., Davis, K., Allen, L., Huang, E., Chentsova Dutton, Y. and Schwartz, M. D., 2019. Factors associated with Chinese American and White cancer survivors' physical and psychological functioning. *Health Psychology*, 38 (5), 455-465.

Ward, S., Viergut,z G., Torme,y D., DeMuln, J. and Paillen, A.,1992. Patients' reactions to completion of adjuvant breast cancer therapy. Nursing Research, 42(6), 362 – 366.

Watson, E.K., Rose, P.W., Loftus, R. and Devane, C., 2011. Cancer survivorship: the impact on primary care. *British Journal of General Practice*, 61(592):e763–5.

Watson, E.K, O'Brien, R., Campbell, C., Weller, D., Neal RD, Wilkinson C. and Rose, P.W., 2011. Views of health professionals on the role of primary care in the follow-up of men with prostate cancer. *Family Practice*, 28(6), 647–54.

Wells, M., Semple, C. J. and Lane, C., 2015. A national survey of healthcare professionals' views on models of follow-up, holistic needs assessment and survivorship care for patients with head and neck cancer. *European Journal Of Cancer Care*, 24 (6), 873-883.

Wesely, P. M., 2011. Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences by TEDDLIE, CHARLES, & ABBAS TASHAKKORI. Modern Language Journal [online], 95 (1), 152-153.

Wettergren, L., Björkholm, M., Axdorph, U. and Langius-Ekiöf, A., 2004. Determinants of Health-Related Quality of Life in Long-Term Survivors of Hodgkin's Lymphoma. *Quality of Life Research* [online], 13 (8), 1369-1379.

WHO QoL Group, 1993. Study Protocol for the World Health Organization Project to Develop a Quality of Life Assessment Instrument (WHOQOL). *Quality of Life Research*, (2), 153.

Williams, A., 1990. EUROQOL - A new facility for the measurement of health-related quality-of-life. *Health policy*, 16 (3), 199-208.

Williams, G.R., Deal, A.M., Sanof, H.K., Nyrop, K.A., Guerard, E.J., Pergolotti, M., Shachar, S.S., Reeve, B.B., Bensen, J.T., Choi, S.K. and Muss, H.B. 2019. Frailty and health-related quality of life in older women with breast cancer. *Supportive Care in Cancer*, 27(7),2693–2698. https:// doi.org/10.1007/s00520-018-4558-6.

Wisdom, J. and Creswell, J.W., 213. Mixed Methods: Integrating Quantitative and Qualitative Data Collection and Analysis While Studying Patient-Centered Medical Home Models. Rockville, MD: *Agency for Healthcare Research and Quality*, AHRQ Publication No. 13-0028-EF.

Wolfensberger, W., 1994. Let's hang up 'quality of life' as a hopeless term. In: Goode, D. A., ed. Quality of life for persons with disabilities: International perspectives and issues. Cambridge, MA: Brookline Books, 285-321.

Wolford, J. L. and McDonald, G. B., 1988. A problem-oriented approach to intestinal and liver disease after marrow transplantation. *Journal Of Clinical Gastroenterology*, 10 (4), 419-433.

Woo-kyoung, S., Sihan, S., So-Youn, J., Eunsook, L., Zisun, K., Hyeong-Gon, M., Dong-Young, N. and Jung Eun, L., 2017. The association between physical activity and health-related quality of life among breast cancer survivors. *Health and Quality of Life Outcomes*, (1), 1.

Woolley, C. M., 2009. Meeting the Mixed Methods Challenge of Integration in a Sociological Study of Structure and Agency, *Journal of Mixed Methods Research*, 3 (1),7-25.

World Health Organization (WHO), (2015) ICD-10 version: 2015 malignant neoplasms, state or presumed to be primary, of lymphoid, haematopoietic and related tissue (C81-C96). http://apps.who.int/ classifications/icd10/browse/2010/en#/C81-C96. Accessed February 2018

World Medical Association., 2013. WMA Declaration of Helsinki— Ethical Principles for Medical Research Involving Human Subjects. Retrieved from: https://www.wma.net/policiespost/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/. Accessed September 21, 2019.

Yi, J. C. and Syrjala, K. L., 2017. Anxiety and Depression in Cancer Survivors. *The Medical Clinics of North America* [online], 101 (6), 1099-1113.

Yogaparan, T., Panju, A., Minden, M., Brandwein, J., Mohamedali, H. Z. and Alibhai, S. M., 2009. Information needs of adult patients 50 or older with newly diagnosed acute myeloid leukaemia, *Leukaemia Research*, 3(9),1288-1290.

Yonemoto, T., Kamibeppu, K., Ishii, T., Iwata, S., Hagiwara, Y. and Tatezaki, S. I., 2009. Psychosocial Outcomes in Long-term Survivors of High-grade Osteosarcoma: A Japanese Single-center Experience, *Anticancer Research*, 29 (10),4287-4290.

Yost, K. J., Hahn, E. A., Zaslavsky, A. M., Ayanian, J. Z. and West, D. W., 2008. Predictors of health-related quality of life in patients with colorectal cancer. *Health And Quality Of Life Outcomes* [online], 6, 66-66.

Younes, A., Ansell, S., Fowler, N., Wilson, W., de Vos, S., Seymour, J. and Vose, J.,2017. The landscape of new drugs in lymphoma. Nature reviews. *Clinical Oncology*, 14(6), 335–346. doi:10.1038/nrclinonc.2016.205.

Yvonne Feilzer, M., 2010. Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research* [online], 4 (1), 6-16.

Zebrack, B. J., 2000. Cancer Survivor Identity and Quality of Life. *Cancer Practice* [online], 8 (5), 238-242.

Zittoun, R., Achard, S. and Ruszniewski, M., 1999. Assessment of Quality of Life During Intensive Chemotherapy or Bone Marrow Transplantation, *Psychooncology*, 8(1),64-73.

Zhu, J., Yan, X.X., Liu, C.C., Wang, H., Wang, L., Cao, S.M., Liao, X.Z., Xi, Y.F., Ji, Y., Lei, L., Xiao, H.F., Guan, H.J., Wei, W.Q., Dai, M., Chen, W. and Shi, J.F., 2021. Comparing EQ-5D-3L and EQ-5D-5L performance in common cancers: suggestions for instrument choosing. *Quality of Life Research*, 30(3),841–854. https://doi.org/10.1007/s11136-020-02636-w

Appendix 1: Letter of invitation from clinicians to participants with CLL

{Name}

{Address} date

Dear {name}

A study of quality of life among adult haematological cancer survivors

Research is being conducted to help health care professionals learn about the quality of life of older people who have been treated for blood and lymphatic cancers within the last 5 years. The information gathered during the research will help to improve services and care for older people surviving cancer in the future. The research is being conducted as part of a MPhil by Anita Immanuel (phone: 01202726246) and is funded by the Dorset Cancer Network and supervised by experienced researchers at Bournemouth University.

As part of this study, questionnaires have been included with this letter. These include the EORTC QLQ-C30, the EQ-5D-3L and the QLQ-CLL16. The EORTC QLQ-C30 is a cancer-specific questionnaire, the EQ-5D-3L measures general health and the QLQ-CLL16 is a disease specific questionnaire. These questionnaires are valid and reliable as they have been used before to identify the quality of life concerns of people with different types of cancer to the ones investigated in my research. If you decide to take part in this study please complete the questionnaires as soon as possible but at your convenience and return it in the self-addressed envelope provided. You will be asked to complete the questionnaires only once. If you do not want to take part in the study nothing further needs to be done. You may at a later stage be invited to take part in an interview which may take place at your house or at the hospital outpatients department depending on your preference and for your convenience. Please state on the reply slip whether or not you wish to be approached for the interview part of the study and return it with the questionnaires. A reminder letter will be sent in two weeks' time.

Thank you very much in advance,

Yours sincerely,

Name of haematologist

Appendix 2: Letter of invitation from clinicians to participants with MM

{Name } date

{Address}

Dear {name}

A study of quality of life among adult haematological cancer survivors

Research is being conducted to help health care professionals learn about the quality of life of older people who have been treated for blood and lymphatic cancers within the last 5 years. The information gathered during the research will help to improve services and care for older people surviving cancer in the future. The research is being conducted as part of a MPhil by Anita Immanuel (phone: 01202726246) and is funded by the Dorset Cancer Network and supervised by experienced researchers at Bournemouth University.

As part of this study, questionnaires have been included with this letter. These are the EORTC QLQ-C30, the EQ-5D-3L and the QLQ-MY20. The EORTC QLQ-C30 is a cancer-specific questionnaire, the EQ-5D-3L measures general health and the QLQ-MY20 is a disease specific questionnaire. These questionnaires are valid and reliable as they have been used before to identify the quality of life concerns of people with different types of cancer to the ones investigated in this research. If you decide to take part in this study, please complete the questionnaires as soon as possible but at your convenience and return it in the self-addressed envelope provided. You will be asked to complete the questionnaires only once. If you do not want to take part in the study nothing further needs to be done. You may at a later stage be invited to take part in an interview which may take place at your house or at the hospital outpatients department depending on your preference and for your convenience. Please state on the reply slip whether or not you wish to be approached for the interview part of the study and return it with the questionnaires. A reminder letter will be sent in two weeks' time.

Thank you very much in advance,

Yours sincerely,

Appendix 3: Letter of invitation from researcher to participants with Lymphoma

{Name} date

{Address}

Dear {name}

A study of quality of life among adult haematological cancer survivors

Research is being conducted to help health care professionals learn about the quality of life of older people who have been treated for blood and lymphatic cancers within the last 5 years. The information gathered during the research will help to improve services and care for older people surviving cancer in the future. The research is being conducted as part of a MPhil and is funded by the Dorset Cancer Network and supervised by experienced researchers at Bournemouth University.

As part of this study, questionnaires have been included with this letter. These include the EORTC QLQ-C30 and the EQ-5D-3L. The EORTC QLQ-C30 is a cancer-specific questionnaire and the EQ-5D-3L measures general health. These questionnaires are valid and reliable as they have been used before to identify the quality of life concerns of people with different types of cancer to the ones investigated in my research. If you decide to take part in this study, please complete the questionnaires as soon as possible but at your convenience and return it in the self-addressed envelope provided. You will be asked to complete the questionnaires only once. If you do not want to take part in the study nothing further needs to be done. You may at a later stage be invited to take part in an interview which may take place at your house or at the hospital outpatients department depending on your preference and for your convenience. Please state on the reply slip whether or not you wish to be approached for the interview part of the study and return it with the questionnaires. A reminder letter will be sent in two weeks' time.

Thank you very much in advance,

Yours sincerely,

Anita S Immanuel

MPhil student/Bournemouth University and Research Nurse

Appendix 4: Letter of invitation - Reminder

{Name} date

{Address}

Dear {name}

A study of quality of life among adult haematological cancer survivors

You may remember you were sent some questionnaires to complete a couple of weeks ago. If you have already sent us the completed questionnaires, thank you. If not, you can still complete the questionnaires and return it in the self-addressed envelope enclosed if you decide to take part. The information gathered during the research will help to improve services and care for older people surviving cancer in the future. Please find attached original information and questionnaires enclosed in case it was never received or lost the first time around. If you require any further information, please feel free to contact me or Anita Immanuel at the number below.

Contact Details

Anita Immanuel

MPhil student Bournemouth University/Research Nurse

Royal Bournemouth Hospital

Department of Haematology, Castle Lane East

Bournemouth

BH7 7DW

Phone- 01202 726246

Thank you very much in advance,

Yours sincerely,

Anita Immanuel

Appendix 5: Reply slip

{Name}

{Address}

A study of quality of life among adult haematological cancer survivors

Reply to Invitation

I would like to take part in the interview which is the second part of the study.

Please contact me on telephone number:

Name:

Signature:

Date:

.....

I would not like to take part in the interview which is the second part of the study.

Name:

Signature:

Date:

Appendix 6: Participant information sheet

A study to examine the quality of life of adult haematological cancer survivors

Participant Information Sheet

You may remember we sent you some questionnaires to complete some time ago. Thank you for completing the questionnaires. Now you are being invited to take part in the second part of this study. Before you decide whether or not to take part, it is important for you to understand why the research and perhaps also the second part of the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish before deciding whether you wish to take part. Thank you for taking the time to read this information sheet.

What is the purpose of the study?

To develop a more comprehensive understanding of the quality of life of patients who have been treated for cancers of the bloodstream and lymphatic system within the last 5 years.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of follow up care you receive.

What will happen to me if I take part?

If you agree to take part in the study you will be asked to sign a consent form and will be interviewed. The interview will last for approximately an hour and you may be asked some questions to prompt a general discussion. You will be asked to talk about your experience of living with cancer and about different aspects of your life after finishing your treatment. The interview will take place at a time and place convenient to you.

What will happen to the results of the research study?

I will record the interview on a digital recorder and write it up into what is called a transcript to help me, at a later date, read what you have said. All the information acquired will be stored on a computer to help identify important issues for

participants. I will then write up a detailed report called a thesis and also hope to publish the results of the study in a scientific journal. All your personal information will be kept confidential and will not be identifiable in the report or any subsequent publications.

What are the possible risks or benefits of taking part?

There is a small possibility of finding some of the questions in the interviews upsetting. However, many people find it helpful to participate in the research of this type because it provides an opportunity to talk about aspects of life after cancer treatment. Potential benefits of taking part in the study as a whole are that you may help to increase health care professionals' limited understanding of the quality of lives of adults treated for cancers of the bloodstream and lymphatic system, with the long term benefit of improving services in the future for people like you.

What if there is a problem?

If you have any concerns about this stage of the study, please feel free to speak to me and I will do my best to answer any of your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital. In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements.

Will my taking part in the study be kept confidential?

Yes. All the information obtained from you and about your participation in this stage of the study, as with the first stage, will be kept confidential. You will not be identified in any of the reports or transcripts. All identifiable details will be kept in a secure place until the interviews are complete.

Who will know that I am taking part in this study?

Your GP will be written to explaining the study and you may speak to him or her about it.

Who can I contact to discuss this study further?

My name is Anita Immanuel and I am doing this research as part of a MPhil. I am being supervised by three very experienced supervisors, two of whom also have the clinical experience of working with people with bloodstream and lymphatic system cancers. Please feel free to contact me for any further information.

Anita S Immanuel

Network-Wide Haematology Research Nurse and postgraduate student (Bournemouth University)

Department of Haematology

Royal Bournemouth Hospital

Castle Lane East

Bournemouth

BH7 7DW

Tel: 01202726246

Who will be organising and funding the research?

This research being organised by the Haematology Department at The Royal Bournemouth Hospital and The Bournemouth University and funded by the Dorset Cancer Network.

Who has reviewed the study?

This study is being overseen by MPhil supervisors and an academic review team at Bournemouth University have approved the study. Favourable ethical opinion has been given by the NRES Committee South Central- Southampton A.

Thank you for taking the time to read this sheet and your consideration.

Appendix 7: Participant consent form

Participant Consent Form

		Please initial boxes
1.	I have read the attached Information Sheet Version 2.0 dated (05 February 2013)	☐
2.	I have had an opportunity to discuss this study and ask questions	☐
3.	I understand that I am free to withdraw from the study: - at any time - without having to give reasons	☐
4.	I give permission to tell my GP about my participation in the study	☐
5.	All personal details will be treated strictly confidential and will be stored only until the interviews are complete. This information will be used for this study only and I will be identified with a code. I will not be identified in any way in the analysis and reporting of results.	☐
6	I give permission for the researcher to access my medical records in order to obtain necessary information for the study.	☐
7.	I am willing to take part in the study.	☐

_____ _____ _____

Name of participant Signature of participant Date

_____ _____ _____

Name of researcher Signature of researcher Date

Appendix 8: Demographic questionnaire

It will help me understand your answers to the questions better if I have some background information on you. Please complete the following questions.

1. What is your age in years?

2. Are you: (Please tick one box only)

Male ☐ Female ☐

3. What is your marital status? *(Please tick one box only)*

Single/divorced/separated ☐

Married/cohabitating ☐

Widowed ☐

4. Do you have children? (Please tick one box only)

Yes No

☐ ☐

5. If you have children how many do you have?

6. What is the highest level of education you have completed?

Primary school ☐

High school ☐

College ☐

Degree ☐

Professional qualification ☐

Postgraduate Degree ☐

Other (please specify): …….. ☐

7. Which of the following best describes your employment status? *(Please tick one box only)*

   Employed /self-employed ☐

   Retired ☐

   Unable to work ☐

   Other (please specify): ….. ☐

8. How would you describe your ethnic origin? *(Please tick one box only)*

   White ☐

   Asian (of Indian, Pakistani, Bangladeshi ancestry) ☐

   Black or Afro-Caribbean (of African or Caribbean ancestry) ☐

   Chinese ☐

   Other European Country ☐

   Other ethnic origin ☐

9. In general, would you say your health is: *(Please tick one box only)*

   Very good ☐

   Good ☐

   Average ☐

   Poor ☐

   Very poor ☐

Appendix 9: EORTC QLQ C-30 questionnaire

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year): 31

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4

14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall <u>health</u> during the past week?

1 2 3 4 5 6 7

Very poor Excellent

30. How would you rate your overall <u>quality of life</u> during the past week?

1 2 3 4 5 6 7

Very poor Excellent

Appendix 10: UK_(English)_EQ-5D-3L 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 ❑

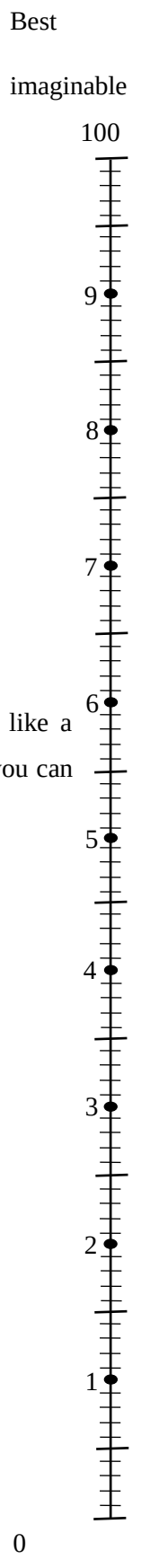
Anxiety/Depression

I am not anxious or depressed ❑

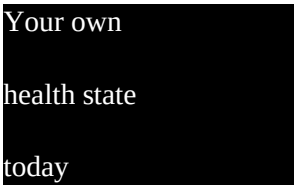
I am moderately anxious or depressed ❑

I am extremely anxious or depressed ❑

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.



We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.



Appendix 11: EORTC QLQ – MY20

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at All		A Little	Quite a Bit	Very Much
31.	Have you had bone aches or pain?	1	2	3	4
32.	Have you had pain in your back?	1	2	3	4
33.	Have you had pain in your hip?	1	2	3	4
34.	Have you had pain in your arm or shoulder?	1	2	3	4
35.	Have you had pain in your chest?	1	2	3	4
36.	If you had pain did it increase with activity?	1	2	3	4
37.	Did you feel drowsy?	1	2	3	4
38.	Did you feel thirsty?	1	2	3	4
39.	Have you felt ill?	1	2	3	4
40.	Have you had a dry mouth?	1	2	3	4
41.	Have you lost any hair?	1	2	3	4
42.	Answer this question only if you lost any hair: Were you upset by the loss of your hair?	1	2	3	4
43.	Did you have tingling hands or feet?	1	2	3	4
44.	Did you feel restless or agitated?	1	2	3	4
45.	Have you had acid indigestion or heartburn?	1	2	3	4
46.	Have you had burning or sore eyes?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
47. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
48. Have you been thinking about your illness?	1	2	3	4
49. Have you been worried about dying?	1	2	3	4
50. Have you worried about your health in the future?	1	2	3	4

Appendix 12: EORTC QLQ – CLL16

EORTC QLQ – CLL16

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at All	A Little	Quite a Bit	Very Much
31. Have you lost weight?	1	2	3	4
32. Have you had a dry mouth?	1	2	3	4
33. Did you bruise?	1	2	3	4
34. Did you have abdominal discomfort?	1	2	3	4
35. Has your temperature been going up and down?	1	2	3	4
36. Did you have night sweats?	1	2	3	4
37. Have you had skin problems (e.g. itchy, dry)?	1	2	3	4
38. Did you feel ill or unwell?	1	2	3	4
39. Did you feel lethargic?	1	2	3	4
40. Have you felt “slowed down”?	1	2	3	4
41. Were you limited in planning activities, for example meeting friends, in advance?	1	2	3	4
42. Were you worried about your health in the future?	1	2	3	4

During the past four weeks:	Not at All	A Little	Quite a Bit	Very Much
43. Have you had trouble with chest infections?	1	2	3	4
44. Have you had trouble with other infections?	1	2	3	4
45. Have you needed repeated courses of antibiotics?	1	2	3	4
46. Have you worried about picking up an infection?	1	2	3	4

Appendix 13: GP letter

Bournemouth University

Dear Dr.

GP INFORMATION SHEET

A study to examine the quality of life of adult haematological cancer survivors

Your patient ..... has agreed to participate in this study. The research is being conducted as part of a MPhil and is funded by the Dorset Cancer Network and supervised by experienced researchers at Bournemouth University. He/she will be taking part in an interview which may take place at their house or at the hospital outpatients department depending on their preference and convenience. I have enclosed a copy of the patient information sheet for your records. You do not need to do anything for this study but if you would like any further information please do not hesitate to contact me on 01202 726246.

Yours sincerely

Appendix 14: CIRS-G scoring sheet

CUMULATIVE ILLNESS RATING SCALE FOR GERIATRICS (CIRS-G)

Miller, Paradis, and Reynolds 1991

PATIENT_____AGE_____

RATER_____DATE_____

Instructions: Please refer to the CIRS-G manual. Write brief descriptions of the medical problem(s) that justified the endorsed score on the line following each item. (Use the reverse side for more writing space).

RATING STRATEGY

0- No problem

1- Current mild problem or past significant problem

2- Moderate disability or morbidity/requires _first line_ therapy

3- Severe/ constant significant disability/ _uncontrollable_ chronic problems

4- Extremely severe/ immediate treatment required/ end organ failure/ severe impairment in function

SCORE

HEART.....

VASCULAR.....

HEMATOPOIETIC.....

RESPIRATORY.....

EYES, EARS, NOSE, THROAT AND LARYNX.....

UPPER

GI.....

LOWER GI.....

LIVER.....

RENAL.....

GENITOURINARY.....

MUSCLOSKELETAL/INTEGUMENT.....

NEUROLOGICAL.....

ENDOCRINE/METABOLIC AND

BREAST.....

PSYCHIATRIC ILLESS.....

TOTAL NUMBER OF CATEGORIES

ENDORSED.....

TOTAL

SCORE.....

Severity index: (total score/total number of categories endorsed).....

The number of categories at level 3 severity.....

The number of categories at level 4 severity...….....

Appendix 15: Semi-structured interview schedule

You may remember completing a few questionnaires some time ago. The purpose of this interview is to determine the quality of life for patients who have completed treatment for haematological cancer. I would like to remind you that you can stop the interview at any time or skip answering specific questions.

- Opening questions
    - Can you tell me a little about yourself?
    - How are you feeling today?
    - Would like you to describe what your typical day looks like?
    - How often do you visit the hospital for follow up appointments and how do you feel about this?

- Tell me how are coping on a day-to-day basis?

- How do you think your family cope with your illness?

- Has your disease and treatment affected/influenced your relationships with family, friends etc. and if so how?

- Tell me about the support from your doctor and other staff in the hospital?

- How would you describe your quality of life?

- How has your illness and treatment changed your perception of life?

- What concerns and worries do you have about your future?

- Is there anything you would like to add that has not been asked in this interview? (in relation to living with your condition)

Appendix 16: Ethics approval letter

NHS
Health Research Authority
NRES Committee South Central - Southampton A
Bristol Research Ethics Committee Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1381
Facsimile: 0117 342 0445

04 March 2013

Mrs Anita Sathyamalar Immanuel
Network Haematology Research Nurse
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
Department of Haematology
Castle Lane East
Bournemouth
BH7 7DW

Dear Mrs Immanuel

Study title:	**An examination of the quality of life among adult haematological cancer survivors**
REC reference:	**12/SC/0708**
IRAS project ID:	**104303**

Thank you for your letter of 28 February 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Maxine Knight, nrescommittee.southcentral-southamptona@nhs.net.

Confirmation of ethical opinion

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

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).

Non-NHS sites

Conditions of the favourable opinion

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

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 the 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).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		29 November 2012
GP/Consultant Information Sheets	1.0	27 November 2012
Investigator CV		27 November 2012
Letter from Sponsor		17 September 2012
Other: CV- Jane Alison Hunt	Jan 2012	
Other: CV- Prof Edwin van Teijlingen		28 October 2012
Other: CV- Helen McCarthy		18 October 2012
Other: Cumulative Illness Rating Scale for Geriatrics (CIRS-G)		
Other: Letter of invitation- all others from research team	2.0	05 February 2013

Other: Letter of invitation- all others from clinician	1.0	05 February 2013
Other: Letter of invitation- CLL from research team	2.0	05 February 2013
Other: Letter of invitation- CLL from clinician	1.0	05 February 2013
Other: Letter of invitation- Myeloma from research team	2.0	05 February 2013
Other: Letter of invitation- Myeloma from clinician	1.0	05 February 2013
Other: Reminder letter from research team	1.0	05 February 2013
Other: Reminder letter from clinician	1.0	05 February 2013
Other: Reply invitation	2.0	05 February 2013
Participant Consent Form	2.0	05 February 2013
Participant Information Sheet	2.0	05 February 2013
Protocol	1.0	27 November 2012
Questionnaire: Demographic	1.0	27 November 2012
Questionnaire: EQ-5D-3L		
Questionnaire: EORTC QLQ-C30		
Questionnaire: EORTC QLQ-MY20		
Questionnaire: EORTC QLQ-CLL16		
REC application		03 December 2012
Response to Request for Further Information		

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:

- 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/0708	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp
Dr Simon Kolstoe
Vice Chair

Email:nrescommittee.southcentral-southamptona@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Robert Chapman, Royal Bournemouth Hospital*

Appendix 17: Professional Study visits undertaken/conferences & meetings participated

2019 Attendance and poster presentation at the PEER Nurse Academy for Haematology Research Nurses

2018 Poster presentation at The International Conference on Quality Cancer Care, Oxford, UK.

2016 Invited Speaker, 6th Annual Scientific Meeting of Saudi Society of Blood and Marrow Transplantation, May 2016.

2015 Poster Presentation at the UAE Cancer Congress, Intercontinental Dubai Festival City, Dubai

2015 2-week study visit to The Cancer Nursing Research Unit, Sydney, Peter Mc Callum Cancer Centre, Melbourne, Australia)

2015 3-week study visit to Princess Margaret Cancer Centre, Toronto, Canada and British Columbia Cancer Agency, Vancouver, Canada

(Awarded by The Winston Churchill Memorial Trust Travel Fellowship, U.K.)

2014 2-week study visit to Yale Cancer Centre awarded by Santander Grant to study survivorship Care Models at Yale Cancer Centre, Connecticut, USA

2014 1st Survivorship conference organised by EORTC (European Organisation for Research and Treatment in Cancer), Brussels, Belgium

2013 International Society of Geriatric Oncology Annual Meeting – Denmark

2013 MASCC (Multinational Association of Supportive care in Cancer) – Germany

2012 EORTC (European Organisation for Research and Treatment of Cancer) Quality of Life Conference organised by EORTC group - Belgium 2011

Appendix 18: Awards/Grants and presentations

Immanuel A, Hunt J, McCarthy H, van Teijlingen E, Sheppard ZA. Quality of life in survivors of adult haematological malignancy. European Journal of Cancer Care. 2019; e13067. https://doi.org/10.1111/ecc.13067 (Publication attached)

Immanuel, A., Hunt, J., van Teijlingen, E., McCarthy, H (2018). Poster presentation at The International Conference on Quality Cancer Care, Oxford, UK. An examination of the quality of lie and unmet supportive care needs in survivors of adult haematological malignancies.

Immanuel, A., Hunt, J., van Teijlingen, E., McCarthy, H. and Sheppard, Z (2015). Poster Presentation at the UAE Cancer Congress, Dubai. An examination of the quality of life of adult haematological cancer survivors.

Immanuel (2015). Travel Grant by the British Geriatrics Society to present a poster at the UAE Cancer Congress.

Immanuel, A., Hunt, J., McCarthy, H., van Teijlingen, E. (2014)**.** An examination of the quality of life of adult haematology cancer survivors, *Psycho-Oncology* **23**(Suppl.2): 7.

Immanuel A (2013). An award granted by the Winston Churchill Memorial Trust to study comprehensive survivorship care models in Canada and Australia.

Immanuel A (2013). An examination of the quality of life of adult haematological cancer survivors. Healthcare Interdisciplinary Research Conference, Dublin

Immanuel A (2013). Santander Mobility Grant to visit Yale Cancer Centre. Awarded by Santander to study survivorship care models - Yale Cancer Centre, USA.

Immanuel A (2013). Travel Grant by the British Geriatrics Society to attend The International Society of Geriatric Oncology Annual Meeting in Denmark.

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DOI: 10.1111/ecc.13067

ORIGINAL ARTICLE

European Journal of Cancer Care WILEY

Quality of life in survivors of adult haematological malignancy

Anita Immanuel MSc (Advanced Nursing Studies), RN, PhD Candidate[1] | Jane Hunt PhD, SRN, RSCN, Senior Lecturer Children's and Young People's Nursing[1] | Helen McCarthy PhD, MBBS, FRCP, FRCPath, Haematology Consultant[2] | Edwin van Teijlingen PhD, MEd, MA (Hon), Professor, Visiting Professor, Book Review Editor Sociological Research Online[1,3,4] | Zoë A. Sheppard BSc, PhD, Head of Research[5]

[1]Faculty of Health & Social Sciences, Bournemouth University, Bournemouth, UK

[2]Royal Bournemouth Hospital, Bournemouth, UK

[3]MMIHS, Tribhuvan University, Kirtipur, Nepal

[4]Nobel College, Pokhara University, Lekhnath, Nepal

[5]Research and Innovation, Dorset County Hospital, Dorchester, UK

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Email: aimmanuel@bournemouth.ac.uk

Funding information
Royal Bournemouth Hospital

Abstract

Background: Survivors of haematological malignancies endure long-term effects of both treatment and disease. This paper examines factors that influence their quality of life through reporting on the results of a survey.

Methods: Survey using previously validated quality of life questionnaires for use in cancer management. Participants were adults aged 18 and over who had completed treatment for a haematological malignancy and were between 1 and 5 years post-treatment.

Findings: A total of 131 participants, median age of 66, completed questionnaires (66% response rate). Significant associations were found between age, global quality of life, physical and role functioning. Men reported better physical functioning and lower symptom scores than women. Employed participants reported better quality of life. Increasing age was associated with lowest quality of life. Best role functioning was also noted in participants who lived beyond 2.5 years following treatment completion. The survey suggested a gender difference with men reporting better physical functioning, fewer symptoms of pain and less loss of sleep compared with women.

Conclusion: This study contributes to the underdeveloped area of care for and research into adult haematological cancer survivors. Knowledge and understanding of the factors that affect the quality of life of such adults may provide an insight into implementation measures.

KEYWORDS
cancer survivors, EORTC QLQ-C30, EQ 5D-3L, haematological malignancies, quality of life, quantitative research

1 | INTRODUCTION

There has been a steady increase in survival rates of all patients with cancer in the UK when compared with the United States and Europe with 50% of patients surviving for ten years and beyond (Cancer Research UK, 2014). Overall, the approximated two million cancer survivors in the UK will increase by 3% per year as the population ages (Maddams et al., 2009) and by 2030 the number of cancer survivors in the UK is estimated to be four million (Maher & McConnell, 2011).

Haematological malignancies are the fourth most frequent cancer type in the developed world, and incidence rates are increasing, in part, secondary to our ageing population (Chihara et al., 2014; Howlader et al., 2014; Smith, Howell, Patmore, Jack, & Roman, 2011). B-cell malignancies such as chronic lymphocytic leukaemia (CLL), lymphoma and multiple myeloma (MM) are some of the most common haematological malignancies, and this study focused on patients who were treated for these conditions. In 2011, the numbers of new cases registered in the UK were 12,783 with non-Hodgkin's lymphoma (NHL), 1,845 with Hodgkin's lymphoma (HL), 3,233 with CLL and 4,792 with MM (Office for National Statistics [ONS], 2015). Although many of these malignancies are not curable, the routine use of novel and targeted therapies has led to a steady improvement in survival rates (Hall, Lynagh, Bryant, & Sanson-Fisher, 2013; Sant et al., 2014). Individuals treated for a B-cell malignancy are no longer viewed as victims but as survivors who go on to live for many years following diagnosis (Aziz & Rowland, 2003).

In England, the 5-year overall survival for men diagnosed with HL during 2011–2015 and followed up until 2016 was over 80%, 64.9% for NHL, 53.3% for all leukaemia and 51.9% for survivors of MM. During the same period, women showed survival rates of 83% for HL, 69.4% for NHL, 52.4% for all types of leukaemia and 50.8% for survivors of MM (ONS, 2018). The 5-year survival for a patient treated for CLL is 67.0% for men and 73.0% for women in England (De Angelis, Sant, & Coleman, 2014). These figures show improvement in survival rates compared to previous years.

Contrary to other malignant diseases, chemotherapy treatment regimens for B-cell malignancies are often more complex and intense. Hence, they can be more physically and psychologically burdensome with prolonged, intensive treatments (De Vita, Lawrence, & Rosenburg, 2008; Junlen et al., 2015; Mounier et al., 2015; Pulte, Jansen, Castro, & Brenner, 2016). These treatments have also led to significant improvements in survival rates (Mounier et al., 2015; Pulte et al., 2016). When a patient is diagnosed with a B-cell malignancy, the treatment not only affects clinical outcomes, but also it can influence their quality of life (QoL) (van de Poll-Franse et al., 2018). The physical difficulties (e.g. fatigue, decreased physical capacity) and psychosocial problems (e.g. anxiety, depression, stress, insecurity, grief, decreased self-esteem, hindered job reintegration, social isolation) experienced by these survivors may lead to diminished QoL (Gotay, Holup, & Pagano, 2002; Tomich & Helgeson, 2002).

The intense treatment received, especially in patients with haematological malignancies, can cause deficits in one or more QoL domains (Hassan & Abdi-Valugerdi, 2014). Studies investigating the long-term adverse effects of treatment for haematological malignancies have identified problems with the eye, endocrine function, neurosensory and cardiopulmonary impairments (Aleman & van Leeuwen, 2007; Hess et al., 2011; Hodgson, Grunfeld, Gunraj, & Giudice, 2010; Punnett, Tsang, & Hodgson, 2010; Walsh, 2010). Treatment-related toxicities such as acute confusion and sometimes metabolic disturbances have been reported (Hallek et al., 2010; Hassan & Abdi-Valugerdi, 2014). Those who survive adverse effects of treatment and go on to experience prolonged remission, often continue to live with decreased functioning and reduced QoL (Efficace, Novik, Vignetti, Mandelli, & Cleeland, 2007), because they continue to deal with the daily challenges of living with the late- and long-term adverse effects of treatment and fear of disease recurrence. QoL has, thus, been incorporated as an important outcome parameter in clinical trials and in daily clinical practice, enabling haematologists to assess the effectiveness of a treatment and guide in making tailored treatment decisions (Lopez-Herce, Rollon-Mayordomo, Lozano-Rosado, Salazar-Fernandez, & Gallana, 2009).

During the acute phase, most patients interact with nursing staff on haematology day units for emotional and psychological support (Swanson & Koch, 2010). Most haematology departments have access to social workers if required. Therefore, issues that affect physical, social or emotional functioning, thereby having an impact on the QoL of patients during this phase, are mostly addressed and dealt with (Lobb et al., 2009). It is following completion of treatment when patients feel the lack of such support measures in place (Lobb et al., 2009) as they move into long-term follow-up in an outpatient setting and lose interaction with the healthcare providers. Patients have many needs that emerge which can influence their QoL during this time. In Dorset, cancer care centres employ social workers who provide services to both inpatients and outpatients departments.

This study sought to examine the QoL of adult survivors treated for a B-cell malignancy, and this cohort appears to be largely an older group, which represents the majority of patients in Dorset. Dorset is a unique county in the UK as it has the largest population of older adults with 28.3% being 65 years and older which is significantly higher than the 18% average for England and Wales (ONS, 2016). The high proportion of older cancer survivors in this cohort and factors that influence their QoL will provide insight into the future ageing UK cancer survivors' population as a whole. This may, in turn, inform future healthcare planning strategies.

2 | METHODS

A cross-sectional design was used in this study, which was part of a wider mixed-methods study in a population of patients who were treated for a haematological malignancy. This paper only reports the first quantitative survey data collected between July 2013 and May 2014.

2.1 | Recruitment

Potential participants were identified by treating haematologists at three hospital sites. They were contacted by mail and in the outpatient clinics by their clinicians, and/or they were directly approached by the first author in outpatient clinics following confirmation of eligibility by the clinicians.

Eligible participants were mailed an invitation letter detailing the purpose of the study, a demographic questionnaire designed specifically for this study, QoL questionnaires namely, the EORTC QLQ-C30, the EQ-5D and a postage-paid reply envelope. Those participants approached in outpatient clinics were given the same

by hand. To enhance the response rate, a reminder letter and pack were sent out after 2 weeks to all the participants who had initially received the pack either by hand or by post.

Inclusion criteria were >18 years of age, in clinical remission, as determined by treating clinicians. They must have completed treatment for a B-cell malignancy (CLL, all lymphomas, MM) 1–5 years prior to the commencement of the study, lived within the catchment area and/or attended one of the three hospitals. Exclusion criteria included cognitive impairment or a history of major psychiatric illness and those who lacked the capacity to provide informed consent. Participants determined by treating clinicians to be too unwell to complete questionnaires were also excluded from the study. Basic proficiency in the English language was expected, as there were no resources for translation. The study received ethical approval from the National Research Ethics Committee South Central—Southampton A (12/SC/0708). All participation was voluntary, and people returning questionnaires were perceived to have implied consent.

2.2 | Demographic data and variables

The demographic questionnaire captured socio-demographic data such as age, gender, marital status, living arrangements, educational status, employment status, health status and ethnic origin of the participants. Clinical information about diagnosis and time of treatment completion was extracted from the medical records or hospital database and recorded on an Excel spreadsheet and later transferred onto SPSS. Data were electronically stored securely on a hospital shared drive which was password protected.

2.3 | The EORTC QLQ-C30 questionnaire

EORTC QLQ-C30 is a health-related QoL questionnaire developed by the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Study Group to assess the QoL of patients with cancer (Aaronson et al., 1993; Sprangers, Cull, Bjordal, Groenvold, & Aaronson, 1993). The validity and reliability of this questionnaire have been verified in several studies (Groenvold, Klee, Sprangers, & Aaronson, 1997; Luckett et al., 2011), and the instrument is available in several languages (Fayers et al., 2001).

The questionnaire comprises 15 scales with 30 questions in total, including physical, emotional, cognitive, social and role functioning, fatigue, pain, nausea/vomiting, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial difficulties and global health status. The questions were rated from 1 to 4 with scores corresponding from "not at all" to "very much." Questions 29 and 30 were rated from 1 to 7 (very poor to excellent) (Aaronson et al., 1993). Each rated scale was used to compute a score ranging from 0 to 100 according to the scoring manual of Fayers et al. (2001).

2.4 | EQ-5D quality of life questionnaire

The EQ-5D, validated by the European QoL group, measures generic health-related QoL. This questionnaire has been used to measure the QoL of individuals with long-term health conditions. It consists of five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Participants were requested to choose from one of the three options (levels) which best described how they feel day to day ranging from "no problems" to "extreme problems." The EQ-5D VAS (visual analogue scale) a part of this questionnaire ranges from 0 to 100 the latter being the best imaginable health state. Participants were requested to mark their health status on the scale, and this was used as a quantitative measure to report their health outcomes. Data from the questionnaires were analysed descriptively in accordance with the European Quality of Life Group User Guide (Williams, 1990). The three options (levels) were combined into dichotomous variables in SPSS version 19—option 1 (no

TABLE 1 Characteristics of survivors of a B-cell malignancy in Dorset, UK

Characteristics	*N* (%)
Median age in years (interquartile range)	66 (21–95)
Gender	
Female	53 (40.5)
Male	78 (59.5)
Marital status	
Single/divorced/separated	27 (20.6)
Married/cohabitating	92 (70.2)
Widowed	12 (9.2)
Children	
Have children	104 (79.4)
Do not have children	27 (20.6)
Educational status	
Up to college	81 (61.8)
Graduate and above	44 (33.6
Employment status	
Employed	39 (29.8)
Not employed	80 (61.1)
Living status	
Living alone	39 (29.8)
Not living alone	92 (70.2)
Ethnic origin (White)	131 (100)
Diagnosis	
Leukaemia	14 (10.7)
Lymphoma	102 (77.9)
Myeloma	14 (10.7)
Time since completion of treatment	
≤2.5 years	55 (41.9)
>2.5 years	76 (58.1)
Health status	
Good	74 (59.6)
Average	35 (28.2)
Poor	15 (12.2)

TABLE 2 Associations between Quality of Life domains and socio-demographic characteristics of survivors of a B-cell malignancy in Dorset, UK (EORTC QLQ C-30)

Factor	QoL	Physical Functioning	Role Functioning	Emotional Functioning	Cognitive Functioning	Social Functioning	Fatigue	Financial Difficulties	Pain	Dyspnoea	Sleep Loss	Appetite	Constipation	Diarrhoea
Age*														
Z	−0.139	−0.277	−0.218	0.136	−0.048	−0.065	0.105	−0.163	0.150	0.188	0.020	−0.025	0.093	−0.119
p Value	0.032	0.000	0.002	0.039	0.489	0.341	0.108	0.023	0.030	0.007	0.741	0.727	0.188	0.102
Gender														
Male	65.94	52.67	61.99	64.01	67.11	62.80	62.65	63.57	55.80	65.51	57.61	63.19	65.20	62.32
Female	61.20	41.29	59.59	62.75	59.52	64.53	64.75	64.52	74.80	66.72	76.96	68.86	65.93	66.51
Z	−0.724	−2.039	−0.408	−0.195	−1.213	−0.286	−0.324	−0.209	−3.210	−0.202	−3.190	−1.228	−0.135	−1.065
p Value	0.469	0.041	0.683	0.846	0.225	0.777	0.746	0.834	0.000	0.840	0.001	0.219	0.893	0.287
Living arrangements														
Living alone	60.64	53.34	64.96	62.68	70.28	71.84	60.23	65.46	60.70	63.85	69.85	70.62	59.32	60.76
Not living alone	65.38	45.65	59.19	63.84	61.42	60.03	64.86	63.40	64.60	66.91	63.64	63.31	68.15	65.33
Z	−0.671	−1.291	−0.925	−0.168	−1.310	−1.808	−0.659	−0.382	−0.620	−0.480	−0.950	−1.476	−1.512	−1.078
p Value	0.502	0.197	0.355	0.866	0.190	0.071	0.510	0.703	0.540	0.631	0.340	0.140	0.131	0.281
Education														
Upto college level	61.29	44.62	58.19	61.32	59.75	62.68	60.36	61.46	59.90	65.14	65.24	63.35	61.51	61.54
Graduate and above	60.48	47.18	57.63	60.42	63.27	56.59	60.76	60.17	61.70	59.07	57.52	60.95	64.30	61.42
Z	−0.124	−0.456	−0.094	−0.139	−0.562	0.999	−0.062	−0.261	−0.300	−1.017	−1.270	−0.525	−0.510	−0.031
p Value	0.901	0.649	0.925	0.889	0.574	0.318	0.951	0.794	0.760	0.309	0.205	0.600	0.610	0.975
Employment														
Employed	73.61	58.88	73.10	63.21	71.38	69.03	40.34	56.05	43.30	48.32	46.38	51.84	51.54	58.07
Not employed	51.14	33.86	46.08	55.43	52.22	52.56	66.38	59.69	65.30	65.69	65.73	63.14	63.28	58.71
Z	0.732	−4.591	−4.590	−1.214	−3.055	−2.714	−3.979	−0.732	−3.670	−2.941	−3.190	−2.157	−2.157	−0.162
p Value	0.464	0.000	0.000	0.225	0.000	0.007	0.000	0.464	0.000	0.003	0.001	0.031	0.031	0.464
Time since completion of treatment														
≤2.5 years	55.85	45.46	52.08	56.13	54.84	52.20	59.68	52.83	58.20	61.37	61.86	60.68	58.93	58.92
>2.5 years	56.98	47.23	63.36	56.78	57.74	58.79	53.20	59.25	54.30	56.33	55.03	55.94	57.28	55.58
Z	−0.186	−0.323	−1.977	−0.109	−0.498	−1.184	−1.069	−1.368	−0.710	−0.904	−1.220	−1.104	−0.323	−0.907
p Value	0.853	0.747	0.048	0.913	0.619	0.236	0.285	0.171	0.480	0.366	0.224	0.270	0.747	0.364

Note. *Kendall's Tau correlation coefficient used for age and Mann–Whitney U test used for other variables. For functioning scales: higher the scores, better the functioning. For symptom scales: higher the scores, higher the magnitude of the symptoms.

problems) was relabelled as "no problems" and option 2 (some problems) and option 3 (extreme problems) together as "problems."

2.5 | EORTC QLQ-C30 scores and analysis

Descriptive statistics were first calculated; numerical data were described using median and interquartile range when skewed. Here, age was the only continuous variable that was skewed. Non-parametric Kendall's tau correlation coefficient was used to determine associations between age and QoL subscales with a two-tailed significance test ($p < 0.05$) to assess the strength of the dependence of two variables (Bland, 2000) and data collected from the EORTC QLQ-C30 questionnaires were considered ordinal, and QoL measurement was considered nominal ordered. The associations between socio-demographic, clinical factors and QoL subscales were determined using the Mann–Whitney U test. This test is used when two independent random samples are compared and when data are ordinal as in this sample (Bland, 2000). Raw scores of this questionnaire were transformed to a linear scale ranging from 0 to 100. Higher scores represent higher functioning and QoL and a higher level of symptoms. Scoring was undertaken using directions from the EORTC scoring manual (Kaasa et al., 1995; Groenvold et al., 1997; Gulbrandsen, Hjermstad, Wisloff, & Nordic Myeloma Study Group, 2004).

2.6 | EQ-5D scoring and analysis

The independent samples *t* test was used to determine associations between age and the EQ-5D dimensions. This test was used as it identifies statistical differences between the means of two groups of reasonable size (Petrie & Sabin, 2009). The independent sample *t* test requires the assumption of homogeneity of variance. The test that is used for this assumption is Levene's test. The associations between age and the EQ-5D VAS were determined using Spearman's rank correlation coefficient as age was considered non-normal. This test is a non-parametric test and has been used to measure the strength and direction of two variables (Petrie & Sabin, 2009). Associations between the socio-demographic variables and the dichotomised EQ-5D dimensions were determined using cross-tabulations. Row percentages were chosen as they were more useful and appropriate in answering the research question. If one cell had an expected count of <5, then Fisher's exact test was used (Foster, Jefferies, & Foster, 2014).

3 | RESULTS

3.1 | Patient and clinical characteristics

A total of 200 participants were invited to take part resulting in 131 completed questionnaires with a response rate of 66%. The median (interquartile range) age of participants was 66.0 years (21.0–95.0) reflecting the prevalence of these types of haematological malignancies in an older population. Demographic and clinical characteristics of participants are summarised in Table 1.

The proportion of men (59.5%) was more than women in the sample enrolled in the study. More than 70% of the sample was married or cohabitating but nearly one-third (29.8%) of participants were living alone at the time of data collection; the majority (79.4%) had children. Almost two-thirds (61.8%) of the sample had been educated to graduate level, and nearly two-thirds (61.1%) of the enrolled participants were not in employment and/or retired. All the participants were Caucasian. The main disease type represented in the sample enrolled was NHL and HD (78%); nearly 11% of the respondents reported having been treated for MM, and similarly, a tenth of them was treated for CLL (10.7%). More than half of the people enrolled (58%) had completed treatment for a B-cell malignancy more than two and a half years previously. Less than two-thirds (59.6%) and almost 30% of the respondents rated their general health status as good and average, respectively, whereas 12.2% of participants rated their general health status as poor. All the enrolled participants were in remission at the time of data collection.

3.2 | EORTC QLQ-C30 questionnaire

The correlation between the QoL domains in the EORTC QLQ-C30 questionnaire and the socio-demographic characteristics are presented in Table 2. Age showed a significant negative correlation with global QoL, physical functioning and role functioning. Significant QoL differences were observed by gender with men reporting better physical functioning ($p = 0.041$) when compared to women. In addition, men reported fewer symptoms of pain ($p = 0.000$) and less sleep loss ($p = 0.001$) compared with women. Employed participants experienced better physical functioning ($p = 0.000$), role functioning ($p = 0.000$) and cognitive functioning ($p = 0.000$), social function ($p = 0.0007$) compared to those who were not employed (as above). Unemployed participants experienced more fatigue ($p = 0.000$), more symptoms of pain ($p = 0.000$), dyspnoea ($p = 0.003$), sleep

TABLE 3 Survivors treated for a B-cell malignancy who reported any problems in Dorset, UK (EQ-5D)

	No problems		Problems	
Dimension	Number	Percentage	Number	Percentage
Mobility	84	64.6	46	35.4
Self-care	116	89.9	13	10.1
Usual activity	82	64.1	46	35.9
Pain/discomfort	80	61.5	50	38.5
Anxiety/depression	96	73.8	34	26.2

TABLE 4 Associations between socio-demographic characteristics, EQ-5D-3L and VAS of survivors of a B-cell malignancy

	Mobility				Self-care			
	No problem % [n]	Problem % [n]	Total % [n]	*p* Value	No problem % [n]	Problem % [n]	Total % [n]	*p* Value
Gender								
Male	66.2 [51]	33.8 [26]	100.0 [77]	0.642	90.8 [69]	9.2 [7]	100.0 [76]	0.695
Female	62.3 [33]	37.7 [20]	100.0 [53]		88.7 [47]	11.3 [6]	100.0 [53]	
Treatment Compl[a]								
≤2.5 years	56.0 [28]	44.0 [22]	100.0 [50]	0.690	86.0 [43]	14.0 [7]	100.0 [50]	0.102[b]
>2.5 years	72.3 [47]	27.7 [18]	100.0 [65]		95.3 [61]	4.7 [3]	100.0 [64]	
Living								
Living alone	69.2 [27]	30.8 [12]	100.0 [39]	0.471	92.3 [36]	7.7 [3]	100.0 [39]	0.753[b]
Not living alone	62.6 [57]	37.4 [34]	100.0 [91]		88.9 [80]	11.1 [10]	100.0 [90]	
Children								
Yes	60.0 [63]	40.0 [42]	100.0 [105]	**0.024***	88.5 [92]	11.5 [12]	100.0 [104]	0.461[b]
No	84.0 [21]	16.0 [4]	100.0 [25]		96.0 [24]	4.0 [1]	100.0 [25]	
Education								
Up to College	62.5 [50]	37.5 [30]	100.0 [80]	0.373	91.1 [72]	8.9 [7]	100.0 [79]	0.754[b]
Graduate and above	70.5 [31]	29.5 [13]	100.0 [44]		88.6 [39]	11.4 [5]	100.0 [44]	
Employment								
Employed	89.5 [34]	10.5 [4]	100.0 [38]	**<0.001**	100.0 [38]	0.0 [0]	100.0 [38]	**0.009**[b]
Not employed	50.0 [40]	50.0 [40]	100.0 [80]		84.8 [67]	15.2 [12]	100.0 [79]	
Health								
Good	100.0 [25]	0.00 [0]	100.0 [25]	**<0.001**	100.0 [25]	0.0 [0]	100.0 [25]	**<0.001**
Average	100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	
Poor	100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	

Bold values represent statistically significant difference with a $p < 0.001$.
[a]Duration of completion of treatment. [b]Fisher's exact test. *Statistically significant.

loss ($p = 0.001$), appetite ($p = 0.031$) and constipation ($p = 0.031$) compared with those employed. Other variables such as "time since completion of treatment", "living arrangements" and "educational status" did not have a significant impact on other QoL domains.

3.3 | EQ-5D QoL questionnaire

Associations between the QoL domains and the socio-demographic characteristics are presented in Table 3. Amongst the five dimensions, fewest problems were reported for self-care (10.1%) and the most for pain/discomfort (38.5%), followed by usual activity (35.9%). Almost two-thirds (61.5%) of participants reported being problem-free.

The proportion of participants reporting any/no problems in the five dimensions of the EQ-5D descriptive system is shown in Table 4. According to the EQ-5D-3L questionnaire, most participants did not report problems with self-care or anxiety/depression. However, a high proportion of participants reported problems with mobility (35.4%), usual activities (35.9%) and pain/discomfort (38.5%).

There was little difference by gender in mobility, self-care, usual activities and anxiety/depression, and two-thirds (66.2%) of men and 62.3% of women reported no problems with mobility. Most (90.8% of men/88.7% of women) reported no problems with self-care activities, and 68% of men and 58.5% of women had no problems in continuing with usual activities. However, there were significant gender differences in reporting of pain/discomfort. The proportion of men who reported no problems with pain/discomfort (70.1%) was higher than the proportion of women (49.1%) who reported no problems with the same symptom. This difference was statistically significant with a *p*-value of 0.015. All participants reported the lowest proportion of problems in the self-care dimension (10%). Participants with children were more likely to report problems with mobility (40.0%) than those without children (16.0%). A statistically significant difference was observed here with a *p*-value of 0.024. Participants with children were less likely to report no problems with usual activities (59.2%) than those without children (84.0%) with a *p*-value of 0.021. The variable that was significant for all dimensions was employment. Employed participants reported no problems with

Usual activities				Pain/Discomfort				Anxiety/Depression			
No problem % [n]	Problem % [n]	Total % [n]	p Value	No problem % [n]	Problem % [n]	Total % [n]	p Value	No problem % [n]	Problem % [n]	Total % [n]	p Value
68.0 [51]	32.0 [24]	100.0 [75]	0.269	70.1 [54]	29.9 [23]	100.0 [77]	**0.015***	76.6 [59]	23.4 [18]	100.0 [77]	0.385
58.5 [31]	41.5 [22]	100.0 [53]		49.1 [26]	50.9 [27]	100.0 [53]		69.8 [37]	30.2 [16]	100.0 [53]	
58.0 [29]	42.0 [21]	100.0 [50]	0.154	62.0 [31]	38.0 [19]	100.0 [50]	0.906	72.0 [36]	28.0 [14]	100.0[50]	0.547
70.8 [46]	29.2 [19]	100.0 [65]		63.1 [41]	36.9 [24]	100.0 [65]		76.9 [50]	23.1 [15]	100.0 [65]	
69.2 [27]	30.8 [12]	100.0 [39]	0.420	69.2 [27]	30.8 [12]	100.0 [39]	0.238	74.4 [29]	25.6 [10]	100.0 [39]	0.931
61.8 [55]	38.2 [34]	100.0 [89]		58.2 [53]	41.8 [38]	100.0 [91]		73.6 [67]	26.4 [24]	100.0 [91]	
59.2 [61]	40.8 [42]	100.0 [103]	**0.021***	58.1 [61]	41.9 [44]	100.0 [105]	0.098	71.4 [75]	28.6 [30]	100.0 [105]	0.199
84.0 [21]	16.0 [4]	100.0 [25]		76.0 [19]	24.0 [6]	100.0 [25]		84.0 [21]	16.0 [4]	100.0 [25]	
64.1 [50]	35.9 [28]	100.0 [78]	0.841	60.0 [48]	40.0 [32]	100.0 [80]	0.516	75.0 [60]	25.0 [20]	100.0 [80]	1.000
65.9 [29]	34.1 [15]	100.0 [44]		65.9 [29]	34.1 [15]	100.0 [44]		75.0 [33]	25.0 [11]	100.0 [44]	
92.1 [35]	7.9 [3]	100.0 [38]	**<0.001***	78.9 [30]	21.1 [8]	100.0 [38]	**0.004***	86.8 [33]	13.2 [5]	100.0 [38]	**0.035***
48.7 [38]	51.3 [40]	100.0 [78]		51.3 [41]	48.8 [39]	100.0 [80]		68.8 [55]	31.3 [25]	100.0 [80]	
100.0 [25]	0.0 [0]	100.0 [25]	**<0.001**	100.0 [25]	0.0 [0]	100.0 [25]	**<0.001**	96.0 [24]	4.0 [1]	100.2[5]	**<0.001**
100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	
100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	

mobility (p-value < 0.001) when compared to unemployed or retired participants. All employed participants reported no problems with self-care. Most (92.1%) employed participants reported no problems with carrying out usual activities with the differences being statistically significant (p-value < 0.001). Most (78.9%) employed participants did not report any pain/discomfort (p = 0.004). Anxiety/depression was not a problem reported in 86.8% of participants who were employed (p = 0.035).

4 | DISCUSSION

4.1 | EORTC QLQ C30

The key findings of the importance of gender for pain, having children for mobility and usual activities, employment status and health status for all dimensions are presented. This study addressed issues that were predominant amongst the survivors. It explored the impact of selected socio-demographic variables on the QoL of survivors of B-cell malignancies. Increasing age was associated with lower QoL. These findings support those of Priscilla et al. (2011) who reported reduced QoL with impaired physical and role functioning in older patients with a haematological cancer. A similar trend is seen in the study conducted by SlovacekSlovackova, Pavlik, and Jebavy (2007).

Men reported lower pain scores and less loss of sleep than did women. Studies by Mellon, Northouse, and Weiss (2006) and Matthews, Tejeda, Johnson, Berbaum, and Manfredi (2012) add support to these findings where women reported lower QoL than men. However, these findings were not specific to survivors of a haematological malignancy but encompassed all cancer survivors. A significant difference was seen in the domain of physical functioning with men reporting higher levels of physical functioning (p < 0.05) in these studies.

Employed survivors reported significantly better physical functioning and social functioning and fewer role limitations and symptoms than those who were not employed. In general, employed participants, therefore, reported a much better QoL than those who were not employed. To add, most of the participants with more symptoms of fatigue, pain, sleep loss, appetite loss and constipation

were unemployed or retired (Table 2). Participants who lived beyond two and a half years following completion of treatment for haematological malignancy reported better role functioning than those who completed treatment less than 2.5 years previously ($p = <0.048$). Other QoL dimensions did not show significant associations with time since completion of treatment. No significant associations were found between the QoL dimensions and the marital status and/or living arrangements of participants.

The correlation between the QoL domains in the EORTC QLQ-C30 questionnaire and the socio-demographic characteristics are presented in Table 2. Age showed a significant negative correlation with global QoL, physical functioning and role functioning. Significant QoL differences were observed in gender with men reporting better physical functioning ($p = 0.041$) compared with women. In addition, men reported fewer symptoms of pain ($p = 0.000$) and less sleep loss ($p = 0.001$) compared with women. Employed participants experienced better physical functioning ($p = 0.000$), role functioning ($p = 0.000$) and cognitive functioning ($p = 0.000$) compared with those who were not employed/retired. Unemployed participants experienced more fatigue ($p = 0.000$), more symptoms of pain ($p = 0.000$), dyspnoea ($p = 0.003$), sleep loss ($p = 0.001$), appetite ($p = 0.031$) and constipation ($p = 0.031$). Other variables such as "time since completion of treatment," "living arrangements" and "educational status" did not have a significant impact on the other QoL domains. Overall, younger participants, men and those in employment reported better quality of life.

4.2 | EQ-5D questionnaire

Less than 30% of participants reported problems with self-care and anxiety/depression. The present findings seem to be consistent with other studies amongst patients with lymphoma who had received chemotherapy (Cull et al., 1996) and patients with acute leukaemia with anxiety and depression showing an improvement towards the end of treatment and after (Zittoun, Achard, & Ruszniewski, 1999). Another study by Heinonen et al. (2001) suggested that the level of anxiety and depression was lower in the post-treatment follow-up phase than in the active treatment phase for peripheral stem cell transplant recipients. However, over 35% of participants reported having problems with mobility, usual activity and pain or discomfort. A study of cervical cancer survivors showed comparable results (Lang, Chuang, Shun, Hsieh, & Lan, 2010) for the self-care dimension; however, only <10% of participants had problems with mobility.

Pain or discomfort was the most frequently reported symptom amongst all the other dimensions in this group of survivors of haematological malignancy with 38.5% of survivors reporting moderate or severe pain or discomfort. Women reported more pain or discomfort when compared to men with >50% of women reporting moderate or severe levels of pain/discomfort, whereas <30% of men reported moderate/severe problems with pain/discomfort. These findings were consistent with the findings of earlier studies (Baker, Haffer, & Denniston, 2003; Matalqah, Radaideh, Yusoff, & Awaisu, 2011; Oh, Han, Park, Park, & Chung, 2014).

Performing usual activity was the second most frequently reported problem in this group of survivors (35.9%) followed by mobility dimension which was the next frequently reported dimension where participants reported moderate or severe problems (35.4%). A study by Oh et al. (2014) also showed similar results with self-care being the lowest reported dimension with moderate to severe problems. These symptoms may also be attributed to a predominantly older population. This indicates that even if the survivors are disease free, they may experience debilitating symptoms of pain/discomfort and other issues such as mobility and performing a usual activity to a certain degree which can have a significant impact on their quality of life. These factors can also be attributed to an ageing population as in Dorset. It is therefore very important as healthcare providers to pay attention to and address these needs.

The main strength of the study was that it was representative of an ageing population with haematological malignancies of the whole UK. A high completion and return rate of the questionnaires was also strength of this study. The use of a combination of validated generic and disease-specific questionnaires that enabled capturing of data in greater detail was also strength of this study. However, it is important to address some limitations here. Due to the cross-sectional nature of the study, it has not been possible to explore the changes in QoL over time as in longitudinal studies. The participants' mental status at the time of completion of questionnaires may have influenced their answers and the EQ-VAS scores. Based on the sample of 131 in total, the number of participants with a diagnosis of MM and CLL was relatively small, and it did not allow for comparison of the QoL amongst the groups. The number of participants with MM and CLL was 15 each. Those with a diagnosis of any type of lymphoma were predominant in this population, which may not be representative of the quality of life assessment of the smaller groups (CLL and MM). The limitation of the EORTC QLQ-C30 questionnaire is that it provides an overview of health-related QoL in general and not a greater understanding of the different aspects of QoL that may affect patients who have completed treatment for a haematological malignancy. As it gathers the subjective experience of the patient about their symptoms and functions, it can be interpreted in various ways; pain may be due to malignant disease or another co-morbid condition. A validated questionnaire that explores in greater detail specific issues pertinent to survivors may have been immensely useful but none was available at the start of the study. Another consideration is the multiple significance tests and that differences have been found by chance.

5 | CONCLUSION

Men and those in employment who have completed treatment for haematological malignancy reported better QoL in this study. Women reported lower physical functioning, more pain and less sleep when compared to men. Age had a significant negative correlation with global QoL, physical and role functioning. These issues need to be addressed when planning long-term survivorship care as

it must be tailored to suit individual needs. With the gender differences in QoL identified, different clinical approaches are warranted in male and female survivors. These different approaches may enable healthcare providers to provide tailored treatment modalities to optimise outcomes and improve QoL. In order to provide ongoing support and set up robust systems in the cancer care pathway, it is very important to understand the experiences of these survivors and the possible long-term effects, the malignancy and its treatment entails. Assessment at an early stage will prepare healthcare providers to determine the level of support each patient may require in the survivorship phase. To optimise QoL for these survivors, healthcare services must focus and target on the disease and treatment associated sequelae that may influence a patient in the survivorship phase. Structured survivorship care models can be implemented to further enhance the quality of lives of these survivors. It is evident that patients' needs and concerns may change along their cancer spectrum. It is important to utilise assessment tools that report concerns of survivors and enable conversations with healthcare providers with "care planning," continued communication between primary care physicians and haematologists, access to health and well-being services is recommended as the optimal approach in delivering personalised survivor care. A further validated questionnaire that specifically addresses needs pertinent to survivors of a haematological malignancy is required. These questionnaires will facilitate the capturing of such needs and may enable the development of care models. This study warrants the investigation of a systematic long-term follow-up care model in larger studies.

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REFERENCES

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., … Takeda, F. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in International Clinical Trials in oncology. *JNCI: Journal of the National Cancer Institute*, *85*(5), 365–376. https://doi.org/10.1093/jnci/85.5.365

Aleman, B. M., & van Leeuwen, F. E. (2007). Are we improving the long-term burden of Hodgkin's lymphoma patients with modern treatment? *Hematology/Oncology Clinics of North America*, *21*(5), 961–975. https://doi.org/10.1016/j.hoc.2007.07.005

Aziz, N. M., & Rowland, J. H. (2003). Trends and advances in cancer survivorship research: Challenge and opportunity. *Seminars in Radiation Oncology*, *13*(3), 248–266. https://doi.org/10.1016/S1053-4296(03)00024-9

Baker, F., Haffer, S. C., & Denniston, M. (2003). Health-related quality of life of cancer and noncancer patients in Medicare managed care. *Cancer*, *97*(3), 674–681. https://doi.org/10.1002/cncr.11085

Bland, M. (2000). *An introduction to medical statistics*, 3rd ed. Oxford, UK: Oxford University Press.

Cancer Research UK (2014). http://www.cancerresearchuk.org/health-professional/cancer-statistics/survival, Accessed August 2018.

Chihara, D., Ito, H., Matsuda, T., Shibata, A., Katsumi, A., Nakamura, S., … Matsuo, K. (2014). Differences in incidence and trends of haematological malignancies in Japan and the United States. *British Journal of Haematology*, *164*, 536–545. https://doi.org/10.1111/bjh.12659

Cull, A., Hay, C., Love, S. B., Mackie, M., Smets, E., & Stewart, M. (1996). What do cancer patients mean when they complain of concentration and memory problems? *British Journal of Cancer*, *1996*(74), 1674–1679.

De Angelis, R., Sant, M., & Coleman, M. P. (2014). Cancer survival in Europe 1999–2007 by country and age: Results of EUROCARE-5 - A population-based study. *Lancet Oncology*, *2014*(15), 23–34.

De Vita, V. T., Lawrence, T. S., & Rosenburg, S. A. (2008). *De Vita, Hellman, and Rosenburg's cancer: Principles and practices of oncology*. 8th ed. Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams and Wilkins.

Efficace, F., Novik, A., Vignetti, M., Mandelli, F., & Cleeland, C. S. (2007). Health-related quality of life and symptom assessment in clinical research of patients with hematologic malignancies: Where are we now and where do we go from here? *Haematologica*, *92*(12), 1596–1598.

Fayers, P. M., Aaronson, N. K., Bjordal, K., Groenvold, M., Curran, D., & Bottomley, A.; On behalf of the EORTC Quality of Life Group (2001). *EORTC QLQ-C30 scoring manual*, 3rd ed. Brussels, Belgium: EORTC.

Foster, I., Jefferies, J., & Foster, L. (2014). *Beginning statistics: An introduction for social scientists*. Los Angeles, CA: Sage.

Gotay, C. C., Holup, J. L., & Pagano, I. (2002). Ethnic differences in quality of life among early breast and prostate cancer survivors. *Psycho-Oncology*, *11*(2), 103–113. https://doi.org/10.1002/pon.568

Groenvold, M., Klee, M. C., Sprangers, M. A., & Aaronson, N. K. (1997). Validation of the EORTC QLQ-C30 quality of life questionnaire through combined qualitative and quantitative assessment of patient-observer agreement. *Journal of Clinical Epidemiology*, *50*(4), 441–450. https://doi.org/10.1016/S0895-4356(96)00428-3

Gulbrandsen, N., Hjermstad, M. J., Wisloff, F., & Nordic Myeloma Study Group. (2004). Interpretation of quality of life scores in multiple myeloma by comparison with a reference population and assessment of the clinical importance of score differences. *European Journal of Haematology*, *72*, 172–180.

Hall, A., Lynagh, M., Bryant, J., & Sanson-Fisher, R. (2013). Supportive care needs of haematological cancer survivors: A critical review of the literature. *Critical Reviews in Oncology/Hematology*, *88*, 102–116.

Hallek, M., Fischer, K., Fingerle-Rowson, G., Fink, A. M., Busch, R., Mayer, J., … Stilgenbauer, S. (2010). Addition of rituximab to fludarabine and cyclophosphamide in patients with chronic lymphocytic leukaemia: A randomised, open-label, phase 3 trial. *The Lancet*, *376*(9747), 1164–1174. https://doi.org/10.1016/s0140-6736(10)61381-5

Hassan, M., & Abdi-Valugerdi, M. (2014). Hematologic malignancies in elderly patients. *Haematologica*, *99*(7), 1124–1127. https://doi.org/10.3324/haematol.2014.107557

Heinonen, H., Volin, L., Uutela, A., Zevon, M., Barrick, C., & Ruutu, T. (2001). Quality of life and factors related to perceived satisfaction with quality of life after allogeneic bone marrow transplantation. *Annals of Hematology*, *2001*(80), 137–143. https://doi.org/10.1007/s002770000249

Hess, S. L., Johannsdottir, I. M., Hamre, H., Kiserud, C. E., Loge, J. H., & Fossa, S. D. (2011). Adult survivors of childhood malignant lymphoma

are not aware of their risk of late effects. *Acta Oncologica*, *50*(5), 653–659. https://doi.org/10.3109/0284186X.2010.550934

Hodgson, D. C., Grunfeld, E., Gunraj, N., & Del Giudice, L. (2010). A population-based study of follow-up care for Hodgkin lymphoma survivors: Opportunities to improve surveillance for relapse and late effects. *Cancer*, *116*(14), 3417–3425. https://doi.org/10.1002/cncr.25053

Howlader, N., Noone, A. M., Krapcho, M., Garshell, J., Miller, D., Altekruse, S. F., & Cronin, K. A. (2014). SEER cancer statistics review, 1975–2011. Bethesda, MD: National Cancer Institute. Available from: http://seer. cancer.gov/csr/1975_2011/ based on November 2013 SEER data submission, posted to the SEER website [last accessed June 2017].

Junlén, H. R., Peterson, S., Kimby, E., Lockmer, S., Lindén, O., Nilsson-Ehle, H., … Wahlin, B. E. (2015). Follicular lymphoma in Sweden: Nationwide improved survival in the rituximab era, particularly in elderly women: A Swedish Lymphoma Registry study. *Leukaemia*, *29*(3), 668–676. https://doi.org/10.1038/leu.2014.251

Kaasa, S., Kvikstad, A., Bjordal, K., Aaronson, N., Moum, T., Wist, E., & Hagen, S. (1995). The EORTC Core Quality of Life questionnaire (QLQ-C30): Validity and reliability when analysed with patients treated with palliative radiotherapy. *European Journal of Cancer*, *31*(13–14), 2260–2263. https://doi.org/10.1016/0959-8049(95)00296-0

Lang, H. C., Chuang, L., Shun, S.-C., Hsieh, C.-L., & Lan, C.-F. (2010). Validation of EQ-5D in patients with cervical cancer in Taiwan. *Supportive Care in Cancer.*, *18*(10), 1279–1286.

Lobb, E. A., Joske, D., Butow, P., Kristjanson, L. J., Cannell, P., Cull, G., & Augustson, B. (2009). When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Education and Counseling*, *77*(1), 103–108. https://doi.org/10.1016/j.pec.2009.02.005

Lopez-Herce, J., Rollon-Mayordomo, A., Lozano-Rosado, R., Salazar-Fernandez, C. I., & Gallana, S. (2009). Quality of life in long-term oral cancer survivors: A comparison with Spanish general population norms. *Journal of Oral & Maxillofacial Surgery*, *67*(8), 1607–1614. https://doi.org/10.1016/j.joms.2008.12.039

Luckett, T., King, M. T., Butow, P. N., Oguchi, M., Rankin, N., Price, M., … Heading, G. (2011). Choosing between EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: issues, evidence and recommendations. *Annals of Oncology*, *21*, 1–12.

Maddams, J., Brewster, D., Gavin, A., Steward, J., Elliott, J., Utley, M., & Møller, H. (2009). Cancer prevalence in the United Kingdom: Estimates for 2008. *British Journal of Cancer*, *101*(3), 541–547. https://doi.org/10.1038/sj.bjc.6605148

Maher, J., & McConnell, H. (2011). New pathways of care for cancer survivors: Adding the numbers. *British Journal of Cancer*, *105*, S5–S10. https://doi.org/10.1038/bjc.2011.417

Matalqah, L. M., Radaideh, K. M., Yusoff, Z. M., & Awaisu, A. (2011). Health-related quality of life using EQ-5D among breast cancer survivors in comparison with age-matched peers from the general population in the state of Penang, Malaysia. *Journal of Public Health*, *19*(5), 475–480. https://doi.org/10.1007/s10389-011-0406-6.

Matthews, A. K., Tejeda, S., Johnson, T. P., Berbaum, M. L., & Manfredi, C. (2012). Correlates of quality of life among african american and white cancer survivors. *Cancer Nursing*, *35*(5), 355–364. https://doi.org/10.1097/NCC.0b013e31824131d9

Mellon, S., Northouse, L. L., & Weiss, L. K. (2006). A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing*, *29*(2), 120–131. https://doi.org/10.1097/00002820-200603000-00007

Mounier, M., Bossard, N., Remontet, L., Belot, A., Minicozzi, P., De Angelis, R., … Giorgi, R. (2015). Changes in dynamics of excess mortality rates and net survival after diagnosis of follicular lymphoma or diffuse large B-cell lymphoma: Comparison between European population-based data (EUROCARE-5). *Lancet Haematology*, *2*(11), 481–491. https://doi.org/10.1016/S2352-3026(15)00155-6

Office for National Statistics [ONS] (2015). Cancer Registration Statistics: England Statistical Bulletins (Accessed June 2017). https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2015.

Office for National Statistics [ONS] (2016). Mid-Year Estimates (MYE) 2016 (Accessed August 2018).

Office for National Statistics [ONS] (2018). Cancer Survival Statistics: England Statistical Bulletins. (Accessed December 2018). https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016#cancer-survival-in-england-patients-diagnosed-between-2011-and-2015-and-followed-up-to-2016-national-statistics

Oh, M. G., Han, M. A., Park, C.-Y., Park, S.-G., & Chung, C. H. (2014). Health-related quality of life among cancer survivors in Korea: The Korea National Health and Nutrition Examination Survey. *Japanese Journal of Clinical Oncology*, *44*(2), 153–158. https://doi.org/10.1093/jjco/hyt187

Petrie, A., & Sabin, C. (2009). *Medical statistics at a glance*, 3rd ed. Oxford, UK: Wiley-Blackwell.

Priscilla, D., Hamidin, A., Azhar, M. Z., Noorjan, K. O. N., Salmiah, M. S., & Bahariah, K. (2011). Quality of life among patients with haematological cancer in a Malaysian hospital. *Medical Journal of Malaysia*, *66*(2), 117–120.

Pulte, D., Jansen, L., Castro, F. A., & Brenner, H. (2016). Changes in the survival of older patients with hematologic malignancies in the early 21st century. *Cancer*, *122*(13), 2031–2040. https://doi.org/10.1002/cncr.30003

Punnett, A., Tsang, R. W., & Hodgson, D. C. (2010). Hodgkin lymphoma across the age spectrum: Epidemiology, therapy, and late effects. *Seminars in Radiation Oncology*, *20*(1), 30–44. https://doi.org/10.1016/j.semradonc.2009.09.006

Sant, M., Minicozzi, P., Mounier, M., Anderson, L. A., Brenner, H., Holleczek, B., … De Angelis, R. (2014). Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EUROCARE-5, a population-based study. *The Lancet Oncology*, *15*, 931–942. https://doi.org/10.1016/S1470-2045(14)70282-7

Slovacek, L., Slovackova, B., Pavlik, V., & Jebavy, L. (2007). Health-related quality of life in acute myeloid leukaemia and multiple myeloma survivors undergoing autologous progenitor stem cell transplantation: A retrospective analysis. *Reports of Practical Oncology & Radiotherapy*, *12*, 231–238. https://doi.org/10.1016/S1507-1367(10)60062-4

Smith, A., Howell, D., Patmore, R., Jack, A., & Roman, E. (2011). The incidence of haematological malignancy by sub-type: A report from the Haematological Malignancy Research Network. *British Journal of Cancer*, *105*, 1684–1692. https://doi.org/10.1038/bjc.2011.450

Sprangers, M. A. G., Cull, A., Bjordal, K., Groenvold, M., & Aaronson, N. K. (1993). The European Organization for Research and treatment of cancer approach to quality of life assessment: Guidelines for developing questionnaire modules. *Quality of Life Research*, *2*(8), 287–295. https://doi.org/10.1007/bf00434800

Swanson, J., & Koch, L. (2010). The role of the oncology nurse navigator in distress management of adult in patients with cancer: A retrospective study. *Oncology Nursing Forum*, *37*, 6976.

Tomich, P. L., & Helgeson, V. S. (2002). Five years later: A cross-sectional comparison of breast cancer survivors with healthy women. *Psycho-Oncology*, *11*(2), 154–169. https://doi.org/10.1002/pon.570

Van de Poll-Franse, L., Oerlemans, S., Bredart, A., Kyriakou, C., Sztankay, M., Pallua, S., … Efficace, F. (2018). International development of four EORTC disease-specific quality of life questionnaires for patients

with Hodgkin lymphoma, high- and low-grade non-Hodgkin lymphoma and chronic lymphocytic leukaemia. *Quality of Life Research*, 27(2), 333–345. https://doi.org/10.1007/s11136-017-1718-y

Walsh, M. C. (2010). Impact of treatment-related cardiac toxicity on lymphoma survivors: An institutional approach for risk reduction and management. *Clinical Journal of Oncology Nursing*, *14*(4), 505–507. https://doi.org/10.1188/10.CJON.505-507

Williams, A. (1990). EUROQOL - A new facility for the measurement of health-related quality of life. *Health Policy*, *16*(3), 199–208.

Zittoun, R., Achard, S., & Ruszniewski, M. (1999). Assessment of quality of life during intensive chemotherapy or bone marrow transplantation. *Psychooncology*, *8*, 64–73. https://doi.org/10.1002/(SICI)1099-1611(199901/02)8:1<64:AID-PON337>3.0.CO;2-R

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Glossary of Abbreviations

BU	Bournemouth University
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CIRS	Cumulative Illness Rating Scale (for rating comorbidities)
CLL	Chronic Lymphocytic Leukaemia
CTD	Cyclophosphamide, Thalidomide and Dexamethasone
EORTC	European Organisation for Research & Treatment of Cancer
EORTC C-30	QLQ of EORTC for cancer patients
EORTC CLL-16	QLQ of EORTC for CLL patients
EORTC MY-20	QLQ of EORTC for Multiple Myeloma Patients
EQ-5D	QLQ of the European QoL group
HL	Hodgkin's Lymphoma
HR QoL	Health Related Quality of Life
HUI	Health Utilities Index
MM	Multiple Myeloma
MMR	Mixed-Methods Research
MRC	Medical Research Council
NHL	Non-Hodgkin's Lymphoma
NCSI	National Cancer Survivorship Initiative
NHS	National Health Service
NRES	National Research Ethics Service
ONS	Office for National Statistics
QLQ	Quality of Life Questionnaire
QoL	Quality of Life

SED	Sequential Explanatory Design
USA	United States of America
VAS	Visual Analogue Scale
VCD	Velcade, Cyclophosphamide, Dexamethasone
VTD	Velcade, Thalidomide, Dexamethasone
WHO	World Health Organization