AN INTERPRETIVE PHENOMENOLOGICAL EXPLORATION OF QUALITY OF LIFE ISSUES IN AUTOLOGOUS BLOOD CELL TRANSPLANT RECIPIENTS

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DECLARATION

I, Patricia Joyce declare that the thesis entitled *An Interpretive Phenomenological Exploration of Quality of Life Issues in Autologous Blood Cell Transplant Recipients* is my own work, other than where due reference has been made, and has not been submitted, in whole or in part, in respect of any other academic award.

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Signature of Candidate Date

ACKNOWLEDGEMENTS

I wish to acknowledge the staff of Victoria University for their assistance in the preparation of this thesis, particularly Dr Jenny Cheung and Professor Helen Baker. As Principal Supervisor, Dr Cheung has provided insight, support and understanding, and without her efforts this thesis would not have been possible. Professor Helen Baker provided invaluable advice in the final draft of the thesis.

I would also like to thank those participants who bravely related their stories. Without their cooperation this thesis would not have been possible. Sadly some have since passed away, and this thesis is dedicated to their memories.

Finally, I would like to thank my family and colleagues at the Peter MacCallum Cancer Centre. They have supported this project throughout, providing much needed understanding and encouragement.

ABSTRACT

Autologous blood cell transplantation (ABCT) has been successfully used to treat a variety of haematological cancers and some solid tumours. The number of patients who are long term survivors and free of disease following this treatment is growing rapidly. To enable nurses and health care workers to provide optimal supportive care for these patients, an understanding of how the transplant has affected their quality of life (QOL) is essential. In the last two decades numerous studies have focused on QOL issues in this patient group. However, the majority of these studies tend to approach QOL from a bio-physiological perspective, generating knowledge about the treatment and its side effects. Little is known about the patients' experiences and how they interpret their QOL in the years following their transplants. The purpose of this study was to explore QOL issues from the perspectives of 12 patients who had undergone an ABCT. Heideggerian phenomenology (interpretive phenomenology) was chosen as the theoretical framework for the study, as it allows for the transparent world of people's everyday lived experiences to be illuminated, and so reveal how they interpret their QOL. The aims of this study was to gain a deeper understanding of QOL issues through the participants interpretations of their experiences, and to uncover themes and different patterns of meaning which embody the participants' QOL. Data was collected through in-depth, unstructured interviews with each participant. Thematic analysis, exemplars and paradigm cases were utilised to present the participants' interpretations of their QOL. The findings showed that the participants' QOL was influenced by their interpretations of embodiment, being in time, being in society and re-appraisal of life. The findings also revealed that QOL following an ABCT is a highly individualised, dynamic experience that depends on the challenges the participants confront in their everyday lives. As the participants re-interpreted their lives following their transplants, their perspectives on their QOL changed. For some this was a positive experience, but for others their QOL diminished. The implication of this study is that nurses must be committed to providing individualised, patient focused care following an ABCT. The findings of this study offer a deeper understanding of patients' everyday lived experiences and their QOL following an ABCT, and will enable nurses and other health professionals to develop supportive care infrastructure to assist patients during their recoveries, thus improving their QOL.

TABLE OF CONTENTS

CHAPTER FOUR – FINDINGS: COMMON THEMES AND EXEMPLARS 53

CHAPTER FIVE - FINDINGS: PARADIGM CASES 86

APPENDIX A

INVITATION

TO PARTICIPATE IN A RESEARCH STUDY

I am a registered nurse at the Peter MacCallum Cancer Institute, and currently undertaking a Master of Health Science Degree in the Nursing Department at the Victoria University of Technology. As part of my degree I am interested in interviewing people, like yourself, who have undergone an autologous blood cell transplant.

The purpose of this research is to gain a better understanding of quality of life issues faced by autologous blood cell transplant recipients. Your contribution will assist in broadening the knowledge of healthcare professionals in issues which you confronted after your transplant.

If you agree to participate, I would like to arrange a meeting to discuss your experience at a time and place that is convenient to you. The interview, of approximately one hour's duration, will be taped and later transcribed. It will be treated in total confidence, and your anonymity will be maintained throughout the project by the adoption of pseudonyms. You will be forwarded a copy of your transcript for verification and, if necessary amendment. On completion of this study you will receive a summary of findings of the report.

You are under no obligation to participate in this study. If you do so, you are free to withdraw at any time. You may refuse to answer any questions, and are under no obligation to discuss any issues you feel uncomfortable with. If during the interview you feel distressed or discomforted the session will be discontinued. I would encourage that you have a relative or close friend in the vicinity to provide support if required.

I will be pleased to discuss any questions regarding your participation. You can contact me on 03 9489 2559 (home), 03 9656 1022 (business) or my supervisor, Dr. Jenny Cheung on 03 9688 4654.

Thank you for your assistance

Yours sincerely

Patricia Joyce

RN, Grad Dip of Cancer Nursing.

APPENDIX B

CONSENT FORM

I,...

of...

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the research study entitled:

An exploration of quality of life issues from the perspectives of autologous blood cell transplant recipients.

being conducted by Patricia Joyce at Victoria University of Technology.

I certify that the objectives of the study, together with any risks to me associated with the procedures listed hereunder to be carried out in the study, have being fully explained to me by **Patricia Joyce** , and that I freely consent to participation involving the use on me of these procedures.

Procedures:

- An unstructured interview for approximately one hour
- Tape recording of interview
- Verification of the transcript and clarification of any ambiguities, if necessary

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from the study at any time and that this withdrawal will not jeopardise me any way. Also should I wish to have a relative or close friend in the vicinity during the interview I may do so. I have been informed that the information I provide will be kept confidential.

Participant:

Signed...Date...

Witness other than the researcher:

Signed...Date...

Any queries about your participation in this study may be directed to the researcher Patricia Joyce, 03 9489 2559 or her supervisor, Dr. Jenny Cheung, 03 9688 4654. If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428, MCMC, Melbourne, 8001 or Ph No: 03 9688 4710.

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

As nurses, we are concerned with the symptoms of cancer and cancer treatment, and ultimately the patients’ wellbeing. Quality of life (QOL) is wellbeing, yet the experiential aspects of patients’ QOL, are largely ignored. In caring for our patients we need to understand their QOL experiences, and what they mean to the patients, if we are to provide holistic care and assist them in their journeys from diagnosis through to survival. As a registered nurse working in the area of bone marrow transplantation (BMT), I was frustrated by an inability to understand the experiential aspects of autologous blood cell transplantation (ABCT), and what this meant to patients in terms of their QOL. The majority of studies assessing QOL issues in BMT patients approach it from a bio-physiological perspective. This approach generates knowledge regarding the effectiveness of the treatment and its side effects, as well as documenting the length of time to recovery and the overall survival rate. But the patients’ experiences of their transplants and how they interpret their QOL following their treatments has largely been unexplored. Thus, this study was planned, developed and conducted to explore QOL issues in patients who had undergone an ABCT from their individual perspectives.

In the closing decades of the twentieth century, the concept QOL was adapted for use in the health care setting. As medical treatments became more effective and sophisticated there was a shift in focus from simply documenting treatment outcomes in terms of the patient’s bio-physiological wellbeing, to including QOL as an outcome measurement. In the oncology setting the number of patients surviving cancer began to increase, and researchers began to question the quality of this survival. Nowhere was this more justified than in the area of BMT. It is an aggressive form of cancer treatment which certainly has an impact on the patient’s QOL. Much progress has been made in the field of BMT, and nowadays the term blood cell transplantation (BCT) is used interchangeably to describe this form of treatment.

ABCT has been successfully used to treat a variety of haematological malignancies and some solid tumours. Many patients with non-Hodgkin's lymphoma, Hodgkin's disease and some solid tumours can enjoy long-term, disease-free survival as a result of this treatment. The growth of ABCT as a treatment modality is evident in the number of patients who undergo this treatment each year. Horowitz (2004) estimates between 45,000 to 50,000 patients worldwide undergo some form of stem cell transplantation annually. There are now more than 100,000 people surviving 5 years or more following their transplants (Horowitz, 2004). In Australia alone in 2003, a total of 1,112 BMTs were performed, of which 711 BMT recipients were male and 401 recipients were female (ABMTRR, 2003)

However, undergoing an ABCT is a lengthy, complex and, occasionally, a life threatening experience for the patient. It involves the administration of very high doses of chemotherapy or chemoradiation to eradicate the malignancy, followed by the re-infusion of the patient's own stem cells. The latter is a rescue package to assist the patient’s bone marrow function to recover more quickly. The patient is faced with significant physical and psychosocial problems, both during and following the treatment. During the transplant the patient has to cope with the immediate side effects of the transplant such as infection, an ulcerated mouth, difficulty in eating and drinking, nausea, vomiting, diarrhea, fatigue, and separation from family and loved ones. Following the transplant and discharge from hospital some of the physical side effects linger, and new challenges arise as the patients attempt to regain their roles within the family unit and return to work. They may experience difficulty resuming personal relationships, and must cope with alterations in their physical appearances. All of these challenges invariably will impact on the patient's QOL (McQuellon et al., 1996; Marks, Friedman, Carpini, Nezu & Nezu, 1997).

The treatment involves four stages: the collection of the stem cells, the administration of the high dose chemotherapy or chemoradiation, the immediate post-transplant recovery, and the long-term recovery phase. Each phase places unique demands on the patient and their families, though perhaps it is the two recovery phases which particularly challenge the patient's QOL. As patients leave hospital and begin to resume their pre-transplant roles, the impact of the transplant may have altered their perceptions of their QOL, particularly in relation to lifestyle, future goals, personal relationships and career options. Yet, very little is known about this and how the patients interpret the quality of their lives following an ABCT.

Understanding the patients' lived experiences is central, not only to nursing practice, but also in exploring their QOL. As Benner (1985) suggests, QOL should be approached from the perspective of being, and not merely from the perspective of doing and achieving. However, the majority of QOL studies with BMT recipients in the main do not share Benner's view. They adopt the medical model, which objectifies the patients, and ignores their worlds and lived experiences. Such studies tend to be epistemologically driven, generating knowledge which contributes to our understanding on the seqaelae following bone marrow transplantation. However, they offer little of how the person experiences this treatment and somehow the experience of the illness is subsumed in the world of scales and measurements inherent in this approach.

Benner (1985, p.2) further suggests "that people do not die or survive strictly according to our best biochemical and physiological accounts.” She also contends that “the person's understanding of his or her body and illness experience must be taken into consideration to account for alterations in the disease process at the tissue level"(p.2). In other words, the patient must be viewed as a subject or the experiencing being, and not just as an object. While the medical model has provided us with statistics on survival, the major physiological disruptions, and the prognostic features to predict a good recovery, very little is provided about the essence of the experience for the patients. Invariably, nurses and other health care professionals influenced by this approach are more likely to provide prescriptive care through generalising patients' experiences and behaviours, thereby ignoring the patients’ worlds and their understanding of their experiences.

Heslop and Oates (1995, p.271) argue that "humanistic/interpretive caring discourses emphasised the subjectivity of patients and their illness experiences". These scholars also argue that such approaches to caring also enable nurses "to uncover the essences behind the patient's disposition". Instead of providing prescriptive care, patient care needs to be individualised to meet their unique needs. In order to assist in this process, nurses promoting QOL in patients who have undergone an ABCT need to understand the patients’ way of being in the world, their lived experiences and how they interpret meaning in their everyday lives. What are the QOL issues for patients who have undergone an ABCT? The best way to explore this question in this patient group is to understand their lived experiences from their perspectives.

1.2 PURPOSE, AIMS AND SIGNIFICANCE OF STUDY

The purpose of this study is to explore QOL issues, from the perspectives of patients who have undergone an ABCT. The aims of this study are, firstly, to gain a deeper understanding of QOL issues through the patients' interpretations of their experiences following an ABCT. And, secondly, to present descriptions of people's experiences of how they perceive their QOL following an ABCT and, in doing so, to uncover themes and different patterns of meanings embedded in their ordinary everyday lives.

By utilising an interpretive phenomenological approach, it is hoped that new insights from the patient's perspective will be illuminated, and that this will contribute to the growing body of QOL literature from an alternative viewpoint. It is also hoped this study will increase awareness among nurses of the importance of focusing on the human response to illness, thereby adding to the well established humanistic dimension of the profession. In doing so, the study will contribute to the development of nursing and supportive care in the BMT setting. Furthermore, new ideas for designing and implementing supportive networks for patients who undergo ABCT might be identified. More importantly, the insights gained from this study will hopefully assist nurses and healthcare professionals to provide more patient focused care to patients following their transplants and ultimately improve the quality of their lives.

ORGANISATION OF THE THESIS

Chapter two presents the literature review, as well as an overview of ABCT. The literature review will present the different approaches utilised to study QOL in this population group. Chapter three discusses the methodology of the study. This includes the theoretical framework underpinning the study, method, data collection and management, method and technique of analysis, issues of rigour and credibility of interpretation, and ethical considerations. Chapters four and five present the findings of the study. Chapter four outlines the major themes and associated sub-themes which emerged from the interview text, as well as presenting exemplars. Chapter five discusses the participants' interpretations of their QOL through the presentation of paradigm cases. Chapter six provides a discussion of the findings within the context of the literature. Chapter seven concludes by discussing the limitations of the study and the implications of the findings for the nursing profession, nursing practice, nursing research and nursing education.

CHAPTER TWO

LITERATURE REVIEW

Over the past 20 years, scholars, notably from the fields of medicine and psychology, have undertaken both quantitative and qualitative research into health care outcomes, with a particular focus on QOL issues. The findings of these studies have been determined by the authors' varying conceptualisations of QOL which, in turn, have shaped their methodological approaches. As this review of the literature reveals, these studies have provided invaluable and diverse information about QOL in various patient groups. However, because of the diversity of the findings, a consensual conceptualisation of QOL cannot be easily established. The concept is far more complex than suggested in the methodological approaches used in quantitative and some qualitative studies. As this chapter will argue through a review of the literature, an interpretive phenomenological approach, in exploring the lived experiences from the participants' perspectives, embraces the diversity and complexity of the concept, and therefore adds to an already well established body of knowledge.

In addressing these issues, this chapter consists of five sections: the rationale for using autologous blood cell transplantation (ABCT); the concept of QOL; the research approaches used to measure QOL, including studies focusing on the physiological and psychosocial determinants; and the patients' experiences of QOL, which will include discussion on the different qualitative approaches. These sections encompass the uniqueness of the treatment rationale and plot the theoretical evolution of QOL. Details of studies will be presented to highlight the diverse range of knowledge encompassed within the concept. It will be contended that such diversity adds intellectual weight for a greater emphasis on a phenomenological approach to QOL.

2.1 BONE MARROW TRANSPLANTATION

The number of patients surviving cancer is increasing and nowhere is this more apparent than in the area of BMT. Horowitz (2004) estimates that between 45,000 to 50,000 patients worldwide undergo this treatment annually, with an increase of ten to 20% expected each year. There is a number of reasons for this expansion. Firstly, BMT has become an established treatment option with proven efficacy in the medical management of many haematological malignancies. Secondly, it provides the sole chance of cure for many patients and the prospect of long-term disease free survival (Beatty, 1994). Whereas once BMT was offered as a final recourse for patients with advanced disease, it is now administered earlier in the courses of their illnesses. With improved patient selection and advances in supportive care, the number of patients surviving BMT is increasing. In 2003 a total of 1,112 BMTs were performed in Australia (ABMTRR, 2003). It is now estimated that there are over 100,000 BMT recipients worldwide who have survived five years or more (Horowitz, 2004).

BMT is probably the most aggressive form of contemporary cancer treatment (Snyder, 1999). It involves the administration of high doses of chemotherapy - with or without radiotherapy - which though necessary to eradicate the malignancy, causes serious bone marrow toxicity. To overcome the latter, it is necessary to reinfuse previously collected haematopoietic stem cells (HSC) (Armitage, 1994). These stem cells can be collected from the patient's sibling, if that person is an appropriate tissue match. This is referred to as an allogeneic transplant. Conversely, the HSCs may be collected from the patient, which is referred to as an autologous stem cell transplant. In Australia, in 2003, 752 autologous and 360 allogeneic transplants were performed (ABMTRR, 2003). Historically, the HSCs were collected from the bone marrow, hence the term bone marrow transplant. Nowadays, a more efficient and effective way of collecting HSCs is from the person's blood stream, hence the term blood cell transplant (BCT) (Applebaum, 1996; McCarthy, Williams & Holmes, 2000).

Undergoing a BCT requires a stay in hospital of approximately 3-4 weeks. This phase of the treatment is characterised by dealing with the immediate side effects of the treatment, separation from family and friends, unfamiliar procedures and environment, and waiting for blood counts to return to normal (Andrykowski & McQuellon, 1999). Physical side effects experienced during this period are related to the high dose treatment, which affects renewal cell tissues such as bone marrow, epithelial lining of the gastro-intestinal tract, and skin and hair follicle cells. As a result, the patient has to deal with extremely discomforting symptoms which include nausea and vomiting, diarrhea, anorexia, taste changes, fatigue, alopecia, mucositis, enteritis, and skin erythema (Kapustay & Buchsel, 1999; Klumpp, 1995; Poliquin, 1997). Other side effects include infection, idiopathic pneumonia, haemorrhagic cystitis and renal complications (Saba, Abraham & Keating, 2000).

Progress and setbacks punctuate the patient's stay in hospital. Indeed, the unpredictable nature of the BCT journey appears to be one of the major sources of psychological distress and anxiety for the patient (Lesko, 1994). The stay in hospital is a period of "watchful waiting" (Andrykowski & McQuellon, 1999, p.399). The patient anxiously awaits the first signs of engraftment, which heralds the return of his/her bone marrow's function. Once engraftment has taken place, and the patient is otherwise well, he/she can be discharged home (Tierney, 2000).

Though the day of discharge is eagerly awaited, this phase of the transplant process can prove to be a very frustrating time for the patient. Even though the patient was deemed medically fit for discharge, a long and protracted period of rehabilitation lies ahead (Dimeo, Tillman, & Bertz et al., 1997). Frustrating symptoms such as persistent fatigue, lack of stamina, physical functional limitations, poor appetite and recurring infections make it difficult for the patient to return immediately to their pre-morbid roles (Baker et al., 1994; Feigin et al, 2000). The patient may also have to contend with delayed side effects such as sexual dysfunction, infertility, cognitive problems and the risk of a secondary malignancy (Winer & Sutton, 1994). Baker, Zabora, Pollard and Winegard (1999) highlighted many psychological problems encountered by BMT patients as they attempted to resume their lives. These included fear of recurrence and death, financial concerns, a sense of loss of control, and anxiety and depression. For the ABCT recipient returning to his/her former roles, either at work or in their homes, can be difficult. Indeed, returning to "normal" following an ABCT is an extremely testing process, which invariably impacts on the patient's QOL (Hjermstad & Kaasa, 1995; Syrjala, Chapko, Vitaliana, Cummings & Sullivan, 1993).

2.2 THE CONCEPT OF QUALITY OF LIFE

In the post WW II era, Western society in general has enjoyed greater socio-economic prosperity and, as a result, an enhanced QOL. The eradication of a wide variety of infectious diseases, improved medical technology, and advances in pharmacology mean that people are living longer and enjoying a better QOL (Mackay, 2003).

As a consequence, interest in QOL assessment has grown exponentially in recent years. This is evident in the growth of international bodies such as the Society for Quality of Life Research, which was founded in 1994 to promote the global exchange of information about QOL (Grant & Rivera, 1998). Furthermore, the United States Food and Drug Administration now utilise QOL assessments to approve new anti-cancer drugs. QOL has become an important outcome measurement in evaluating healthcare delivery in cancer care. Partly, this is because of the prevailing ideological adherence amongst health administrators to economic determinism. As Zebrack (2000, p.1396) noted "recent economic changes and pressures [have] forc[ed] healthcare providers to reconcile quality care and cost-effectiveness." With the economic bottom-line an important determinant in the provision of healthcare, empirical data has been increasingly employed to substantiate decision-making. However, this connection between empiricism and economic rationalism, when employed to determine the measurement of QOL, limits the understanding of the concept's complexities, and the issues faced by cancer patients during and following their treatments. This is particularly relevant given the lack of a global definition to describe QOL.

2.2.1 Defining QOL

The definition and measurement of QOL has been the source of contentious and prolonged debate. There is no one universally accepted definition. As King et al. (1997, p.29) suggested "it may be too amorphous to [be] adequately capture[d] in words". But researchers do agree that QOL is multi-dimensional (Farquhar, 1995; Ferrans, 1990), incorporating physical, psychological, social and - more recently -

spiritual wellbeing (Ferrell et al., 1992). This multi-dimensionality has been traced to the Ancient Greeks. According to Molassiotis (1997, p.573), Aristotle (384 BC-322 BC) suggested that each person's "happiness" differ[ed] according to their situation. The wise – among whom Aristotle is numbered - perceived happiness "to be something obvious and familiar, like pleasure or money or eminence". But, Aristotle cautioned, one's perception of "happiness" altered with circumstance. When the wise man is "hard up" he measures happiness by money, and "[w]hen he falls ill he says that it is health." Aristotle realised that "happiness" - or the quality of one's life - was subjective, individualised and, most importantly, a dynamic concept determined by circumstance (Molassiotis, 1997).

Of course, the term QOL had not been coined in Aristotle's time. It was not until after World War II that QOL gained credence. In 1947, the World Health Organisation (WHO) declared health as "a state of complete physical, mental and social well being and not merely the absence of disease and infirmity" (WHO, 1947, P.29). But it was not until 1966 that QOL first appeared in modern medical literature - the sole article of its type that year (Elkington, 1966). Between 1991 and 1996, over 8,820 articles on a variety of QOL issues were published (Draper, 1997). Indeed, in 1992 the first journal devoted solely to QOL issues, *Quality of Life Research*, was established, and two years later the International Society of Quality of Life Research was formed to globally disseminate information about QOL concerns (Grant & Rivera, 1998). All the while, the definition was expanding to include the patient's perspective. The WHO’s Quality of Life Group in 1994 defined QOL as "an individual's perception of their position in life within the context of their culture and value systems, taking into account their goals, expectations, standards and concerns" (Montazeri, Gillis & McEwen, 1996, p.165). This definition suggested that QOL is best understood by studying the person within their context, allowing them to voice their lived and often unique experiences.

2.2.2 Measuring QOL

When investigating QOL issues, most researchers choose instruments, such as scales or questionnaires, based on the aspects of QOL they wish to explore. Some studies focus on the disease and treatment effects only, while others examine more diverse facets of the concept. However, a unifying theme in the literature is that QOL is best evaluated by asking the patient (King et al., 1997).

QOL is about the judgment and value a person gives to different aspects of his/her life. The judgment and values ascribed will be different for each person. Ferrans (1990) argued that members of the general population will differ as to how important various aspects of life are to their QOL. To overcome this, most studies include questionnaires, which consist of multi-item measurement scales for each QOL dimension. But such approaches are restrictive, because they may not adequately address the unique interpretation of each patient's QOL. King et al. (1997) recognised that the lack of patient perspective in the literature was an important area for future QOL research, and suggested using qualitative methods to explore QOL from the patients’ perspectives.

Over the last two decades, the growth of QOL studies in cancer care has been exponential, reflected in the area of BMT/BCT. As the success of this treatment modality has grown, researchers and clinicians have changed their focus to concentrate on the long term survival of this patient group and their QOL. The literature details a variety of conceptual approaches used to measure and assess QOL, which are determined by the focus of each study. However, there is a tendency to draw from this literature a view that QOL is defined in terms of the bio-psychosocial functioning of the individual. This research provides valuable information in terms of how the individual's level of functioning affects his/her QOL. But QOL is a profoundly personal experience, and perspectives will differ according to the individual. What is needed is a greater insight into the patient’s interpretation of his/her QOL following a BMT/BCT. In addition to the biomedical approach researchers and nurses are utilising other research approaches that focus on the experience of the illness (Steeves, 1992; Cohen & Ley, 2000; Thain & Gibbon, 1996).

2.3 APPROACHES USED TO ASSESS QOL IN BMT/BCT RECIPIENTS

In the following section the different approaches used to study QOL in this specific patient population will be presented. A review of the literature discovered that the majority of QOL research in this area focused either on the physiological determinants of QOL or the psychosocial determinants of QOL. Both approaches will be discussed along with their benefits and limitations.

2.3.1 Physiological Determinants of QOL

A common approach used by researchers is to assess QOL in terms of the individual's bio-physiological level of functioning. This approach provides valuable information regarding the level of physical dysfunction experienced by BMT/BCT recipients. Fatigue, pain and insomnia are commonly reported symptoms following a BMT (Baker et al. 1994; Bush, Haberman, Donaldson & Sullivan, 1995; Schmidt et al. 1993; Winer et al., 1999). Dissatisfaction with sexual performance and sexual dysfunction following the transplant is a common sequelae, and is frequently described in the literature as contributing to a poorer QOL (Baker et al., 1994; Prieto et al., 1996; Schmidt et al., 1993). Other studies also documented poor appetite and an inability to sleep as variables involved in predicting a poorer QOL following a BMT (Chao et al., 1995; Griffiths & Beaver, 1997). The presence of chronic graft-versus-host-disease (GVHD), specifically in patients who have undergone an allogeneic transplant, also impacts on the patient's level of functioning and correlates with a lower QOL (Prieto et al. 1996). However, despite these physical side effects, these studies found that the majority of patients were satisfied with most areas of their lives related to their physical recoveries. A finding common in the majority of studies was the strong correlation between the older the patient at the time of their transplant and a reduced QOL (Baker et al. 1994; Bush et al., 1995; Prieto et al. 1996; Schmidt et al. 1993).

When BMT/BCT recipients' health and functional status was compared to that of age-adjusted population norms, most of the transplant survivors reported diminished QOL. Hann et al. (1997) compared a group of women who had undergone either an ABMT or ABCT for breast cancer, with another group of women of the same age who had had no history of breast cancer. The authors concluded that the women who had undergone the treatment suffered from significantly impaired physical and role functioning, and diminished general health and vitality compared with the group who had no history of breast cancer. This study suggests that the ABMT/ABCT recipients' QOL is much lower when compared with the general population. However, the findings are inconsistent with other studies, which suggest that most ABCT recipients rate their QOL as above average to excellent (Baker et al., 1994; Molassiotis et al., 1995; Winer et al., 1999). This disparity indicates the diverse nature of the findings, and the need for a methodology that can both encompass and explain difference.

The site of the cancer might also have an impact on the individual's QOL, and add to the diversity of the findings. For example, women with breast cancer have to contend with far greater body image issues than other cancer patients (Cohen, Kahn & Steeves, 1998), which may impact on their QOL. Some authors argue that targeting a particular diagnostic group provides a more accurate assessment of the QOL issues unique to that group (Hann et al., 1997; Larsen, Garduff, Nordström, Björkstrand, Ljungman, 1996; McQuellon et al., 1996). Larsen et al. (1996) and McQuellon et al. (1996) presented similar areas of concern for women with breast cancer who had undergone an ABCT. Both studies utilised standardized, self-administered questionnaires. The findings include general role limitations, a decreased capacity for work, issues related to altered physical appearance, and difficulties with intimate relationships and future orientation. Such findings are reflected in other studies which are not cancer specific (Baker et al., 1994; Bush et al., 1995; Hensel, Egerer, Schneeweiss, Goldsmith & Ho, 2002; Lee et al., 2002; Saleh & Brockopp, 2001; Whedon, Stearns & Mills, 1995)

Overall, the results of studies in this area suggest that even with the persistence of physical symptoms and restricted role functioning, individuals who have undergone a BMT/BCT consider themselves fortunate to be alive, despite the limitations now placed on their lives. Fayers and Machin (2000) also found a weak correlation existed between the physical signs, such as symptoms and toxicity, and the patient's overall QOL, and suggested, "many patients are willing to accept unpleasant or toxic therapy for seemingly modest benefits in terms of cure" (Fayers & Machin, 2000, p. 15). The results suggest the limitations of assessing QOL solely on physiological determinants, as this approach fails to encompass the existential nature of QOL.

2.3.2 Psychosocial Determinants of QOL

In the latter part of the 1980s QOL research in the field of BMT/BCT extended to include the psychosocial aspects of the treatment. Both researchers and clinicians began to document the psychological and sociological aspects of transplantation. Up to this point very little had been written regarding these aspects. These studies expanded on the bio-physiological approach to include an assessment of the psychosocial sequelae following a BMT/BCT, and how it impacts on the individual's QOL.

There is sufficient empirical data to indicate that BMT/BCT recipients are faced with high levels of psychosocial distress, as they journey through the various stages of their transplants (Andrykowski et al., 1995; Gaston-Johansson & Foxall, 1996; Molassiotis, Boughton, Burgoyne & van den Akker, 1996; Whedon & Ferrell, 1994). Depression and anxiety are the two most common causes of psychological distress, both before and following the transplant (Keogh, O’Riordan, McNamara, Duggan & McCann, 1998). Some studies identified anxiety as peaking in the pre-transplant phase and, significantly, decreasing over time (Keogh et al., 1998; Molassiotis et al., 1996). Studies have identified fear of dying from the procedure (Baker et al. 1994), loss of control and uncertainty (Andrykowski et al., 1990; Molassiotis, 1997), cognitive impairment (Andrykowski et al., 1990), disruption of roles and responsibilities within the family unit (Baker, Curbow & Wingard, 1991; Fromm, Andrykowski & Hunt, 1996), and occupational and financial issues (Molassiotis, 1996; Somerfield, Curbow, Wingard, Baker & Fogarty, 1996) as the major contributors to high levels of anxiety and depression in the BMT/BCT recipient, which impacts negatively on the person's QOL.

Undergoing a BMT/BCT not only affects the recipient, but also to a lesser degree the primary care giver, and family and friends. Molassiotis et al. (1996) suggest that social support and family relationships may contribute to a better QOL following a BMT/BCT. The latter factor has been identified in other studies (Ferrell et al., 1992; Gaston-Johansson & Foxall, 1996; Hacker et al., 2003; Whedon, Stearns & Mills, 1995). While strong family and social support networks have the ability to positively impact on BMT/BCTS recipients' QOL it is also an area which if not functioning well could be a source of psychosocial distress (Baker et al., 1999). Other areas identified which contributed to impaired psychosocial adjustment following a BMT/BCT and a poorer QOL included difficulties in sexual relationships (Molassiotis & Morris, 1999), occupational adjustment (Andrykowski et al., 1995) impaired cognitive functioning (Andrykowski et al., 1995; Hacker et al., 2003), financial difficulties (Haberman, Bush, Young & Sullivan, 1993) and role adjustment within the family unit (Molassiotis, 1997).

Studies have also assessed how BMT/BCT recipients reintegrate into their pre-transplant roles, and the challenges they confront as they attempt to return to 'normality'. Andrykowski et al. (1995) and Baker et al. (1999) suggest that despite the optimistic results of the majority of studies in this field, only a minority of BMT/BCT recipients would consider that their lives have returned to normal. Challenges that these people confront as they set out on their journeys of reintegration include physical role limitations, psychological problems including fear about their futures, and community reintegration concerns. Such challenges invariably impact on their QOL (Baker et al., 1999).

As presented above, there is a large and growing body of literature concentrating on the physiological and psychosocial sequelae following a BMT/BCT, and how this correlates with the person's QOL. These studies house common characteristics, which inevitably impact on how their results are interpreted. Firstly, the research method chosen is predominantly a quantitative approach, as the majority of studies use a variety of measurement tools to address the research question. This is evident in such studies as Baker, Curbow and Wingard (1991), Andrykowski et al. (1990), McQuellon et al. (1996), Molassiotis et al. (1996) and Fromm et al. (1996). In general, the tools used – whether a single or multiple measurement – reflect the multidimensional nature of QOL. A frequently utilised measurement tool is the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ C-30). This tool encompasses five functional scales: a global QOL/health status scale, three multi-item symptom scales and six single item questions (Hacker, 2003). The advantages of using these tools are that they provide specific domain scores, thereby allowing the researcher to identify specific areas of concern. Conversely, they do not provide an overall view of QOL score. No single measurement tool exists which can comprehensively address all aspects of QOL for all patients, emphasising the need for a methodology that embraces difference.

The measurement tools utilised are chosen by the researcher, depending on the focus of the research question. As Hacker (2003, p.627) aptly stated, "different situations call for different tools", for example, Molassiotis et al. (1996) chose the psychosocial adjustment to illness scale (PAIS), the hospital anxiety and depression scale (HADS) and the Rotterdam symptom check list (RSCL) to compare the overall QOL in fifty long term survivors of autologous and allogeneic BMT. The study focused on the psychosocial response to the transplant, and the researchers' choice of measurement tools reflected their quest to assess the impact of the transplant in these areas. Indeed, the use of such quantitative measurement tools allows the researcher to impose his/her predetermined assumptions on the patient's QOL. Consequently, this approach fails to capture the diverse and complex experience of QOL, and what it means to the individual.

Secondly, the majority of studies detailed above have used small sample sizes. Most comprise 100 or less participants (Andrykowski et al., 1995; Baker et al., 1994; Belec, 1992; Litwins, Rodrigue & Weiner, 1994). Sample size is an issue for quantitative studies, as it renders it difficult to generalise results to other BMT/BCT patients. Moreover, as Hacker (2003, p. 623) suggested in a review of QOL studies in BMT/BCT recipients, the small sample sizes make it difficult to identify from among the findings statistical trends which may be clinically significant.

Thus, focusing on the physiological and psychosocial functioning of the individual, through the use of multi-dimensional instruments, does not provide a comprehensive understanding of QOL. While these instruments are usually cancer specific - and sometimes BMT specific – their effectiveness is often limited to the specific areas they address. Consequently, QOL becomes a quantifiable concept, which though valuable, does not capture the concept's diversity and complexity. The limited scope of the instruments used, fails to capture the patient's experience of his/her QOL. As

Cella (1992) suggests QOL is not about the level of bio-psychosocial function or dysfunction, but about understanding the manner in which a person appraises their current life situation.

Understanding the impact of bio-psychosocial dysfunction on the person's QOL is particularly relevant to nursing practice. Nurses are concerned with promoting health and wellbeing, and play an integral role in assisting the patient to return to 'normality' following their treatments. As well as the knowledge gained from quantitative studies documenting the physiological and psychosocial response to the transplant , studies which provide nurses with a more in-depth understanding of the patient's experience are also necessary. As Draper (1997, p.380) suggests, "the everyday work of nurses seeks to identify the circumstances in which human beings are likely to flourish". This being so, the understanding and insight gained from a qualitative approach towards exploring QOL can assist nurses and other health professionals to address the unique needs of each patient, promote their QOL, and also allow them to 'know' their patients, so that professional and humanistic care can be delivered.

2.4 THE PATIENT'S EXPERIENCE

In the late 1970s and early 1980s, the traditional quantitative research approach was being questioned as a suitable methodology to study human life experiences (Benner, 1985). As a result, many nursing researchers began to use qualitative research methodologies to capture the complex array of everyday lived and human experiences (Van der Zalm & Bergum, 2000). Over the last decade an increasing number of qualitative studies examining QOL issues, predominantly from nursing scholars, have begun to enter the BMT field (Baker et al., 1999; Berterö & Ek, 1993; Ersek, 1992;

Feigin et al., 2000; Haberman et al., 1993; Shuster, Steeves, Onega & Richardson, 1996; Steeves, 1992; Thain & Gibbon, 1996). These studies have enriched the current body of QOL knowledge, because they have allowed the individual to share the lived reality of the transplant experience through their stories and narratives. They have provided richer, descriptive and personal accounts of what the experience was like for them (Steeves, 1992; Thain & Gibbon, 1996).

Ferrell (1996) who has been a prolific contributor to oncology nursing research related to QOL has acknowledged this fact. In one of her earlier studies investigating QOL as an outcome variable in patients with cancer related pain, she became frustrated, because she felt she was not capturing the essence of the patient's experience. She attempted to overcome her frustration by adding more quantitative measures, but to no avail. Finally, on the advice of a mentor, she decided to ask the patients to explain what the experience was like for them. As Ferrell found, it is not a matter of the superiority of one research methodology over another, but the necessity of melding complementary approaches to better address the complex nature of QOL issues.

2.4.1 Qualitative Approaches to Assess QOL

The qualitative methods used to explore QOL issues in BMT/BCT recipients may merely involve the inclusion of some open-ended questions at the end of a structured questionnaire, or the use of a semi-structured interview. The advantage of this approach utilised by these researchers (Baker et al., 1999; Belec, 1992; Haberman et al., 1993) is that it combines both quantitative and qualitative methods, with the latter providing more in-depth responses than the psychometric testing of set questionnaires. However, like choosing a measurement tool which limits responses to items on the questionnaire, it could be argued that the same is true of a semi-structured interview. For example, in Belec's study (1992) a number of questions were posed on life satisfaction and life altering experiences since the transplant. Though broadly framed, the questions, in being pre-determined by the researcher, limited the scope of the responses to the parameters of the questions. The questions implicitly invite certain responses rather than allowing the person to tell of their everyday lived experiences, unencumbered.

Other studies (Ersek, 1992; Ferrell et al., 1992) rely on qualitative methods alone, and collect the data through the use of semi-structured interviews. While Ferrell et al. (1992) explored the meaning of QOL for BMT survivors, and collected data through single interviews with 119 participants, they utilised pre-determined questions based on the authors' previous work in QOL assessment in oncology patients. Conversely, some researchers utilised unstructured interviews (Cohen & Ley, 2000; Thain & Gibbon, 1996). Thain and Gibbon (1996) used this method to collect data on six BMT recipients to gain their perceptions of the transplant experience. The authors chose this method because it allowed the participants "maximum freedom of expression" (1996, p.531), and removed the researchers' predetermined concerns. These studies allowed the individual to articulate, in their own words, what the experience was like for them (Berterö & Ek, 1993; Cohen & Ley, 2000; Feigin et al., 2000; Steeves, 1992; Thain & Gibbon, 1996;).

In the growing number of qualitative studies exploring the BMT recipients' QOL, different stages of the transplant journey have been explored. For example, some studies concentrated on the patient's hospitalisation phase (Steeves, 1992; Thain &

Gibbon, 1996), while others focused on the first 12 months and beyond (Baker et al., 1999; Cohen & Ley, 2000; Feigin et al., 2000; Ferrell et al., 1992). Together, these studies have identified a diverse range of findings. Confronted by a life threatening illness the transplant provided them with a second chance to re-assess their priorities and values, and hence enhanced their appreciation for life (Belec, 1992; Berterö & Ek, 1993; Ferrell et al., 1992). Even though the transplant was both physically and psychologically damaging, the participants felt privileged to be given the opportunity to undergo the transplant and afterwards felt lucky to be alive (Belec, 1992; Thain & Gibbon, 1996).

The importance of support in the post-transplant phase was commonly acknowledged (Belec, 1992; Berterö & Ek, 1993; Ferrell et al., 1992). Support from the participants' families was a crucial factor in assisting their recoveries, and in some studies the participants described a strengthening of their family ties. Despite this, some studies noted the disintegration of relationships (Feigin et al., 2000; Ferrell et al., 1992). The importance of self-control was a common finding also. Being independent and autonomous had become important qualities in the participants' lives (Berterö & Ek, 1993; Ferrell et al. 1992; Steeves, 1992). Perhaps this emphasized how much control they had lost as a result of the transplant experience. The importance of being healthy – both physically and psychologically - was apparent in most studies (Belec, 1992; Feigin et al., 2000). As one respondent following her transplant commented "if you have health you have the most important tool in controlling QOL" (Ferrell et al., 1992, p.157).

However this was not the case in all studies, which again indicates the complex and diverse nature of the concept. Some studies suggested that BMT survivors attached little importance to the physical effects of the treatment (Berterö & Ek, 1993; Steeves, 1992; Thain & Gibbon, 1996). Likewise Haberman et al. (1993) found that BMT recipients who were greater than five years following their transplants were willing to compensate for the lingering physical side effects they experienced, because they felt lucky to be alive. Fears of the cancer returning and death were common themes in most studies (Berterö & Ek, 1993; Cohen & Ley, 2000; Feigin et al., 2000, Ferrell et al., 1992; Steeves, 1992). Fear also manifested on the participants' discharge from hospital. They were no longer under the watchful eye of the BMT unit, and worried about how their recoveries would progress (Cohen & Ley, 2000; Feigin et al., 2000). As these findings show, despite the presence of some common themes, the knowledge garnered is diverse, reflecting the complexity of QOL issues. It suggests that QOL is different for each person, because each individual makes an assessment of QOL based on his/her self-interpretations and the unique world in which he/she resides.

BMT/BCT is a very aggressive form of treatment and offered to the patient only when their primary treatment has failed. It may be patients' last option for a complete cure. Given the life threatening circumstances, it is obvious there are unique characteristics which shape these patients' worlds and their QOL. Knowing the level of physiological and psychosocial dysfunction that these patients endure is crucial in predicting outcomes. However, an alternative research approach is required to assist our understanding of the meanings these patients ascribe to the everyday lived experiences of their QOL.

Benner (1985) argued that QOL should be approached from the perspective of being, and not the more blinkered constructs of "doing" or "achieving". Furthermore, she argues that “such a perspective is highly relational and requires research strategies that uncover meaning and relational qualities” (1985, p.5). While the quantitative approach focuses on the bio-psychosocial functioning of the patient and how this relates to QOL, an interpretive phenomenological approach studies the person in his/her world. Interpretive phenomenology (hermeneutic phenomenology) is an alternative research methodology which explores the every day lived experiences of the person, taking into account the person as a self-interpreting being who is both shaped by, and shapes, his/her world. As Benner (1985, p.11) acknowledged:

> nursing requires access to concrete problems and dilemmas associated with health, illness, suffering, and disease and an understanding of the power of human practices, skills, and relationships that engender hope and promote healing.

Entering a person's world provides a deeper understanding of what the experience was like for the individual. As Benner suggests, this approach uncovers each individual's unique set of circumstances. Using an interpretive phenomenological approach, allows for a greater understanding of the unique meanings and concerns embedded in everyday lived experiences. Some researchers argue that understanding the individual's experience is critical for understanding QOL (Carter, 1993; Leigh, 1997; Pelusi, 1997). After all, most researchers agree that QOL is a highly individualised and subjective concept, and that research into this area should include study designs which can capture the experiential nature of this concept.

2.4.2 Interpretive Phenomenological Approach

At the time of commencing this study, in 1998, the literature revealed little research in this area that used an interpretive phenomenological approach to explore QOL issues in patients following an ABCT. Hence, there is a need to redress this gap in the literature.

Steeves (1992) is one of the few studies which employed an interpretive phenomenological approach. It provided a very deep and insightful understanding into BMT recipients' ways of constructing meaning, and how this impacted on their wellbeing. All six participants in this study underwent an allogeneic BMT, and data was collected during the first 100 days following their transplants. Shuster et al. (1996), also adopted a hermeneutic approach, and described the patterns of meaning employed by patients in attempting to cope with their BMT experience during their stay in hospital. Eleven patients were observed, ten of whom had undergone an allogeneic transplant, while the other had undergone an autologous transplant. The patients struggled with their disease, and interpreted the transplant as a fight between body and mind. The body was the source of the problem, but it also had the potential to heal itself. This study was significant for the insight it provided into the coping strategies used by these BMT patients. The results suggested that the patients made sense of their experiences in a way that was very different to what nurses are taught in university. The notion of holism is central to nursing care, however, the patients perceived themselves as composed of different parts, which enabled them to cope with the experience. The study's findings contradict the holistic essence of nursing care, and reveal that nurses must listen carefully to the experiences of their patients in order to gain an insight into their coping strategies and QOL.

By contrast, Cohen and Ley (2000) provided one of the few studies that explored patients' experiences of undergoing an autologous BCT from an interpretive phenomenological viewpoint. Differing from Steeves (1992) and Shuster et al.

(1996), all patients in this study were recovering at home, and the mean number of months since their transplants was 16. This enabled the study to provide a more comprehensive insight into the experiences of these patients as they attempted to return to their formal roles. Fear of death was the dominant theme, amplified by the fear of the unknown and the uncertainty about the future. Intertwined with these fears were the losses they also experienced, such as the loss of control over their lives and their bodies. The loss of control over physical functioning engendered feelings of vulnerability, and forced them to lose trust in their own bodies. The transplant was described as a life-altering experience. The participants experienced a heightened awareness of both the finiteness and fragility of human life, and spoke about the need to bring some closure to the experience. The results indicated that this patient group required significant support as they journeyed through the treatment trajectory, and particularly as they entered the survival phase.

Such results would not have been possible within the parameters of the medical model. An interpretive phenomenological approach provides a deeper understanding of a profoundly human and pragmatic phenomenon, such as QOL. Gaskill, Henderson and Fraser (1997) found that unless nurses gain an insight and appreciation of the patients understanding of his/her situation through utilising such an approach, then the former risk neglecting the holistic nature of nursing care, and not recognising the complexities of the experiences encompassed in QOL

2.5 CONCLUSION

From the studies presented it can be ascertained that QOL issues play a vital part in the BMT survivorship experience. It is universally agreed that QOL is a subjective concept, which encompasses a multi-dimensional perspective. Much of the early literature is based on using psychometric instruments to investigate the effect of the transplant on the disease by measuring outcomes and predictors of outcomes. The generation of such objective data was done within the empirical-analytical paradigm. The late eighties and early nineties saw an increased emphasis on the psychosocial aspects of BMT and their relationship to QOL. In the mid-nineties, the literature expanded further to include studies which adopted a qualitative approach towards assessing QOL issues in this patient group.

More recent studies have focused on the patient's perspective and interpretation of QOL following an ABCT. As Zebrack (2000, p.1396) explains:

> To ensure adequate clinical care for cancer survivors, healthcare providers can best serve this population by knowing both the biomedical and psychosocial effects of disease on health, wellbeing and function, as well as the varied ways in which these individuals adapt and live the remainder of their lives.

Consequently, qualitative studies have been increasingly utilised to explore QOL issues in BMT recipients. Such studies have used various approaches, including uniquely designed questionnaires, semi-structured and structured interviews. However, very little interpretive phenomenological research has been published about QOL issues in this patient group. The empirical-analytical paradigm has provided us with excellent knowledge regarding the biomedical and psychosocial outcomes. But in order to provide holistic care to individuals undergoing ABCT, health care providers need to understand both the diversities and complexities of the patients' every day lived experiences and their interpretations of their QOL. This can be achieved through the use of interpretive phenomenology. If nurses model their practice solely on the biomedical paradigm's emphasis on prescriptive care, they ignore the experiential aspects of the patient's illness experience.

In summary, QOL is a human experience, which is unique to each person's set of circumstances. It encompasses each person's way of being, and how they give and derive meaning from their everyday practices. The most appropriate methodology to gain such understanding about QOL is interpretive phenomenology. As Benner (1985, p.1) states, it "is a holistic strategy because it seeks to study the person in the situation rather than isolating person variables and then trying to put them back together again"

Drawing on Benner’s work, this study seeks to explore QOL issues from the perspectives of ABCT recipients, utilising Heideggerian interpretive phenomenology. In the following chapter the philosophical underpinnings of this theoretical framework will be discussed. Also, the recruitment of participants, and the method of data collection, management and analysis will also be discussed.

CHAPTER FOUR

FINDINGS: COMMON THEMES AND EXEMPLARS

This chapter presents the major themes and sub-themes which emerged from the analysis of the interview text. Six major themes were identified: loss of physical wellbeing; loss of control; altered self-concept, family and peer relationships, fear of relapse and life is precious. Each theme will be described, discussed and accompanied by illustrative quotes from the data. Under each major theme were various sub-themes which will be presented, followed by narratives illustrating their meanings. Exemplars will also be presented to describe particular situations in the participants' everyday lives, which will depict their experiences, concerns,and practices. As explained in Chapter Three, themes describe specific incidents whereas exemplars are specific instances which present aspects of a particular situation and the participants' responses.

4.1 LOSS OF PHYSICAL WELLBEING

For the participants QOL meant physical wellbeing. Before the transplant their physical wellbeing went unnoticed, as their bodies were well and there were no restrictions on what they could do. But following the transplant the participants were intensely aware of their bodies and how each daily activity was cumbersome and constrained. Physical activities they could do without contemplation prior to the transplant now were difficult. The exhausting fatigue that all participants experienced was a major physical limitation in their lives. The participants' physical wellbeing was also disrupted by niggling physical discomforts such as lingering aches and pains, hot and cold flushes, and loss of taste sensation. Although these discomforts were not serious, they were annoying, and served to remind the participants that their bodies were still not well. This was a source of much frustration for many of the participants. They told of how frightened they were when they first discovered that the natural instinctive functions of their bodies were restricted. Thus, loss of physical wellbeing was a major theme which disrupted the participants' QOL. The sub-themes, fatigue and discomfort, which contributed to the participants' loss of physical wellbeing, will be presented.

4.1.1 Fatigue

Fatigue was one of the most common side-effects that persisted long after the transplant. The participants had never experienced fatigue like this before, and some found it difficult to describe to their family and friends how physically exhausted they actually were. As Yamon commented:

> I remember when I came home [from hospital] I just laid down and people came to visit me, and they asked me why I was lying down, and I said I don't know, I just feel dead.

The fatigue they experienced left them feeling angry and frustrated, as it disrupted the once confident manner in which they had pursued their daily activities. It also altered the roles they played within the family. Pastimes they once enjoyed with their children and partners now became a chore, which placed pressures on family relationships. The participants were simply too tired to be involved in the everyday activities which once gave them so much pleasure. It was even frightening for some of the participants to discover how weakened their bodies had become.

Linda remarked on the limitations and pressures placed on her by the fatigue she was experiencing. The following account illustrates this theme:.

> Before the transplant I would have the housework done before I would take [the children] to school, everything was done. But now I put things off and that really frustrates me. I want to do things with [the children]. I will try and go for a bicycle ride or play basketball, but I just cannot move around the way I used to. Running is very difficult. I was pretty active before. I never stopped. And I still try and do that, and I get angry because I can't keep up the pace, and I get really tired, and I have to stop.

Linda's everyday routine had been disrupted, and her world had changed. A very important part of her world, prior to the transplant, was being a housewife and mother. Because of the fatigue she experienced, she struggled to fulfill these roles.

Other participants felt they were invincible before their illnesses, and believed what they could achieve with their lives was endless. When they left hospital and started to return to their everyday routines, however, they too realised how weakened their bodies had become. Fatigue, or rather the intensity of fatigue, was something they did not expect and were not prepared for. They attempted to do the normal things, but discovered their bodies were not capable of responding in the usual confidant manner. As Miles commented:

> When I first got out of hospital I could not run and I had no muscles. I was trying to cross a street and I nearly got hit because I could not run. I thought I could do it, but obviously the transplant does not affect your brain, it affects your body. The brain was willing, but the body was not.

For many participants the fatigue was a transitory symptom, while for others it persisted for many years following the transplant, creating a physical inertia. Kevin highlighted this when he compared himself to an "old man". For Kevin, aging represented sluggishness and feebleness, apparent in his following statement:

> You can't imagine how fit I was. I could do anything and I would not be exhausted. I was very weak for three months [following the transplant], and I mean weak. I was walking like I was worse than an old man. I am healthy, but everything is slowly for me now. I just take it step by step. I can't take three steps at a time. Sometimes my body could be going [one] way, and my mind is telling it to go the other way.

Fatigue placed limitations on the participants' lives and, thus, affected the quality of their lives. Physical strength and stamina were taken for granted before their transplants. Activities they could do easily prior to the transplant now took a much longer time. While this was a source of frustration for many of the participants, others were more accepting of this limitation. As a philosophical Jim explained about his approach to life following the transplant:

> Things I could do before [the transplant] I cannot do now. Like I said, the energy is not there. I still like to do bits and pieces of [carpentry work], but it might take me a couple of hours or all day, whereas before it was only one hour’s work. But I don't find that frustrating. I quite enjoy it really. I have done all that before. What is all the rush for?

The participants who returned to either part-time or full-time employment struggled with ongoing fatigue. Joan commented on how difficult it was in the beginning, and even two years later, she still sometimes perceived fatigue as a limiting factor in her life. As she explained:

> When I first started work I was rushing, because I was running late, and I got off a tram and started running, but my ankles felt like I had huge bricks on them, and I just could not move. That really scared me. Even now I find it difficult sometimes at work to keep up with the pace of everything and everyone.

For those participants who had not returned to work, the fatigue they experienced created anxiety about their ability to resume their pre-transplant working roles. Some felt they would not be able to cope with a full day's work, and so declined to return to their former roles. Others were very protective of their bodies. The transplant experience had taught them to value their health and respect their bodies. Fatigue symbolised to them a sick body. Whereas in the past they had pushed themselves to achieve, now they were more wary and listened to their bodies. Fatigue also disrupted the participants' intimate relationships. Sexual activity was impossible, particularly in the immediate months following the transplant, and fatigue was one of the major contributing factors.

The participants realised how much they had taken their physical wellbeing for granted. Fatigue was equated with "stamina", and the participants spoke of how they did not have the same stamina for life. The most intense period of fatigue was experienced in the months following their discharge from hospital. However, over time, the participants' energy levels did improve, but this was a gradual and prolonged process.

In summary, fatigue altered the participants' QOL in different ways. It forced them to view their bodies as clumsy and awkward. Every activity had to be contemplated and planned beforehand. Fatigue was not something they anticipated as been a major hurdle to overcome following the transplant. Hence, they were not prepared for it, which meant it caused even greater intrusions into their daily lives. Compounding this were other physical discomforts that the participants also experienced during the post-transplant period.

4.1.2 Discomfort

Some participants continued to experience physical discomforts following their discharge from hospital. Even though these discomforts were minor annoyances, they hampered the participants' everyday lives, and restricted their return to their pre-transplant roles. Linda, who was in her mid-forties, explained how these niggling discomforts prevented her from gardening, which was one of her favourite pastimes, and performing household chores.

> I have just started doing my gardening again and that makes me feel good. But my knees are still a bit of a problem. I can't get up unless there is someone there to help me. The pain is not there like it was, but I still get it when I kneel down, and I can't get up. One day I was doing the housework and I got down on my knees and I could not get up. I stayed there for about one hour and a half, until I could get someone to come in and help me up.

Gaye too struggled with persistent and nagging aches and pains. She no longer felt comfortable with her body, and was conscious of her every movement. As she explained:

> I sort of always ache. Every time I moved something hurt or ached, and I am never comfortable. The back hurts or the hips hurt. I can’t ride the horse because the hips are sore for days afterwards.

Despite the pain the participants experienced, some perceived it to be part of the transplant package, and a small price to pay for getting rid of the cancer. Kevin, had non-Hodgkin’s lymphoma and was now in remission. His following account illustrates this.

> Well, I have got a bit of pain, but I am a lot better off than some other people. Some people end up being handicapped for the rest of their lives. I can walk and stretch my arms. Now, maybe I am a bit sore from what I have gone through, but my QOL can only be improved by me and no one else, and that is what I am striving for.

Loss of physical wellbeing was also related to loss of appetite and changes in taste. These had been taken for granted functions of the body, which the participants struggled with following their transplants. Marsella particularly found these changes annoying. Foods that she had enjoyed before the transplant were now not palatable, exemplified in her following statement:

> For quite a while after the transplant I was not seriously ill, but I had a lot of discomfort in a lot of areas … I used to like a glass of red wine, but for a long time [after the transplant] I could not drink wine. So it does affect one's taste buds permanently I feel.

Similarly, Rick commented: "I love to eat ... but I could not eat very well after the transplant". As with the others who experienced appetite and taste changes, it took many months before this returned to normal.

Such problems may have been trivial from the medical profession's perspective, but from the participants' viewpoint they caused disruption to their everyday lives and impacted on their QOL. For example, Kevin who was five years post-transplant posed the question: "Why am I so sore? My feet still feel sore if I walk too much. I still have constant pain since the transplant". Maurice too wondered why his physical discomforts continued for many years following the transplant. Even though his cancer was in remission, he was frustrated that the medical profession could not provide solutions to his lingering discomforts, which included recurring skin rashes and a dry mouth. He recalled:

> With all these side effects I have had I would ask [the doctors] at the clinic and I would be told, 'yes another 3 weeks'. And those three weeks would turn into three months and four months and then five months. And in a lot of cases I got the impression from the clinic that they didn't know themselves. I cannot imagine that all patients are so dramatically different.

Like the rest of the participants, he wanted to feel comfortable in his body again, and to return to a state of wellbeing. He perceived that his physician was not addressing the niggling side-effects he continued to experience. Maurice's perception of his QOL differed from that of his physician. While the latter was interested in conquering the cancer, which Maurice was grateful for, he also wanted his body to be well again and free of all discomforts. The removal of these discomforts was very important to Maurice in defining his QOL.

Another discomfort described by the female participants were the hot and cold flushes they experienced during and following the transplant. Marsella was post-menopausal when she underwent the transplant, but the remaining female participants were pre-menopausal and perceived they were experiencing a premature menopause after their transplants. They believed that the flushes were directly related to this. While annoying and embarrassing, the flushes were also a source of physical discomfort. As Gaye explained:

> I can be freezing cold like I have never experienced before ... like my bones are cold right to the core ... and next minute I am roasting hot and everything comes off. But it is frustrating when [I] try and go to sleep at night, and I am cold and hot, and my bones ache. I think that is a big thing. I go to work at night and I am running around looking after patients, and the sweat is dripping down my back. Or I might be talking to someone, and all of a sudden my face will go absolutely crimson ... Everyone I work with is aware [of this], but when I meet a stranger it is dreadful.

Marsella, who was post-menopausal prior to the transplant, discovered that she could not tolerate hot weather after her transplant. She found this quite distressing and, as a result, could not accompany her husband on holidays to Asia. She recounted:

> On very hot days, or after I have done something physical, my whole body will prickle and that bothers me. On a very hot day I can stand in the sun for about 30 seconds and I start to prickle, so I have to move into the shade. I find it gets me really on edge, so I just try and stay out of the sun, and stay cool and have a cool bath. My husband loves to go to Asia on holidays, but I feel it would be too distressing for me to be constantly moving into the shade.

Marsella and Gaye did not have to contend with these physical discomforts prior to the transplant. They were annoying and embarrassing, limited the scope of their daily activities and, thus, impacted on their QOL.

All participants described loss of physical wellbeing, which interfered with their everyday lives, in varying ways. It created discomforts in their lives, but more importantly constrained their activities. Many participants defined QOL as doing what they wanted to do without limitations; a thought they would not have considered prior to the transplant. Following the transplant, however, this was no longer possible, because the loss of their physical wellbeing had altered their quality of life.

4.2 LOSS OF CONTROL

QOL for the participants meant having control over their lives. They wanted to be able to plan their futures, look forward to their children growing up and not feeling threatened by the fear of relapse. During and after the transplant the participants perceived they had lost some control over their lives. Some participants spoke of how their control was ripped away from them during their treatments. This was both a humiliating and undignified experience for them.

Furthermore, career advancement and professional success was an important contributing factor in the participants' QOL. Before the transplant their careers were strategically mapped out, providing them with a sense of knowing where they were headed. After the transplant, however, some participants found it difficult to return to their pre-transplant roles. As cancer survivors they no longer controlled their futures. Some perceived an external locus of control governing their lives, which was the constant fear that the cancer would return. The uncertainty surrounding this loss of control created havoc in their lives. They could no longer strategically plot their lives, as they once had done. Indeed, following the transplant they realised that nothing in life was guaranteed.

All participants related stories or events of how their lives had been transformed by loss of control. Gayes' interview particularly presented how much her life had spiraled out of control following the transplant. She was aware of this and yet was not able to stop it. However, she attempted to create a safe haven for both herself and her children. The following account is an illustration of this.

> I bought a pony for the children following my treatment. She is just gorgeous and the children adore her. The pony lives in the country, and it is so peaceful and everyone is lovely there. I have learned so much about horses from not knowing anything about them. We go to the shows and competitions, and what fun we have at them. But suddenly I am jolted back and I think no, [life] is not so wonderful.

For Gaye, the interludes in the country were not only an escape, but also a semblance of control. The pony was a symbol of a world devoid of threats, over which she had control. But these escapes were brief, and she inevitably returned to the normality of domesticity where life was not so secure.

Similarly, Yamon spoke of how he desperately tried to maintain some control over his life both during and following the transplant. But unlike Gaye's case, Yamon's battle to maintain control during the transplant had a positive effect afterwards. It forced him to become a lot more independent and accountable for his life, and this he believed had improved the quality of his life. He reassessed his work options and he ultimately became self-employed. The following exemplar depicts Yamon's experience of loss of control and how this challenged him to change his work practices.

> I work for myself now. [Following the transplant] I started going back to work and I discovered I could not work with other people any longer. I could not work with [managers] because [the transplant experience] forced me to take control of my life and I had never done that before. So I opened my own business with computers and telecommunications and it is going well.

Related to the major theme, loss of control, were the following sub-themes: uncertainty, loss of control related to the treatment, loss of control related to career pathway, and loss of control related to cognitive impairment.

4.2.1 Uncertainty

Linked to the participants' perceived loss of control was the uncertainty that now permeated their everyday lives. There were no guarantees that their cancers would not return, and so they had to deal with the ever present fear this engendered. The uncertainty this wrought following the transplant shattered their senses of security and affected the quality of their lives. As one of the participants articulated, "I learned that the future is very elastic, [and] I cannot plan too far ahead". For Linda, in particular, the uncertainty she experienced following the transplant caused her so much confusion and frustration that it dominated her life. The control and routine that once structured her life had vanished. She feared the recurrence of her disease more than death itself, and related how she coped better when she knew had the cancer. The following account illustrates this theme.

> I coped better before, when I knew something might happen straight away. I felt I knew what I was doing. But now this uncertainty. Well, it is just month to month … that feeling of what is important. I go around in circles … I don't know what to do with myself.

Getting on with everyday living was very difficult, particularly making decisions about her future and her children's future, which proved almost impossible for her. The uncertainty looming over her life prevented her from regaining any semblance of control.

Similarly, the uncertainty Gaye experienced played havoc with her everyday life. She was married with two young children, and she was constantly mindful of the uncertainty shrouding her future. She was convinced that the cancer would return one day, it was just a question of time, and this affected her family life, as Gaye attempted to compensate for her perceived reduced life span. She believed she would not be alive to see her children grow up, so it was vital that she did as much as she could with them now. She bought them expensive presents, and provided them opportunities that she would not have otherwise. She treated each Christmas as if it would be her last. As a result, Gaye found herself in serious financial difficulty, which caused her considerable anxiety and inevitably affected her marriage. As she explained:

> And I am dreadful. I just cannot control myself. If I see something for the kids I will go and I will get it. I have just got myself into such a hole with my credit cards. And then I think I might not be here tomorrow. I am in

> debt up to my eyeballs and I can't see an end to it. That's why I need to win Tattslotto.

Gaye perceived that the quality of her life had changed. The uncertainty formed by her fear of recurrence had created much confusion in her life.

Ron also punctuated his interview with remarks suggesting that uncertainty lurked beneath his everyday life. He, however, was attempting to recreate a sense of certainty, relating:

> I think after the first time I was diagnosed, we were saying we would retire when I was 55. And then hopefully we would have a few years to enjoy retirement. And that is still foremost in our minds.

By creating a structure in his life he was attempting to compromise for the uncertain nature of his life. This became evident as he explained how he provided support to his daughter who was having difficulty coming to terms with his illness. He recounted:

> [I said] to my daughter to look at it this way. Dad's cancer was picked up early enough, hopefully early enough. I was picked up early enough and if anything happens I have check-ups every 2 months. And if something comes back, well, hopefully they will be able to do something.

As with all participants, once in remission there was always the uncertainty of what the future might hold. Uncertainty contributed to the perceived loss of control the participants experienced and disrupted the quality of their lives.

4.2.2 Loss of Control related to the Treatment

Some of the participants described the importance of attempting to maintain some personal control during their stay in hospital. Being adequately informed about, and prepared for, the transplant and its side-effects greatly assisted the participants. The nurses were excellent at explaining the treatment and preparing them for what lay ahead, and this helped the participants maintain a sense of control. However, some participants stated that the drugs they received robbed them of their senses of control. As Yamon related after the reinfusion of his stem cells:

> I was feeling fuzzy all day because they had given me some [medication] to knock me out, and it made me feel funny and out of control.

Yamon did not mind when his morphine drip was discontinued and his mouth still hurt. His main concern was to maintain control over what was happening to him while in hospital.

Similarly, Rachael refused narcotic analgesia, because it prevented her from being in control of her recovery. She did not like the "sleepiness" and "vagueness" caused by morphine, which took away her sense of self-control. As she recounted:

> I just liked to be totally conscious all of the time. I didn't like that floaty feeling.

The side-effects of the chemotherapy also contributed to this loss of control. The majority of participants experienced a degree of vomiting or diarrhoea at some stage during their treatments. This was viewed as a factor beyond their control, and they found the unpredictable nature of it humiliating. As Marsella commented:

> All of this suffering and discomfort, and a lot of the treatment, I found undignified ... I hated having the catheter [Hickman line] in, and having to get up and rush to the toilet, and sometimes not getting there on time. That for me was the most distressing thing, to be out of control.

For the participants it was important to maintain some control over their lives during their hospitalisation, when most aspects of the illness experience were almost beyond their control.

4.2.3 Loss of Control related to Career Pathway

Some participants experienced difficulties returning to their pre-transplant working roles and, consequently, had to search for alternative employment. Many factors contributed to this. Joan, for example, returned to the corporate world, feeling that she could not compete any longer in the entertainment industry. The following illustration describes this theme.

> I was quite successful [before the transplant] ... Once I got sick again I felt like I had fallen off a cliff. After the transplant I had to start all over again. It was really hard to get back into the entertainment industry. It is so dependent on your appearance, and I just could not compete with that ... So I took a job in the corporate setting, but I always questioned my ability ... I hated the fact I was not singing. I hated being back in the corporate setting, and that made me really, really angry.

She no longer had the power to determine her career path, and so had to settle for a job option which she considered was second best.

Kevin's health prevented him from returning to work for five years following the transplant. During this period he lost the required skills and expertise to return to his former employment. Prior to the transplant, he had control over his career path and plotted his advancement. But after the transplant, he would happily take what he was offered. In the following account Kevin’s describes his concerns realted to this theme.

> My career path was very good [before the transplant] ... and that is a different matter altogether now. I knew my potential [then] ... I know I have been out of action for five years, but through Commonwealth rehabilitation services I have applied for computer courses, and I have completed all of the computer applications to date. People now say to me five years is a long time to be out of action ... Maybe I am not as fast as I

> was, but all I ask is to try me.

Many participants, however, returned seamlessly to their pre-transplant working roles, though over a period of time. But for others it proved more difficult. They experienced physical problems and questioned their ability to compete in their chosen profession. Consequently their self-esteem suffered, and the control they once possessed over their careers had diminished.

4.2.4 Loss of Control related to Cognitive Impairment

Loss of control was also related to cognitive problems, of which forgetfulness was the most common. Many participants related how their memories were not as sharp as before their transplants. Linda considered this was a significant barrier which prevented her from returning to work. The following account presents the difficulties she experienced in her everyday life.

> That high dose treatment was really something. For days I did not know where I was. I was forgetful. I mean I am forgetful now, but during the high dose treatment I felt so disoriented. [Now] I forget things, which I should not forget. And that is one of the things with my work ... There is so much book work ... I even write notes to get here.

The transplant also affected the participants' ability to concentrate. Marsella was an avid reader, but following the transplant she found it difficult, as her ability to concentrate for long periods was reduced. As she explained:

> For a long time I did not want to read a book … I could not be bothered. I could only flick through a magazine and even then I would put the magazine away and think, what did I just read?

Once again, the taken for granted functions of the body had been disrupted. The control the participants once possessed over their bodies had vanished, ultimately interfering with their QOL. It restricted the participants from pursuing their pastimes and, more importantly, created anxiety about their ability to return to their pre-transplant working roles.

4.3 ALTERED SELF-CONCEPT

For all of the participants the sense of who they once were had been lost. The physical changes they experienced led them to develop an altered picture of their selves, which they now found foreign. They had to contend with changes in how their bodies responded to various bodily stimuli, which again felt strange and unfamiliar. The participants felt they no longer knew their bodies like they once did, and so the body was seen as something to mistrust and dislike. This resulted in an altered self-concept, which will be described under the sub-themes, altered body image and sexual expression.

4.3.1 Altered Body Image

Most participants experienced an altered body image. For some, it was the shock realisation that they no longer recognised themselves. Following the transplant their bodies had changed. The physical changes they underwent created an altered body image, which resulted in a loss of self-esteem. Their bodies now felt foreign, as the perceived change in body image was so dramatic for some participants that it left them grieving for the way they once were. The following account from Gaye's interview illustrates this theme.

> I look in the mirror and think what a mess I am now. I will never feel normal again. Things have changed and it is always going to be like that. You cannot turn the clock back and say, I still have my breast and I don't

> have this scar across my belly. I am always conscious of it. Body image really was not important to me before [the transplant]. I mean I had two breasts and a saggy stomach, but it didn't really bother me. I didn't feel abnormal. But now I feel freaky, because I have all these scars and my [reconstructed] breast feels lumpy and it is always there.

Gaye had grown estranged from her own body. It had not been perfect prior to the transplant, but it felt complete and, more importantly, Gaye felt comfortable within it. Linda, too, experienced an altered body image. She hated the way her body had changed, and this has left her feeling isolated and lonely. She related:

> It is like you don't know yourself. I really don't like looking in the mirror. I know that sounds vain, but the change is so dramatic. I was a lot thinner, and I had a lot of energy. [Even] after the mastectomy I had a lot of energy. But now [following the transplant] I am three sizes larger, and I have curly hair instead of straight. Now I know that doesn't mean much, but I just look so different.

An altered body image was not just an issue for the female participants. Some male participants also told of how the changes in their physical appearance impacted on their QOL. Maurice, in particular, was surprised that body image could mean so much to him. He recalled:

> My QOL only seems to be affected when I look in the mirror with glasses on and I don't recognise who is there, because this is not how I think of myself. You see I think of myself as how I was before [the transplant]. And there may be a certain lack of confidence that goes with that. I am not sure, only others could say that.

Following the transplant, the participants told of how their perceptions of their bodies had changed, which left them feeling clumsy, more self-conscious and less confident in their every day experiences and so hampered their QOL.

In some participants the altered body image they experienced led to an internalised stigma. They perceived themselves as strange and not fitting in to the norm of society. For example, Gaye told of how she felt ‘freakish’ because of the changes that have taken place in her body. Her perceived stigma was not socially derived, but came from within herself and her perceptions of how the cancer treatment had transformed her.

The following account is an exemplar of how Kevin’s altered body image affected his every day life.

> The presentation of my body has changed. I had put on quite a lot of body weight. I felt heavy, weighed down, as if I had a tonne of weight on me ... When I went out for a walk occasionally in my neighbourhood, people who would know me would ask questions, and I could see the expression on their faces a mile away. I always wanted to duck for cover ... They could see that something was wrong and most people could tell that [I] did not look well.

Similarly, Joan’s altered body image represented not being “normal”. This is evident from the following exemplar:

> I have been on hormone replacement therapy (HRT) since I started my treatment ... I am not in the normality of life. I am surrounded by late twenty and thirty year-old girls that don't know anything about HRT ... I am on a different planet and in a minority. [I] really have no one to talk to ... I feel like a fish out of water.

Joan perceived she had lost an integral part of her femininity, which she felt had alienated her from her peer group.

4.3.2 Sexuality

For most participants sexuality constituted an important part of who they were. They defined their sexuality in terms of their ability to have children, to experience intimate relationships, and to communicate with those around them. For most, it represented a youthfulness that was lost because of the illness experience.

Alterations in sexual wellbeing were common in most participants. Many of them experienced a loss of libido, and the fatigue they experienced following the transplant was a contributing factor. As Kevin explained:

> I felt very weak. I did not want to have [sexual intercourse] ... [My sexual desire] was not there. It was three months before it started again ... The way I felt then, it was not a priority … But I still get tired when I have sex. I don't have the [same] stamina.

The consequences of undergoing a premature menopause had both a physical and emotional impact on the female participants’ perception of their sexuality. Joan, for example, believed that she had been robbed of her youth, and that she was now trapped in an aging body. The bodily functions and responses that go hand-in-hand with femininity and youth were gone, and it deeply affected her sense of both who she was and her sexuality. She was a different person following her transplant. Moreover, she was startled by how quickly her body had aged, and to be suddenly stripped of her physical and sexual youth was something she was not prepared for.

The male participants also had similar issues related to their masculinity. For Kevin, masculinity and machismo were one. Prior to the transplant, he was proud of his body, particularly its strength and vitality. However, following his transplant, he felt "paralysed", robbed of his youth and masculinity, and considered himself an "old man." As he stated:

> After I stopped the therapy I was weak, and I mean very weak ... I felt heavy. I had put on quite a bit of body weight. I felt weighed down. When I went out for a walk, I wanted to duck for cover, because I did not feel presentable. I felt tired. I felt silly. I was not in very good shape.

But sexuality was about more than just expressing their identities. It was about being able to communicate with their partners on an intimate level. In the following account Rachael speaks openly of her concerns and experiences related to this theme.

> I was aware that it [menopause] was going to happen. But to me, it did not mean anything until I actually went through it. I mean people talk about the likelihood of experiencing it, or getting some aches and pains, and arthritic knees and that sort of thing. But until you actually experience it, it means nothing. Then there are such things as loss of libido and my vagina is nowhere near as moist as it once was, and these things impacted on my relationship. Obviously, we are not having a sexual relationship as often as we used to. It is just like everything is shut down. So, therefore, I will try and compensate for that.

For these women aging prematurely was the silent enemy. Coping with the physical symptoms of menopause was difficult, but what haunted them even more was the perception that their bodies were ageing prematurely, and this threatened their feminine identities and interfered with the quality of their intimate relationships. Changes in their sexuality meant that the natural progression of their lives was lost. Indeed, lost youth was of particular concern for Linda and Joan. Both felt uncomfortable in their altered and prematurely aging bodies. They were angry, horrified that their bodies could age so quickly. As Linda related:

> But if I aged gradually I could accept it. But with such a major change ... you know I never looked my age, and then all of a sudden I have aged 10 years or more. I look at clothes on other people and I think I used to be able to wear that ... And it is like a put down of myself all the time.

For many participants, being unable to fulfil their dream of becoming a parent was a devastating consequence of the treatment. Fertility was an important aspect of Yamon's sexuality. Having a family represented hope for the future, and something to look forward to when the treatment was completed. However, the transplant had rendered him infertile. The following exemplar presents Yamon’s concerns and the practical implications related to this theme.

> QOL is my family … This makes it difficult, because the treatment affects your fertility as well … so without kids it makes it very difficult. When you go and marry somebody, and you have to tell them you are going to have problems having kids, it may affect your ability to get married and your overall life. If you are on your own, you are basically crippled. It is a disability. And it affects your entire life.

Loss of fertility for Yamon meant he had lost an integral part of how he identified himself. Fertility was part of his sexual expression and his QOL.

Altered body image, and changes in sexuality and the manner in which they internalised these perceptions, contributed to the participants’ altered self-concept. This, in turn, had significant implications for how they perceived their QOL. The following excerpt from Joan’s interview is an exemplar of this.

> I didn’t feel beautiful as a person. [The transplant] broke my spirit ... I felt I had no procreative abilities and I didn't feel that I could fulfil the need of a spouse. There was no way I could have sex. I just did not feel like it. I didn't feel attractive, my libido had crashed and so there was nothing I could give.

4.4 FAMILY AND PEER RELATIONSHIPS

The participants in this study discovered their cancer experiences impacted on their families and their social networks. For those participants who had strong family support it proved an invaluable resource in their recoveries, which positively impacted on their QOL. For some, the transplant provided the opportunity to reassess their family relationships. Family gained a new sense of importance in their lives, while faltering relationships were rekindled. For those who did not have family support, life following the transplant proved more challenging, as relationships with their peers were threatened by the illness experience. Family and peer support will be presented under the sub-themes rekindled relationships and strained relationships.

4.4.1 Rekindled Relationships

Most participants described a strengthening of intimate relationships. In the face of adversity, it was their partners who were their source of strength. As a result of the cancer and the treatment, they had grown closer together. Some participants found their intimate relationships strengthened by the transplant experience and this had a positive impact on their QOL. As Ron explained:

> I really think my wife and my mother-in-law were my support, particularly the support I got from my wife. I just cannot explain it. Maybe I would have not been able to cope on my own, but my wife really helped me keep my feet on the ground. She said, 'look this is it, you are going to do the transplant, the doctors are trying to help you, so let's go for it'. So, I did not get a chance to wallow in my misery.

For some of the participants the transplant experience provided them with the opportunity to reflect on what they considered the important things in life. Following the transplant relationships with their loved ones took on a greater significance. Some participants described a strengthening of their intimate relationships. Rachael struggled with some aspects of her relationship with her partner, but overall she perceived they were much closer as a result of the transplant experience, evident in the following:

> When I think through the whole experience we are a lot closer, and I know that I certainly get what I want a lot easier. Like we all have wish-lists and the items on my wish list seem to appear a lot more these days; and we go out a lot more, and go to pictures and shows.

Miles spoke of the support and love he received from his parents and partner, and how his relationship with his father had changed. He explained:

> Everything change[d]. [My] whole life change[d]. My Dad never spoke to me very much [before the transplant]. His parents never showed him love so why should he show his kids love. I wasn't brought up showing love, but I like showing love now, and I like helping people. I had nothing growing up, and then this happened and everything is different. Dad speaks to me now and asks me how things are going.

The transplant experience had made Miles more sensitive to other people's needs, enabling him to become a more understanding individual. As a consequence, he found renewed respect and love for his partner. As he explained:

> [In the beginning] I took [my girlfriend] for granted because I was upset and grumpy. She stuck by me through all of this, and it takes a strong person to do that ... I used to look forward to her coming in and I did not with my parents. It was good to see my parents, but I looked forward to [my girlfriend] coming in. She was the most important thing.

Family relationships were also strengthened as a result of the experience. The illness increased the participant's awareness of other people's needs. As Marsella commented:

> I have become a lot closer [to my husband] and it has made me a lot more considerate of him. Because I have been sick, I am more aware of how other people are feeling.

The transplant forced the participants to realise what a significant role their partners and family played in their lives. The transplant was not only demanding on the participants, but also on their loved ones, and the participants understood this. Hence, there was immense respect for the love and support they received, which assisted the participants during the difficult times.

4.4.2 Strained Relationships

However, not all of the participants experienced improved personal and family relationships following the transplant. For some the transplant experience had exacerbated pre-existing tensions. Gaye's relationship with her partner suffered under the strain of the illness. Her immediate family lived overseas, and without personal and family support, the period following the transplant was a very difficult and lonely one. Support for Gaye represented recognition and understanding of what she had being through, but also of her need to be loved and accepted, despite the physical changes which had taken place in her body. As she related:

> My relationship with [my husband] is very changed. He sort of pushes me away … I think it is his way of coping … It is sort of like living separately, but in the same house.

Gaye no longer had an intimate relationship with her husband. She acknowledged in her interview that there were problems with their marriage prior to the transplant, but following the treatment these issues intensified. She received no words of encouragement or understanding from her husband, and the quality of her life suffered as a consequence. She attempted to seek out help by attending support groups. She needed to find empathy and understanding from people who were going through similar experiences. The support groups she attended mostly consisted of people who had been in remission for many years and their lives were back to normal. But Gaye needed more than this, and struggled to find a support group that could fulfill her specific needs.

Joan’s partner was extremely supportive and understanding of her needs. Despite this, a lot of stress was placed on their relationship following the transplant. The tension in their relationship was fuelled by Joan's feelings of inadequacy. With the fatigue she experienced following the transplant, she felt she could not be a part of his active lifestyle. Furthermore, not being able to have children, as well as feeling physically unattractive, heightened her perception of being an inadequate spouse in her partner's eyes. The following exemplar presents Joan's concerns and how these impact on her everyday life.

> I felt really ugly when I was having the transplant, because of my hair not been there and the smell. Also, I was immobile and Martin was such an active person. He likes his skiing, or whatever, and there is no way I could have done that. So I felt really inadequate in that sense. I felt like I had no procreative abilities, and I did not feel I could fulfill the need as a spouse. Sexually, there was no way I could have sex, I just did not feel like it. And so there was nothing I could give. I actually pushed him away and I rang his Mum up and said we were splitting up.

Nonetheless, she struggled with these issues, despite having a very supportive partner. The illness disrupted the quality of her life, and as Joan stated; "it broke my spirit, I wasn't me anymore".

Some participants believed surviving cancer was a unique experience, which only those who had lived through it could truly understand. Most participants experienced a lack of support and understanding from their friends. In fact, the majority of the participants felt estranged or alienated, as friends found it difficult to "confront the cancer thing". Furthermore, many participants felt that the experience had changed them. They were now confronted with new challenges and had different priorities. Others believed they could no longer compete within their social group and, as a result, began to withdraw from society. The following account is taken from Linda's interview describing the isolation she experienced.

> It is like my friends don't know how to be with me anymore. They don't know how to relate to me and everything. It is really weird, because I thought they were close friends and they have gone the opposite way. That is what I find hard. I don't see them anymore. I have rung a few times and said come over but I haven't seen anybody. And when I do meet them, and they say how are you. And I will say fine. I really do want to talk, but I can see that they really don't want to talk. It is horrible.

Miles, too, was disappointed over the lack of support he received from his close friends. He commented:

> But some of my friends don't even call any more. I had a few friends out there who never contacted me at all through all of this, and they were good friends. One of my closest friends never came. I have known him for about ten years. We are like a couple of shot guns together. I can't comprehend that. Everyone is different. I am here. I am sick. I would be there for them. But not everyone can do that.

The transplant experience placed stress on the participants' relationships and resulted in diminished support, which contributed to the participants’ feelings of estrangement from their peer groups. Many felt estranged and alienated from their friends. Some found this confusing and believed that their friends found it difficult to confront the cancer. Furthermore, the participants blamed themselves for this situation. They longed to be accepted as they always had been, but also wanted their peers to recognise what they had been through. Yet some of their friends could not empathise with them. Understanding could only come from people who had gone through a similar experience.

Marsella spoke about the comfort and understanding she received from participating in a support group, and the importance of sharing her experience with other cancer survivors who understood. She explained:.

> I did not feel the need to talk about [my fears] at home because I had other

> people I could talk with, like the people I meditate with. They were wonderful. In the group so many of us had cancer or were being treated for cancer, so it was very supportive. There is such a fantastic atmosphere there. When I walk into the room, it is just so comforting. It has an aura, and for me that was very comfortable.

For some participants there was a stigma attached to being a cancer survivor. They felt that they were perceived as lesser people in the eyes of the community, which was humiliating for them. As a result the changes that the illness experience had wrought on the participants' family and peer relationships affected their perceptions of the qualities of their lives.

4.5 FEAR OF RELAPSE

Fear of relapse permeated through all of the participants' interviews. For some of them it dominated their lives, and each had to learn to live with this fear on their terms. Many participants believed their life span was reduced. Some were angry and resentful about this, while others focused on, and were thankful for, the opportunities that the transplant had provided them. Associated with the fear of relapse was the uncertainty about their futures, which impacted on their QOL. Everyday living had become more uncertain with the fear of relapse ever present. Linda, for example, tried to condense as much as possible into her family life to compensate for her presupposed shortened life. The following account is an exemplar of this.

> I live life each day, and I try and pack so much into each day. I know I am probably pushing [the children] too much, but I feel like I have got to teach them so much, so fast. I am probably not letting them do the things they want to do. I feel like I am trying to do things that should come later as we grow together. I feel like I am trying to do it all today, like there is no tomorrow. It is horrible.

The fear of the cancer’s return totally consumed her life. Yamon too attempted to compensate for his assumed lost time. Unlike Linda, however, he adopted a philosophical attitude to quell his fear. The following exemplar presents Yamon’s experience of this fear.

> Last year we went to Disneyland and we took our daughter. We have done things, which I wanted to do with her. I want to do as much as possible. I want to have some good memories. Because you never know what is going to happen tomorrow and that is it. For me it is never finished. It is always there, and I don't think it will ever go away. I used to be jealous of every old man I saw. They were bastards. So I don't think about it now. I would like to be there some day, but I accept it may not happen. I have the possibility of a shorter lifespan than I would have otherwise, but listen, you never know what may happen tomorrow. You can be in a plane and fall out of the sky, so there are no guarantees. There are no worries. I am here and happy; thank you very much. I don't think about the future. You learn that the future is very elastic. You plan one day at a time, short, short, short.

He initially felt angry and cheated on realizing that he might not reach old age. Over time, however, he learned to temper his anger and accommodate his fears, with the realisation that life holds neither guarantees nor certainties, and so structured his time accordingly. Joan adopted a similar approach, though she found an outlet for her fears in her music. As she explained:

> I can be really positive and say you know it is not going to come back, one hundred percent it is not going to come back. But again, because I am human being, and I don't know what the future holds. I have fears. But I just dismiss them, and I guess I do live on a more day-to-day basis. I work towards my music. What I want to give back to the world are my fears and concerns.

Dealing with the fear of relapse is a legacy of her transplant experience. Like Yamon, she knows her future is uncertain and lives "day-to-day."

While fear of relapse was very evident in all of the interviews, underpinning this fear was the belief that nothing could be done if the cancer came back following the transplant, and so relapse represented death. The possibility of death lurked in all their sub-consciousness. Ron spoke openly about this fear:

> I keep on thinking if I have to die, I would like to be able to go to sleep one night and never get up.

Marsella too had become aware of her mortality since her transplant. She feared not death itself, but the nature of it. As she remarked:

> Before, I did not think about death very much. Now, I am more conscious of it. I am accepting of it. It does not frighten me. I have no fear of dying, but I have a fear of how I will die. I would not like to die in agony.

4.6 LIFE IS PRECIOUS

While the fear of recurrence was present in all the participants' interviews, most of them inverted that fear and used it to help in their quest for spiritual wellbeing. They seized each day and concentrated on the things that mattered in their lives. Life was precious. Some participants had a new respect for their bodies. They were mindful not to put their bodies under undue stress and were more conscious of eating well, and getting enough rest and exercise. The experience forced them to prioritise the things they valued most in their lives. Some participants spoke of how "lucky" they felt to be alive, and felt that the transplant had given them a "second chance". As Yamon commented:

> My QOL for me is to take everyday as it comes. I wake up in the morning and I happy that I am [alive]. Previously that was not the case. Everyday I say thank you very much for giving me a second chance.

Similarly, Rachael recounted how the transplant experience changed her outlook on life.

As she stated:

> What do I value more now compared to what I valued back then? [Before] the transplant I valued my career and career options, and material things. Whereas now I sit back and reflect, and think they are not important ... I appreciate the fact that everybody is here, so I want to spend more time with them ... We do a lot more fun things, and we have holidays a lot more frequently, because you just don't know what is around the corner ... After all, life is all about enjoying it and making the most of it.

Though Marsella made "plans", she did not look "too far into the future." Every day was important to her, and "not to be wasted." Rachael took more time to "catch-up with old friends and [do] more fun things", because she knew her time could be shortened. Many other participants also spoke of having a greater appreciation for life since the transplant and wanted to seize each moment. This is evident in Rick's interview as he explained:

> My friends and wife have been at me for years to slow down and give up work, so I decided [after the transplant] would be a good time to do it. [The transplant] persuaded me to do things I wanted to do rather than put them off, for example leaving work and going travelling.

They sought out loved ones who they had often taken for granted prior to their transplants. For others the transplant experience gave them a *raison d'etre*. As Ron stated:

> It makes me realise we are here for some reason, and maybe I was not putting that reason up as high as I should have before ... And I think now it has brought me to my senses, and I do appreciate what this has done for me.

There was an awakening of other dimensions to their characters. Some of the participants described themselves as 'stronger' people, more aware and knowing of life's realities. Marsella spoke of how the transplant experience had enhanced her own personal growth. She believes she now is a more sensitive and considerate person. She understands what it is like to be fighting for one's life, and this has allowed her to empathise with people who are dealing with similar or related problems. She explained:

> [The cancer experience] made me a stronger person. I think it has made me much more considerate of ill people, and it has made me aware that so many people are sick. You just don't think about things like that unless you have being ill yourself.

Many of the participants had a new respect for their bodies. Being healthy was a fundamental priority in life, and going through the transplant forced them to realise how much they had taken their health for granted. As Kevin explained:

> The main thing for me today is to be healthy, and to be with my wife and to enjoy life ... Sometimes we don't listen to our bodies, and I have learned through this experience that I have gone through to listen to my body ... I am not scared of the disease coming back, but there is always that chance [that it might]. But if I take care of my body well enough, and if I eat good food and don't smoke or drink, or over indulge, the chances are [small].

Similarly, Miles was more aware of his physical limitations. As he explained:

> If I feel like I am pushing too much I will stop. You learn so much about your body and how far you can push yourself.

The experience of the transplant made the participants realise their health was precious, but it also provided them with a greater understanding of their physical well being.

4.7 CONCLUSION

This chapter presented the findings through the identification of major and sub-themes which emerged from the text. Exemplars were presented to demonstrate how the participants responded to the changes in their everyday lives. The themes presented describe a journey of recovery, engulfed in irrevocable change and immense loss. However, despite all of this, most of the participants reclaimed some quality back into their lives. While the transplant cured their cancers, it was also associated with significant toxicities which disrupted the quality of their lives. Conversely, the transplant experience also offered the opportunity to redefine who they were and find purpose in their changed lives. In Chapter Five the findings will conclude through the presentation of paradigm cases.

CHAPTER THREE

METHODOLOGY

The theoretical framework chosen for this study is Heideggerian phenomenology. This chapter will discuss the philosophical underpinnings of this research tradition and why it has been chosen for this study. The chapter will also outline the research design, procedures for participant recruitment, data collection, data management and the method of data analysis. Finally, the chapter will discuss issues related to rigour and ethical considerations.

3.1 HEIDEGGERIAN PHENOMENOLOGY

Heideggerian phenomenology was chosen as the theoretical framework for this study. It is a branch of interpretive phenomenology originating from the work of Martin Heidegger (1889-1976). Heidegger was a student of Husserl (1859-1938) but his philosophical viewpoint was different from that of Husserl. Whereas Husserlian phenomenology is the study of phenomena as they appear through the consciousness (Koch, 1995), Heideggerian phenomenology focused on what it is to be a person and the nature of being. Heidegger asked the question, what does it mean to be a person? and sought explanation in the concept of *Dasein*. He referred to *Dasein* as human existence or being-in-the-world (Walters, 1995).

Heideggerian phenomenology allows for the illumination of peoples' "beings" and the true essence of the lived experience to be understood. It provides a unique way to interpret the being of human beings. Heidegger suggested that the way we transact within our worlds is so familiar that we lose sight of our being from existing within this familiarity (Dreyfus, 1991). Our everyday way of existing in our worlds goes unnoticed. When studying human behaviour, it is necessary to explore and understand this familiarity, because it is within this that knowledge and meanings reside. The goal of Heideggerian phenomenological research is to uncover the everydayness of peoples' lives, because it is here that the lived experience of a phenomenon can be truly understood.

The everydayness of peoples’ lives is the quality of their lives. Quality of life (QOL), as Benner (1985) suggests, is about the quality of being - it is a lived experience. The lived experience is accessed through an exploration of peoples’ perceptions, skills, practices, expectations, joys and fears. Quality of life is a subjective concept and means different things to different people. Any exploration of QOL must take into account peoples’ worlds and how they transact within their worlds. Heideggerian phenomenology provides the means to do this.

Heideggerian phenomenology or interpretive phenomenology is sometimes referred to as hermeneutics. The latter was the science used for interpreting the Scriptures. Hermeneutics has been further developed and is now used as a methodology for understanding human inquiry (Gadamer, 1976). While Heideggerian phenomenology and hermeneutics both are involved in the study of human experiences, utilising Heideggerian phenomenology as a theoretical framework assumes a unique approach towards human beings and human experience (Leonard, 1989). This Heideggerian phenomenological view of the person will be discussed under the following headings: the person as having a world; the person as beings for whom things have significance and value; the person in time; and the embodied self (Leonard, 1989).

3.1.1 The Person as having a World

Heidegger rejected epistemological or more specifically Cartesian thought for the ontological focus of the nature of being and its meaning to each person. He maintained that each person has a world into which they are born (Walters, 1995). The literary meaning of world as it is defined as nature or environment is different from the phenomenological meaning. In the phenomenological sense it refers to the meaningful set of relationships, practices, language and traditions that we have by virtue of being born into a culture, and this provides us with our background understanding (Leonard, 1989). It presents us with the means to interpret our worlds. As Heidegger explained, each person is shaped - in a non-reflective manner - through the interpretation of practices, traditions and linguistic skills which exist in the world that person is raised in. The person does have the freedom to choose their own ends, but because they are situated in their world they are ultimately constrained by a particular language, culture, and history (Koch, 1995). Thus, when exploring an existential concept such as QOL, the researcher needs to take into account how that person is situated in his/her world, because this will have a bearing on their perceptions of their QOL.

Heidegger also claimed that the everydayness of peoples' lives within their worlds is so mundane that it goes unnoticed. It is this taken-for-granted mode of being in the world that Heidegger refers to as the ready-to-hand mode (Dreyfus, 1991)). In this study exploring the ready-to-hand mode of being in the world is paramount. This way of being is illuminated through a Heideggerian approach. Unlike the empirical-analytical approach, which objectifies and reduces QOL to causal objective determinants, a Heideggerian approach enables the researcher to explore the everyday experiences of peoples' lives and the totality of their being.

3.1.2 The Person as a Being for Whom Things have Significance and Value

Heidegger further explained the way of being in the world is significant. It is a self-interpreting activity. As human beings we understand and interpret things because of our personal and cultural history. As Leonard (1989, p.47) stated: "Nothing can be encountered without reference to our background understanding. Every encounter entails an interpretation based on our background". Hence, we can make sense of the world and gain meaning from it based on our background understanding.

As human beings we are what we pursue and care for. In other words, the person gives significance and value to his/her world at a moment in time, depending on the cultural background the person brings to it, and the situations that bear upon it. Each person will have different values and concerns, and so will confront similar situations differently. To understand each person’s experience, it is necessary to enter the person’s world, and explore how he/she brings meaning and value to his/her life at a moment in time (Koch, 1995; Leonard, 1989).

3.1.3 The Person in Time

Existential phenomenologists hold a particular perspective on time. Instead of the western conceptualisation of linear time, they give it a qualitative dimension, and refer to it as temporality. Temporality is a theme which permeates Heidegger's philosophy (Heidegger, 1962). As interpreted by Annells (1996) and Leonard (1989) temporality refers to time as a "connectedness" (Annells, 1996, p. 706) and is "constitutive of being" (Leonard, 1989, p. 49). In other words, human beings exist in time. The way a person exists in the present is dependent on the person's past experiences and his/her anticipation of the future. Benner and Wrubel (1989, p.64) in describing time in the Heideggerian sense stated: "time creates a story". They suggest that when a person is faced with a life threatening illness, the new self-understanding that person gains forces a review of his/her life. During this process different aspects of the situation will gain a new importance. How the person perceives his/her future will also have a bearing on his/her current situation. Temporality is integral to every day life experience. A person's perception of his/her QOL will ultimately be shaped by his/her temporality.

3.1.4 The Person as Embodied

Another notion central to the Heideggerian phenomenological view of the person is embodiment (Leonard, 1989). Rather than viewing the body as an object which we possess, we are embodied. How a human being transacts within his/her world is expressed and experienced through one's body. As Benner and Wrubel (1989) suggest the role of the body may be radically altered during an illness experience. The Heideggerian phenomenological view of the person contributes to the uniqueness of each individual's interpretation of their everyday life experiences.

3.1.5 Rationale for Choosing Heideggerian Phenomenology

Some of the theses of Heideggerian phenomenology (interpretive phenomenology) discussed herein are embedded within a person's way of living and the complexities of these notions can be explicated through the interpretation of text. The latter refers to a person’s interpretation of his/her world. The researcher interprets this world through language, written and oral. QOL issues from the patients’ perspectives, contextual issues such as their worlds, their lived experiences, what matters to them, their fears and concerns need to be taken into account. All of these will have a bearing on how the person interprets the meaning of his/her existence. These interpretations can be illuminated using in-depth interviewing and through Heideggerian phenomenological inquiry often referred to as hermeneutic inquiry. It is through the latter that the researcher aims to explore the participants’ ways of being in their worlds in order to develop an understanding of their quality of life following an autologous blood stem cell transplant.

The goal of a hermeneutic study is to develop a deep understanding of a phenomenon through the interpretation of text (Benner, 1985). The text in this study was the transcribed interviews. The narratives from each provided an insight into how the participants interpreted their lives and the meaning they ascribed to the quality of their lives following the treatment. This insight will enable the reader to gain a deeper understanding of this very subjective and highly contextualized phenomenon. As Robertson-Malt (1999, p.292) suggests the success of hermeneutics “lies within its ability to gain greater understanding of an experience whilst maintaining the context of the everyday lived experience where meaning resides”

3.2 METHOD

The following paragraphs will discuss the rationale for choosing a qualitative design, how the researcher gained access to the participants and the characteristics of the participants, how the data was collected and managed, and finally the method of analysis.

3.2.1 Research Design

QOL from a phenomenological perspective can best be understood through accessing the participants’ own stories. It is in their own narratives that the richness and essence of their lived experiences, and in turn their perspectives on QOL will be illuminated. Therefore a qualitative research design was chosen to capture the unique and personal experience of the participants in this study following an ABCT. A qualitative approach enables the researcher to collect this type of data. It offers a way of accessing and compiling narrative text, which can then be interpreted in order to discover the meaning each individual draws from the experience.

3.2.2 Access to, and Description of Participants

While the research was undertaken, the researcher was working as a registered nurse at the Peter MacCallum Cancer Centre (PMCC), in Victoria, Australia. The PMCC is a leading cancer care and research centre providing state of the art treatment and expert care to people experiencing cancer. One of the many specialist treatments PMCC offers is autologous blood cell transplantation.

In order to seek volunteer participants the researcher submitted a proposal to the Ethics Committee at the PMCC, which approved the study. All patients who have undergone an ABCT at the PMCC are entered into a transplant database which is maintained by the secretary of the Haematology Unit. It was agreed by the Ethics Committee that potential participants would be identified through the transplant database by the secretary. The researcher had no direct involvement in identifying the participants. In addition, approval to conduct the study was sought and gained from the PMCC Medical Research Committee and the Victoria University Ethics Committee.

Selection of the participants was based on three different criteria. Firstly all participants were older than 18 years of age. PMCC has a policy not to accept patients under the age of 18 years, as more specialised care is provided for this age group at the Royal Childrens Hospital, Melbourne, Victoria, Australia. Secondly, this study focused on English speaking participants. This was crucial in order for them to articulate succinctly their experiences with the researcher. It also clarified accurate interpretation of meaning during the interview process and afterwards during data analysis. Consequently, people from non-English speaking backgrounds were excluded limiting the cultural diversity of the findings, and this will be discussed further in Chapter six. Furthermore, funds were unavailable to employ translation services. Finally, all of the participants had undergone an ABCT at least six months prior to their interviews. According to Andrykowski and McQuellon (1999), a return to pre-transplant roles and a resumption of normal everyday activity usually occurs between three to six months following BMT. Consequently, the researcher chose to select participants at a minimum of six months following their transplant so that a broader understanding of QOL would be captured.

On behalf of the researcher, the secretary of the Haematology unit contacted the first twelve participants identified from the database and through a letter of invitation informed them of the study and acknowledged PMCC approval of the research (Appendix A).. All twelve agreed to participate in the study. They contacted the researcher by telephone and expressed their desire to be involved in the study. The researcher organised a date, time and place to conduct the interview, that was convenient to the participant. Written informed consent was obtained prior to commencement of their participation in the study (Appendix B). The consent form described the procedures the participants would undergo. These included a tape recorded unstructured interview lasting approximately one hour in duration and verification of the transcribed interview if ambiguities arose. The consent form also detailed the participants' rights. These included their rights to have any questions answered and more importantly at any time the participants could withdraw their consent from the study and this withdrawal would not jeopardise the participants in any way and finally their right to complete confidentiality.

Twelve participants agreed to share their experiences, comprising five women and seven men, ranging in age from 26 to 58 years. Pseudonyms were used to protect their identity. All were in relationships at the time of their interviews, and nine had children except for Kevin, Miles and Joan. They all underwent an ABCT, for a range of cancers which included non-Hodgkin's lymphoma, Hodgkin's disease, breast cancer and acute lymphoblastic leukemia. All participants were at least 6 months post-transplant at the time of their interviews. The intervals since their transplants ranged from nine months to four years. As Melbourne is a multicultural city the PMCC treats patients from different ethnic backgrounds. Even though all of the participants spoke English the ethnic diversity was reflected in their backgrounds which included Greek, Middle-Eastern, and Anglo Saxon. However as mentioned before culture diversity was not the focus of this study.

3.2.3 Data Collection and Management

Data were collected through unstructured in-depth interviews. In-depth interviewing allowed for the collection of rich contextual data because it is through the participants' language that their lived experiences are expressed. The unstructured nature of the interviews meant that the researcher dispelled with the formal interview line of questioning and held only minimal control over the interview. According to Minichiello, Aroni, Timewell and Alexander "the unstructured interview takes on the appearance of a normal everyday conversation" (1995, p. 65).

The researcher commenced each interview with the leading questions, "What does QOL mean to you (name)?, and "in what way has your QOL changed since the transplant (name)?" Subsequent questions were derived from the participant's responses. In order to clarify meaning at various times during the interview re-focusing questions such as "What do you mean by [. . .]?" and "How does [. . .] concern you?". All interviews were tape-recorded and transcribed verbatim using pseudonyms. All participants were reassured that issues of confidentiality would be respected and that their identity, and the identities of the people they spoke about, would be respected through the use of pseudonyms.

Each participant nominated where they felt most comfortable being interviewed. Apart from two interviews, which took place in the privacy of the participants' homes, all remaining interviews were held in a room in the outpatient clinic area at the PMCC. Interviews lasted between one to two hours, usually at this point the participants had exhausted their need to talk and no new issues were emerging. All of the participants appeared to be very willing to talk about their experiences. There were intervals in many of the interviews where the participants became tearful, particularly whilst discussing painful and poignant issues. However, for many the interview process was a cathartic experience and some of the participants verified this by stating that they felt better after sharing their stories. It seemed they needed someone to listen to their experiences and in some ways it was a debriefing.

3.2.4 Method and Technique of Analysis

The data were analysed using Heideggerian hermeneutic analysis. Hermeneutics is a systematic approach to interpreting a text. As Benner described “the interpretation entails a systematic analysis of the whole text, a systematic analysis of parts of the text, and a comparison of the two interpretations for conflicts and for understanding the whole in relation to the parts, and vice versa” (1985, p.9). This method was chosen because it allowed the researcher to uncover the everyday lived experiences of the participants and to understand the contextualised nature of their worlds. Benner (1985 & 1994) and Leonard (1989) proposed three strategies to make conspicuous the socially embedded knowledge trapped in the familiarity of peoples’ mundane everyday lives. They are paradigm cases, thematic analysis and exemplars. All three are interpretive, inter-related strategies and serve to present the highly contextualised meanings that emerge from the text.

Benner’s (1994) approach in using the strategies outlined above in interpretive phenomenology is firstly to identify paradigm cases. As she suggested “this is the most usual way of entering the dialogue with the text” (1994, p. 113). A paradigm case is a strong incident of a particular pattern of meaning. The next step is thematic analysis. The text is read to identify meaningful patterns or concerns, which involves the researcher moving back and forth between the whole text and parts of the text in an attempt to clarify differences and similarities. The identification of exemplars, which are smaller than paradigm cases, is the final strategy used to interpret the text. As Benner (1994) explained: “exemplars convey aspects of a paradigm case or a thematic analysis” (1994, p. 117). Exemplars are specific episodes or incidents which present aspects of a particular situation and the participants’ responses to them.

Leonard’s (1989) method of analysis in a hermeneutic study is slightly different to Benner (1994). The former uses the three interpretive strategies previously outlined, but begins the process with a thematic analysis, followed by the identification of exemplars and finally the presentation of paradigm cases. This study followed Leonard’s approach and the three interpretational strategies as relevant to this study will be discussed under the headings, thematic analysis, exemplars and paradigm cases. The three interpretational strategies will be discussed below.

3.2.4.1 Thematic analysis

In this study all twelve interviews were transcribed verbatim and the transcriptions formed the text. Firstly, the text was read several times to enable the researcher to achieve a global analysis (Leonard, 1989). From this a coding system was developed to label the themes that constantly emerged from the text. This system was then used to code each interview. As this analysis was being carried out further themes emerged which were added to the coding system and the text was subjected to additional interpretive analysis. Thematic analysis allows for the presentation of common themes which form the basis of the study. Verbatim excerpts from the text substantiated the themes in order to provide evidence of the theme to the reader. Six major themes were identified as follows: loss of physical wellbeing; loss of control; altered self-concept; family and peer relationships; fear of relapse and life is precious.

3.2.4.2 Exemplars

The second phase of the analysis was the identification of exemplars. Exemplars captured the participants responses to a particular situation. Exemplars depicted the participants’ experiences, and their concerns and practices, and offered a presentation of how each participant transacted within his/her world. Exemplars capture the meaning in the situation so that the reader is able to recognise the same meaningful transaction in a different situation (Leonard, 1989). Exemplars will be presented in Chapter Four.

3.2.4.3 Paradigm cases

A paradigm case is larger than an exemplar and is a much stronger instance of a particular pattern of meaning. They embody clear and vivid events and offer a clear understanding of the transactions that take place in each participant's individualised world. A paradigm case not only offers an understanding of how a person interprets his/her world but also offers an understanding of the person's background, practices and concerns (Benner, 1985). Paradigm cases will be presented in Chapter Five, under the headings embodiment, being in time, being in society, and re-appraisal of time.

3.3 ISSSUES OF RIGOUR AND CREDIBILITY OF INTERPRETATION

The task in this study was to describe the lived experience of the participants, as accurately as possible, so that a greater understanding of their perspectives of QOL could be achieved. Such is the subjective nature of this research that ensuring rigour calls for different approaches from those used in quantitative research. To demonstrate the study is rigorous, trustworthiness must be established (Koch, 1994). According to Holloway and Wheeler, (1996) trustworthiness is a crucial concept in evaluating qualitative research. A key part of this concept is what Sandelowski (1986) originally referred to as the decision trail and this was later supported by Koch (1994). The decision trail provides succinct evidence to the reader of the different choices and decisions the researcher made throughout all stages of the research process.

When evaluating qualitative research the traditional criteria used to critique a quantitative approach is deemed inappropriate (Holloway & Wheeler, 1996). Utilising such criteria as validity and reliability that Minichiello, Aroni, Timewell, and Alexander (1990) refer to as the objectivity of the study, would be incongruent with this study's philosophical and theoretical commitment. Different assumptions underpin quantitative and qualitative methods, therefore a different set of criteria is called for to evaluate each type of research. Holloway and Wheeler (1996) argued against using such criteria as validity and reliability to evaluate qualitative research and presented four alternatives based on the original work of Guba and Lincoln (1985, 1989). The four criteria, credibility, transferability, dependability and confirmability as presented by Holloway and Wheeler

(1996) are used to ensure rigour in this study. These will form the foundation to demonstrate both trustworthiness and the decision trail of this study.

3.3.1 Credibility

To establish credibility in a study the researcher must ensure that participants of the study are accurately described (Holloway & Wheeler, 1996). The participants in this study were described in section 3.2.2. To improve or embellish credibility Holloway and Wheeler (1996) discussed peer debriefing as a means to evaluate data analysis and findings. As part of peer debriefing, the researcher's supervisor provided regular guidance of the data analysis process to ensure the necessary steps were taken to establish trustworthiness of the research process.

3.3.2 Transferability

Transferability refers to how the findings from a representative sample can be generalised to the whole group. However, in qualitative research it is not about finding out the distribution of a phenomenon in a population but rather understanding it (Holloway & Wheeler, 1996). Firstly, to meet this criterion it is important to state the characteristics and settings of the participants. The researcher chose a purposeful sample for this study, that is all the participants had undergone an ABCT. However, as argued by Holloway and Wheeler (1996) this cannot justify the transferability of the findings to other groups. To enable the reader to decide if the case or cases described in a particular setting can be transferred to another setting, a detailed account of the theoretical framework of the study must be provided by the researcher. The reader must be able to follow the researcher's decision trail. Heideggerian phenomenology was chosen as the theoretical framework for this research. Heideggerian phenomenology uncovers the everydayness of people’s lives so that the mundane QOL activities that often go unnoticed will be illuminated. This is discussed in section 3.1. The method and technique of analysis is discussed in section 3.2.4. From this, it is apparent that the cases presented in this study’s setting can be transferred to similar settings where the person is confronted with a life threatening or life altering illness. The preliminary findings of this research were presented to the ‘International Society of Nurses in Cancer Care Conference’ held in Jerusalem in 1998, the ‘International Council of Nurses Conference’ held in London in 1999, the ‘School of Nursing‘s Research Colloquial Meeting’ held in November 1998 at Victoria University, Melbourne and also to the ‘Cancer Nurses Society of Australia - Winter Congress’ held in Melbourne, June 2001. The audiences commented on how meaningful and relevant the findings were to their practice because it both personalised and broadened their understanding of the illness experience.

3.3.3 Dependability

Dependability refers to ensuring that the procedures used in the research process have followed acceptable standards. As Holloway and Wheeler (1996) emphasised this relates to the concept of the decision trail. In this study the researcher has succinctly discussed the decisions taken on theoretical, methodological and analytical choices, as outlined in sections 3.1 and 3.2.4.

3.3.4 Confirmability

The final criterion used to establish the rigour and trustworthiness of this study was confirmability. Confirmability refers to the assessment made by the reader that the study’s findings come directly from the data (Holloway & Wheeler, 1996). In this study, to ensure accurate representation of the participant's narratives each interview was tape-recorded as unobtrusively as possible and all interviews were transcribed verbatim. Data were analysed through three interpretational strategies as outlined by Leonard (1989), and previously discussed in section 3.2.4. Emerging themes and patterns of meaning were identified. Written notes were recorded on the latter and these formed the beginning of the analysis trail. Both the researcher and the principal investigator frequently returned to this data source. This enabled the supervisor to follow the trail used in the analysis process and to challenge the interpretations and ensure the findings were a true representation of the data. Confirmability was achieved by providing adequate excerpts from the texts to support the development of themes and exemplars.

The four criteria presented above as outlined by Holloway and Wheeler (1996) provided the basis to establish the trustworthiness of this study.

3.4 ETHICAL CONSIDERATIONS

Ethical issues are paramount in any research approach, however, qualitative research generates specific ethical problems which need to be given due consideration by the researcher. The ethical issues pertaining to this research are discussed under the following headings, as outlined by Holloway and Wheeler (1995): access to participants; informed consent and voluntary participation; and anonymity and confidentiality.

3.4.1 Access to Participants

Following approval from the Human Research Ethics Committee at the Victoria University in Melbourne, and from the Ethics Committee at the Peter MacCallum Cancer Centre (PMCC), potential participants were recruited. This was arranged with the assistance of the secretary of the Haematology Unit at the PMCC, who, on behalf of the researcher mailed a letter of invitation and consent form to potential participants identified from the bone marrow transplant database.

The letter of invitation (Appendix A) invited potential participants to participate in the research study. It described the study and the interview process. The invitation letter clearly stated that the interview would be treated in total confidence and that the anonymity of the participants would be protected throughout the research study with the use of pseudonyms. It also declared the right of the participants to withdraw from the study at any time, and if during the interview process they became distressed or discomforted the interview would be discontinued. The invitation letter also mentioned that the potential participants were under no obligation to participate in the study.

3.4.2 Informed Consent and Voluntary Participation

According to Holloway and Wheeler (1995, p.224) informed consent “is set firmly within the principle of respect for autonomy”. Inherent in this principle is the voluntary nature of participation in research, but, also it demands that participants must be made aware of the potential risks and benefits to them. This was clearly outlined in the invitation letter (Appendix A) and also in the consent form (Appendix B). Prior to commencing each interview, the researcher reviewed the consent form with the participant, explaining their rights and answering any questions they had. Finally, once the participants were comfortable, they provided written informed consent.

Each participant related their experiences following the transplant. They disclosed extremely sensitive, emotive and confidential information. It was anticipated that sadness, anger and frustration might occur as the participants spoke about issues and concerns, which they may not even have challenged or acknowledged themselves. It was believed that this unearthing of repressed memories and emotions had the potential to create psychological distress. To minimise the risk of emotional stress the researcher ensured participants were well informed about the study, both verbally and through a letter of invitation (Appendix A). The latter indicated that participation in the study was entirely voluntary and that participants could withdraw from the study at any time without concern that their future care would not be jeopardised as a result. To increase the comfort level of the participants, the researcher gave them the opportunity of being interviewed in their own homes. However, at the request of the participants, only two opted for this. The remaining ten participants were interviewed in a private room at the PMCC. As explained in the invitation letter (Appendix A) the researcher also gave the participants the choice of having a relative/close friend in the vicinity to provide support, if needed.

Each interview was approached in a sensitive and caring manner. At no time did any participant express any discomfort or desire to cease the interview. Nonetheless, the researcher was aware of the need to exercise professional judgment and skills in order to identify signs of discomfort or distress and to act accordingly if these occurred

A plan of action was devised should the participants show any signs of discomfort or distress during the interview process. The researcher planned to give each participant the option to continue the interview; cease the interview; seek supportive counselling or any combination of these options. Supportive counselling was made available to participants from the PMCC or from the Anti Cancer Council of Victoria. Prior to commencing each interview all participants were reassured that they could withdraw from the study at any time, and that details regarding their participation would not be disclosed. However, it was not necessary to employ any of these strategies.

3.4.3 Anonymity and Confidentiality

Given its nature, qualitative research can be more intrusive than quantitative research and so it calls on the researcher to be extremely sensitive and cognisant of the concerns and rights of the participants (Holloway and Wheeler, 1995). Issues pertaining to the confidential nature of this research and the participants' anonymity were discussed with each of them.   The researcher was bound by the University’s Code of Ethics as well as the Nurse’s Code of Ethics to ensure that confidentiality was maintained throughout all aspects of the research. Pseudonyms were employed to hide the participants' true identity. All tapes were labeled with pseudonyms and stored in a locked cupboard in the researcher’s home, to which only she had access. The signed consent forms were also stored in this cupboard. The transcribed interviews as well as data pertaining to the analysis and findings of the study were electronically stored on the researcher’s personal computer to which she had sole access, through the use of a secret password. On completion of the study, data stored on the computer was down loaded onto a disk and in accordance with the National Health and Medical Council regulations it will be stored in a locked cupboard at the University for five years and then destroyed along with the interview tapes and consent forms.

3.5 CONCLUSION

This chapter presented the theoretical framework and discussed the philosophical underpinnings of Heideggerian phenomenology (interpretive phenomenology) pertaining to this study. This chapter also discussed the research design, research method, access to participants, data collection and the process of data analysis. And finally issues related rigour and ethical considerations were discussed. The following chapter will present the findings of the study.

CHAPTER FOUR

FINDINGS: COMMON THEMES AND EXEMPLARS

This chapter presents the major themes and sub-themes which emerged from the analysis of the interview text. Six major themes were identified: loss of physical wellbeing; loss of control; altered self-concept, family and peer relationships, fear of relapse and life is precious. Each theme will be described, discussed and accompanied by illustrative quotes from the data. Under each major theme were various sub-themes which will be presented, followed by narratives illustrating their meanings. Exemplars will also be presented to describe particular situations in the participants' everyday lives, which will depict their experiences, concerns,and practices. As explained in Chapter Three, themes describe specific incidents whereas exemplars are specific instances which present aspects of a particular situation and the participants' responses.

4.1 LOSS OF PHYSICAL WELLBEING

For the participants QOL meant physical wellbeing. Before the transplant their physical wellbeing went unnoticed, as their bodies were well and there were no restrictions on what they could do. But following the transplant the participants were intensely aware of their bodies and how each daily activity was cumbersome and constrained. Physical activities they could do without contemplation prior to the transplant now were difficult. The exhausting fatigue that all participants experienced was a major physical limitation in their lives. The participants' physical wellbeing was also disrupted by niggling physical discomforts such as lingering aches and pains, hot and cold flushes, and loss of taste sensation. Although these discomforts were not serious, they were annoying, and served to remind the participants that their bodies were still not well. This was a source of much frustration for many of the participants. They told of how frightened they were when they first discovered that the natural instinctive functions of their bodies were restricted. Thus, loss of physical wellbeing was a major theme which disrupted the participants' QOL. The sub-themes, fatigue and discomfort, which contributed to the participants' loss of physical wellbeing, will be presented.

4.1.1 Fatigue

Fatigue was one of the most common side-effects that persisted long after the transplant. The participants had never experienced fatigue like this before, and some found it difficult to describe to their family and friends how physically exhausted they actually were. As Yamon commented:

> I remember when I came home [from hospital] I just laid down and people came to visit me, and they asked me why I was lying down, and I said I don't know, I just feel dead.

The fatigue they experienced left them feeling angry and frustrated, as it disrupted the once confident manner in which they had pursued their daily activities. It also altered the roles they played within the family. Pastimes they once enjoyed with their children and partners now became a chore, which placed pressures on family relationships. The participants were simply too tired to be involved in the everyday activities which once gave them so much pleasure. It was even frightening for some of the participants to discover how weakened their bodies had become.

Linda remarked on the limitations and pressures placed on her by the fatigue she was experiencing. The following account illustrates this theme:.

> Before the transplant I would have the housework done before I would take [the children] to school, everything was done. But now I put things off and that really frustrates me. I want to do things with [the children]. I will try and go for a bicycle ride or play basketball, but I just cannot move around the way I used to. Running is very difficult. I was pretty active before. I never stopped. And I still try and do that, and I get angry because I can't keep up the pace, and I get really tired, and I have to stop.

Linda's everyday routine had been disrupted, and her world had changed. A very important part of her world, prior to the transplant, was being a housewife and mother. Because of the fatigue she experienced, she struggled to fulfill these roles.

Other participants felt they were invincible before their illnesses, and believed what they could achieve with their lives was endless. When they left hospital and started to return to their everyday routines, however, they too realised how weakened their bodies had become. Fatigue, or rather the intensity of fatigue, was something they did not expect and were not prepared for. They attempted to do the normal things, but discovered their bodies were not capable of responding in the usual confidant manner. As Miles commented:

> When I first got out of hospital I could not run and I had no muscles. I was trying to cross a street and I nearly got hit because I could not run. I thought I could do it, but obviously the transplant does not affect your brain, it affects your body. The brain was willing, but the body was not.

For many participants the fatigue was a transitory symptom, while for others it persisted for many years following the transplant, creating a physical inertia. Kevin highlighted this when he compared himself to an "old man". For Kevin, aging represented sluggishness and feebleness, apparent in his following statement:

> You can't imagine how fit I was. I could do anything and I would not be exhausted. I was very weak for three months [following the transplant], and I mean weak. I was walking like I was worse than an old man. I am healthy, but everything is slowly for me now. I just take it step by step. I can't take three steps at a time. Sometimes my body could be going [one] way, and my mind is telling it to go the other way.

Fatigue placed limitations on the participants' lives and, thus, affected the quality of their lives. Physical strength and stamina were taken for granted before their transplants. Activities they could do easily prior to the transplant now took a much longer time. While this was a source of frustration for many of the participants, others were more accepting of this limitation. As a philosophical Jim explained about his approach to life following the transplant:

> Things I could do before [the transplant] I cannot do now. Like I said, the energy is not there. I still like to do bits and pieces of [carpentry work], but it might take me a couple of hours or all day, whereas before it was only one hour’s work. But I don't find that frustrating. I quite enjoy it really. I have done all that before. What is all the rush for?

The participants who returned to either part-time or full-time employment struggled with ongoing fatigue. Joan commented on how difficult it was in the beginning, and even two years later, she still sometimes perceived fatigue as a limiting factor in her life. As she explained:

> When I first started work I was rushing, because I was running late, and I got off a tram and started running, but my ankles felt like I had huge bricks on them, and I just could not move. That really scared me. Even now I find it difficult sometimes at work to keep up with the pace of everything and everyone.

For those participants who had not returned to work, the fatigue they experienced created anxiety about their ability to resume their pre-transplant working roles. Some felt they would not be able to cope with a full day's work, and so declined to return to their former roles. Others were very protective of their bodies. The transplant experience had taught them to value their health and respect their bodies. Fatigue symbolised to them a sick body. Whereas in the past they had pushed themselves to achieve, now they were more wary and listened to their bodies. Fatigue also disrupted the participants' intimate relationships. Sexual activity was impossible, particularly in the immediate months following the transplant, and fatigue was one of the major contributing factors.

The participants realised how much they had taken their physical wellbeing for granted. Fatigue was equated with "stamina", and the participants spoke of how they did not have the same stamina for life. The most intense period of fatigue was experienced in the months following their discharge from hospital. However, over time, the participants' energy levels did improve, but this was a gradual and prolonged process.

In summary, fatigue altered the participants' QOL in different ways. It forced them to view their bodies as clumsy and awkward. Every activity had to be contemplated and planned beforehand. Fatigue was not something they anticipated as been a major hurdle to overcome following the transplant. Hence, they were not prepared for it, which meant it caused even greater intrusions into their daily lives. Compounding this were other physical discomforts that the participants also experienced during the post-transplant period.

4.1.2 Discomfort

Some participants continued to experience physical discomforts following their discharge from hospital. Even though these discomforts were minor annoyances, they hampered the participants' everyday lives, and restricted their return to their pre-transplant roles. Linda, who was in her mid-forties, explained how these niggling discomforts prevented her from gardening, which was one of her favourite pastimes, and performing household chores.

> I have just started doing my gardening again and that makes me feel good. But my knees are still a bit of a problem. I can't get up unless there is someone there to help me. The pain is not there like it was, but I still get it when I kneel down, and I can't get up. One day I was doing the housework and I got down on my knees and I could not get up. I stayed there for about one hour and a half, until I could get someone to come in and help me up.

Gaye too struggled with persistent and nagging aches and pains. She no longer felt comfortable with her body, and was conscious of her every movement. As she explained:

> I sort of always ache. Every time I moved something hurt or ached, and I am never comfortable. The back hurts or the hips hurt. I can’t ride the horse because the hips are sore for days afterwards.

Despite the pain the participants experienced, some perceived it to be part of the transplant package, and a small price to pay for getting rid of the cancer. Kevin, had non-Hodgkin’s lymphoma and was now in remission. His following account illustrates this.

> Well, I have got a bit of pain, but I am a lot better off than some other people. Some people end up being handicapped for the rest of their lives. I can walk and stretch my arms. Now, maybe I am a bit sore from what I have gone through, but my QOL can only be improved by me and no one else, and that is what I am striving for.

Loss of physical wellbeing was also related to loss of appetite and changes in taste. These had been taken for granted functions of the body, which the participants struggled with following their transplants. Marsella particularly found these changes annoying. Foods that she had enjoyed before the transplant were now not palatable, exemplified in her following statement:

> For quite a while after the transplant I was not seriously ill, but I had a lot of discomfort in a lot of areas … I used to like a glass of red wine, but for a long time [after the transplant] I could not drink wine. So it does affect one's taste buds permanently I feel.

Similarly, Rick commented: "I love to eat ... but I could not eat very well after the transplant". As with the others who experienced appetite and taste changes, it took many months before this returned to normal.

Such problems may have been trivial from the medical profession's perspective, but from the participants' viewpoint they caused disruption to their everyday lives and impacted on their QOL. For example, Kevin who was five years post-transplant posed the question: "Why am I so sore? My feet still feel sore if I walk too much. I still have constant pain since the transplant". Maurice too wondered why his physical discomforts continued for many years following the transplant. Even though his cancer was in remission, he was frustrated that the medical profession could not provide solutions to his lingering discomforts, which included recurring skin rashes and a dry mouth. He recalled:

> With all these side effects I have had I would ask [the doctors] at the clinic and I would be told, 'yes another 3 weeks'. And those three weeks would turn into three months and four months and then five months. And in a lot of cases I got the impression from the clinic that they didn't know themselves. I cannot imagine that all patients are so dramatically different.

Like the rest of the participants, he wanted to feel comfortable in his body again, and to return to a state of wellbeing. He perceived that his physician was not addressing the niggling side-effects he continued to experience. Maurice's perception of his QOL differed from that of his physician. While the latter was interested in conquering the cancer, which Maurice was grateful for, he also wanted his body to be well again and free of all discomforts. The removal of these discomforts was very important to Maurice in defining his QOL.

Another discomfort described by the female participants were the hot and cold flushes they experienced during and following the transplant. Marsella was post-menopausal when she underwent the transplant, but the remaining female participants were pre-menopausal and perceived they were experiencing a premature menopause after their transplants. They believed that the flushes were directly related to this. While annoying and embarrassing, the flushes were also a source of physical discomfort. As Gaye explained:

> I can be freezing cold like I have never experienced before ... like my bones are cold right to the core ... and next minute I am roasting hot and everything comes off. But it is frustrating when [I] try and go to sleep at night, and I am cold and hot, and my bones ache. I think that is a big thing. I go to work at night and I am running around looking after patients, and the sweat is dripping down my back. Or I might be talking to someone, and all of a sudden my face will go absolutely crimson ... Everyone I work with is aware [of this], but when I meet a stranger it is dreadful.

Marsella, who was post-menopausal prior to the transplant, discovered that she could not tolerate hot weather after her transplant. She found this quite distressing and, as a result, could not accompany her husband on holidays to Asia. She recounted:

> On very hot days, or after I have done something physical, my whole body will prickle and that bothers me. On a very hot day I can stand in the sun for about 30 seconds and I start to prickle, so I have to move into the shade. I find it gets me really on edge, so I just try and stay out of the sun, and stay cool and have a cool bath. My husband loves to go to Asia on holidays, but I feel it would be too distressing for me to be constantly moving into the shade.

Marsella and Gaye did not have to contend with these physical discomforts prior to the transplant. They were annoying and embarrassing, limited the scope of their daily activities and, thus, impacted on their QOL.

All participants described loss of physical wellbeing, which interfered with their everyday lives, in varying ways. It created discomforts in their lives, but more importantly constrained their activities. Many participants defined QOL as doing what they wanted to do without limitations; a thought they would not have considered prior to the transplant. Following the transplant, however, this was no longer possible, because the loss of their physical wellbeing had altered their quality of life.

4.2 LOSS OF CONTROL

QOL for the participants meant having control over their lives. They wanted to be able to plan their futures, look forward to their children growing up and not feeling threatened by the fear of relapse. During and after the transplant the participants perceived they had lost some control over their lives. Some participants spoke of how their control was ripped away from them during their treatments. This was both a humiliating and undignified experience for them.

Furthermore, career advancement and professional success was an important contributing factor in the participants' QOL. Before the transplant their careers were strategically mapped out, providing them with a sense of knowing where they were headed. After the transplant, however, some participants found it difficult to return to their pre-transplant roles. As cancer survivors they no longer controlled their futures. Some perceived an external locus of control governing their lives, which was the constant fear that the cancer would return. The uncertainty surrounding this loss of control created havoc in their lives. They could no longer strategically plot their lives, as they once had done. Indeed, following the transplant they realised that nothing in life was guaranteed.

All participants related stories or events of how their lives had been transformed by loss of control. Gayes' interview particularly presented how much her life had spiraled out of control following the transplant. She was aware of this and yet was not able to stop it. However, she attempted to create a safe haven for both herself and her children. The following account is an illustration of this.

> I bought a pony for the children following my treatment. She is just gorgeous and the children adore her. The pony lives in the country, and it is so peaceful and everyone is lovely there. I have learned so much about horses from not knowing anything about them. We go to the shows and competitions, and what fun we have at them. But suddenly I am jolted back and I think no, [life] is not so wonderful.

For Gaye, the interludes in the country were not only an escape, but also a semblance of control. The pony was a symbol of a world devoid of threats, over which she had control. But these escapes were brief, and she inevitably returned to the normality of domesticity where life was not so secure.

Similarly, Yamon spoke of how he desperately tried to maintain some control over his life both during and following the transplant. But unlike Gaye’s case, Yamon’s battle to maintain control during the transplant had a positive effect afterwards. It forced him to become a lot more independent and accountable for his life, and this he believed had improved the quality of his life. He reassessed his work options and he ultimately became self-employed. The following exemplar depicts Yamon’s experience of loss of control and how this challenged him to change his work practices.

> I work for myself now. [Following the transplant] I started going back to work and I discovered I could not work with other people any longer. I could not work with [managers] because [the transplant experience] forced me to take control of my life and I had never done that before. So I opened my own business with computers and telecommunications and it is going well.

Related to the major theme, loss of control, were the following sub-themes: uncertainty, loss of control related to the treatment, loss of control related to career pathway, and loss of control related to cognitive impairment.

4.2.1 Uncertainty

Linked to the participants’ perceived loss of control was the uncertainty that now permeated their everyday lives. There were no guarantees that their cancers would not return, and so they had to deal with the ever present fear this engendered. The uncertainty this wrought following the transplant shattered their senses of security and affected the quality of their lives. As one of the participants articulated, "I learned that the future is very elastic, [and] I cannot plan too far ahead". For Linda, in particular, the uncertainty she experienced following the transplant caused her so much confusion and frustration that it dominated her life. The control and routine that once structured her life had vanished. She feared the recurrence of her disease more than death itself, and related how she coped better when she knew had the cancer. The following account illustrates this theme.

> I coped better before, when I knew something might happen straight away. I felt I knew what I was doing. But now this uncertainty. Well, it is just month to month … that feeling of what is important. I go around in circles … I don't know what to do with myself.

Getting on with everyday living was very difficult, particularly making decisions about her future and her children's future, which proved almost impossible for her. The uncertainty looming over her life prevented her from regaining any semblance of control.

Similarly, the uncertainty Gaye experienced played havoc with her everyday life. She was married with two young children, and she was constantly mindful of the uncertainty shrouding her future. She was convinced that the cancer would return one day, it was just a question of time, and this affected her family life, as Gaye attempted to compensate for her perceived reduced life span. She believed she would not be alive to see her children grow up, so it was vital that she did as much as she could with them now. She bought them expensive presents, and provided them opportunities that she would not have otherwise. She treated each Christmas as if it would be her last. As a result, Gaye found herself in serious financial difficulty, which caused her considerable anxiety and inevitably affected her marriage. As she explained:

> And I am dreadful. I just cannot control myself. If I see something for the kids I will go and I will get it. I have just got myself into such a hole with my credit cards. And then I think I might not be here tomorrow. I am in

> debt up to my eyeballs and I can't see an end to it. That's why I need to win Tattslotto.

Gaye perceived that the quality of her life had changed. The uncertainty formed by her fear of recurrence had created much confusion in her life.

Ron also punctuated his interview with remarks suggesting that uncertainty lurked beneath his everyday life. He, however, was attempting to recreate a sense of certainty, relating:

> I think after the first time I was diagnosed, we were saying we would retire when I was 55. And then hopefully we would have a few years to enjoy retirement. And that is still foremost in our minds.

By creating a structure in his life he was attempting to compromise for the uncertain nature of his life. This became evident as he explained how he provided support to his daughter who was having difficulty coming to terms with his illness. He recounted:

> [I said] to my daughter to look at it this way. Dad's cancer was picked up early enough, hopefully early enough. I was picked up early enough and if anything happens I have check-ups every 2 months. And if something comes back, well, hopefully they will be able to do something.

As with all participants, once in remission there was always the uncertainty of what the future might hold. Uncertainty contributed to the perceived loss of control the participants experienced and disrupted the quality of their lives.

4.2.2 Loss of Control related to the Treatment

Some of the participants described the importance of attempting to maintain some personal control during their stay in hospital. Being adequately informed about, and prepared for, the transplant and its side-effects greatly assisted the participants. The nurses were excellent at explaining the treatment and preparing them for what lay ahead, and this helped the participants maintain a sense of control. However, some participants stated that the drugs they received robbed them of their senses of control. As Yamon related after the reinfusion of his stem cells:

> I was feeling fuzzy all day because they had given me some [medication] to knock me out, and it made me feel funny and out of control.

Yamon did not mind when his morphine drip was discontinued and his mouth still hurt. His main concern was to maintain control over what was happening to him while in hospital.

Similarly, Rachael refused narcotic analgesia, because it prevented her from being in control of her recovery. She did not like the "sleepiness" and "vagueness" caused by morphine, which took away her sense of self-control. As she recounted:

> I just liked to be totally conscious all of the time. I didn't like that floaty feeling.

The side-effects of the chemotherapy also contributed to this loss of control. The majority of participants experienced a degree of vomiting or diarrhoea at some stage during their treatments. This was viewed as a factor beyond their control, and they found the unpredictable nature of it humiliating. As Marsella commented:

> All of this suffering and discomfort, and a lot of the treatment, I found undignified ... I hated having the catheter [Hickman line] in, and having to get up and rush to the toilet, and sometimes not getting there on time. That for me was the most distressing thing, to be out of control.

For the participants it was important to maintain some control over their lives during their hospitalisation, when most aspects of the illness experience were almost beyond their control.

4.2.3 Loss of Control related to Career Pathway

Some participants experienced difficulties returning to their pre-transplant working roles and, consequently, had to search for alternative employment. Many factors contributed to this. Joan, for example, returned to the corporate world, feeling that she could not compete any longer in the entertainment industry. The following illustration describes this theme.

> I was quite successful [before the transplant] ... Once I got sick again I felt like I had fallen off a cliff. After the transplant I had to start all over again. It was really hard to get back into the entertainment industry. It is so dependent on your appearance, and I just could not compete with that ... So I took a job in the corporate setting, but I always questioned my ability ... I hated the fact I was not singing. I hated being back in the corporate setting, and that made me really, really angry.

She no longer had the power to determine her career path, and so had to settle for a job option which she considered was second best.

Kevin's health prevented him from returning to work for five years following the transplant. During this period he lost the required skills and expertise to return to his former employment. Prior to the transplant, he had control over his career path and plotted his advancement. But after the transplant, he would happily take what he was offered. In the following account Kevin’s describes his concerns realted to this theme.

> My career path was very good [before the transplant] ... and that is a different matter altogether now. I knew my potential [then] ... I know I have been out of action for five years, but through Commonwealth rehabilitation services I have applied for computer courses, and I have completed all of the computer applications to date. People now say to me five years is a long time to be out of action ... Maybe I am not as fast as I

> was, but all I ask is to try me.

Many participants, however, returned seamlessly to their pre-transplant working roles, though over a period of time. But for others it proved more difficult. They experienced physical problems and questioned their ability to compete in their chosen profession. Consequently their self-esteem suffered, and the control they once possessed over their careers had diminished.

4.2.4 Loss of Control related to Cognitive Impairment

Loss of control was also related to cognitive problems, of which forgetfulness was the most common. Many participants related how their memories were not as sharp as before their transplants. Linda considered this was a significant barrier which prevented her from returning to work. The following account presents the difficulties she experienced in her everyday life.

> That high dose treatment was really something. For days I did not know where I was. I was forgetful. I mean I am forgetful now, but during the high dose treatment I felt so disoriented. [Now] I forget things, which I should not forget. And that is one of the things with my work ... There is so much book work ... I even write notes to get here.

The transplant also affected the participants' ability to concentrate. Marsella was an avid reader, but following the transplant she found it difficult, as her ability to concentrate for long periods was reduced. As she explained:

> For a long time I did not want to read a book … I could not be bothered. I could only flick through a magazine and even then I would put the magazine away and think, what did I just read?

Once again, the taken for granted functions of the body had been disrupted. The control the participants once possessed over their bodies had vanished, ultimately interfering with their QOL. It restricted the participants from pursuing their pastimes and, more importantly, created anxiety about their ability to return to their pre-transplant working roles.

4.3 ALTERED SELF-CONCEPT

For all of the participants the sense of who they once were had been lost. The physical changes they experienced led them to develop an altered picture of their selves, which they now found foreign. They had to contend with changes in how their bodies responded to various bodily stimuli, which again felt strange and unfamiliar. The participants felt they no longer knew their bodies like they once did, and so the body was seen as something to mistrust and dislike. This resulted in an altered self-concept, which will be described under the sub-themes, altered body image and sexual expression.

4.3.1 Altered Body Image

Most participants experienced an altered body image. For some, it was the shock realisation that they no longer recognised themselves. Following the transplant their bodies had changed. The physical changes they underwent created an altered body image, which resulted in a loss of self-esteem. Their bodies now felt foreign, as the perceived change in body image was so dramatic for some participants that it left them grieving for the way they once were. The following account from Gaye's interview illustrates this theme.

> I look in the mirror and think what a mess I am now. I will never feel normal again. Things have changed and it is always going to be like that. You cannot turn the clock back and say, I still have my breast and I don't

> have this scar across my belly. I am always conscious of it. Body image really was not important to me before [the transplant]. I mean I had two breasts and a saggy stomach, but it didn't really bother me. I didn't feel abnormal. But now I feel freaky, because I have all these scars and my [reconstructed] breast feels lumpy and it is always there.

Gaye had grown estranged from her own body. It had not been perfect prior to the transplant, but it felt complete and, more importantly, Gaye felt comfortable within it. Linda, too, experienced an altered body image. She hated the way her body had changed, and this has left her feeling isolated and lonely. She related:

> It is like you don't know yourself. I really don't like looking in the mirror. I know that sounds vain, but the change is so dramatic. I was a lot thinner, and I had a lot of energy. [Even] after the mastectomy I had a lot of energy. But now [following the transplant] I am three sizes larger, and I have curly hair instead of straight. Now I know that doesn't mean much, but I just look so different.

An altered body image was not just an issue for the female participants. Some male participants also told of how the changes in their physical appearance impacted on their QOL. Maurice, in particular, was surprised that body image could mean so much to him. He recalled:

> My QOL only seems to be affected when I look in the mirror with glasses on and I don't recognise who is there, because this is not how I think of myself. You see I think of myself as how I was before [the transplant]. And there may be a certain lack of confidence that goes with that. I am not sure, only others could say that.

Following the transplant, the participants told of how their perceptions of their bodies had changed, which left them feeling clumsy, more self-conscious and less confident in their every day experiences and so hampered their QOL.

In some participants the altered body image they experienced led to an internalised stigma. They perceived themselves as strange and not fitting in to the norm of society. For example, Gaye told of how she felt ‘freakish’ because of the changes that have taken place in her body. Her perceived stigma was not socially derived, but came from within herself and her perceptions of how the cancer treatment had transformed her.

The following account is an exemplar of how Kevin’s altered body image affected his every day life.

> The presentation of my body has changed. I had put on quite a lot of body weight. I felt heavy, weighed down, as if I had a tonne of weight on me ... When I went out for a walk occasionally in my neighbourhood, people who would know me would ask questions, and I could see the expression on their faces a mile away. I always wanted to duck for cover ... They could see that something was wrong and most people could tell that [I] did not look well.

Similarly, Joan’s altered body image represented not being “normal”. This is evident from the following exemplar:

> I have been on hormone replacement therapy (HRT) since I started my treatment ... I am not in the normality of life. I am surrounded by late twenty and thirty year-old girls that don't know anything about HRT ... I am on a different planet and in a minority. [I] really have no one to talk to ... I feel like a fish out of water.

Joan perceived she had lost an integral part of her femininity, which she felt had alienated her from her peer group.

4.3.2 Sexuality

For most participants sexuality constituted an important part of who they were. They defined their sexuality in terms of their ability to have children, to experience intimate relationships, and to communicate with those around them. For most, it represented a youthfulness that was lost because of the illness experience.

Alterations in sexual wellbeing were common in most participants. Many of them experienced a loss of libido, and the fatigue they experienced following the transplant was a contributing factor. As Kevin explained:

> I felt very weak. I did not want to have [sexual intercourse] ... [My sexual desire] was not there. It was three months before it started again ... The way I felt then, it was not a priority … But I still get tired when I have sex. I don't have the [same] stamina.

The consequences of undergoing a premature menopause had both a physical and emotional impact on the female participants’ perception of their sexuality. Joan, for example, believed that she had been robbed of her youth, and that she was now trapped in an aging body. The bodily functions and responses that go hand-in-hand with femininity and youth were gone, and it deeply affected her sense of both who she was and her sexuality. She was a different person following her transplant. Moreover, she was startled by how quickly her body had aged, and to be suddenly stripped of her physical and sexual youth was something she was not prepared for.

The male participants also had similar issues related to their masculinity. For Kevin, masculinity and machismo were one. Prior to the transplant, he was proud of his body, particularly its strength and vitality. However, following his transplant, he felt "paralysed", robbed of his youth and masculinity, and considered himself an "old man." As he stated:

> After I stopped the therapy I was weak, and I mean very weak ... I felt heavy. I had put on quite a bit of body weight. I felt weighed down. When I went out for a walk, I wanted to duck for cover, because I did not feel presentable. I felt tired. I felt silly. I was not in very good shape.

But sexuality was about more than just expressing their identities. It was about being able to communicate with their partners on an intimate level. In the following account Rachael speaks openly of her concerns and experiences related to this theme.

> I was aware that it [menopause] was going to happen. But to me, it did not mean anything until I actually went through it. I mean people talk about the likelihood of experiencing it, or getting some aches and pains, and arthritic knees and that sort of thing. But until you actually experience it, it means nothing. Then there are such things as loss of libido and my vagina is nowhere near as moist as it once was, and these things impacted on my relationship. Obviously, we are not having a sexual relationship as often as we used to. It is just like everything is shut down. So, therefore, I will try and compensate for that.

For these women aging prematurely was the silent enemy. Coping with the physical symptoms of menopause was difficult, but what haunted them even more was the perception that their bodies were ageing prematurely, and this threatened their feminine identities and interfered with the quality of their intimate relationships. Changes in their sexuality meant that the natural progression of their lives was lost. Indeed, lost youth was of particular concern for Linda and Joan. Both felt uncomfortable in their altered and prematurely aging bodies. They were angry, horrified that their bodies could age so quickly. As Linda related:

> But if I aged gradually I could accept it. But with such a major change ... you know I never looked my age, and then all of a sudden I have aged 10 years or more. I look at clothes on other people and I think I used to be able to wear that ... And it is like a put down of myself all the time.

For many participants, being unable to fulfil their dream of becoming a parent was a devastating consequence of the treatment. Fertility was an important aspect of Yamon's sexuality. Having a family represented hope for the future, and something to look forward to when the treatment was completed. However, the transplant had rendered him infertile. The following exemplar presents Yamon’s concerns and the practical implications related to this theme.

> QOL is my family … This makes it difficult, because the treatment affects your fertility as well … so without kids it makes it very difficult. When you go and marry somebody, and you have to tell them you are going to have problems having kids, it may affect your ability to get married and your overall life. If you are on your own, you are basically crippled. It is a disability. And it affects your entire life.

Loss of fertility for Yamon meant he had lost an integral part of how he identified himself. Fertility was part of his sexual expression and his QOL.

Altered body image, and changes in sexuality and the manner in which they internalised these perceptions, contributed to the participants’ altered self-concept. This, in turn, had significant implications for how they perceived their QOL. The following excerpt from Joan’s interview is an exemplar of this.

> I didn’t feel beautiful as a person. [The transplant] broke my spirit ... I felt I had no procreative abilities and I didn't feel that I could fulfil the need of a spouse. There was no way I could have sex. I just did not feel like it. I didn't feel attractive, my libido had crashed and so there was nothing I could give.

4.4 FAMILY AND PEER RELATIONSHIPS

The participants in this study discovered their cancer experiences impacted on their families and their social networks. For those participants who had strong family support it proved an invaluable resource in their recoveries, which positively impacted on their QOL. For some, the transplant provided the opportunity to reassess their family relationships. Family gained a new sense of importance in their lives, while faltering relationships were rekindled. For those who did not have family support, life following the transplant proved more challenging, as relationships with their peers were threatened by the illness experience. Family and peer support will be presented under the sub-themes rekindled relationships and strained relationships.

4.4.1 Rekindled Relationships

Most participants described a strengthening of intimate relationships. In the face of adversity, it was their partners who were their source of strength. As a result of the cancer and the treatment, they had grown closer together. Some participants found their intimate relationships strengthened by the transplant experience and this had a positive impact on their QOL. As Ron explained:

> I really think my wife and my mother-in-law were my support, particularly the support I got from my wife. I just cannot explain it. Maybe I would have not been able to cope on my own, but my wife really helped me keep my feet on the ground. She said, 'look this is it, you are going to do the transplant, the doctors are trying to help you, so let's go for it'. So, I did not get a chance to wallow in my misery.

For some of the participants the transplant experience provided them with the opportunity to reflect on what they considered the important things in life. Following the transplant relationships with their loved ones took on a greater significance. Some participants described a strengthening of their intimate relationships. Rachael struggled with some aspects of her relationship with her partner, but overall she perceived they were much closer as a result of the transplant experience, evident in the following:

> When I think through the whole experience we are a lot closer, and I know that I certainly get what I want a lot easier. Like we all have wish-lists and the items on my wish list seem to appear a lot more these days; and we go out a lot more, and go to pictures and shows.

Miles spoke of the support and love he received from his parents and partner, and how his relationship with his father had changed. He explained:

> Everything change[d]. [My] whole life change[d]. My Dad never spoke to me very much [before the transplant]. His parents never showed him love so why should he show his kids love. I wasn't brought up showing love, but I like showing love now, and I like helping people. I had nothing growing up, and then this happened and everything is different. Dad speaks to me now and asks me how things are going.

The transplant experience had made Miles more sensitive to other people's needs, enabling him to become a more understanding individual. As a consequence, he found renewed respect and love for his partner. As he explained:

> [In the beginning] I took [my girlfriend] for granted because I was upset and grumpy. She stuck by me through all of this, and it takes a strong person to do that ... I used to look forward to her coming in and I did not with my parents. It was good to see my parents, but I looked forward to [my girlfriend] coming in. She was the most important thing.

Family relationships were also strengthened as a result of the experience. The illness increased the participant's awareness of other people's needs. As Marsella commented:

> I have become a lot closer [to my husband] and it has made me a lot more considerate of him. Because I have been sick, I am more aware of how other people are feeling.

The transplant forced the participants to realise what a significant role their partners and family played in their lives. The transplant was not only demanding on the participants, but also on their loved ones, and the participants understood this. Hence, there was immense respect for the love and support they received, which assisted the participants during the difficult times.

4.4.2 Strained Relationships

However, not all of the participants experienced improved personal and family relationships following the transplant. For some the transplant experience had exacerbated pre-existing tensions. Gaye's relationship with her partner suffered under the strain of the illness. Her immediate family lived overseas, and without personal and family support, the period following the transplant was a very difficult and lonely one. Support for Gaye represented recognition and understanding of what she had being through, but also of her need to be loved and accepted, despite the physical changes which had taken place in her body. As she related:

> My relationship with [my husband] is very changed. He sort of pushes me away … I think it is his way of coping … It is sort of like living separately, but in the same house.

Gaye no longer had an intimate relationship with her husband. She acknowledged in her interview that there were problems with their marriage prior to the transplant, but following the treatment these issues intensified. She received no words of encouragement or understanding from her husband, and the quality of her life suffered as a consequence. She attempted to seek out help by attending support groups. She needed to find empathy and understanding from people who were going through similar experiences. The support groups she attended mostly consisted of people who had been in remission for many years and their lives were back to normal. But Gaye needed more than this, and struggled to find a support group that could fulfill her specific needs.

Joan’s partner was extremely supportive and understanding of her needs. Despite this, a lot of stress was placed on their relationship following the transplant. The tension in their relationship was fuelled by Joan's feelings of inadequacy. With the fatigue she experienced following the transplant, she felt she could not be a part of his active lifestyle. Furthermore, not being able to have children, as well as feeling physically unattractive, heightened her perception of being an inadequate spouse in her partner's eyes. The following exemplar presents Joan’s concerns and how these impact on her everyday life.

> I felt really ugly when I was having the transplant, because of my hair not been there and the smell. Also, I was immobile and Martin was such an active person. He likes his skiing, or whatever, and there is no way I could have done that. So I felt really inadequate in that sense. I felt like I had no procreative abilities, and I did not feel I could fulfill the need as a spouse. Sexually, there was no way I could have sex, I just did not feel like it. And so there was nothing I could give. I actually pushed him away and I rang his Mum up and said we were splitting up.

Nonetheless, she struggled with these issues, despite having a very supportive partner. The illness disrupted the quality of her life, and as Joan stated; "it broke my spirit, I wasn't me anymore".

Some participants believed surviving cancer was a unique experience, which only those who had lived through it could truly understand. Most participants experienced a lack of support and understanding from their friends. In fact, the majority of the participants felt estranged or alienated, as friends found it difficult to "confront the cancer thing". Furthermore, many participants felt that the experience had changed them. They were now confronted with new challenges and had different priorities. Others believed they could no longer compete within their social group and, as a result, began to withdraw from society. The following account is taken from Linda’s interview describing the isolation she experienced.

> It is like my friends don't know how to be with me anymore. They don't know how to relate to me and everything. It is really weird, because I thought they were close friends and they have gone the opposite way. That is what I find hard. I don't see them anymore. I have rung a few times and said come over but I haven't seen anybody. And when I do meet them, and they say how are you. And I will say fine. I really do want to talk, but I can see that they really don't want to talk. It is horrible.

Miles, too, was disappointed over the lack of support he received from his close friends. He commented:

> But some of my friends don't even call any more. I had a few friends out there who never contacted me at all through all of this, and they were good friends. One of my closest friends never came. I have known him for about ten years. We are like a couple of shot guns together. I can't comprehend that. Everyone is different. I am here. I am sick. I would be there for them. But not everyone can do that.

The transplant experience placed stress on the participants' relationships and resulted in diminished support, which contributed to the participants' feelings of estrangement from their peer groups. Many felt estranged and alienated from their friends. Some found this confusing and believed that their friends found it difficult to confront the cancer. Furthermore, the participants blamed themselves for this situation. They longed to be accepted as they always had been, but also wanted their peers to recognise what they had been through. Yet some of their friends could not empathise with them. Understanding could only come from people who had gone through a similar experience.

Marsella spoke about the comfort and understanding she received from participating in a support group, and the importance of sharing her experience with other cancer survivors who understood. She explained:.

> I did not feel the need to talk about [my fears] at home because I had other

> people I could talk with, like the people I meditate with. They were wonderful. In the group so many of us had cancer or were being treated for cancer, so it was very supportive. There is such a fantastic atmosphere there. When I walk into the room, it is just so comforting. It has an aura, and for me that was very comfortable.

For some participants there was a stigma attached to being a cancer survivor. They felt that they were perceived as lesser people in the eyes of the community, which was humiliating for them. As a result the changes that the illness experience had wrought on the participants' family and peer relationships affected their perceptions of the qualities of their lives.

4.5 FEAR OF RELAPSE

Fear of relapse permeated through all of the participants' interviews. For some of them it dominated their lives, and each had to learn to live with this fear on their terms. Many participants believed their life span was reduced. Some were angry and resentful about this, while others focused on, and were thankful for, the opportunities that the transplant had provided them. Associated with the fear of relapse was the uncertainty about their futures, which impacted on their QOL. Everyday living had become more uncertain with the fear of relapse ever present. Linda, for example, tried to condense as much as possible into her family life to compensate for her presupposed shortened life. The following account is an exemplar of this.

> I live life each day, and I try and pack so much into each day. I know I am probably pushing [the children] too much, but I feel like I have got to teach them so much, so fast. I am probably not letting them do the things they want to do. I feel like I am trying to do things that should come later as we grow together. I feel like I am trying to do it all today, like there is no tomorrow. It is horrible.

The fear of the cancer's return totally consumed her life. Yamon too attempted to compensate for his assumed lost time. Unlike Linda, however, he adopted a philosophical attitude to quell his fear. The following exemplar presents Yamon's experience of this fear.

> Last year we went to Disneyland and we took our daughter. We have done things, which I wanted to do with her. I want to do as much as possible. I want to have some good memories. Because you never know what is going to happen tomorrow and that is it. For me it is never finished. It is always there, and I don't think it will ever go away. I used to be jealous of every old man I saw. They were bastards. So I don't think about it now. I would like to be there some day, but I accept it may not happen. I have the possibility of a shorter lifespan than I would have otherwise, but listen, you never know what may happen tomorrow. You can be in a plane and fall out of the sky, so there are no guarantees. There are no worries. I am here and happy; thank you very much. I don't think about the future. You learn that the future is very elastic. You plan one day at a time, short, short, short.

He initially felt angry and cheated on realizing that he might not reach old age. Over time, however, he learned to temper his anger and accommodate his fears, with the realisation that life holds neither guarantees nor certainties, and so structured his time accordingly. Joan adopted a similar approach, though she found an outlet for her fears in her music. As she explained:

> I can be really positive and say you know it is not going to come back, one hundred percent it is not going to come back. But again, because I am human being, and I don't know what the future holds. I have fears. But I just dismiss them, and I guess I do live on a more day-to-day basis. I work towards my music. What I want to give back to the world are my fears and concerns.

Dealing with the fear of relapse is a legacy of her transplant experience. Like Yamon, she knows her future is uncertain and lives "day-to-day."

While fear of relapse was very evident in all of the interviews, underpinning this fear was the belief that nothing could be done if the cancer came back following the transplant, and so relapse represented death. The possibility of death lurked in all their sub-consciousness. Ron spoke openly about this fear:

> I keep on thinking if I have to die, I would like to be able to go to sleep one night and never get up.

Marsella too had become aware of her mortality since her transplant. She feared not death itself, but the nature of it. As she remarked:

> Before, I did not think about death very much. Now, I am more conscious of it. I am accepting of it. It does not frighten me. I have no fear of dying, but I have a fear of how I will die. I would not like to die in agony.

4.6 LIFE IS PRECIOUS

While the fear of recurrence was present in all the participants' interviews, most of them inverted that fear and used it to help in their quest for spiritual wellbeing. They seized each day and concentrated on the things that mattered in their lives. Life was precious. Some participants had a new respect for their bodies. They were mindful not to put their bodies under undue stress and were more conscious of eating well, and getting enough rest and exercise. The experience forced them to prioritise the things they valued most in their lives. Some participants spoke of how "lucky" they felt to be alive, and felt that the transplant had given them a "second chance". As Yamon commented:

> My QOL for me is to take everyday as it comes. I wake up in the morning and I happy that I am [alive]. Previously that was not the case. Everyday I say thank you very much for giving me a second chance.

Similarly, Rachael recounted how the transplant experience changed her outlook on life.

As she stated:

> What do I value more now compared to what I valued back then? [Before] the transplant I valued my career and career options, and material things. Whereas now I sit back and reflect, and think they are not important ... I appreciate the fact that everybody is here, so I want to spend more time with them ... We do a lot more fun things, and we have holidays a lot more frequently, because you just don't know what is around the corner ... After all, life is all about enjoying it and making the most of it.

Though Marsella made "plans”, she did not look “too far into the future." Every day was important to her, and "not to be wasted." Rachael took more time to "catch-up with old friends and [do] more fun things”, because she knew her time could be shortened. Many other participants also spoke of having a greater appreciation for life since the transplant and wanted to seize each moment. This is evident in Rick’s interview as he explained:

> My friends and wife have been at me for years to slow down and give up work, so I decided [after the transplant] would be a good time to do it. [The transplant] persuaded me to do things I wanted to do rather than put them off, for example leaving work and going travelling.

They sought out loved ones who they had often taken for granted prior to their transplants. For others the transplant experience gave them a *raison d'etre*. As Ron stated:

> It makes me realise we are here for some reason, and maybe I was not putting that reason up as high as I should have before ... And I think now it has brought me to my senses, and I do appreciate what this has done for me.

There was an awakening of other dimensions to their characters. Some of the participants described themselves as 'stronger' people, more aware and knowing of life's realities. Marsella spoke of how the transplant experience had enhanced her own personal growth. She believes she now is a more sensitive and considerate person. She understands what it is like to be fighting for one's life, and this has allowed her to empathise with people who are dealing with similar or related problems. She explained:

> [The cancer experience] made me a stronger person. I think it has made me much more considerate of ill people, and it has made me aware that so many people are sick. You just don't think about things like that unless you have being ill yourself.

Many of the participants had a new respect for their bodies. Being healthy was a fundamental priority in life, and going through the transplant forced them to realise how much they had taken their health for granted. As Kevin explained:

> The main thing for me today is to be healthy, and to be with my wife and to enjoy life ... Sometimes we don't listen to our bodies, and I have learned through this experience that I have gone through to listen to my body ... I am not scared of the disease coming back, but there is always that chance [that it might]. But if I take care of my body well enough, and if I eat good food and don't smoke or drink, or over indulge, the chances are [small].

Similarly, Miles was more aware of his physical limitations. As he explained:

> If I feel like I am pushing too much I will stop. You learn so much about your body and how far you can push yourself.

The experience of the transplant made the participants realise their health was precious, but it also provided them with a greater understanding of their physical well being.

4.7 CONCLUSION

This chapter presented the findings through the identification of major and sub-themes which emerged from the text. Exemplars were presented to demonstrate how the participants responded to the changes in their everyday lives. The themes presented describe a journey of recovery, engulfed in irrevocable change and immense loss. However, despite all of this, most of the participants reclaimed some quality back into their lives. While the transplant cured their cancers, it was also associated with significant toxicities which disrupted the quality of their lives. Conversely, the transplant experience also offered the opportunity to redefine who they were and find purpose in their changed lives. In Chapter Five the findings will conclude through the presentation of paradigm cases.

CHAPTER FIVE

FINDINGS: PARADIGM CASES

This chapter will capture the participants' descriptions of their QOL as they journeyed from their pre-transplant or old worlds where all was known and certain, onto new and uncertain frontiers in their post-transplant worlds. From the main themes identified and discussed in the previous Chapter, the participants' perspectives of QOL could be interpreted as quality of being and described through the dimensions of embodiment, being in society, being in time and re-appraisal of life. The interpretations of the participants' QOL will be presented under these headings, and paradigm cases will be utilised to demonstrate the participants' actions and understanding which emerged from their every day lives.

5.1 EMBODIMENT

As discussed in Chapter Three, individuals do not possess a body, but are embodied. Through their bodies the participants experienced their worlds. Their bodies were the anchors, which situated them within their worlds. Even though many of the participants had treatments before their transplants, including surgery and chemotherapy, they did not experience the complete breakdown of their physical selves in the same way as they did following the transplant. Thus, complete breakdown was experienced not at the point of diagnosis but following their transplants.

Prior to their transplants, the participants had taken their bodies for granted. Thus, the role their bodies played within their worlds had passed unassumed and unnoticed. In their old worlds each participant had experienced their bodies as ready-to-hand; in other words, they were not cognisant of their bodies' functions or actions.

However, during and following their transplants this changed. As the participants traversed their respective physical frontiers from their old worlds, each experienced their bodies in a state of breakdown, without the reassurance of its former familiarity. They had become disembodied, and more aware of their problematic bodies. The fatigue, pain and discomforts which lingered after their treatments prevented some participants from resuming their normal everyday lives. Their bodies had turned rebellious and unreliable. The confident manner in which they had expressed who they were was lost. Each participant related the frustration and devastation accompanying these changes which, they perceived, had negatively affected the qualities of their lives. Only when their bodies had ineptly refused to respond in their usual ways, did the participants realise the significant role physical well-being played in how they now interpreted their QOL.

Indeed, for many, returning to full health and feeling comfortable with their bodies became the most important aspect of their QOL. Encouraged by their cancers being in remission, many participants modified their lifestyles and began to reinterpret the transplant as a positive experience which had enhanced their QOL. They set about regaining their physical fitness and wellbeing, in the belief that if they cared for their bodies and closely monitored their health, recurrences of their cancers might be prevented.

Maurice was particularly challenged by the loss of embodiment he experienced. He was 58 years old at the time of his transplant and a retired military intelligence officer. He was married and had two grown up children. Even though he had retired, he continued to keep in touch with his working colleagues and attended frequent work related social events. As he poignantly remarked: "my QOL seems only to be affected when I look in a mirror". He had lost so much weight that he barely recognised himself, and was shocked that his self-concept could play such a role in determining his QOL. In order to survive in his altered world, he attempted to develop coping strategies and new ways of being. The strategies he developed empowered him to re-situate his life according to his altered circumstances.

In the following paradigm case, Maurice described how his QOL had changed, directly relating this to his altered self-concept. Challenged by this alteration, he was trying to accommodate this change into his life. As he recounted:

> My QOL has changed. I only admit that to myself because of my looks; both my face and body, and probably my hair. And that probably is the major challenge which I have to face ... My QOL only seems to be effected when I look in the mirror with my glasses on, and I don't recognise who is there. And there may be a certain lack of confidence that goes with that. I try and compensate for what I look like now compared to what I looked like before [the transplant] ... I don't have an appetite. I find if I am side-tracked I will just [forget to eat]. I have a very dry mouth. Food doesn't taste the same as it once did, and worse still, beer doesn't taste the same. However, I persevere and I try ... The satisfaction or enjoyment isn't there. [Eating] was a big problem in the early stages, when all I could get down was soup and scrambled eggs, but [now] my appetite is gradually improving.
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> I will eventually go back [to work]. It is just a matter of getting my energy back. I find I get really fatigued and tired. Every day I walk the dog and rake up the leaves, but I find I really need to sit down and rest afterwards. I had a blood transfusion about 3 months after my transplant, and that was one of the few times I felt back to my old self.

> I am coming to terms with what I look like now, and I think it is only a matter of time. I get a jolt when I pass a mirror and I see my reflection, because it is not how I think of myself. I think of myself as how I was before. I have asked myself once or twice, did I do the right thing having the [transplant] because of this? But this is a purely personal and private thing. I don't know if others have perceived me the same way, but it is something which I have noticed about myself ... There maybe something lurking in the subconsciousness that says, I was in pretty good shape when I came into hospital and now look at me. That is something I just think about when I am lying in bed, or something like that, just thinking about the meaning of life and things like that.
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> Body image affects everybody differently but I will tend to compensate for it in certain ways. I have to be more outgoing in my personality than I was before. It is kind of hard to define. I used to be able to go to a party for instance, and I knew that other people knew that I arrived, be it by my appearance or confidence, or something else … Of the parties that I have been to [since the transplant], I find that I actually do preparation, so I [would] remember who would be there and what their interests are, and had thought about the sort of things that I could talk to them [about], even before I got there. And I think that is compensating for appearance. I think it is. So you could see, there is a perceived lack of confidence, or maybe it is my own perceived lack of impact that I then have to find another way to get that across. Now, I hope that does not come across as being too vain. I would not have believed if you asked me before I had it [the transplant] whether it would affect me, I would have said no. I am passed the stage when I need to impress people. It would have been different if I was on television or something like that. And yet I have found when I pass a mirror I think, what I have done; what has happened to me.

Maurice has described how he has become disembodied since the transplant, and how this has changed his perceptions of his QOL. He was not aware of an embodied sense of himself prior to the treatment, only in his body’s state of breakdown has he arrived at this understanding. The confident and familiar way he once negotiated his world has vanished. However, he is developing new ways to help him adjust to his altered sense of self.

Other participants were not so successful at challenging the loss of embodiment they experienced. They battled the changes, feeling disengaged from their bodies. Their physical appearances had altered, and consequently this affected how they expressed themselves and ultimately the quality of their lives. Thus, they lost confidence and self-esteem, and struggled with their personal identities. Confidence in, and contentment with, their self-concepts had been an important determinant of their QOL in their pre-transplant worlds. After all, their self-concepts played a fundamental role in how the participants related to others, and how they negotiated their worlds.

Linda struggled with the fracture between self and body. Feeling comfortable and confident with her self-image was an important determinant in defining her pre-transplant QOL. Linda was 42 years old and a widow. She had two young children and just started in a new relationship prior to her transplant. She worked full-time in the local bowling club. She was always full of energy, and juggled the demands of motherhood and full-time work successfully. However, following her transplant, Linda struggled with the personal changes she had undergone, and felt that she no longer belonged in her world. She battled with "loneliness", and felt that her friends no longer recognised her as Linda. How she once expressed herself was no longer possible and, as a result, she felt alienated in her world. This alienation starkly contrasted to the certainties and transparent nature of her pre-transplant world. Like the other participants, she was grateful to be alive and in remission. But she had not been prepared for the physical and psychological disruptions of the transplant experience, and so felt like she had lost her old self. For Linda, her re-appraisal of her QOL following the transplant was defined by her experience of loss of embodiment. As she explained in the following paradigm case:

> It is like [I] don't know [myself]. I really don't like looking in the mirror, and I know that sounds vain, but the [change] is so dramatic. Well, I was a lot thinner [before the transplant]. I was a size 10. I had a lot of energy, and that is why we could not believe I was sick, because I did not lose that energy. After they removed my breast I still had a lot of energy. But now I have curly hair instead of straight, and I know that does not mean much, but I look so different. People don't recognise me when they walk past me. I don't know, I really don't know. It is like a loneliness. I feel really lonely ... It is like I am not me. Even though I try and go back to the bowling club where I worked to see people, they just don't recognise me. But I just don't feel comfortable any more with all the old people I used to know, so I don't go. I am in the house most of the time. I only go out if I have to ... I know it sounds funny, but I feel like I have lost my self-confidence. And I really had a lot of it before [the transplant] and I liked the way I was. I really liked myself before, but now as I say, I look at myself and I just don't feel like me.
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> I want to do things with the [children], but a lot of the things I used to do with them I cannot do any more. Charles will say let's do them, and I will try and go for a bike ride or play basketball. But I can't move around the way I once did. I get very insecure, and I think people are looking at me, and I feel funny ... Before [the transplant], when I was working, I would have all the housework done before I would take the children to school. Everything was done. I was just like that. But now when I have to put things off and I think I cannot really do that, it really frustrates me. And I think there is a lot of anger in that, because I cannot do the things I want to do. I know they are not important, but they are important to me, to feel as though I am still here doing something.
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> My fingers are really stiff, and I still get a few aches and pains in the morning when I get up. It is like I really have to get everything moving, my ankles and everything. I really have to shuffle around, but once I get going I am alright. Running is very laboured. I was pretty active before. I never stopped. And I still try and do that, and I get angry because I can't keep up the pace, and I get really tired and I have to stop ... I want to do things.
>
> It is like I am looking for recognition. I want to be recognised before it is too late again. I can't explain it. I feel like I want to go back and do everything and make my mark. I don't know if you understand me. It is like Linda is gone. This is another person.

Similarly Gaye had great difficulty dealing with the perceived changes in her self-concept. She felt like a "freak". The transplant experience continued to haunt her.

She too was reminded of it every day when she looked in the mirror. Her weight had increased, and she had been left with scars and a reconstructed breast without sensation. Like Linda, her body felt unfamiliar, uncomfortable and clumsy. Prior to the transplant she was accustomed to, and contented with, the mundaneness of her everyday world. Following the transplant, she no longer felt at one with her body or had a sense of belonging to her world. Her life had moved onto a new unknown frontier, but she was not prepared to adapt to its new set of circumstances or develop new ways of being.

Joan also experienced a similar sense of disembodiment. She was 38 years old at the time of her transplant. Joan was not married, and had no children, but had a very supportive boyfriend. She was a professional singer, and performed at live venues frequently. For Joan, having a positive self-concept was not only important in her personal life, but also in her professional life. The following paradigm case captured Joan's account of being at one with her body, and how this was significant in defining her QOL. However, as she recounted, the transplant had changed her body and, consequently, her sense of self:

> My body has changed and I have changed. Acceptance of being a different person is a big thing ... I have got white hairs now and I did not have these before the transplant. If I do not moisturise my skin it gets very dry. I have not got my period, and I am taking hormonal replacement therapy (HRT). I feel like I am aging really rapidly, and I think what is [happening]. So I am a different person in every way, and I think it is really hard coming from a young person's perspective to be suddenly aging like this. When I first started work, I was running late, and I was running to catch a tram. My ankles felt like they had bricks on them; huge irons on my legs. I was so unfit, I could not move and that really scared me. It was a horrible feeling. I felt really inadequate.
>
> [Before the transplant] I was doing what I wanted to do, and working towards the success of [my career] Following the transplant, I felt like

> I had fallen off a cliff, because I had to start all over again. The industry in which I work is very dependent on a person's appearance, and there is no way I could compete with that. It was really, really hard. I felt so inadequate. We went on a skiing holiday to New Zealand following the transplant, and that was really good - not that I was able to go skiing. I was the one who kept the fire warm. When we got back, I started part-time work in a bank. It was very difficult because my confidence was gone down the drain. And I always questioned my ability, [particularly] because my physical appearance had changed. I had put on a lot of weight and, of course, my hair was not the same.

Joan's way of being in her world had altered, her circumstances had changed, and so too had her QOL. She had to re-negotiate her world in an attempt to restore some quality into her life. None of the participants were prepared for the impact of disembodiment. How could they be when the nature of embodiment is such that it is so familiar and transparent that it goes unnoticed? It was the ordinary everyday experiences, which they had taken for granted in their pre-transplant worlds, that were most affected. In terms of moving on with, and regaining some quality into, their lives, it was the ways in which they re-negotiated their lives that ultimately determined if their QOL improved or deteriorated.

All of the participants experienced difficulties in resuming their pre-transplant roles which altered how they negotiated their changed worlds. Having a sense of embodiment was a significant determinant in how the participants interpreted the quality of their lives. Consequently, some were devastated by the experience of disembodiment, as it significantly interrupted their everyday lives. They yearned to have their 'old bodies' back, and to once again feel comfortable and be at one with their bodies.

5.2 BEING IN SOCIETY

Being in society refers to the different ways the participants related to their spouses, parents, family and friends following the transplant. For all of the participants, their personal relationships assumed a greater significance and value in their lives following their transplants, and this shaped their perceptions of their QOL. Their ways of being in their worlds had changed following their transplants. The experience of loss of embodiment invariably affected how they related to others. The transplant experience forced them to re-evaluate their lives and, as a result, they acquired new perspectives, which either solidified the support they received from family and friends or conversely drove a wedge between them. Being in society following the transplant meant going through a period of social adjustment, which was quite distressing for those participants who were not prepared for the unexpected reactions from their family and friends.

Support from the participants' respective partners and families played a positive role in their recoveries and QOL. In their old worlds this support had been taken for granted. The participants had undervalued the roles their partners and families had played in their lives prior to their transplants. Indeed, for many this prompted a strengthening of family relationships.

However, each participant sought understanding from family and friends for what they had gone through, and this created the potential for rifts to develop in established relationships, because family and friends no longer shared the same life experiences as the participants. As a consequence many participants experienced difficulties resuming their social relationships following their transplants. Yamon particularly struggled with this. He was 37 years old, and had recently immigrated to Australia from Israel. He was married and had one little daughter. He was a journalist and worked with a team of people on a radio show. The following paradigm case taken from Yamon's interview captured his experience of being in society following the transplant and how it affected his QOL. He explained:

> I don't know how you can prepare somebody for something like this [the transplant]. You cannot. People do not grasp it. You just look at people running around like nutcases. Just come and visit the hospital [where I had my transplant] and see what people are going through, and that will turn your head around about what is important in life.
>
> My main achievement is to have a family and fight very hard to keep that family ... Lisa did a good job. She was always there for me, and I appreciate that very much. I also had a friend who visited me every second day. He was a lawyer in the city and he would bring me in this and that. Every time I would wake up he was there. And you remember things like that.
>
> The friends I have are very close. As I said before, I am not as patient as I once was, and am not willing to put in as much of an effort. I used to have so many friends. [The transplant experience] has changed my attitude a great deal. I am not as patient as I used to be; not as nice as I used to be. I am seeing somebody, and I am going through a grieving process over the time that I have lost. And I am angry at the four years I have missed out in, and I want to catch up. I have lost quite a few friends because I am angry; I am just so angry. I am not as patient, I do not put up with a lot, and I am not as charming.
>
> I was a bit disappointed, but maybe people could not handle my illness. It takes time, and it takes time for me too to adapt and open up and allow them to come in if they want to. It takes along time to get back, I mean we talked about if it changed my life. Of course it changed my life. The family is still here, which is the most important thing, and little by little I will open up and let other people in. Because people don't understand it is a bit hard sometimes. I have alienate[d] some of the people I knew previously. For them nothing had happened. Life is going on and I am fine now. This is true, but I still have these war troubles. What do you call it when you still have to battle something?

Unlike their peers, the participants had undergone life threatening experiences which changed their perspectives on life. While their friends' worlds had remained unchanged, the participants’ worlds had irrevocably altered. The transplant experience consumed the participants' everyday lives, and their peers could not relate to this. The latter's lack of understanding and support disappointed the participants. In some instances a complete breakdown of friendships occurred. This alienation caused hurt and resentment to the participants, and forced some of them to seek support from people who had undergone similar experiences. Furthermore, at a crucial point in their lives, they had lost the well established supportive network of friends, who had once constituted their worlds.

Like Yamon, other participants saw themselves as not belonging to their peer groups. This was partly due to the ways they perceived they had changed, and partly because of the reaction of their peers following the transplant. Belonging to a peer group meant one had to behave in a particular way and share common developmental milestones. The younger participants particularly struggled from peer group pressure. Joan who was a 38-year-old-woman had to confront a mid-life crisis as a result of the transplant in a premature menopause. She felt the pressures to conform to peer group expectation, yet her biological body kept reminding her she was nearing mid-life. As well as the pressure to conform, there was the added drawback that Joan was not receiving any support or empathy from her peers. Understandably, this created enormous stress and confusion in her world and ultimately the quality of her life. The following paradigm case demonstrates how she interpreted this in her every day life.

> If I don't take my hormone replacement therapy, I get really agitated and reactive. Once, there was an issue at work where I responded so badly, my manager told me to have the rest of the afternoon off. And there was another time, where I had my make-up on, and I had sweated so much that my colleague looked at me and said you are melting. I thought, oh no, she noticed, and I had to go and touch up ...

> Psychologically, it is very depressing. I just feel like I am going around the bend.

As well as feeling alienated from their peer groups, some participants also perceived there was a stigma attached to being a cancer survivor. Not being able to fulfill the physical expectations of someone their age left them feeling inept and discounted by society. Some perceived themselves as abnormal and felt ashamed about the changes that had taken place in their bodies. They never had to deal with this prior to the transplant, and this had a negative impact on their QOL. Kevin, for example, rather than be seen in public in a debilitated state, chose to avoid people. The stigma of the experience invariably affected their QOL.

In the following paradigm case Linda explains how the estrangement from her family and friends influenced how she interpreted her QOL.

> The reunion was great; it was great to catch up with all the patients who I had met along the way. My friends don't know how to be with me anymore. They don't know how to relate to me. It is really weird because I thought they were close friends, but they have gone the opposite way. That is what I found hard. I thought they were my friends, but I don't see them anymore. I have rung them a few times and said come over, but I have not seen anyone. It is really weird. I do not know how to talk with people. When I do meet people, they say how are you, and I will say fine. I really want to talk with them, but I can see that they do not really want to talk. It is horrible. And all I wanted to say was I don't feel very well today, I feel lousy, but thanks for asking. So it is hard. It is like I am not me. Even though I try to go back to the bowling club where I worked to see people, they just do not know me. A lot of them just walk past me and then they might hear me talking and [come over]. But I just do not feel comfortable with all the old people I once knew. So I don't go out very much, I stay in the house most of the time.
>
> And my family - I really do not now what to do with them anymore. It is like I am pushing myself to get better to go and visit them to prove that I am alright. And I have stopped doing that. And I have stopped ringing because it was always me on the phone. Since [my family] found out I was in remission they thought, oh well that is good ... I basically did that chemotherapy by myself. I did not have anyone sitting with me. That was really hard watching everyone else, and

> really feeling sick and horrible and scared. And I did not have anyone with me. I really think everyone should have someone with them.
>
> I just started seeing my partner when I got sick. He just slipped into playing a father role to my children. And I am grateful for that, but we have no relationship. I don't know whether he keeps me at a distance, because I am sick or he still classes me as sick. It makes me feel like he does not want to come near me or touch me. One minute we were just seeing each other and the next minute he is there looking after my children. My life went on hold and I have not picked it back up again. There is no relationship to the extent that there should be.

For Linda and the other participants, they realised, following the transplant, how important it was to have a supportive family and they now considered this to be an important aspect in defining their QOL. Those participants who did not have the support and understanding of their families and friends perceived their QOL suffered as a consequence, as Linda emphasised above.

On the other hand, those participants who had supportive partners and families perceived it enriched their QOL, something they never would have realised prior to the transplant. Ron, for example, having undergone the transplant, realised the importance of his family's support and how much he had taken their love for granted. He now devotes more time to his family and is more considerate of their needs. He perceived that family love and support determined his QOL, and realised that the transplant had "brought him to [his] senses", and forced him to appreciate them. Other participants, the most notable of whom was Yamon, shared Ron's perspective. Yamon's wife and family meant everything to him, and having them by his side during the transplant gave him something to live for. Indeed, as Yamon suggested, "QOL is my family".

Those participants, whose relationships were strained prior to their transplants, also struggled following the transplant. Invariably, their relationships deteriorated, lurching from crisis to crisis. For some, the transplant forced them to confront unresolved issues. Tellingly, Gaye and Linda did not acknowledge their partners roles - if any - in defining their post-transplant QOL. Gaye's marriage had pre-existing problems, which were exacerbated by the transplant experience. She had no close family in Australia, and so felt lonely and isolated. Furthermore, her perceived changes to her body image caused her to feel like a "freak." Hence, her relationship with her husband had deteriorated, and she considered that they "live[d] separately but under the same roof". She was staying with him for the sake of their children. Linda's relationship had also suffered. She had commenced a new relationship prior to her transplant. When she underwent the transplant, her partner automatically assumed a father's role with her children. However, Linda felt that he neglected her welfare. They no longer shared an intimate relationship. She felt unloved and unsupported at a time in her life when she needed it most.

Being in society was an important aspect of the participants’ QOL. Prior to the transplant they had not fully realised the significance of this. Indeed it took the rupture of their worlds to highlight the importance of their families and friends in their everyday lives. The participants needed to feel loved and supported to assist them on their journey of recovery. The participants needed their families and friends to acknowledge and understand the anguish and suffering they had experienced, and indeed continued to experience, long after their transplants.

5.3 BEING IN TIME

While being in society shaped the participants' perceptions of the quality of their lives, so too did being in time. In the participants' post-transplant worlds, their senses of time had altered, which also shaped their interpretations of their QOL. Living with the constant fear of relapse forced all of the participants to reflect on their temporality. Temporality, as discussed in Chapter Three, is a phenomenological term which refers to the way a person exists in the present, and how this is dependent on that person's past experiences and their anticipation of the future.

A perceived foreshortening of their futures prompted the participants to reflect on their lives and their altered circumstances. For most of them, their ways of being in the present assumed immediacy. Many of the participants now placed greater importance in the here-and-now. For example, living for every moment gave Rachael's life a quality she did not have prior to the transplant experience. She was able to redefine her goals and purpose in life. Rachael perceived her life was embellished as a result of the illness experience. While she was happy to return to work, and did so with ease, she was also very mindful not to let her career become a dominant force in her life. Unsure of her future, she wanted to maximise the time she spent with her family and friends. While Rachael was very aware that the cancer could return without warning, she did not allow this fear to engulf her life. Instead, she countered the fear by interpreting the transplant experience as a positive influence in her QOL.

Likewise, other participants began to re-evaluate what mattered most in their lives. Aware that their time maybe limited, they were now more aware of the simple things life had to offer, and had a greater appreciation for life in general. Hence, they took time to ‘smell the roses’. Prior to the transplant, many of the participants were consumed in their respective careers and often too busy to spend time with their loved ones. But following the transplant, the participants developed a new self-understanding and awareness of time which prompted them to reinterpret their pasts in light of their illness experiences. For some participants, like Rachael, this was a positive experience. Rachael was 37 years old at the time of her transplant and worked as a part-time school teacher. She was married with two children. Her family life was happy and supportive with no personal or social issues to compound the impact of the transplant. In the following paradigm case Rachael’s interpretation of being in time and how it affected her QOL is presented.

> I think the cancer experience gave me the opportunity to sit back and reflect, and think what is important now, and what are the things that really matter. [Life] is more tenuous, more fragile. Perhaps I might not see my kids grow up. Perhaps I will not be around. I would like to be, but the reality is I might not be. Therefore, I value things more now. And probably the things I valued before were career and career-options, and material things, whereas now I sit back and think they are not important. It is the fundamental things in life which are important, like family and relationships and friends ... But now it is more important to catch up, and to make an effort to write letters and communicate with people, and spend more time with my parents. And the same with my children and husband. I appreciate the fact that everyone is there, so I tend to want to spend more time with them … I look at life as being more precious and nothing is guaranteed. But, on the other hand, nothing is guaranteed for anybody, and everybody should seize the day and live life to the fullest.
>
> If my lymphoma was to recur, I think I would fight it with the same gusto and the same positiveness as I have before. And I can only hope that it does not recur ... Naturally, the fear of relapse enters my mind. I mean obviously as soon as things appear like a cough I automatically think, oh no, and then it goes away in a few days. In any case, I do knock it out [of my mind] now, and I don't think about it as much ... I don't sort of dwell on it, but everyday when I get up and I leap out of bed, I think how lucky I am to be alive.

However, for other participants temporality was interpreted differently. The immediacy, which consumed their everyday lives created disruption and anxiety, and as a consequence, caused them to overcompensate for what they perceived to be their foreshortened futures. Time was perceived as 'the grim reaper', constantly lurking in the shadows, waiting for them. Linda and Gaye, in particular, struggled with the constant fear that their cancers would return; it was just a matter of time. Both had young children and lacked the social support which was afforded the other participants. The uncertainty created by the fear of relapse played havoc with their lives. Both lived their lives erratically, hurrying life along to compensate for the prospect of lost time.

Linda perceived that her QOL had diminished since the transplant, a perception shaped by her temporality. Her constant fear of relapse unsettled her relationship with her children. She attempted to pack as much as she could into each day, though without purpose or goals in her life. Fearful of her reduced time, she sought to hurry her children’s lives along, so she could celebrate their special events with them. Unlike some participants who seized each new day, Linda’s QOL was being destroyed by the prospect of living on borrowed time. Before the transplant her world had structure and routine. She worked full-time, as well as being a mother to her children, and in order to juggle her very busy lifestyle, she was extremely organised and in control. However, following the transplant, her ordered world was threatened. She hated the limitations placed on her life and the uncertainty which now dictated her life. Moreover, when she was first diagnosed her doctor told her she only had three to six months to live. She perceived that she had coped better then, "knowing that something might happen", rather than living with the uncertainty of not knowing.

Similarly, the way Gaye experienced her temporality shaped how she defined her QOL. Every aspect of her life was directly or indirectly determined by thoughts of her cancer's return, so she over compensated for the possibility of a shortened life. She too attempted to hurry life along, packing as much as possible into her children’s lives. But this was at great personal cost. QOL for Gaye was to maximise her children's happiness, because she strongly believed she would not see them grow into young adults. Though Gaye was undoubtedly sharing some wonderful moments with her children, she also allowed other aspects of her life - such as her marriage and self-esteem - to disintegrate. Broader societal pressures further exacerbated this fear. For both Gaye and Linda, Linda McCartney's death from breast cancer was a reminder of their vulnerability. They could never escape the fear of recurrence. The following paradigm case is Linda's account of what being in time signifies for her, and how it has affected her QOL.

> You know you dream of your children growing up and getting married, and I hope I am going to be there. But deep down I know I am not. I feel it. I don't know why. I just feel that I am not going to be there. It is like I am hurrying the children to grow up and I don't want that. It is like I am pushing them too much and I don't want that. I just want us to enjoy life, and we are not enjoying it. Each day is just a battlefield. All I want for them is to have quality time.
>
> I am living each day and I want to pack so much into each day. I try to get the kids to understand things. I know I am pushing them too much, but I feel like I have got to teach them so much, so fast. I am probably not letting them do the things they want to do. I feel like I am trying to do things that should come later on, as we grow together. I feel like I am trying to do it all today, like there is no tomorrow. It is horrible.
>
> When Linda McCartney died that really set me off. I think that was when I was at my worst. There was so much in the papers about her and her breast cancer. [In one article] it said if a woman has secondary cancer in her liver there is no hope. [That is what I had]. I think I have been worse since then. [I thought] how much time are we really talking about. It is not fair someone who is famous gets sick, and everyone wants to know about it, and what they can do for them. And

> then people like me; who is there for me? Who will help my children when I am not here? I am scared, because who is going to help my children.
>
> There is just so much uncertainty. I coped better before, when I knew something might happen straight away, and I felt I could cope better. Now I do not know what is important. I go around the house in circles. Is it important to do this with the house or that with the house? How far do I go with the kids? I just wander from room to room thinking, yes I should do that, and then I think, no that is not important. I just cannot make a decision.

All the participants defined their QOL through being-in-time. Their ways of being in the present were dependent on how they reinterpreted their past lives and anticipated their futures. QOL was quality of being, and this was shaped by their understanding of the tenuous nature of their lives following their transplants.

5.4 RE-APPRAISAL OF LIFE

The participants' QOL following their transplants was shaped by an acute awareness of their temporality. This was in part the impetus for participants to re-appraise their lives. For some, this coupled with the totality of the transplant experience prompted an extensive review of their lives. Their perspectives and priorities in life had now changed. For some participants, this awareness empowered them to seize each day and make the most of their every day lives. As Rachael stated:

> Well, the cancer experience brought a huge change. It was a huge impact. After I got the initial shock I evaluated [it]. I thought, well, so many other people have this disease also. I thought let’s deal with it and get the appropriate treatment, and then [afterwards] try and recapture what was normal ... I also [wanted] to learn from this, and take the opportunity to improve on life and the quality of life. Because now I know what it is like to be sick, and I know how precious things are which perhaps I took for granted before, when I was too busy working and thinking I was very important

QOL as defined by the participants meant having a purpose and direction in life. All struggled, in varying degrees, with the losses they had experienced and the limitations now placed on their lives. Confronted with life-changing and traumatic experiences, the participants began to reflect on, and reinterpret, the foundations of their worlds and what they valued as a quality in their lives. They developed new perspectives and priorities in life, which redefined who they were and how they negotiated their individualised worlds. While this review of their lives was driven by their senses of being in time, for some it was also the search to find meanings to their altered lives.

Many of the participants spoke of how their values in life had changed. They began to re-evaluate what "mattered' most in their lives. They were now more aware of the simple things life had to offer, and had a greater appreciation for life in general. Prior to the transplant many of the participants were wrapped up in their respective careers, often too busy to spend time with their loved ones. Now their priorities had changed. Many of the participants interpreted these changes as improving their QOL. As Kevin stated:

> I have to get on with my life I have so many things planned. I would like to go on an adventure. I like to get out with my friends and entertain my friends. I love to go to the movies. There is so much to do with my life, there is so much to see and some people say they are bored. How can they be bored. I can pick a thousand things just now. There is so much to be captivated by. There is a wealth of lovely things out there.

For some of the participants this greater appreciation of life was driven by the realisation of the tenuous nature of their existences. While the latter caused huge anxieties and disruption in some of the participants' lives, others were able to recast this fear, and allowed it to contribute in a positive way to their QOL. For some participants the transplant experience forced them to reflect on their lives, and to prioritise on what mattered most to them. Their values in life had changed with the realisation of how tenuous life could be. Living for every moment gave some of the participants a quality they did not have prior to the transplant experience. They were able to redefine their goals and purpose in life, and perceived their lives were embellished as a result of the transplant experience.

Yamon spent prolonged periods reflecting on his illness experience and its impact on his everyday life. In many ways, he perceived the search for meaning had improved his QOL. He looked for reasons for his illness in order to regain some control over his life. The loss of control he experienced during his transplant still haunted him. As a consequence, he attempted to assert control over his life in the months following the transplant by redefining his life. Thus, he reshaped his world and was reborn as a cancer survivor. Having become defiant and independently minded, he now works for himself and is proud that he "does not have to answer to anyone". He is more willing to take risks with his life, and believes anything is possible. This re-appraisal of his life not only restored certainty to his life, but also embellished the quality of his life by broadening his horizons.

Other participants also searched for meanings and sought to positively re-appraise their lives. Miles, having survived the transplant experience, reinvented himself as a survivor. The experience forced him to alter his perspectives and values in life. As a result he believed the transplant had come to "change" him. Thus, he redefined his life, interpreting the transplant experience as a positive influence on his world and his QOL. The experience had given him a purpose in life and enabled him to recreate himself as a cancer survivor. Though the transparent nature of his old world, with its underlying certainties, had been shattered, he had learned from the experience that nothing was guaranteed and not to take his life for granted. In having survived the transplant, Miles considered himself as a member of an elect group of survivors. As with Yamon, he identified himself as a cancer survivor, and though he did not overtly seek acknowledgment from others for what he had been through, he wanted some form of recognition that he had survived. This recognition enabled him and some participants to redefine themselves, empower their worlds and bring quality back into their lives.

For some participants, a re-appraisal of their lives led them down spiritual pathways. Joan believed a higher being was orchestrating her life, which helped her cope with the losses and trauma she experienced following the transplant, by providing her with comfort and solace during difficult times. The transplant experience reawakened her spirituality and this contributed in a positive way to her QOL. Others also experienced spiritual awakenings, which bolstered their resilience and the belief that they could conquer any obstacle. This added a dimension to their lives which supported them through their darker moments. They believed they were stronger people for the experience they had undergone. They had conquered the transplant, so now they believed they could conquer anything. Their bodies had been through so much pain, nothing could be worse, not even death itself.

Many of them told of how they would be privileged to share their experiences with other people who were considering undergoing an ABCT. QOL meant having a greater understanding of their spiritual wellbeing, and the comfort and solace that they could draw from this.

There was also a greater respect for their bodies. While the participants were devastated by the feelings of disembodiment they experienced following their transplants, there was also a revelationary moment, when they understood how vulnerable their bodies were, and how important it was to care for them. In re-appraising their lives they pledged to pay better attention to their health.

The following paradigm case is taken from Yamon's account of his re-appraisal of life, and how this allowed him to reinvent himself, re-establish certainty in his life and enhance his QOL.

> I am trying to change in many ways the way I was living before. There is no answer why this happened. So I am trying to change in many ways the ways I was living before. What did I do wrong that caused this to happen? Maybe I let people use me; maybe I was angry so I tried to change my point of view to prevent it from happening again. Because there is no straight answer. Nobody can tell me this is wrong. There is no guarantee, nobody can tell me why it happened. So I looked at [my] overall life, and I will try and change as much as possible to prevent a recurrence.
>
> I work for myself now. I started going back to work and I [found] I could not work with other people any more. I could not work with bosses because [the cancer] actually forced me to take control of my life, and I had never done that before. I am going to win this, and I am going to give what it takes to win this. I took [the cancer] on as a business. This is it. So I had to take control of my life. I had to. I just couldn't be bothered any more with bosses and their politics. I am going out and doing my own thing.
>
> With the whole cancer diagnosis, and the transplant and everything, I asked myself, why do I need this? [As a result] I have become more philosophical and a bit more religious, because I needed something to hang onto. So I feel like I have a role to play, and I was given this role and the only reason I am alive right now is because I did the job right. I feel I was given a job, a task, this is your mission should you wish to accept it, and I did not have a choice. I had to accept it, and I was given a reprieve. You have to look for reason, and sometimes you look for the silliest reasons, but any reason that gives you peace of

> mind is a good one, especially if no one else is willing to give you answers, or not able to give you answers.

Like Yamon, many other participants believed the transplant experience was the catalyst which forced them to look for meaning in their altered worlds. For some participants, this forced a re-appraisal of their lives, while for others it simply provided some answers, and allowed them to cope with the changes that had happened in their individualised worlds. The search for meaning was interpreted by the participants as having a positive influence on the quality of their lives. It provided them with a *raison d'etre.*

5.5 CONCLUSION

This chapter has presented the unique and personal meanings of what QOL means to the participants following an ABCT. It illustrated how each participant interpreted QOL as a lived experience. It also illustrated the subjective nature of QOL and how the participants' meaning of the concept was dependent on their unique set of circumstances. QOL from the perspectives of the participants following an ABCT was described in terms of embodiment, being in society, being in time and a re-appraisal of life. The transplant experience was a life-changing event, which marked a departure from their old worlds, and their old ways of being in those worlds. QOL to each participant was about the experience of this journey. The following chapter will provide discussion on the findings of this study in relation to the wider body of literature.

CHAPTER SIX

DISCUSSION

This chapter will present discussion of the findings in relation to the current literature. Furthermore, it will present significant aspects of the findings which broaden the current knowledge on QOL following an ABCT. As presented in the previous chapter QOL is not a linear progression from treatment to recovery, but an ongoing and dynamic everyday lived experience. QOL for the participants in this study was about their quality of being. 'Being' was described by the participants in existential terms and this influenced how they interpreted their QOL following their transplants.

6.1 QOL – QUALITY OF BEING

The findings of this study illuminate the everyday lived experiences of the participants, and so facilitates an understanding of the quality of their lives following an ABCT. Similarly, in other interpretive phenomenological studies which explore QOL issues in this patient group, a very deep understanding of what the concept QOL means to BMT recipients is also provided (Cohen & Ley, 2000; Shuster, Steeves, Onega & Richardson, 1996; Steeves, 1992). As the participants' experiences in this study showed, QOL is not solely about quantifying the changes - for better or worse – they experienced in their lives, but about the ways in which they interpreted these changes in their everyday worlds. The findings of this study will enable healthcare researchers and practitioners, to better understand that QOL following an ABCT is not simply a matter of documenting the physical and psychosocial sequelae of this treatment. As the perspectives of the participants presented in this study indicate, QOL is more than just a measurement of physical and psychosocial wellbeing, but also encompasses how they interpret the impact of the transplant into their everyday lives.

QOL for the participants meant quality of being. Their quality of being was reflected in how they interpreted the changes they experienced as a result of the transplant. This contention is supported by Benner (1985) who argued that QOL, in encompassing the quality of being, must include an exploration of the person’s understanding of his/her body and lived experience. Benner argued that the mind-body split of the medical world ignores this experiential conceptualisation of QOL. The Heideggerian approach employed in this study further promotes Benner’s position. The study’s findings indicate that QOL cannot be separated or isolated into physical and psychosocial events, which arise in a predictable fashion following an ABCT. Moreover, QOL cannot be fragmented into various life domains, but must be experienced as a whole. For the participants in this study, QOL manifested in changes to their everyday ways of being. Their perspectives show how their QOL had changed, and that these changes rendered the experience a dynamic one. The participants described their QOL in terms of embodiment, being in society and being in time. Because the participants' worlds had changed, they had to reinterpret their lives in the context of their altered circumstances. This enabled some participants to find comfort, and restore wellbeing and quality into their altered lives, while others struggled to adjust to their post-transplant worlds. The diverse nature of the participants’ experiences offer nurses and physicians a better insight into QOL, which will inform their approaches in caring for patients who have undergone an ABCT.

6.2 EMBODIMENT

Central to the participants' interpretations of their QOL was the concept of being at one with their bodies. The ways in which the participants experienced their worlds was through their bodies; in other words, they were embodied (Benner & Wrubel, 1989). Following the transplant the participants experienced their bodies in a state of breakdown, which ruptured the mundane nature and familiarity of their everyday lives. Life following their transplant meant dealing with symptoms such as fatigue, changes in taste, and ongoing aches and pains. In addition, they had to contend with altered self-concepts, which had even more devastating consequences. They lost their self-esteem and self-confidence, and some barely recognised themselves as the person they were before the transplant. Their bodies felt clumsy and unfamiliar, and the ways in which they once constituted their individual worlds was no longer possible. Following the transplant, they experienced a loss of embodiment; in other words, the ways in which they once negotiated their worlds were lost. It was the everyday experience of living with their bodies in a state of breakdown and change that now determined their QOL. Few studies, apart from Cohen and Ley (2000), Gaskill, Henderson and Fraser (1997), Shuster et al. (1996) and Steeves (1992), have acknowledged the existential meaning of QOL following an ABCT. In so doing, this study supports the findings of Halldórsdóttir and Hamrin (1996) in suggesting that the subjective experience of living with a chronic disease such as cancer is far more complex than simply feeling unwell.

6.3 BEING IN SOCIETY

Being in society referred to the different ways in which the participants related to their family and friends following the transplant. Support from partners, and family and friends, was identified as having both positive and negative impacts on the participants' QOL. Undergoing the transplant was both a physically and emotionally transformative experience that invariably affected the participants' families and social circles.

Much has been written about the importance of social support in contributing to a quicker recovery and a better QOL following a BMT/BCT. As the findings of this study indicate, relationships within the family network were mostly strengthened and the participants who had a loving and supportive partner appeared to have a better QOL than those who did not. It has been well documented that support from family plays a key role in BMT recipients' survival trajectory (Molassiotis, 1997; Syrjala, Chapko, Vitaliana, Cummings & Sullivan,1993; Thain & Gibbon, 1996). Indeed, the absence of a supportive and loving partner was evident in Gaye's and Linda's interviews and this adversely affected the quality of their lives. The researcher suggests that their altered self-concepts contributed to this. Shuster et al. (1996) found that physical appearance was altered for BMT recipients, which proved more of a social problem than a physical problem. The findings of this study concur with Shuster et al. (1996) as many of the participants in this study experienced a degree of insecurity in their intimate relationships as well as in their peer groups. This insecurity was a reflection on how much they perceived they had changed since their transplants.

The findings of this study concur with other studies, which identified social isolation and rejection and a lack of understanding from the participant’s families and friends as having a negative affect on their QOL (Haberman, Bush, Young & Sullivan, 1993; Baker et al. 1994; Baker, Zabora, Pollard & Wingard, 1999). The participants in this study were both shocked and disappointed at the reaction from their friends, which for many led to feelings of isolation and stigmatisation.

Some participants interpreted the lack of understanding as a coping strategy and wanted nothing more to do with their friends. Thus, old relationships faltered, though new relationships were formed. Many studies discuss the impact of BMT on relationships but few have described the reaction of many of the participants’ friends presented in this study. Colyer (1996) is one of the few who in describing a “stigma reaction” (p.499) further suggested that the reason so many cancer survivors gain comfort from sharing their experiences in support groups reinforces this explanation. Ferrell and Dow (1996) in their study exploring QOL in cancer survivorship presented a powerful portrait to illustrate the difficulties cancer survivors experience as they live their lives following their illnesses. One of the study’s respondents was a Vietnam survivor who submitted a photograph taken in the last days of the Vietnam War. The picture was of an inscription written on a sidewalk, it read: “Those who were not here will never know what it was to have survived” (1996, p.77). This was interpreted by the authors as an analogy for this respondent’s own fight against cancer. Understanding could only be sought from those who have undergone a similar experience. The findings of this study concur with Ferrell and Dow (1996). Many of the participants in this study grappled with the desire to be understood. However, they found that many of their friends were unable to understand what they had been through.

6.4 BEING IN TIME

Being in time represented the participants' experience of living in the present which was shaped by their past experiences, and how they anticipated their futures. Included in this finding were the themes of uncertainty, loss of control, fear of relapse and the preciousness of life. For the majority of the participants in this study life following their transplants meant living with uncertainty. Suddenly they were more aware of their mortalities and the finite nature of their existences. Though the fear of recurrence was ever present, the experience of living with the uncertainty engendered by it was different for each participant. While other participants allowed the fear of recurrence, and the uncertainty of their futures to dominate their every day living some chose to focus on the moment and enjoy each new day, thereby enriching the quality of their lives.

Living with uncertainty and the fear of recurrence has been well recognised as a QOL determinant in the BMT survival trajectory. Whedon, Stearns and Mills (1995) and Saleh and Brockopp (2001) documented that both constituted a negative determinant in the QOL of BMT survivors.

Interwoven in the participants' experience of being in time was the theme of loss of control. The participants in this study experienced loss of control at various stages throughout the transplant trajectory. For some, it occurred during their treatments, while for others it happened long after their treatment was completed, as they were contemplating their futures and a return to the work force. Cohen and Ley (2000) also identified loss of control as one of the many negative experiences following an ABCT. They discussed it in terms of physical changes, such as loss of control over bodily functions, and the dramatic physical changes in their bodies. Dow, Ferrell, Haberman and Eaton (1999, p.525) found that "QOL in cancer survivorship mean[t] regaining a sense of control in life rather than being controlled by the cancer". Echoing Dow's (1999) findings, some of the participants in this study were driven by the need to regain some control in their lives, which had a positive impact on their QOL. This finding was also supported in Hallórsdóttir and Hamrin's study (1996).

6.5 RE-APPRAISAL OF LIFE

The participants in this study sought to find meaning in the transplant experience, which provided them with a purpose in life and a renewed sense of being, and hence an enhanced quality of life. Following their transplants they began to reflect on the experience, and from this they developed new perspectives and priorities. Their individual searches for meaning allowed them to move on with their lives and begin the healing process. This re-appraisal of life and quest for meaning has been recognised in other studies (Berterö & Ek, 1993; Utley, 1999). Fife (1994, p.311) defined meaning as "an individual's perception of the potential significance of an event, such as the occurrence of a serious illness, for the self and one's plan of action". According to Fife, the search for meaning is a positive determinant in the participants' QOL, as they seek to redefine the roles they played within their altered worlds. Steeves (1992, p.899) also contended that "the way in which people choose to construct the meaning of various experiences has a bearing on their well-being". In his study, the participants sought meaning in their lives by "renegotiating their social position in a new situation and by trying to reach an understanding of their experiences as a whole" (1992, p.899). The findings of this study supports Steeves (1992) who also established the importance for the participants of renegotiating new ways of being in their altered worlds. This process involved changing their priorities and lifestyles, re-defining their roles and reinterpreting their lives as a whole. Ferrell & Dow (1996, p.78) refers to this time in a cancer survivor's life as "transition to a new life" As Kubler-Ross (1995, p.131) suggests, "sadly, it is only when tragedy strikes that most of us begin attending to the deeper aspects of life".

While some QOL studies (Dow et al., 1999; Ferrell et al., 1992; Wyatt et al., 1993) acknowledge this process in determining an individual's QOL following a cancer diagnosis, few have explored the experience of meaning-making and how it enriches the individual's quality of being, following an ABCT. The participants' search for meaning was a significant finding of this study. The role of nurses and health professionals is to understand this experience, and offer the necessary support and understanding to assist these patients in restoring purpose in their lives.

6.6 CONCLUSION

This chapter has provided discussion of the findings within the context of the current literature. The insights presented, not only support, but also add to the body of information available to nurses and other health professionals, attempting to understand QOL issues for patients undergoing an ABCT. This chapter is premised on the fact that QOL is a lived experience. The participants' perceptions of their QOL stemmed from their everyday experience of living with the changes the transplant had brought to their worlds. Exploring their experiences of disembodiment, meaning-making, loss and uncertainty will enhance the current understanding of QOL issues confronting ABCT recipients. Furthermore this study illustrates that exploring QOL issues from a phenomenological perspective provides a deeper understanding of a profoundly personal yet diverse experience beyond the methodological reach of the medical model.

CHAPTER SEVEN

CONCLUSION

This concluding chapter presents the limitations of the study, and the implications for nursing practice, nursing research and nursing education. A summation of the study is also included.

7.1 LIMITATIONS OF THE STUDY

This was a small scale study that focused on a specific group of people. Each participant had undergone an ABCT for a life threatening cancer. ABCT has proven to be a very successful treatment modality used in the fight against cancer, and as mentioned in Chapter One the number of people who are in longterm remission following this treatment is increasing rapidly.At the time of commencing this research in 1998, no study had explored QOL issues in patients who had undergone an ABCT utilising an interpretive-phenomenological approach. The exclusivity of the participants is in itself a limitation, because the data focuses on a specific type of cancer treatment rather than exploring QOL issues in other types of cancers and cancer treatments.

QOL as interpreted by the participants in this study was about their quality of being. They defined their QOL through their different ways of being in their everyday lives. QOL was a highly individualised, dynamic experience, which was challenged by the changes they experienced in their everyday lives and how they re-negotiated their worlds following the transplant. The participants in this study were interviewed at one point only during their recoveries. All participants were more than six months following their transplants. This period of time was chosen because it allowed the participants time to reflect on their QOL and how this might have changed since their transplants. However, how individuals interpret their QOL may change over time, so further understanding of this would require participants, in future studies, to be interviewed at different points during their recovery trajectories.

All of the participants who took part in this study were in remission. The researcher acknowledges that high dose chemotherapy and ABCT is curative only in a certain percentage of patients. If the cancer returns following an ABCT, options for curative treatment are few. Few studies have explored QOL in patients who have suffered a relapse of their cancer. Indeed, QOL studies in this relapse group are paramount if health care professionals are to provide the necessary supportive care to optimise the patient's QOL in this phase of their illness experience.

All participants were selected on the basis that they spoke English. This allowed for the ease of communication between the researcher and participants, but also because of the lack of funding to support an interpreting service. This limited the participation of potential participants from non-English speaking backgrounds. As the number of people from non-English speaking backgrounds is increasing in Australia, there is a need to include their voices in studies like this. Hence, future studies are required to include people from cross-cultural settings, which will capture the unique lived experiences of this population group.

7.2 IMPLICATIONS

The findings of this study have provided a deeper insight into QOL issues as experienced by ABCT recipients. These findings can facilitate a greater understanding by nurses and health care professionals of the lived experience of surviving an ABCT, and how this impacts on the individual's QOL. In order to meet the individual needs of each patient, it is crucial to understand their interpretation of their unique experience. Such an understanding will assist in the development of supportive care infrastructure which can offer both support and guidance to patients as they struggle to re-negotiate their altered worlds. The implications of the findings of this study on nursing practice, research and education are as follows.

7.2.1 Nursing Practice

The findings of this study provide insights into the meanings that individuals attribute to their QOL following an ABCT. Such insights will empower nurses and health professionals to provide more individualised care, which encompasses recognising patients' unique needs, taking into account their backgrounds and supportive networks, promoting their independence, listening to their individual stories, and reinforcing the patients' positive meanings that they attribute to their QOL.

Historically, nursing care delivery in the transplant setting has focused on the transplant phase of the individual's illness trajectory. Indeed, this is the most intensive phase of the transplant experience. Nursing care has focused on promoting health and wellbeing, and providing supportive care to help minimise the physical and psychological toxicities associated with the treatment. The period following their discharge from hospital heralds a different phase in the transplant trajectory, with new challenges and concerns for the patient, which can be just as distressing as the inpatient phase. The findings of this study indicate that when the participants were discharged they struggled to come to terms with the changes that occurred in their respective worlds. Furthermore, many of them felt misunderstood, poorly supported and ill-prepared for the journey ahead. Nurses and health care professionals need to be more cognisant of their patients' individual circumstances during this phase. They need to understand the patients' lived experiences of undergoing an ABCT, and the contexts in which these experiences occurred. Nurses also need to understand that individuals interpret their experiences differently. Munhall (1994) suggests one of the most important gifts one human being can give another human being is the gift of understanding. By understanding a person's lived experience of a life event we can empathise with them. Gahagen (1984) defines empathy as "the ability to perceive the meanings and feelings of another person and to communicate that understanding to the other". Therefore, the delivery of nursing care should embrace these humanistic aspects of nursing practice.

Traditionally, the medical model of patient care has dominated nursing knowledge and practice. This meant the delivery of nursing care was based on an understanding of the medically prescribed treatment. However, over the last two decades nursing has begun to develop as a discipline and build a unique body of professional knowledge and practice. At the heart of this transformation is the essence of nursing - caring. Caring means engaging – or being – with the patient at a humanistic level, and entails the delivery of nursing care which is patient and family focused; in other words, taking into account the patient and family’s personal issues and concerns, and the contexts in which these arise. Consequently, the essence of caring is “being with the patient”. Cheung (1998, p.227) defined caring as “a way of understanding what it means to be a nurse, and as a way of developing the knowledge and skills to better care for patients”. The findings of this study complement Cheung’s concept of caring, and provide nurses with rich and eloquent patient experiences, which will assist them in extending their practice to focus on supporting patients and improving the quality of their lives.

Ironically, in today's health care system it is the period following discharge from hospital when patients receive the least support. The findings of this study suggest that many of the participants in this study needed support from nurses and health care professionals who understood their individual needs and situations. Many also expressed the significance of sharing their stories with someone who had gone through a similar experience. Some participants sought support elsewhere, but were frustrated and disappointed when their needs were not met. The implication is that nurses and health care professionals, who understand the lived experience of surviving an ABCT, need to be freely accessible to this patient group. Such skilled and expert support, by its very nature, would be more in tune with, and understanding of, the individuals' experiences.

This study uncovered that the meanings each individual attributed to their QOL were shaped after they left hospital. As they re-assimilated into their pre-transplant roles, the shock realization of the limitations placed on their lives began to appear. Accordingly, this is when supportive infrastructure needs to be improved to optimise the ABCT recipients' QOL. As the participants attempted to return to their former roles, they struggled with diet and exercise issues. Fatigue was also a factor for many, yet they received no formal education on the management of this symptom. Issues related to sexuality, intimacy, and managing symptoms associated with premature menopause were also not addressed. The implication is that nurses and healthcare professionals need to be more focused on the patient's wellbeing both during and following the transplant. As Maurice poignantly remarked in his interview:

> Everyone was really keen to treat the cancer, but you know thank God they did, I mean that was the primary aim of the exercise. But I got the feeling in the clinic that they didn't have a handle on how I was still feeling and how long this would last.

Introducing nurse-led clinics, which address the supportive care issues of ABCT recipients, would be an appropriate strategy for assessing, managing and supporting these patients. With their focus on caring and symptom management, and the personal and holistic nature of their work, nurses are in the best position to lead such an intervention program.

For the participants in this study, life following an ABCT meant dealing with survivorship issues. Indeed, following the transplant the participants saw themselves as cancer survivors, that is a select group of people with special needs. Many acknowledged the comfort, reassurance and comradeship they received from sharing their stories with other cancer survivors. A shared understanding had developed amongst them, which was difficult to find amongst their peers or, in some cases, their own families. This suggests that this population group is likely to benefit from survivorship forums. Nurses, in collaboration with social workers and clinical psychologists, need to work towards the development of such groups that can facilitate this process. Such forums can allow for the sharing of experiences. They can also be places where this patient group is taught to develop strategies to deal with the psychosocial upheaval in their worlds.

7.2.2 Nursing Research

The findings of this study complement existing QOL literature, and offer nurses and other health professionals a deeper understanding of the lived experience of QOL following an ABCT as interpreted by the individuals concerned. However, further qualitative research is needed that involves the narrative to advance the current knowledge of QOL issues in this patient group.

Support from partners, families and friends, was an important finding which contributed in a positive way to the participants' QOL. Conversely, lack of support contributed to a poorer QOL. The reaction and response from the participants' partners, families and friends demands further exploration. Issues and circumstances contributing to loss of support need to be identified, so that they can then be addressed with the patient and family, and strategies can be developed to meet family and care giver needs. Boyle et al. (2000) identified the following issues in primary care givers of adult ABMT survivors: the demands of role change; the assumption of new and additional responsibilities; the burden of giving continued support to the survivor for years following the transplant, while, at the same time, requiring support themselves. The authors (2000) acknowledged that in order to optimise the survivors’ QOL following the transplant, support from families is paramount. Boyle et al. (2000, p.201) suggested:

> This support should be offered in the form of psychological and educational anticipatory guidance about expectations for the family's future. [This will assist the family] to conquer the newfound challenges synonymous with life after transplantation

In this study, the participants who struggled with lack of support from family and friends found it difficult to comprehend. It was almost as if those close to them expected the participant’s lives to return to normal now that the cancer had gone. There was no understanding amongst their family and friends of how the illness had affected their lives.

As mentioned in Chapter 3, any exploration of QOL must take into account the person's world, and how they transact within this world. A very important part of each person’s world is the family. The current literature on QOL issues in this patient group needs to be expanded to include the carer and family’s perspectives of the impact of this treatment on their QOL. Through such research, nurses and health care professionals will be better educated and informed as to the impact of the treatment and the longterm sequelae within the family unit. The implication of qualitative research focusing on the experiences of the carers of ABCT recipients could further enhance the survivors’ QOL.

Life re-appraisal was a positive experience in the participants' QOL. It was both a healing and enriching experience which helped the participants to find renewed purpose in their changed lives, a renewed sense of being and, ultimately, restored quality in their lives. However, the search to find meaning in their altered lives did not come easily for some of the participants who failed to integrate the transplant experience into their worlds. Further research is required to discover why some individuals positively re-appraise their lives, and learn to accept their altered ways of being, while others do not. In this study some of the participants accepted the changes in their bodies, and the limitations placed on their everyday lives. They focused on the positives of the transplant experience and explored new ways of being in their worlds. However, other participants struggled with the changes they experienced. This phenomenon of positively re-appraising one’s life following an ABCT requires further research. If certain psychological and social factors, which facilitate this phenomenon, could be identified, it would have implications for nursing practice and patient education and support following their transplants.

Also, the experience of disembodiment demands further exploration, particularly in relation to QOL. For the participants in this study the disembodiment experience was very distressing. The familiarity and trust in their bodies was threatened. As Benner and Wrubel (1989, p.53) suggested:

> The notion of the body as a way of knowing and as integrated with the mind can have profound implications for the care of the body during extreme breakdown. In this view the body is not ever an object, the body is continuous with the person.

When their bodies would not perform in familiar ways, the participants were shattered. As well as having an objective understanding of the physiological processes which occur following an ABCT, nurses and health care professionals need to develop an understanding of the experience of living with these symptoms. Further phenomenological studies, are required, which explore the experience of disembodiment and how it relates to the person's QOL. It is through the individual's own narratives that this experience will be described in profound and evocative terms. Empowered with this knowledge, nurses and health care professionals will be better equipped to prepare the patient for life following the transplant, and be able to address their needs in a holistic fashion.

7.2.3 Nursing Education

Interpretive phenomenology was chosen as the theoretical framework for this study. This study has demonstrated that using such an approach provides a very rich, personal account of the meaning of QOL from the participants' perspectives following an ABCT. Nursing as a discipline espouses humanistic values, therefore the implication is that such an approach can be utilised to gain a deeper understanding of other phenomenon which challenges people as they journey through both cancer and non-cancer related illnesses.

The findings of this study illuminate the participants everyday lived experiences. In other words, this study will provide nurses with an increased understanding of a profound personal experience. Because of the rich descriptions this study offers, it can be a resource for undergraduate nursing students as well as other health care students and enables them to develop a sense for what it is like to live with and survive cancer. An increased experiential understanding of the patient adds an empathetic dimension to the nurse/patient relationship which also has the potential to positively impact on the patient's health and illness by giving them a voice to express the illness's humanistic dimensions.

7.3 SUMMATION OF THE STUDY

This study set out to enable a deeper understanding of, and discover new insights into, QOL issues in patients who had undergone an ABCT from the patients' perspectives. It was the intention that the findings of this study contributes to the growing body of QOL literature. It is hoped the study increases awareness amongst nurses of the importance of focusing on the human response to illness, thereby adding to the humanistic dimension of the profession, and the development of nurses and the discipline of nursing as a human science. It is hoped that the knowledge generated from this study leads to the development of nursing care practices based on an empathic understanding of patients as whole human beings, assist in the development of supportive networks for patients and families who undergo an ABCT, and provide impetus for further research into QOL issues following an ABCT.

An interpretive phenomenological approach and hermeneutic analysis of the text derived from the transcribed interviews enabled the researcher to unravel existential-ontological descriptions and meanings of the participants' perspectives of QOL following their transplants. Heideggerian phenomenology was chosen, because it allowed for the study of the person in their context. The findings show that participants' perespectives of their QOL was an ongoing dynamic experience, dependent on the challenges they had to confront in their everyday lives. The participants reinterpreted the meaning of everyday, taken for granted activities and situations within their individualised worlds. As their lives assumed a new significance, they took on a new way of being in their worlds. For all of the participants, this new way of being in their world was very different from their previous way of being. Furthermore, as they reinterpreted the meaning of their everyday lives, their perspectives of their QOL changed. For example, many of the participants believed their lives were enriched following the transplant experience, and so too was the quality of their lives. They were given a second chance to live and embraced the opportunity. Yet, for other participants, the quality of their lives diminished, as they struggled to come to terms with the changes that the transplant experience brought to their individual worlds.

Through Heideggerian phenomenological research, a deeper and richer understanding of the meaning of QOL for individuals who undergo an ABCT can be developed and achieved. Illness is a human experience which disrupts patients' lives. According to Benner and Wrubel (1989, p.xii) the symptoms and side effects of the illness and treatment are laden with meaning stating that "understanding the context and meaning of the symptoms is central to curing and healing." As well as emphasising the bio-physiological processes that occur following an ABCT, QOL research should focus on the patient's lived experience. Once nurses realise the benefits the latter can provide, they will be better prepared to meet the unique and individual needs of these patients.

It is hoped that the insights gained in this study will enhance nurses' knowledge, and the understanding of their patients and the QOL issues faced by patients who undergo an ABCT. It is also hoped that such insights will alter nursing practice. Instead of nurses relying completely on the medical model to direct their practice, it is hoped that they will be encouraged to change their way of thinking, which will in turn alter nursing practice. The latter should emphasise the significance of engaging with the patient in a caring and meaningful way. The new understanding gained from this study emphasises the humanistic values of nursing practice and facilitates the delivery of holistic care.

The evidence of this study shows that QOL is about quality of being. It is an everyday lived experience that is very individual and unique to each patient. Hence, nurses must be committed to provide individualised patient focussed care. Prescriptive nursing practice, which is heavily influenced by the medical model, ignores the unique experiences of each individual. The understanding which is offered by an interpretive phenomenological approach will enable nurses and health care workers to develop supportive care infrastructure that will assist and empower patients to re-negotiate their worlds and ultimately improve the quality of their lives following an ABCT.

REFERENCES

Andrykowski, M.A., Altmaier, E.M., Barnett, R.L., Otis, M.L., Gingrich, R. & Henslee-Downey, P.J. (1990). The quality of life in adult survivors of allogeneic bone marrow transplantation: Correlates and comparison with matched renal transplant recipients. Transplantation, 50, 399 – 406.

Andrykowski, M.A., Brady, M.J., Greiner, C.B., Altmaier, E.M., Burish, T.G., Antin, .H., Gingrich, R., McGarigle, P., & Henslee-Downey, P.J. (1995). 'Returning to normal' following bone marrow transplantation: outcomes, expectations and informed consent. Bone Marrow Transplantation, 15, 573 – 581.

Andrykowski, M.A., & McQuellon, R.P. (1999). Psychological issues in haemtopoietic cell transplantation. In E.D. Thomas, K.G. Blume & S.J. Forman (Eds.), Hematopoietic Cell Transplantation. (2nd Edition) (pp. 398-405). MA, USA: Blackwell Science.

Annells, M. (1996). "Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research". Journal of Advanced Nursing, 23, 705-713.

Applebaum, F.R. (1996). The use of bone marrow and peripheral blood stem cell transplantation in the treatment of cancer. CA: A Cancer Journal for Clinicians, 46, 142 - 164.

Armitage, J.O. (1994). Bone marrow transplantation. The New England Journal of Medicine, 330, 827-838.

Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) (2003). Annual Data Summary 2003. Arrow Foundation Inc.

Baker, F., Curbow, B. & Wingard, J.R. (1991). Role retention and quality of life of bone marrow transplant survivors. Social Science and Medicine, 32, 697 – 704.

Baker, F., Wingard, J.R., Curbpow, B., Zabora, J., Jodrey, D., Fogarty, L., & Legro, M. (1994). Quality of life of bone marrow transplant long-term survivors. Bone Marrow Transplantation, 13, 589-596.

Baker, F., Zabora, J., Pollard, A., Wingard, J. (1999). Reintegration after bone marrow transplantation. Cancer Practice, 7, pp. 190-197.

Beatty, P.G. (1994). Clinical and societal issues in blood and marrow transplantation for haematological diseases. Biology of Blood and Marrow Transplantation, 1, 94-114.

Belec, R.H. (1992). Quality of life: Perceptions of long-term survivors of bone marrow transplantation. Oncology Nursing Forum, 19, (1), 31 – 37.

Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), Interpretive Phenomenology, (pp 99-127),

Benner, P. (1985). Quality of Life: A phenomenological perspective on explanation, prediction and understanding in nursing science. Advances in Nursing Science, 8, 1- 4.

Benner, P. & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, California: Addison Wesley.

Berterö. C. & Ek, A.C. (1993). Quality of life of adults with acute leukemia. Journal of Advanced Nursing, 18, 1346 – 1353.

Boyle, D., Blodgett, L., Gnesdiloff, S., White, J., Bamford, A.M., Sheridan, M. & Beveridge, R. (2000). Caregiver quality of life after autologous bone marrow transplantation. Cancer Nursing, 23, (3), 193 – 203.

Bush, N.E., Haberman, M., Donaldson, G., & Sullivan, K.M. (1995). Quality of life of 125 adults surviving 6-18 years after bone marrow transplantation. Social Science and Medicine, 40, 479 - 490.

Carter, B. (1993). Long-term survivors of breast cancer. A qualitative descriptive study. Cancer Nursing, 16, 354 – 361.

Cella, D.E. (1992). Quality of life: The concept. Journal of Palliative Care, 8, (3), 8-13.

Chao, N.J., Tierney, K., Bloom, J.R., Long, G.D., Barr, T.A., Stallbaum, B.A. (1992) Quality of life after an autologous bone marrow transplantation. Blood, 80, 825 - 830.

Cheung, J. (1998). Caring as the ontological and epistemological foundations of nursing: A view of caring from the perspectives of Australian nurses. International Journal of Nursing Practice, 4, (4), 225 - 233

Cohen, M.Z. Kahn, D.L. & Steeves, R.H. (1998). Beyond body image: the experience of breast cancer. Oncology Nursing Forum, 25, (5), 835 – 841.

Cohen, M.Z. & Ley, C.D. (2000). Bone marrow Transplantation: The battle for hope in the face of fear. Oncology Nursing Forum, 27, (3), 473 – 480.

Coyler, H. (1996). Women's experience of living with cancer. Journal of Advanced Nursing, 23, 496 – 501.

Dimeo, F.C., Tillman, N.H.M., Bertz, H., Kanz, L., Mertelsmann, R. & Keul, J. (1997). Aerobic exercises in the rehabilitation of cancer patients after high dose chemotherapy and autologous peripheral stem cell transplantation. Cancer, 79, 1717-1722.

Dow, K.H., Ferrell, B.R., Haberman, M.R. & Eaton, L. (1999). The meaning of quality of life in cancer survivorship. Oncology Nursing Forum, 26, (3), 519 – 528.

Draper, P. (1997). Nursing Perspectives on Quality of Life. New York:Routeledge

Dreyfus, H. (1991). Being-in-the-World: A Commentary on Heidegger's Being and Time, Division 1. Cambridge, MA: MIT Press.

Elkington, J.R. (1966). Editorial. Medicine and the quality of life. Annals of Internal Medicine, 64,(3), 711-713.

Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. Oncology Nursing Forum, 19, (6), 883 – 889.

Farquhar, M. (1995). Definitions of quality of life: A taxonomy. Journal of Advanced Nursing, 22, 502-506.

Fayers, P.M. & Machin, D. (2000). Introduction. In P.M. Fayers & D. Machin (Eds), Quality of Life: Assessment, Analysis and Interpretation, Chichester: John Wiley and Sons, Ltd. (pp.3 – 27).

Feigin, R., Greenberg, A., Ras, H., Hardan, Y., Rizel, S., Ben Efraim, T., & Stemmer, S.M. (2000). The psychosocial experience of women treated for breast cancer by high-dose chemotherapy supported by autologous stem cell transplant: A qualitative analysis of support groups. Psycho-Oncology,9, 57-68.

Ferrans, C. E. (1990). Quality of life: Conceptual issues. Seminars in Oncology Nursing, 6, (4), 248-254.

Ferrell, B.R. (1996). The quality of lives: 1,525 voices of cancer. Oncology Nursing Forum, 23, (6), 906 0916.

Ferrell, B, Grant, M., Schmidt, G., Rhiner, M., Whitehead, C., Fonbuena, P. & Forman, S. (1992). The meaning of quality of life for bone marrow transplant survivors. Part I: The impact of bone marrow transplant on quality of life. Cancer Nursing,15, (3) 153-160.

Ferrell, B., Grant, M., Schmidt, G., Rhiner, M., Whitehead, C., Fonbuena, P., & Forman, S. (1992). The meaning of quality of life for bone marrow transplant survivors. Part II: Improving quality of life for bone marrow transplant survivors. Cancer Nursing, 15, (4) 247-253.

Ferrell, B.R. & Dow, K.H. (1996). Portraits of cancer survivorship. Cancer Practice, 4, (2), 76 – 80.

Fife, B.L. (1994). The conceptualization of meaning in illness. Social Science in Medicine, 38, 309 – 316.

Fromm, K., Andrykowski, M.A. & Hunt, J. (1996). Positive and negative psychosocial sequelae of bone marrow transplantation: Implications for quality of life assessment. Journal of Behavioral Medicine, 19, 221 – 240.

Gadamer, H.G. (1976). Philosophical Hermeneutics, Berkeley, CA: University of California Press.

Gahagen, J. (1984) Social Interaction and its Management. New Psychology Series P. Heriott (Ed). London, Methuen

Gaskill, D., Henderson, A. & Fraser, M. (1997). Exploring the everyday world of the patient in isolation. Oncology Nursing Forum, 24, (4), 695 – 700.

Gaston-Johansson, F. & Foxall, M. (1996). Psychological correlates of quality of life across the autologous bone marrow transplant experience. Cancer Nursing, 19, (3), 170-176.

Grant, M.M & Rivera, L.M. (1998). Evolution of quality of life in oncology and oncology nursing. In C.R. King & P.S. Hinds (Eds.), Quality of Life. From Nursing and Patient Perspectives (pp3 -17), Toronto, Jones and Bartlett Publishers.

Griffiths, A. & Beaver, K. (1997). Quality of life during high dose chemotherapy for breast cancer. International Journal of Palliative Nursing, 3, (3), 138 – 144.

Guba, E. & Lincoln, Y.S (1985). Effective Evaluation: Improving the Usefulness of Evaluation. Results through Responses and Naturalistic Approaches. San Francisco, Jossey Bass.

Haberman, M., Bush, N., Young, K. & Sullivan, K.M. (1993). Quality of life of adult long-term survivors of bone marrow transplantation: A qualitative analysis of narrative data. Oncology Nursing Forum, 20, (10), 1545-1553.

Hacker, E.D. (2003). Quantitative measurement of quality of life in adult patients undergoing bone marrow transplant or peripheral blood stem cell transplant: A decade in review. Oncology Nursing Forum, 39, (4), 613-629.

Hacker, E.D. & Ferrans, C.E. (2003). Quality of life immediately after peripheral blood stem cell transplantation. Cancer Nursing, 26, (4), 312-322.

Hallórsdóttir, S. & Hamrin, E. (1996). Experiencing existential changes: the lived experience of having cancer. Cancer Nursing, 19, (1), 29 – 36.

Hann, D.M., Jacobsen, P.B., Martin, S.C., Kronish, L.E., Azzarello, L.M. & Fields K.K. (1997). Quality of life following bone marrow transplantation for breast cancer: a comparative study. Bone Marrow Transplantation, 19, 257-264.

Hensel, M., Egerer. G., Schneeweiss, A., Goldsmith, H. & Ho, A.D. (2002). Quality of life and rehabilitation in social and professional life after autologous stem cell transplantation. Annals of Oncology, 13, (2), 209 – 217.

Heslop, L. & Oates, J. The discursive formation of caring. In Genevieve Gray & Roasalie Pratt (Eds.), Scholarship in the Discipline of Nursing, (pp.255-276). Melbourne, Churchill Livingston.

Hjermastad, M.J., & Kaasa, S. (1995). Quality of life in adult cancer patients treated with bone marrow transplantation-a review of the literature. European Journal of Cancer Care, 2, 163-173.

Holloway, I. & Wheeler, S. (1996). The search for truth in qualitative research. In Qualitative Research for Nurses, (pp162-170). Mass, USA:Blackwell Science.

Holloway, I. & Wheeler, S. (1995). Ethical issues in qualitative nursing research. Nursing Ethics, 2, 223-232.

Horowitz, M.M. (2004). Uses and growth of hematopoietic cell transplantation. In K.G. Blume, S.J. Forman, & F.R. Applebaum (Eds.), Thomas' Hematopoietic Stem Cell Transplantation (pp. 9-15). Mass, USA:Blackwell Science.

Kapustay, P.M., Buchsel, C.M. (1999). Proces, complications, and management of peripheral stem cell transplantation. In P.C. Buchsel & P.M. Kapustay (Eds.), Stem Cell Transplantation: A Clinical Textbook (pp. 1.3-1.18). Pittsburgh: Oncology Nursing Press.

Keogh, F., O'Riordan, J., McNamara, C., Duggan, C. & McCann. (1998). Psychosocial adaption of patients and families following bone marrow transplantation: a prospective, longitudinal study. Bone Marrow Transplantation, 22, (9), 905 – 911.

King, C.R., Haberman, M., Berry, D.L., Bush, N., Butler, L., Dow, K.H., Ferrell, B., Grant, M., Gue, D., Hinds, P., Krier, J., Padila, G., & Underwood, S. (1997). Quality of life and the cancer experience: The state-of-the-knowledge. Oncology Nursing Forum, 24, (1), 27-41.

Klumpp, T. (1995). Complications of peripheral blood cell transplantation. Seminars in Oncology, 22, 263 – 270.

Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. Journal of Advanced Nursing, 21, 827-836.

Koch, T. (1994). Establishing rigor in qualitative research: the decision trail. Journal of Advanced Nursing, 19, 976- 986.

Kubler-Ross, E. (1969) On death and dying. New York, Macmillan

Larsen, J., Garduff, A., Nordström, G., Björkstrand, B., & Ljungman, P. (1996). Health-related quality of life in women with breast cancer undergoing autologous stem-cell transplantation. Cancer Nursing, 19, 368-375.

Lee, H.G., Park, E.Y., Kim, H.M., Kim, K., Kim, W.S., Yoon, S.S, Kang, W.K., Park, K.C. & Park, C.H. (2002). Sexuality and quality of life after hematopoietic stem cell transplantation. Korean Journal of Internal Medicine,17, (1), 19 – 23.

Leigh, S. (1997). Quality of life…for life: Survivors influencing research. Quality of Life – A Nursing Challenge, 5 (2), 58 – 61.

Leigh, S., Wilson, .C.M., Burns, R. & Clark, R.E. (1995). Psychosocial morbidity in bone marrow transplant recipients: a prospective study. Bone Marrow Transplantation, 16, 635 – 640.

Leonard, V.W. (1989). A Heideggerian phenomenological perspective on the concept of the person. Advances in Nursing Science, 11, 40-55.

Lesko, L.M. (1994). Bone marrow: Support of the patient and his/her family. Support Cancer Care, 2, 35-49.

Litwins, N.M., Rodrigue J.R. & Weiner, R.S. (1994). Quality of life in adult recipients of bone marrow transplantation. Psychological Reports, 75 (1Pt1), 323 0328.

Mackay, I.R. (2003). The humanism and the suffering of the people. The Internal Medical Journal, 33(4), 195-202.

Marks, D.I., Friedman, S.H., Carpini, L.D., Nezu, C.M. & Nezu, A.M. (1997). A prospective study of the effects of high-dose chemotherapy and bone marrow transplantation on sexual function in the first year after transplant. Bone Marrow Transplantation, 19, 819-822.

McCarthy, P.L, Williams, L.A., Holmes, M. (2000). Stem cell transplantation: Past, present and future. In P.C. Buchsel & P.M. Kapustay (Eds.), Stem Cell Transplantation: A Clinical Textbook (pp. 1.3-1.18). Pittsburgh: Oncology Nursing Press.

McQuellon, R.P., Craven, B., Russell, G.B., Hoffman, S., Cruz, J.M., Perry, J.J. & Hurd, D.D. (1996). Quality of life in breast cancer patients before and after autologous bone marrow transplantation. Bone Marrow Transplantation, 18, 579-584.

Minichiello, V., Aroni, R., Timewell, E. & Alexander, L. (1990). In-depth interviewing. Sydney: Addison Wesley Longman.

Molassiotis, A. (1997). A conceptual model of adaption to illness and quality of life for cancer patients treated with bone marrow transplants. Journal of Advanced Nursing, 26, 572-579.

Molassiotis, A. (1996). Late psychosocial effects of conditioning for BMT. British Journal of Nursing, 5, 1296 – 1302.

Molassiotis, A., Boughton, B.J., Burgoyne, T. & van den Akker, O.B.A. (1996). Comparison of the overall quality of life in 50 long-term survivors of autologous and allogeneic bone marrow transplantation. Journal of Advanced Nursing, 22, 509-516.

Molassiotis, A. & Morris, P.J. (1999). Quality of life in patients with chronic myeloid leukemia after unrelated bone marrow transplantation. Cancer Nursing, 22, 340 – 349.

Molassiotis, A. & Van Den Akkers, O.B.A. (1996). Psychological adaption and symptom distress in bone marrow transplant recipients. Psycho-Oncology, 5, 9-22.

Montazeri, A., Gillis, C. & McEwen, J. (1996). Measuring quality of life in oncology: is it worthwhile? I. Meaning, purposes and controversies. European Journal of Cancer Care, 5, 159-167.

Montazeri, A., Gillis, C. & McEwen, J. (1996). Measuring quality of life in oncology: is it worthwhile? II. Experiences from the treatment of cancer. European Journal of Cancer Care, 5, 168-175.

Munhall, P. (1994). Revisioning phenomenology: Nursing and health science research. New York: National League for Nursing Press.

Pelusi, J. (1997). The lived experience of surviving breast cancer. Oncology Nursing Forum, 24, 1343 – 1353.

Poliquin, C.M. (1997) Overview of bone marrow and peripheral blood stem cell transplantation. Clinical Journal of Oncology Nursing, 1, 11 -17.

Prieto, J.M., Saez, R., Carreras, E., Atala, J., Sierra, J., Rovira, M., Batlle, M., Blanch, J., Escobar, R., Vieta, E., Gomez, E., Rozman, C. & Cirera, E. (1996). Physical and psychosocial functioning of 117 survivors of bone marrow transplantation. Bone Marrow Transplantation, 17, 1133-1142.

Robertson-Malt, S. (1999). Listening to them and reading me: a hermeneutic approach to understanding the experience of illness. Journal of Advanced Nursing, 29,(2), 290-297.

Saba, N., Abraham, R., & Keating, A. (2000). Overview of autologous stem cell transplantation. Critical Reviews in Oncology/Haematology, 36, 27- 48.

Saleh, U.S. & Brockopp, D.Y. (2001). Quality of life one year following bone marrow transplantation: Psychometric evaluation of the quality of life in bone marrow transplant survivors tool. Oncology Nursing Forum, 28, (9), 1457-1464.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8, 27- 37.

Schmidt, G.M., Niland, J.C., Forman, S., Fonbuena, P.P, Dagis, A.C., Grant, M.M, Ferrell, B.R., Barr, T.A., Stallbaum, B.A., Chao, N.J. & Blume, K.J. (1993). Extended follow-up in 212 long-term allogeneic bone marrow transplant survivors. Transplantation, 55, 551-557.

Shuster, G.F., Steeves, R.H., Onega, L. & Richardson, B. (1996). Coping patterns among bone marrow transplant patients: a hermeneutic inquiry. Cancer Nursing, 19, (4), 290 – 297.

Snyder, D.A. (1999). Ethical issues in hematopoietic cell transplantation. In E. Donnall Thomas, K.G. Blume, S.J. Forman (Eds.) Hematopietic Cell Transplantation. MA. Blackwell Science.

Somerfield, M.R., Curbow, B., Wingard, J.R., Baker, F. & Fogarty, L.A. (1996). Coping with the physical and psychosocial sequelae of bone marrow transplantation among long-term survivors. Journal of Behavioral Medicine, 19, 163 – 184.

Steeves, R.H. (1992). Patients who have undergone bone marrow transplantation: Their quest for meaning. Oncology Nursing Forum, 19, (6), 899 – 905.

Syrjala, K., Chapko, M., Vitaliana, P., Cummings, C., Sullivan, K.M. (1993). Recovery after allogeneic marrow transplantation: Prospective study of predictors of long-term physical and psychosocial functioning. Bone Marrow Transplantation, 11, 319-327.

Tierney, D.K. (2000). Quality of life issues for peripheral stem cell transplant recipients. In P.C. Buchsel & P.M. Kapustay (Eds.), Stem Cell Transplantation: A Clinical Textbook (pp. 14.3-14.14). Pittsburgh: Oncology Nursing Press.

Thain, C.W. & Gibbon, B. (1996). An exploratory study of recipients' perceptions of bone marrow transplantation. Journal of Advanced Nursing, 23, 528 – 535.

Utley, R. (1999). The evolving meaning of cancer for long-term survivors of breast cancer. Oncology Nursing Forum, 26, (9), 1519-1523.

Van der Zalm, J.E. & Bergum, V. (2000). Hermeneutic-phenomenology: providing living knowledge for nursing practice. Journal of Advanced Nursing, 31, (1), 211 – 218.

Walters, A.J. (1995). The phenomenological movement: implications for nursing research. Journal of Advanced Nursing, 22, 791- 799.

Whedon, M. & Ferrell, B.R. (1994). Quality of life in adult bone marrow transplant Patients: Beyond the first year. Seminars in Oncology Nursing, 10, 42 – 45.

Whedon, W., Stearns, D. & Mills, L.E. (1995). Quality of life of long-term adult survivors of autologous bone marrow transplantation. Oncology Nursing Forum,22, (10),1527-1535.

Winer, E.P., Lindley, C., Hardees, M., Sawyers, W.T., Brunatti, C., Borstelmann, N.A. & Peters, W. (1999). Quality of life in patients surviving at least 12 months following high dose chemotherapy with autologous bone marrow support. Psycho-Oncology, 8, 167-176.

Winer, E.P. & Sutton, L.M. (1994). Quality of life after bone marrow transplantation. Oncology, 8, (1), 19-27.

Wingard,J.R. (1994). Functional ability and quality of life of patients after allogeneic bone marrow transplantation. Bone Marrow Transplantation, 14, S29-S33.

World Health Organisation. (1947). WHO Chronicle. Geneva, Switzerland: Author

Zebrack, B. (2000). Cancer survivors and quality of life: A critical review of the literature. Oncology Nursing Forum, 27, 1395- 1401.