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An exploration of the post-treatment psychosocial experiences of female adult cancer patients

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CHAPTER 1

Introduction

1.1. Aim

The aim of this research was to explore the post-treatment psychosocial experiences of female adult cancer patients who had recently completed cancer treatment. Furthermore, this study was aimed at identifying common themes in the nature of their experiences, particularly within the South African context.

1.2. Motivation for the study

It was the researcher's objective to gain a clearer understanding of the emotional needs of such patients so that appropriate treatment programmes could be developed to help them cope with the emotional demands after treatment to remission status. This study focussed specifically on psychological well-being and coping strategies of female cancer patients (including accounts of broader emotional experiences, specific emotions and outlook on life) as well as the influence of the treatment and commensurate emotional experiences on their relationships with their marital partners, family members and friends, religious experiences and the wider social context including their social life and social support.

The study focussed on all types of cancer except for breast and gynaecologically related cancer because the loss of a breast or reproductive organs may result in different psychological experiences in comparison to other types of cancer.

1.3. Rationale

Cancer has been one of the most feared and deadly diseases known to man for hundreds of years (Holland and Zittoun, 1990). Before the twentieth century it was regarded as a death sentence as there was no known cure or treatment (Holland, 2001). A major factor

that enhanced interest in the psychological aspects of cancer was the publicity that surrounded the work of Elisabeth Kübler-Ross (1969). She proposed stages through which people pass when they are terminally ill. Building on Kübler-Ross's stage model, Buckman (1999) proposed a conceptual framework consisting of three stages in the process of dying. Such stage models have been invaluable in helping cancer patients deal with terminal illness on an emotional level. However, an improvement in treatment and further cancer research has resulted in increasing numbers of cancer survivors (Tross & Holland, 1989). Nevertheless, Gilchrist and Block (1995) point out that many cancer survivors experience psychological problems related to their survival.

After a thorough analysis of literature in the field of psychosocial outcomes of cancer, research in the area of psychosocial experiences of cancer patients directly after treatment appeared to be very limited. Thus, it was important to explore the post-treatment experiences of cancer patients with the aim of developing an understanding that may broaden our knowledge of how to help cancer survivors cope immediately after completing treatment as they progress into remission. This may in turn help to prevent future serious psychological and social adaptation difficulties in such people. Also, as most research in this field was conducted in other countries particularly the United States of America and Britain, it was important for the researcher to gain a South African perspective.

1.4. Key concepts of the study

For the purposes of this study, cancer was defined as a general term used to indicate any of various types of destructive growths or tumours within the human body, which may cause death of the patient unless adequately treated. Being in remission was in turn described as when there are no visible signs of cancer in the body after a series of tests have been conducted (Stedman, 1990). Oncology was defined as the science dealing with the physical, chemical and biological properties and features of cancers including causation, pathogenesis and treatment. Hence, an oncologist was described as a doctor who specialises in oncology (Dirckx, 2001). Psycho-oncology was in turn defined as the

area of oncology that studies the psychological dimensions of cancer including the psychological impact of cancer on patients, their families and those who treat them as well as the role that psychological, social and behavioural factors play in cancer incidence and survival (Holland, 2001). Radiation was used to refer to the utilisation of radiation in the treatment of cancer, whereas chemotherapy was described as the use of chemical substances or drugs in the treatment of cancer (Dirckx, 2001).

1.5. Outline of chapters

Chapter 2 of this research dissertation reviews literature which contributes to a contextual understanding of the history of cancer and the birth of psycho-oncology, stage models of cancer as terminal illness and cancer survival as well as South African literature on the topic of psycho-oncology.

Chapter 3 describes the research methodology of the study, outlining the research method, data collection method, research design and procedures, data analysis and ethical considerations.

Chapter 4 provides the results of the data analysis and a discussion of the results.

Chapter 5 indicates the main findings, the limitations of the study and implications for further research.

CHAPTER 2

Literature review

Death be not proud, though some have called thee
Mighty and dreadful, for, thou art not so,
For, those, whom thou think'st thou dost overthrow,
Die not, poor Death, nor yet canst thou kill me;
From rest and sleep, which but thy pictures be,
Much pleasure, then from thee, much more must flow,
And soonest our best men with thee do go,
Rest of their bones, and soul's delivery.
Thou art slave to fate, chance, kings and desperate men,
And dost with poison, war, and sickness dwell,
And poppy, or charms can make us sleep as well
And better than thy stroke; why swell'st thou then?
One short sleep past, we wake eternally,
And death shall be no more, Death thou shalt die.

John Donne

2.1. Introduction

This chapter will explore pertinent literature on the topic of psycho-oncology. A broad approach will be followed in delineating the literature, as the specific area of research in this study is relatively new and literature is therefore rather scarce. This study is broadly located within the sub-discipline of Health Psychology.

Firstly, the history of cancer and the birth of psycho-oncology as a sub-speciality of oncology will be explored. This will be followed by a demarcation of stage models of terminal illness which have had a great impact on ways of conceptualising people's reactions to cancer and advocating open communication about this dreaded disease.

Subsequently, an examination of survival research will take place. A crisis model of survival will be outlined, followed by a discussion of literature and research studies on cancer survivors in three phases of survival, namely: the acute survival, extended survival and the permanent survival phases. Lastly, South African research which addresses psychological aspects of cancer will be explored.

2.2. An overview of cancer research and the birth of psycho-oncology

Jimmie C. Holland is one of the forerunners of psycho-oncology and is involved in most accounts of the development of cancer research from a psychological perspective as well as the development of psycho-oncology as its own field of study. As a result, his insight has contributed to most of the references utilised in this section.

Cancer has been a greatly feared and fatal disease for many centuries (Holland & Zittoun, 1990). Before the twentieth century it was regarded as a death sentence as there existed no known cure or treatment. As a result, it was assumed to be cruel and inhumane to reveal a cancer diagnosis to patients and therefore, most patients were ignorant about their condition (Holland, 2001).

Even during the twentieth century, the stigmatisation of the disease and the subsequent fear of infection prevented families from disclosing the diagnosis to others. However, the development of anaesthesia and antiseptics brought with it the possibility that cancer could be removed before it spread and led to an increased awareness of the importance of education and early diagnosis (Holland, 2001; Holland & Zittoun, 1990). With increasingly more successful surgery and the introduction of radiation and chemotherapy as treatment options, attitudes toward this dreaded disease became more optimistic (Holland, 2001).

The thrust of psychoanalysis in the 1930s had an immense impact on forging a relationship between psychology and cancer. Psychodynamic conflicts or traumatic events were viewed as the root of diseases such as hypertension, peptic ulcers and cancer. Retrospective life reviews were specifically used as research tools to discern a pattern of emotional problems that were proposed as the cause of cancer (Holland, 2001).

A major factor that enhanced interest in the psychological consequences of cancer was the publicity that surrounded the work of Elisabeth Kübler-Ross (1969). Her work contributed to more open communication with dying cancer patients about their psychological concerns (Holland, 1989).

By the 1960s and 1970s, clinical and experimental psychologists, who made use of more quantitative measures, started exploring interactions between the body and mind which further fuelled an interest in the link between psychology and cancer (Holland 2001).

Since the late 1970s there has been increased optimism about cancer treatment; greater participation of patients in treatment decisions; frank discussion about this illness; as well as an increase in the number of cancer survivors openly speaking and writing about their experiences. This, in turn, has contributed to increased interest in the field of psycho-oncology in the disciplines of oncology, psychiatry, psychology, social work and nursing as well as the establishment of psycho-oncology as its own subspecialty of cancer research (Holland, 2001; Holland & Zittoun, 1990). Psycho-oncology as an independent

science is thus about 28 years old (Holland, 2001). Thus, psycho-oncology is viewed as a very young science and further research is needed in this field to establish its concepts and theory (Bolund, 1990). Models, theories and research that have contributed to the field of psycho-oncology will be discussed in the following sections.

2.3. Stage models of cancer as a terminal illness

In an attempt to understand people's psychosocial reactions to cancer, various stage models have been developed describing the dying process, relating particularly to dying from cancer. It is important to gain an understanding of such models in order to grasp the historical journey of research on the topic of cancer and psychosocial responses to cancer.

Elisabeth Kübler-Ross's (1969) work in the field of death and dying had a huge impact on the way that cancer was conceptualised. Not only did she gain considerable public and medical attention through her insightful understanding of death, but she brought about a new focus on the psychological experiences of terminally ill cancer patients, which triggered an evaluation of social attitudes about this topic (Holland, 1989). Her model has since become the most widely accepted theory of dying from cancer.

Elisabeth Kübler-Ross (1969) proposed five stages through which people pass psychologically when they are terminally ill. The first stage entails *Denial and Isolation* when patients deny that they are going to die and feel isolated from others. The second stage of *Anger* replaces the first stage when denial cannot be maintained any longer and the logical question becomes "Why me?". The third stage of *Bargaining* involves patients trying to enter into some kind of an agreement which may postpone the inevitable from happening. *Depression* results in the fourth stage when patients can no longer deny their illness and feel a sense of loss and dismay together with events such as hospitalisation, surgery, physical weakness and/or the loss of a job. She proposes that if patients have had enough time and have received help in working through the previous stages, they will reach a stage of *Acceptance*.

Holland (1989) states that for some years after Kübler-Ross proposed her stages of dying, the path of terminal illness was assumed to be predictable and over-zealous application of her principles often led to categorisation of patients without their individual needs and emotions being taken into account. However, Weisman (1972) and his colleagues' emphasis on the need for an understanding of the personal psychological issues of patients helped to ensure that individual responses be taken into account when addressing psychological experiences related to cancer.

Various authors have since offered critique on Kübler-Ross's model (Barraclough, 1999; Buckman, 1999; Holland, 1989; Rando, 1984). Buckman (1999) asserts that specifically within the community of palliative care practitioners, Kübler-Ross's model is seen to have some deficiencies. One of the most prominent criticisms is that experiences of terminally ill patients are not necessarily sequential as proposed in Kübler-Ross's stage model (Buckman, 1999; Morris, 1987; Rando, 1984). It is also asserted that not all the stages of dying as conceived by Kübler-Ross are experienced by all patients, with several patients only experiencing certain stages or remaining in one stage (Barraclough, 1999; Buckman, 1999). Buckman (1999) proposes that certain emotions such as fear of dying, guilt, and the cyclical feelings of hope and despair as well as responses such as fear have not been included in Kübler-Ross's model, although they are commonly seen in palliative care practice. Yet, Barraclough (1999) insightfully warns that this model offers a useful framework for understanding how people adjust to cancer and other serious illnesses and that it should not be viewed as a rigid formula.

Various reconceptualisations have been offered, such as that of Buckman (1999) and Rando (1984). Buckman (1999) proposes two central principles in the dying process. Firstly, patients exhibit a mixture of reactions which are characteristic of the patient and not of a particular stage of the dying process. Secondly, progress is marked by resolution of the resolvable elements of those emotions rather than by a change in the type or nature of emotions. The three stages that Buckman proposes include the *Initial Stage*, which involves emotional responses to the possibility of dying that represents that person's style of coping strategies; the *Chronic Stage* which involves the resolution of those elements of

the initial response that are resolvable and a reduction in the intensity of all emotions; and the *Final Stage*, which is defined by the patient's acceptance of death.

Such stage models have been invaluable in helping cancer patients deal with terminal illness on an emotional level. However, advances in oncology have resulted in an increase in the number of cancer survivors in the past two decades. The psychological and social needs of these survivors have since become a focal point in the field of psycho-oncology. Literature and research studies relating to this field will be discussed in the following section.

2.4. Death is not the only outcome of cancer: the concept of cancer survival

The number of people diagnosed with cancer in South Africa increases yearly with latest research indicating that a total of 29208 new cases were reported in females in 1997 (National Cancer Registry, 2003). However, an improvement in treatment and further research ensures that there are ever-increasing numbers of cancer survivors (Tross & Holland, 1989). Nevertheless, Gilchrist and Block (1995) point out that many cancer survivors experience psychological problems related to their survival. Psychological and social issues around the experience of survival have thus increasingly become an area of focus for health care practitioners. In the following section, a model of reactions to crisis will be examined as a framework for understanding cancer survival. Research and theory around the psychosocial factors affecting patients at various stages of survival will also be explored.

2.4.1. A crisis model of cancer survival

An area of research that can be of benefit in understanding human reaction to cancer is crisis research as the experience of cancer is usually a very traumatic experience (Bolund, 1990). Cullberg (1975), in particular, provides a practical and uncomplicated crisis model (Bolund, 1990). Although this model was developed for reactions to all kinds of

trauma, it can be applied specifically to living with cancer beyond terminal illness and into survival.

In the first phase, known as the *Shock Phase*, the diagnosis of cancer is perceived as catastrophic. There is distrust in the body which is seen as the root of impending death and the future is put on hold. The overwhelming impact of this existential crisis is kept out of consciousness so as to protect the mind from a psychotic reaction. This appears to be similar to the first stage of Denial and Isolation as proposed by Kübler-Ross (1969).

The second phase is called the *Reaction Phase*, when the patient starts to face reality resulting in the basic reaction of anxiety. This is brought on by the threat of impending death and loss.

The *Work Through Phase* includes working through the treatment both physically and mentally and trying to understand the new life situation and how to deal with it. This phase often includes asking "Why?" which corresponds with the reaction of questioning as proposed in the second stage of Kübler-Ross's (1969) model. In this phase, patients may also reinvest in their relationships and focus on mending those that have been unsatisfactory in the past.

The last phase, known as the *Reorientation Phase* occurs at each check-up when the patient experiences fear of detecting new appearances of the cancer. Together with this fear, comes a repeated work-through experience. A feeling of relief is experienced at the end of each check-up that confirms no reappearance of cancer. Patients then re-evaluate their lives and question the meaning of life, their identities and what they want from the rest of their life.

2.4.2. Phases of cancer survival

Mullan (1985) proposed a useful framework for understanding cancer survival from its onset until the disease is no longer perceived as a threat, which he called the "seasons of

survival". This framework provides a practical way of delineating the various phases of survival progression and the challenges that each phase poses. Three stages of cancer survival were put forward, namely acute, extended and permanent survival.

Survival is a term that is loosely referred to in the literature on cancer. Sometimes it refers generally to the period after treatment and at other times only to four or five years after diagnosis when the likelihood of recurrence of cancer is slim. For the purposes of this study, Mullan's (1985) definition of survival will be used in all further references to survival, as described below.

2.4.2.1. Acute survival research

Acute survival occurs from commencement of treatment efforts aimed at curing the cancer and usually lasts until the termination of treatment approximately one year after diagnosis. Although many of the effects of the cancer and treatment are experienced during this phase, some of them continue in the second phase (Mullan, 1985).

A great deal of research has been undertaken that relates to psychosocial issues associated with acute survival (Barraclough, 1999; Fobair, Hoppe, Bloom, Cox, Varghese & Spiegel, 1986; Gotay, Holup & Pagano, 2002; Maguire, Lee, Bevington, Kuchemann, Crabtree & Cornell, 1978; Morris, Greer & White, 1977; Stanton, Danoff-Burg & Huggins, 2002). Some of the earliest research focused on breast cancer (Maguire et al., 1978; Morris et al., 1977). Much of the most recent research in this area has focused on how coping strategies assist patients in adjusting to cancer (Stanton, et al., 2002) and comparative studies like that of Gotay et al. (2002). The study by Gotay et al. (2002) examines ethnic differences in quality of life among two different groups of cancer survivors, namely breast and prostate.

According to Barraclough (1999), a cancer patient's experiences during this phase can be conceptualised in terms of loss or the threat of loss in the future. The primary loss for most patients in the early stages of cancer is the loss of energy and physical strength (Barraclough, 1999; Fobair et al., 1986). This is especially so for those patients who

have labour-intensive jobs and who enjoy sport or physical hobbies (Barraclough, 1999). With physical weakness, comes loss of independence for many patients who are bedridden or who are inactive due to illness. Many patients feel frustrated or think that they are a burden to their family or caregivers (Barraclough, 1989; Rowland, 1989). Furthermore, cancer patients play an extremely passive role in their treatment which can deepen their sense of loss of control or helplessness (Barraclough, 1999; Lambley, 1987).

Patients may worry about who will take over their responsibilities (Rowland, 1989). When duties are taken over by others, cancer patients may experience the loss of important roles in their lives. They may also feel alienated from those people who are in good health. Loss of life expectancy can bring about feelings of sadness or anger as patients have to face the idea of looming death (Barraclough, 1999). Due to illness, cancer patients may also have to alter their goals or potential achievements for the future or put them on hold indefinitely (Barraclough, 1999; Rowland, 1989).

Coping mechanisms may also play an important role in this phase of cancer survival. In a study by Le Vieux (2003), the use of humour as a coping mechanism was explored in fifteen paediatric oncology patients. One of the major themes that emerged in the data was the shock of the diagnosis. The participants revealed that they used humour as a coping mechanism only after they had learned to cope with the realisation that they had cancer and had taken in the huge amount of information provided to them.

Relationships with spouses and family members may impede or facilitate cancer survival. Relationship problems may arise through communication barriers that impede open discussion about cancer (Barraclough, 1999). A person who has a close family may find that support disintegrates during illness, as stress felt by both the patient and the family may result in withdrawal of support and realignment of relationships. However, once the threat of cancer and the stress attached to it have subsided, relationships may result in the receding of communication barriers and more open support (Rowland, 1989).

Manne and Glassman (2000) examined the effects of spouses' unsupportive behaviour on patients' psychological distress among 191 married cancer patients undergoing treatment. They found that unsupportive responses from spouses and other family members are related to psychological distress in cancer patients. Pistrang and Barker (1995) conducted structured interviews with 113 women who had been diagnosed with breast cancer within the previous year. They found that satisfaction with the helping relationship between partners was related to psychological well-being. These findings suggest that the partner plays a penultimate role in the adaptation of breast cancer patients.

Rowland (1989) suggests that close friends often avoid the cancer patient and withdraw their support during illness. Similarly, Silver and Wortman (1980) report that despite the ability to approach sick people, others respond by avoiding them. The disappointment attached to withdrawal from friends is particularly painful for cancer patients even when they can distinguish the reason for the withdrawal. The stress that is felt by both the patient and the friend during illness thus often results in realignment of interactions once the patient recovers from cancer (Rowland, 1989).

2.4.2.2. Extended survival research

Mullan (1985) states that extended survival lasts from the time treatment ends, usually at the end of the first year after diagnosis until about four years after diagnosis and is the stage when there is the greatest chance of cancer recurring. This is the period during which the patient deals with the physical and psychological aftermath of the cancer and the treatment. These effects generally tend to interfere with the patient's daily functioning and resuming of previous activities at home and at work. They may include physical problems like sexual dysfunction or disabilities resulting from the removal of bodily tissue. Removal of a portion of the lung, for example, would make it difficult for the patient to breathe normally. They also include dealing with side-effects induced by the treatment such as hair loss and the emotional adjustment attached to resuming daily activities. Chronic fatigue may also be experienced after treatment has ceased (Servaes, Prins, Verhagen & Bleijenberg, 2002).

One of the most challenging aspects of this phase of survival is the occurrence of Lazarus Syndrome, which may affect the family and close friends of the survivor. In some cases, when the patient survives cancer and the expected loss of that person does not occur, the mourners have already grieved in anticipation of this event resulting in them feeling emotionally detached from the patient. This may in turn result in the survivor feeling isolated from family and friends (Rando, 1984), making emotional and physical support or therapy essential (Mullan, 1985).

By comparison, much less research has been conducted on the social and psychological sequelae of the extended survival phase than on the acute survival phase. The general focus tends to be on breast cancer (Barraclough, 1999; Bleiker, Povwer, van der Ploeg, Leer and Adler 2000; Ganz, Coscarelli, Fred, Kahn, Polinsky & Petersen 1996; Spelten, Sprangers & Verbeek 2002).

Barraclough (1999) points out that the experience of cancer can have a positive impact on the cancer patient, both psychologically and socially. In her research on 155 breast cancer patients two years after diagnosis, the survivors were asked to describe how their illness impacted on their outlook on life. The majority reported positive aspects in their outlook, including an increased appreciation for life, less concern with trivial matters, the ability to focus on living in the present, less concern for material possessions, greater self-confidence and the taking of responsibility for the fulfilment of their own goals in life. In a longitudinal study on the topic of breast cancer Bleiker et al. (2000) found that only one in five women reported a significantly high level of distress in regard to their cancer between two months and two years after diagnosis.

Zemore, Rinholm, Shepel and Richards (1989) utilised content analysis in examining interviews with 87 women, between the ages of 29 and 69. These women had undergone a modified radical mastectomy six to twenty six months previously. The most common concerns among these women were an inability to take part in vigorous physical activity, the possibility that the cancer would return and worry that they had not received the best possible medical care. Reports of problems resulting from stigmatising effects were

evident in fewer than 10% of the survivors. Many of the survivors reported a closer bond with family and a more positive outlook on life.

The experience of cancer may have an impact on family and social relationships in the extended survival phase which may continue into permanent survival. A review of research between 1987 and 1993 undertaken by Blanchard, Albrecht, Ruckdeschel and Grant (1995) aimed at studying the relationship between social support, psychosocial adaptation and survival in cancer patients revealed that social support has a buffering effect for cancer patients.

Terror management theory predicts that people who are made aware of their own mortality will seek to boost their self-esteem through strengthening their social bonds to buffer the anxiety they feel (Little & Sayers, 2004). Thus, mortality salience predicts that cancer survivors and those close to them would be driven to develop a closer bond (Little & Sayers, 2004). Death salience, however, appears to turn people inward to the inner challenges of their subconscious and unconscious minds. This explains why relationships which are close can break down after recovery from cancer (Little & Sayers, 2004).

Lichtman, Taylor and Wood (1987) interviewed 78 breast cancer patients and their significant others to evaluate their perceptions of social support after diagnosis. They found that approximately three quarters of the participants in their study reported that their relationships with family and friends continued to be supportive and warm after the breast cancer episode. However, one quarter of their research participants reported at least one troubled relationship and many more had the experience of instances of withdrawal or rejection. They further purported that within this group, strained communication was a common problem.

Research by Dunkel-Schetter (1984) revealed that 95% of participants reported receiving the same amount of love, advice, assistance and approval during treatment as before treatment from the important people in their lives. Rowland (1989) reports that cancer patients are indeed often surprised at unexpected sources of support that surface during a

crisis. She explains that sometimes a casual friend may provide powerful support that was expected from a close family member.

A thorough search of literature in the field of the psychosocial aspects of cancer indicates that limited research seems to have been conducted on the experiences of cancer patients directly after treatment, during the first few months of extended survival. However, those studies that explored adjustment after treatment have most frequently focused on experiences of breast cancer patients (Rabin, 2003; Tibbs, 2003).

Tibbs (2003) investigated the psychological adjustment and quality of life of 79 patients who were assessed at the conclusion of radiation therapy, two weeks after treatment ended and at the follow-up appointment six weeks after treatment ceased. At the end of treatment, participants reported high levels of depression, mild anxiety levels, generally high levels of hope and moderate quality of life. Depression decreased at two weeks after treatment ended but increased as the follow-up appointment drew nearer, with 29% of patients experiencing clinically significant depression just after treatment and 28% at the follow-up visit. Quality of life significantly improved with time. Women over 55 years reported lower depression and anxiety and higher quality of life when compared to younger women in the study.

Rabin (2003) examined the presence and predictors of distress among 50 breast cancer patients who had completed chemotherapy or chemotherapy as well as radiation treatment. Participants were assessed prior to cessation of treatment, one month after treatment ended and three months after treatment ceased. Results indicated that a number of patients continued to experience higher levels of anxiety in the months after treatment, although elevated levels of depression were not reported. Distress did not increase after treatment cessation. It was, however, found that negative experiences with regard to insurance, romantic partners and inadequate social support led to feelings of stigmatisation. Patients who viewed their cancer as a chronic condition were more anxious, depressed and worried about recurrence than patients who perceived their disease as an acute episode.

The objective of this study is therefore to gain an understanding of the psychosocial experiences of female cancer patients (excluding breast and gynaecological cancer patients) in the hope of developing a clearer picture of how to help such people cope after treatment, once remission begins and later. This study will focus specifically on psychological well-being and coping, specific emotions experienced as well as the spheres of family relations, social support and relationships with friends and religious affiliations.

2.4.2.3. Permanent survival research

Permanent survival occurs from about four to five years after diagnosis, when the chance of recurrence is small and the disease is perceived by oncologists to be under control. During this phase, patients have to endure the long-term effects of treatment; emotional experiences, such as fear that the cancer may return; or life complications, for instance, trying to secure permanent employment again (Mullan, 1985).

Barraclough (1999) proposes that long-term survival of cancer can be perceived as a positive life-enhancing experience, as shatteringly traumatic or as a temporary setback with little lasting impact. For many people who survive cancer, there is a constant fear of recurrence of the disease (Barraclough, 1999; Tross & Holland, 1989). Cancer survivors are necessarily very much aware of their own mortality, which brings about feelings of uncertainty about the future. This experience is known as the *Damocles Syndrome* (Koocher & O'Malley, 1981).

Although there may be no signs of cancer recurrence, survivors may take on a permanent sick role within the family (Barraclough, 1999; Bolund, 1990). This is often enabled through the dynamics of the family system (Bolund, 1990) because survivors frequently receive secondary gains through the attention and dependency they receive from assuming an invalid role (Zittoun, 1990). Cancer survivors may also experience the *Pollyanna Ideal*, when they have anxiety-driven schema which demand that they must be content and happy and should not complain. This is because they experience guilt for having survived the cancer and feel that they are living on borrowed time (Bolund, 1990).

Interpersonal relationships may also be affected due to a sense of physical weakness or disability, social withdrawal or sensitivity to possible rejection (Tross & Holland, 1989).

Tross and Holland (1989) highlight that in the past, the question of whether there were delayed psychological effects impacting on cancer patients into the cure period was debatable. However, they report that by the late 1980s, the answers to this question began to emerge as the numbers of survivors increased and studies were conducted on the general psychosocial functioning and more subtle types of psychological impairment of survivors.

Various studies have focused on long-term survival of cancer. The main body of literature in this area tends to focus on survivors of childhood cancer (Balling, 2003; Holmes & Holmes, 1975; Ostroff & Steinglass, 1996; Parry, 2003; Zebrack & Chesler, 2002). Other more recent studies focused on long-term survival of adulthood cancer like those carried out by Tomich and Helgeson (2002) and Wenzel, Donnelly, Fowler, Habbal, Taylor, Aziz, and Cella (2002) and late adulthood cancer (Deimling, Kahana, Bowman & Schaefer, 2002).

a.) Long-term survival of childhood cancer

The experience of childhood cancer may have a profound long-term psychological effect (Barraclough, 1999). Mixed findings have been reported regarding the experiences of long-term survivors of childhood cancer.

In their study of survivors of childhood malignancies, Koocher and O'Malley (1981) found that a majority of survivors experience mild mental symptoms such as anxiety and nervousness and a minority of survivors experience severe symptoms requiring therapeutic intervention. Only small increases of psychiatric symptoms like depression and anxiety, as well as social problems like divorce and unemployment were noted in young adult long-term survivors of cancer (Barraclough, 1999).

A study by Zebrack and Chesler (2002) evaluated the quality of life in 176 childhood cancer survivors between the ages of 16 and 28. Overall, they reported a generally good quality of life with their physical quality of life highest and their spiritual quality of life lowest. In terms of psychological quality of life, they rated themselves highest on their ability to cope as a result of the cancer, which supports the idea that such people can become resilient after facing a life-changing event. They also rated themselves high on happiness, feeling useful and experiencing life satisfaction. However, their hopefulness was reportedly moderated by uncertainty.

Balling (2003), on the other hand, concluded that the survivors of childhood cancer in her study were having difficulty establishing close partner relationships, but that they had a positive outlook about the future. Other themes included missed childhood and paradoxical experience of cancer. Nevertheless, Parry (2003) found that the processes of coping, healing and development in long-term childhood cancer survivors are intimately related and that deriving meaning is crucial to long-term psychosocial well-being.

b.) Long-term survival of adulthood cancer

Most literature considering the long-term psychological sequelae of cancer in adults has been gathered in the area of breast cancer. Amir and Ramati (2002) found that physical and psychological quality of life was significantly lower in long-term breast cancer survivors than in the control group. Significantly higher rates of full and partial Post Traumatic Stress Disorder and emotional distress, as well as significantly lower physical and psychological quality of life were reported in the group of survivors. Tomich and Helgeson (2002) also evaluated the experiences of long-term breast cancer survivors compared to healthy women. They found that cancer survivors viewed the world as significantly less controllable and more random and experienced less positive affect than the control group. Thus, both studies found that quality of life in long-term survivors of breast cancer is reportedly lower than in control groups.

Long-term survival may also impact on the family as a unit. Mellon and Northouse (2001) examined the quality of life of the family during the permanent survivorship

phase. A random stratified sample of 123 families was interviewed. This study highlighted the importance of addressing resources for the family such as social support and family meaning of the illness as key issues impacting on family quality of life.

Social factors also impact on cancer survival. Waxler-Morrison, Hislop, Mears and Kan (1991) explored the relationship between 133 women's social contexts at diagnosis and chances of having survived breast cancer four years after diagnosis. They found that the number of supportive persons, number of supportive friends, whether the survivors worked, whether the survivors were unmarried, as well as the extent of contact with friends is statistically important for cancer survival.

Religious factors also play a role in long-term survival. In a study by Gall and Cornblat (2002), 52 women between 39 and 70 years of age were asked to write about the role religious and spiritual factors played in their understanding of and coping with breast cancer in their own words. The majority of the participants expressed that spiritual resources played a positive role in their response to the experience of cancer. These spiritual resources included their relationship with God, religious coping activities such as prayer, the finding of meaning and social support. This study suggested that spiritual resources can assist long-term breast cancer survivors in making meaning of cancer and experiencing a sense of life affirmation and personal growth in regard to their experiences of cancer.

Due to such findings about the influence of cancer on the quality of life of long-term cancer survivors and their families, the importance of psychosocial support programmes for long-term cancer survivors has been highlighted (Spiegel 1995; Bland, 1997; Greer, 1999; Ades, Gansler & Eyre, 2001).

2.5. South African research relating to cancer and psychology

As mentioned above, a wealth of international research has been conducted which focuses on psycho-oncology. Such research has been carried out mainly in North

America and Europe. Although the number of studies conducted in South Africa around the topic of psycho-oncology is small in comparison to the sheer volume of literature emerging internationally, it is important to review South African literature as it is applicable to the South African context and way of life.

A search of South African journals and theses revealed that the most widely studied topic is that of breast cancer (Falkson, 2001; Fourie 1992; Hudson, 1999; Mertz 2000; Rubin, 2002).

Mertz (2000) examined the quality of life in patients with metastatic breast cancer from a South African perspective. Hudson (1999) and Rubin's (2002) studies, on the other hand, focused on the coping skills of breast cancer patients, whereas Falkson's (2001) research examined psychological experiences related to breast cancer and its re-emergence.

Fourie (1992) specifically focused on the nature and duration of psychosocial experiences relating to breast cancer and its treatment. A total of 45 breast cancer patients from Tygerberg Hospital participated in the study. Participants were interviewed about their psychosocial adjustment in regard to work, social life, marriage and sexual performance. Psychometric measures were also used to assess levels of depression, state and trait anxiety, feelings of hopelessness and pessimism about the future, health locus of control, self-esteem, personality characteristics, coping strategies and psychiatric symptoms. A relationship between pre-operative personality variables and post-operative adjustment was found. There was no significant relationship between post-operative adjustment and marital status, occupation, importance of religion to the patient, age, income and number of children. There was however, a slight relationship found between post-operative adjustment and religious affiliation, type of treatment received and stage of breast cancer and a significant relationship between post-operative adjustment and educational qualifications.

Studies such as that of Pillay (2001) have examined the psychological experiences of cancer patients in acute survival. Pillay (2001) investigated levels of depression, anxiety

and hopelessness in 50 adults who had been diagnosed with cancer shortly before the study. The Beck Depression Inventory, Beck Anxiety Inventory and Hopelessness Scale were used as measures of these symptoms. The results indicated that the research participants experienced significantly higher levels of depression, anxiety and hopelessness in comparison to non-clinical controls. However, studies addressing extended survival and permanent survival seem to be scarce.

Studies that focus on interpersonal issues such as the functioning of the families of cancer patients have also emerged in South African literature (Roelofse, 1987; Tharratt, 1993; Usher, 1986). Usher (1986) focused on families of childhood cancer patients, while Roelofse (1987) addressed the experiences of families of adolescent cancer patients and Tharratt (1993) examined families of adult cancer patients.

A limited amount of South African research has focused specifically on experiences of cancer survivors directly after treatment. The following research questions have been formulated that will drive this study in the hope of addressing the lack of available literature in this field:

1.) What are the post-treatment experiences of adult cancer patients in remission?

2.) Is there a pattern in the psychosocial experiences of post-treatment adult cancer patients in remission?

It is hoped that this study will contribute to South African literature addressing psychosocial sequelae of cancer, specifically in the area of extended survival research and that this study may be of value in the development of intervention programmes directed at the cancer recovery process.

CHAPTER 3

Methodology

This chapter will focus on describing the methodological framework employed in this research. Firstly, the method will be outlined. This will be followed by a discussion of focus groups as the method of data collection for this research as well as the reliability and validity of this study. The selection of participants and sampling strategy will then be delineated. This will be followed by a description of the research design and procedures. Lastly, the focus group questions, method of data analysis and ethical considerations will be addressed.

3.1. Method

Metatheoretical paradigms are all-encompassing systems of interrelated practice and thinking that define the nature of the researcher's inquiry along three dimensions, namely ontology, epistemology and methodology. Ontology defines the nature of reality and what can be known about it. The ontological foundation of this research was interpretive, since it aimed at explaining the subjective experiences of the participants. Epistemology specifies the nature of the relationship between the researcher and what can be known. The epistemological base of this research regarded the researcher as an empathic observer who was subjective and who aimed at explaining the individual experiences of the participants. The research was therefore interpretive in nature (Terre Blanche & Durrheim, 1999).

The interpretivist paradigm was followed and the methodological paradigm that followed from this was the qualitative approach. Qualitative research is that social research approach whose main point of departure is that of the insider perspective on social action.

The goal of qualitative research is defined as describing and understanding rather than precise explanation and prediction of human behaviour (Babbie & Mouton, 2001).

3.2. Data collection method: focus groups

Due to the research question being exploratory in nature and the researcher's aim of gaining an understanding of the psychosocial experiences of post-treatment female adult cancer patients and exploring whether patterns in experiences exist among a group of people, the focus group was chosen as the method of collecting data in this research. Focus groups involve group discussions exploring a specific topic (Berg, 1995; Kitzinger & Barbour, 1999; Schurink, Schurink and Poggenpoel, 1998). They are distinguished from the broader category of group interviews by the specific use of dynamic group interaction to generate data (Berg, 1995; Kitzinger & Barbour, 1999).

The focus group allows information to emerge that the researcher would not otherwise be able to access, as it allows people to create shared meaning among themselves, rather than individually (Babbie & Mouton, 2001; Bryman, 2004). It is often useful to allow participants to share their thoughts with each other, sparking off new ideas in each other and the consideration of a range of views before answering the researcher's questions (Berg, 1995; Bless & Higson-Smith, 1995). Thus, the sharing of group experiences and the reaching of some kind of consensus about the topic of research is enabled through the focus group (Bless & Higson-Smith, 1995). Furthermore, Berg (1995) suggests that focus groups stimulate synergy, which allows for far more generation of discussion and it is this group energy that distinguishes focus groups from the individual interviewing approach.

Berg (1995) proposes that focus groups are advantageous because they serve a dual purpose. Like participant observation, focus groups allow the researcher to observe the group process of interaction; and like individual interviews, they allow the researcher to gain access to the extensive content of verbally expressed views of the participants. They facilitate the construction of shared meaning and they can be conducted at a modest cost

and necessitate far less time than individual interviews (Berg, 1995; Kerr, Aronoff and Messé, 2000; Krueger, 1994; Schurink, Schurink and Poggenpoel, 1998). They also allow the moderator to probe, which can allow for the flexibility necessary to explore unanticipated issues (Schurink, Schurink and Poggenpoel, 1998).

Disadvantages of focus groups are that they are often difficult to organise due to participants having to meet at a designated place at a stipulated time and that the moderator has less control than in individual interviews (Bryman, 2004; Schurink, Schurink and Poggenpoel, 1998). It is also difficult to control dominating participants, while encouraging passive respondents at the same time (Berg, 1995). A further disadvantage is that the data are difficult to analyse, as a vast amount of data is usually very quickly generated (Bryman, 2004).

3.3. Reliability and validity

In order to improve the external validity of the research (transferability), the research setting is described in detail in the "Procedures" section of this chapter so that future researchers will be able to replicate the setting as far as possible.

Qualitative research is criticised due to a lack of criteria to evaluate the reliability, validity and significance of results. However, it is argued that qualitative knowledge is legitimised through the judgement of appropriate stakeholders, rather than through the existence of systematic research methods (Atkinson, Heath & Chenail; 1991). The researcher of this study accepts that the trustworthiness of this study cannot be realised until rigorous evaluation by other researchers in the psychological domain as well as survivors themselves has taken place.

This research has utilisation appeal in the sense that the findings will be accessible to others in a university library. The findings are presented in such a way that academic concepts have been defined and complex terms have been avoided to ensure that this research is not limited to the academic realm of readers. The usefulness of the research

was also discussed with participants and they reported that it was very useful to them as it gave them the opportunity to share their experiences. They also mentioned that it would be useful to other cancer survivors.

3.4. Participants and sampling

Patton (1990) proposes that quantitative sampling aims at representativeness, while qualitative research necessitates that the data to be collected be rich in description of experiences. This study focuses on a specific context and its purpose was to gain sufficiently rich data. Therefore, the selection of participants was purposive rather than random (Miles & Huberman, 1994). Specifically, in order to ensure rich description among the participants of this research, snowball sampling was used. This is because snowball sampling allows the researcher to gain a holistic understanding of the meanings of interconnected networks (Schurink, 1998b). In the procedure of snowball sampling, the process of referral is systematically repeated until all group members who are willing to volunteer for the study have been identified (Schurink, 1998b). Thus, prospective participants lead the researcher to other prospective participants who fit the criteria for participation. The process of referral started at an oncology centre in Benoni and with a few cancer cases in Secunda familiar to the researcher.

Schurink, Schurink and Poggenpoel (1998) suggest that the ideal size of a focus group is between six and nine participants, as a focus group should be small enough for all participants to gain the opportunity to share their experiences and insights, and large enough to provide a range of experiences. Similarly, Krueger (1994) suggests that focus groups usually involve six to ten people, but that the size can range between four and twelve participants. Bryman (2004) adds that focus groups usually involve at least four participants. A disadvantage of larger focus groups is that there are fewer opportunities for participants to speak and those participants who are more reserved may hide in the crowd, and withhold participation (Fern, 2001).

It was the researcher's aim that approximately six to nine female cancer patients who completed their treatment no more than four months prior to the focus group would take part in this study. Seven participants were recruited, but six participants arrived for the first focus group and five arrived for the second focus group.

Fern (2001) suggests that group homogeneity is most suitable if the researcher is concerned with exposing shared opinions among a population of interest. The participants were all white Christian females who were between the ages of 50 and 62 and who had completed treatment (either chemotherapy, radiation or both) not more than four months prior to the study. Five of the six participants had passed into remission and one had just completed treatment.

3.5. Design

Research design is the systematic planning of research through linking the research question to the implementation of the research (Durrheim, 1999). This research aimed at explicating the central concepts and constructs involving the post-treatment experiences of female adult cancer patients with the objective of identifying patterns in the nature of their experiences. The study was thus non-experimental in design as it did not involve an experiment involving controls. The study was in turn exploratory in purpose (Terre Blanche & Durrheim, 1999).

Bless and Higson-Smith (1995) assert that the aim of exploratory research is to obtain insight into a situation, phenomenon, community or person. Since exploratory studies usually aim at gaining insight and comprehension rather than the collection of detailed, accurate and replicable data, these studies often include the use of in-depth interviews or focus groups, the analysis of case studies or the use of informants (Babbie & Mouton, 2001). The focus group was specifically chosen above individual interviews because of the group process of interaction that would allow shared meaning to come about.

3.6. Procedures

The procedures of this research included a focus group consisting of six participants. The group met on two occasions four days apart. The same participants attended both the focus group sessions, with the exception of one participant who could not attend the second focus group session due to a family emergency.

The focus groups took place at the Swiss Ranch Conference Centre in Trichardt. A relaxed atmosphere was created through the use of an informal room overlooking gardens, which was small enough for six participants and a side table for tea and coffee (the room was approximately four by ten metres large). Privacy was maintained as the participants and researcher were the only people in the room throughout the discussion. Participants were seated around a square table so that each person could have a full view of the others and could view the interaction among all group members.

Audio equipment was used to tape-record the focus groups, so that transcripts detailing the group interactions could be typed and content analysis of the transcripts could be undertaken. Mirrors and recording equipment may result in certain group members withholding participation (Fern, 2001). It was thus ensured that there were no mirrors in the room and that the recording equipment was very small and was not readily visible to ensure comfort among participants.

Before the focus group sessions took place, participants received subject information sheets (APPENDIX A) detailing all procedures in the research process. The research topic and process were explained to each participant. Informed consent was obtained from each participant (see APPENDIX B). Consent was also obtained for the use of recording equipment (see APPENDIX C).

Participants were told when the focus groups would take place and were reminded that they could withdraw from the research at any time. Coffee and tea was provided to the participants at the focus group meetings. Each focus group meeting lasted approximately one and a half hours.

Arrangements were made for psychological counselling to be available in the event that a participant felt emotionally traumatised as a result of discussing her experiences with the rest of the group.

3.7. Focus group questions

The focus group questions were formulated according to the research aims and questions. Semi-structured and open-ended questions were utilised to avoid leading on the part of the researcher (Krueger, 1998). Certain questions were prepared, but the researcher also used probing questions based on the interaction in the group. For a list of the prepared questions, please refer to APPENDIX D. Krueger (1998) suggests that effective questions are brief, clear and logical. He suggests that clear questions are usually short, unambiguous and free of jargon. For this purpose, the questions in this research were kept short and simple.

The first question was an opening question designed to make participants feel comfortable through identifying common characteristics amongst themselves. The second question was an introductory question aimed at introducing the general topic of discussion and to provide participants with an opportunity to reflect on their experiences and connection to the overall topic (Krueger, 1998). Both of these questions served as ice-breakers and were not used in the data analysis.

These questions were followed by the key questions, which drove the study (Krueger, 1998). Since the aim of this study was to gain insight into the experiences of female post-treatment cancer patients on both a psychological and social level, questions were designed to tap into psychological and social spheres of the lives of the participants. The first two key questions were aimed at gaining data about the participant's psychological experiences, while the five subsequent key questions were aimed at gaining data about the participant's social experiences. To avoid jargon, in the first key question, the participants were asked to describe their emotional experiences rather than their

psychological experiences as it was thought that this term relates to specific terminology within the subject of psychology and therefore participants might not understand it.

This was followed by the ending questions in the form of summary questions after the researcher gave a short oral summary of what had been discussed. The purpose of these questions was to bring closure to the discussion.

3.8. Data analysis

Data were analysed by means of categorical content analysis. Content analysis involves the examining of artefacts of social communication by the researcher (Berg, 1995). Both the manifest and latent content were analysed, as codes using the literal terms of the participants as well as categories and constructs formulated by the researcher were utilised in analysing the data (Berg, 1995).

Tesch (1990) advises that there is no neat relationship between data collection and data analysis and thus, there is no right way or set of rules for analysing data. Qualitative data collection and analysis take place simultaneously (Creswell, 1994). Tesch (1990) calls the process of interpreting the data de-contextualisation and re-contextualisation as the data is first taken apart to form smaller pieces and then re-emerges as a larger consolidated picture.

The following process, which is a combination of the steps provided by Tesch (1990) and Creswell (1994), was followed in analysing the data of this research:

1. Getting a sense of the whole by reading through all of the transcripts carefully
2. Segmenting data into relevant and meaningful units
3. Categorising data segments into clusters to form topics
4. Abbreviating the topics as codes and writing the codes next to the appropriate topics
5. Formulating a descriptive word for the topics and turning them into categories
6. Trying to reduce the total list of categories by grouping similar topics

7. Formulating an abbreviation (code) for each category and alphabetising the list of codes
8. Performing a preliminary analysis
9. Recoding the existing data, if necessary
10. Higher-level synthesising of the results of the analysis

In the process of this research, the researcher simultaneously collected data from the field, sorted the data into categories and interpreted the data. The focus group data were transcribed and then analysed by means of coding.

3.9. Researcher Reflexivity

As my own mother has suffered from cancer, it was very valuable as a researcher and as a daughter to gain understandings of cancer from the perspective of the person who suffered from it. It gave me much insight into my mother's experiences and how she may be feeling as a cancer survivor.

As a researcher, I felt that the facilitation of the focus group provided me with valuable insight into the methodology of research and how it is put into practice. I also gained more knowledge and experience on how to analyse data once it has been collected.

In terms of participation, each person in the group contributed by speaking about her experiences. Generally, there were those who spoke more than others, but each person contributed to the questions. There were no participants who remained silent through any of the questions.

It was quite amazing to see how the group established its own set of group norms from the outset of the focus group. Each person took a turn to answer the question posed, without much interruption from other members. The answering progressed in order from speaker 1 to speaker 6. Only thereafter would people generally start a conversation with each other where everyone would contribute at varying times. Perhaps, it was everyone's

way of letting others recount their experiences due to the realisation of the importance of being able to be free to tell one's story and gain some sort of acknowledgement through it.

In terms of group dynamics, I found that participation was enhanced and increased through the process of listening to others' experiences. The sharing of experiences of one person seemed to spark off thoughts in others of experiences they had not shared and further sharing thus came about. Also, participants thanked me for giving them the opportunity to share their experiences with others who had similar experiences as it made them feel good to know that they are not alone in their experiences. This seems to support the claim that a shared meaning is created through the sharing of experiences in focus groups.

3.10. Ethical considerations

Various ethical considerations influenced the implementation of this research. Permission was obtained from the oncologist allowing patients to be approached by the researcher prior to the research taking place. It was not necessary to get permission from the Department of Health for this study because the oncologist in question is a private practitioner and could give permission without consulting the Department.

Ethical considerations that were addressed included seeking informed consent from the participants to participate in the study and to be audio-taped. The participants were asked to sign an informed consent form. It was also made clear to the participants that participation in the study was voluntary and that the conducting of a focus group could jeopardise confidentiality, although the participants would remain anonymous. The researcher explained each of these issues clearly and conveyed what was required from each participant and what they could expect. Furthermore, the researcher conveyed that the participants could withdraw at any point if they so wished. No pressure was placed on any of the potential participants to take part in the study and participants were assured that they would not be negatively affected if they chose not to participate.

CHAPTER 4

Results and discussion

This chapter will present the results of the data analysis and a discussion of these results simultaneously. The two research questions will be discussed concurrently as they are linked in many cases. Even though the questions in this study focused on the post-treatment experiences of the participants, they often referred to their experiences of diagnosis and treatment and these experiences were often linked. Those experiences of the participants during treatment that are indeed relevant to the findings outlined in the literature review will be described with the purpose of either validating or diverging from those findings.

The transcripts used in this study were analysed by means of coding. Several units of analysis were taken into account in the coding process. Relevant phrases, sentences and sometimes whole paragraphs served as the units of analysis.

Three levels of coding were used. Firstly, exact accounts of the participants were grouped into topics that were coded. Later, these codes were divided into categories by analysing patterns that occurred in the data (which were then coded into categorical codes) and finally theoretical constructs were derived from the categorical codes (Berg, 1995). The categories that were identified included emotional experiences, physical effects, relationships with partners, relationships with family members, social support from friends and acquaintances, social life, lifestyle, religious experiences and outlook on life.

Within each category various themes and trends were established and they were processed descriptively to generate a representation of the accounts of the group of

participants as well as patterns in these accounts. Answers to the research questions were formulated through this process.

In the outlining of the results of the focus group discussions, firstly, the emotional experiences of the respondents and the physical effects of cancer survival will be delineated. This will be followed by an outline of how their relationships with their partners and family members have been affected, respectively. Subsequently, the impact on their social support from friends and acquaintances as well as their social lives and lifestyle will be outlined. Lastly, the religious experiences of the participants and their outlook on life will be explored.

4.1. Presentation of results

4.1.1. Emotional experiences

There are various emotions that the participants experienced both during the acute survival and extended survival phases. As mentioned above, only those emotional experiences during the acute survival phase that are pertinent to the literature that has been discussed will be included, as this study focuses specifically on the extended survival phase.

4.1.1.1. Emotional experiences during acute phase of survival

a.) Shock and isolation

All of the participants agreed that it was a great shock for them when they were diagnosed with cancer as one always thinks it will never happen to oneself. This suggests that there was an element of denial in their reaction to discovering that they had cancer.

Speaker 6: …you always think it can't catch you.
Group: Yes, yes, yes.
Speaker 6: It's only, "It's not gonna get me".

Speaker 6: …you think it could never happen to you…
Group: Yes, yes, yes.

Speaker 4: Yes umm, you umm, don't think that something like that, why would you think that something like that would happen to you? I mean you live and you carry on yes, you hear of others that have cancer and yes then suddenly you realise that you are a part of them now, and umm yes, you umm, it was a shock for you. It was a shock for me. It was an enormous shock,

Speaker 5: Yes, never in your wildest dreams did you expect that, that having cancer would happen to you. It always is going to happen to somebody else, but never to you. It's very hard to come to terms with that and how you, and how to handle it is not always very easy.
Speaker 3: I agree it was hard to actually accept that.
Group: Yes, yes.

Speakers 1, 2, 3, and 6 reported that when they were undergoing treatment they felt isolated and lonely even though they had support from people.

Speaker 1: I mean we all know, nobody can do that treatment for you, and it's a lonely road you walk. On the one hand you've got all this support of your husband, but you still have to do it yourself, so it's a lonely road,

Speaker 2: …I learned that, you know, there is a part that you walk alone.

Speaker 3: It was hard for me because I was basically alone,…

Speaker 6: …it feels like I was alone.

These two emotional reactions are consistent with Kübler-Ross's (1969) stage of Denial and Isolation, where patients deny that they could have cancer and feel isolated from their loved ones. A recent study by Le Vieux (2003) involving paediatric oncology patients also revealed that one of the major themes that emerged was that patients experienced a shock when informed about the diagnosis of cancer.

b.) Anger

One out of six participants mentioned that when she was diagnosed with cancer, she went through a period of angry questioning.

Speaker 3: …and you ask questions, why did it happen to you, why, why?
There were a lot of questions: "Why? Why did this happen? Why did this happen to me?"
Then I said, "God why did you do this to me, what did I do wrong?"

The reactions of Speaker 3 correspond with Elisabeth Kübler-Ross's (1969) second stage of Anger. This anger can be seen in her asking why it happened to her and what she had done wrong to deserve it, which corresponds with Kübler-Ross's suggestion that when patients think they are going to die they ask "Why me?". However, the other participants did not mention a similar experience. This corresponds with claims by Barraclough (1999) and Buckman (1999) that Kübler-Ross's stages are not experienced by all patients. This questioning is also consistent with the Work Through Phase of Cullberg's (1975) crisis model. The patient tries to work through the treatment both physically and mentally and tires to understand the new life situation and how to come to terms with it. This often includes critical questioning.

c.) Guilt and fear of death

One of the participants mentioned that she experienced guilty feelings for not always being able to cope.

Speaker 2: …and a feeling of guilt, of course that was the worst. You know feeling guilty that you can't continue on this road sometimes,…

In the case of Speakers 3 and 6, it was mentioned that they apologised to God for doubting, implying that they felt guilt as a consequence of their doubt.

Speaker 6: I, I, I say sorry Lord that I do doubt you at times,…

Speaker 3: …I am sorry for the day, days that I doubted,…

Speaker 3 also mentioned that she had a fear of death and uncertainty about her future.

Speaker 3: You know, I feel there was a time that I, I had a fear, you know that I was going to die. You know, you feel, I wasn't sure of anything,

These experiences correspond with Buckman's (1999) assertion that patients experience certain emotions such as guilt and fear of dying, which are not included in Kübler-Ross's model. The fear of death that was reported by Speaker 3 is consistent with the Reaction Phase as proposed by Cullberg (1975) in his crisis model. In this phase the patient starts to face the reality of the threat of impending death, resulting in the basic reaction of anxiety.

d.) Depressed feelings

Four out of six participants admitted that they experienced depressed feelings after their diagnosis and during treatment.

Speaker 6: It was so easy to go the other way.
Speaker 2: …it was so easy, umm, so if I said it wasn't always easy, definitely not, there was times that you, that I wanted to withdraw myself that I umm, that you, that I was so depressed, unbelievable,…
Speaker 6 : With us all sitting here, I mean it is not an easy road, for definite.
Speaker 2: Yes.
Speaker 6: It's not easy.

Speaker 2: …I probably drank anti-depressants for three months.
…that terrible overwhelming feeling that I had - just to withdraw, it's the easiest, the easiest to do…

Speaker 3: I didn't care what happened around me, but then I, I pulled myself together…

Speaker 5: …you know, you could crawl in a corner…

These experiences of depressed feelings, withdrawal from usual activities and apathy correspond with Kübler-Ross's (1969) stage of Depression and her assertion that when patients can no longer deny their illness, they feel a sense of loss and dismay.

e.) Acceptance

All of the participants agreed that they had made peace with death towards the end of the acute survival phase, which has been carried through into the extended survival phase resulting in a feeling of acceptance of death. Even though they have now completed their

treatment, they understand and accept that cancer could recur and that it might result in their death.

Speaker 4: …and umm, I made peace if I have to go. We never know when we must go. It doesn't matter if we have to walk out here and get a heart attack or if we get bumped by a car; we don't know when our time comes; and I made peace.
Speaker 6: But, it's like you say is, is that even if mine ever comes back, I have already made peace with the Lord. That's it. I'll most probably go through it again.
Group: Yes, yes.
Speaker 6: If it's gonna be my end, it's going to be my end.
Group: Yes, yes.

Speaker 4: I realise now that if I umm, have to die then I accept it.

This is consistent with Kübler-Ross's (1969) stage of Acceptance and her proposal that when patients have had enough time to work through their emotions they will be able to accept death. However, contrary to Kübler-Ross's assertions, even though not all of the participants went through all of the previous stages, all of them did indeed reach a feeling of acceptance of death. The reaching of acceptance by the participants seems to be more in line with Buckman's (1999) assertion that each participant reacts to the possibility of death in their own way with their own characteristic coping strategies and that the resolution of those elements that are resolvable will lead to a reduction in the intensity of all emotions and the eventual acceptance of death.

4.1.1.2. Emotional experiences during extended phase of survival

a.) Relief

Four out of the six participants reported an experience of sheer happiness and relief on discovering that there were no signs of cancer in their bodies after post-treatment tests were conducted.

Speaker 2: …it's a wonderful feeling.

Speaker 1: …elation on the one hand,…

Speaker 4: …I was very happy, when I was cured…

Speaker 3: …but now I am more, you feel more joy in your heart…

Speaker 4: I was very happy. I immediately got on the phone, sent everybody I could sms's to tell them that I am cured. So it was a great joy,…

This experience of relief and happiness corresponds to the Reorientation Phase of Cullberg's (1975) crisis model, which proposes that a feeling of relief is experienced at the end of each check-up that confirms no reappearance of disease.

b.) Mixed emotions

Nevertheless, four of the six participants agreed that they have felt mixed emotions, ranging from elation on the one hand to depressed feelings on the other hand, since they had completed their treatment and discovered that there are no signs of cancer in their bodies.

Speaker 3: …you know many days you are so down and then you laugh again,…
It is, it's something terrible if they tell you, you are clean. You know I cried so much. I don't know why I cried. I should have rejoiced. I was happy.

Speaker 1: …elation on the one hand, that suits you better; but I am also kind of depressed,…

Speaker 5: …you know, you could crawl in a corner and then there were other days, and you were fine…

Speaker 2: …I am very grateful for what happened to me, but there was emotions, horrific emotions sometimes,…
…and I really went through all the emotions…

Speaker 1: Umm, on the one hand…you're sort of like fifty-fifty; on the one hand you, you're glad; well again and on the other hand you do have, you know you always have that thought in your mind that, you know, that it could come back.

Speaker 3: You know, you feel happy about that, but I am still some days, I also sometimes sit on a heap.

This corresponds with a study conducted by Tibbs (2003) which reported elevated depression and mild anxiety, yet high levels of hope at the end of treatment, with 29% of patients experiencing clinically significant depression just after treatment and 28% at the follow-up visit. It is also consistent with research conducted by Rabin (2003) which concluded that a number of patients continued to experience higher levels of anxiety in the months after treatment. However, the reports of depressed feelings by participants in this study contradict reports by Rabin (2003) that her participants did not experience elevated levels of depression or distress after treatment cessation.

c.) The "Sword of Damocles"

All of the participants expressed anxiety that the cancer could come back at any time.

Four of the six participants agreed that once they had completed their treatment, it felt as though a sword was hanging over their heads.

Speaker 1: …you always feel like there is a, like a sword hanging over your head.
Speaker 3: It's always on your shoulder, hey!

Speaker 6: …we all know when we're sitting here we have to keep on going back for, for tests. Umm, if that bug is there, then you don't know when it returns to say hello.
I just think that I must know that it can always come back. That is one thing. It can always come back,…

Speaker 4: …umm, yes, there is a sword over my head.
You never know what comes your way.

This is consistent with the Damocles Syndrome where cancer survivors are constantly reminded of their own mortality, which brings about feelings of uncertainty and anxiety about the future (Koocher & O'Malley, 1981).

Two of the participants added that in fact, they could never forget that they had cancer, which reflects the implied sword which continuously hangs over their heads.

Speaker 6: You can never forget the fact that you had it.

Speaker 2: Yes, I think that's the thing.
Speaker 6: It's impossible.

Four of the participants agreed that even though they had completed the treatment and there were no signs of cancer in their bodies, they still experienced doubts at times.

Speaker 6: …I don't know about you people, but I still sometimes have doubts as you say.
Speaker 2: Yes, yes, there are doubts of course, of course.
Speaker 5: I think it is quite natural to have doubts,…

Speaker 3: When they told me I was clean, I still had some doubts,…
…you still doubt sometimes. I know I am one of them,…

Three out of the six participants elaborated that whenever they had the slightest ailment, they feared that the cancer had returned.

Speaker 5: …when something that feels a little bit out of place, you worry. I think it is quite natural to have doubts, you think umm, you hope everything is all right, that this is not going to happen again.
Speaker 1: Well the first few weeks, when I was in remission you are inclined to overreact to every little pain you get, you know, you want to run to the doctor and I think I spent a lot more time at the doctor (laugh) first when, you know, the first few weeks after remission, you know, than I normally did. I did find that you are a bit more scared umm, anxious about things, you know little pains that you get and things that, you know, if you got colds or flu or a temperature or something, you know, you definitely are more anxious.
Speaker 3: When they told me I was clean, I still had some doubts, because I cough, which is now chronic.

Speaker 4: You, you always have it if there is a little pain here or a little pain there. Then you wonder, you wonder, did it start again or has it moved to another part, another place, in another organ? So yes, no, you have that in the back of your head, or in your subconscious, that umm, it will happen again.

These fears of the return of cancer are consistent with claims by Barraclough (1999) and Tross and Holland (1989) that there is a constant fear of recurrence of cancer for many who have entered the permanent survival phase. They are also consistent with research conducted by Zemore, Rinholm, Shepel and Richards (1989) which found that one of the

most common concerns of cancer survivors who had undergone a radical mastectomy was that the cancer would return.

d.) Loss of sense of control

Four out of the six participants mentioned that before they had cancer, they tended to be enveloped in a routine and wanted to control every aspect of their lives. However, now that they have survived cancer, they have learned that they don't possess as much control over their lives as they thought they had.

Speaker 1: Umm, I was also a bit of a control freak so for me it's, it's, my outlook, it's difficult because I realised that God is in control! You're not in control of your life. God is in control and for, for me that, that was difficult, that, to let go and let God,…

Speaker 2: I agree with that, same with me. I, you, you know the control, the control freak thing its exactly with me the same and when you're on that path you never realise that you are such a control freak. You know everything is supposed to be, and I, in my post-graduate studies…it was even worse; it was you know, I was in such a routine. I couldn't get out of that routine. It was impossible to get out of that routine. Everything was measured by that routine and umm, I know now that God knows that it was the best way to umm, give me a melanoma in my eye; not in another place, or another sort of cancer. I was reading a lot and umm, I'm still reading a lot and umm, I think it was the best way to get my attention.

Speaker 4: …everything also had to be perfect. There is routine and I realised that you have to live while you live,…
Umm, there is a God that has control and yes, it is His will that we are here tomorrow or if we are still going to do this tomorrow, and if we will do that tomorrow,…

Speaker 5: Yes, I think the hardest lesson I had to learn, after this was to accept what I couldn't change.

This can also be related to the fact that cancer survivors are reminded of their mortality, resulting in a lack of certainty about the future as well as a loss of a sense of control (Barraclough, 1999; Tross & Holland, 1989). This also corresponds with research by Tomich and Helgeson (2002), which found that cancer survivors in the permanent survival phase viewed the world as significantly less controllable than the control group.

e.) Resentment towards those who abuse their bodies

In the case of Speaker 1, it was reported that she felt resentment towards other people who abuse their bodies as she realised that one's health should not be taken for granted.

Speaker 1: …I get very angry now when I see people abusing their body, like smoking or drinking. You know I feel like walking up to them and telling them, "What you are doing is wrong. You know, you should look after your health,"…
But also I umm, I don't know if it's got to do with the previous question, but I also find that I, I get, which never worried me before, I also get quite annoyed with these skinny little ladies, that only eat lettuce leaves and tomato, when I have seen people that, because of the treatment they having, are as thin as a rake and they would do anything to be able to eat normally, so I find that, that is irritating for me.

Although no direct literature could be found which pertains to this experience in cancer patients, it is apparent that this participant is acutely aware of her own mortality as a result of having experienced cancer similar to observations by Barraclough (1999) and Tross and Holland (1989). This awareness of mortality and anxiety that cancer may return seems to have resulted in her resenting others because of their ignorance of their own mortality and their taking of life for granted.

f.) Humour as a coping mechanism

Three out of the six participants reported that they used humour as a coping mechanism after they had worked through the initial shock of the diagnosis.

Speaker 3: I have my, my way in life, you know to make jokes and…
Group: Yes, yes.
Speaker 3: …that carried me through everything, yes.

Speaker 4: …life isn't always easy, but you can laugh…

Speaker 5: and also I never stopped laughing and smiling.
Then there is that gift: you can laugh at yourself and laugh, which helps…

Speaker 3: I always make, always laugh and make jokes and go on,…

The use of humour as a coping mechanism in these participants is consistent with research conducted in paediatric oncology patients which revealed that they make use of humour as a coping mechanism (Le Vieux, 2003). Similarly, in this study, patients revealed that they used humour only after they had come to terms with the fact that they had cancer and absorbed the vast information they had received.

4.1.2. Physical effects

Five of the six participants mentioned that since they had survived cancer they experienced certain physical effects, either as a consequence of the cancer, its removal or the treatment. These physical effects had an impact on their quality of life.

Speaker 6 and Speaker 2 mentioned that they could not go into the sun as a result of the effects of the harsh treatment on their skin and Speaker 3 mentioned that the chemotherapy resulted in the numbing of sensations in her fingers and problems with circulation in her legs. Speaker 3 also mentioned that the chemotherapy caused hair loss.

Speaker 6: I love it; I love the sun, and now I cannot go into the sun, so that has changed my life, to think you're at the coast and you can't go in the sun. I had to wear a hat and I hate a hat! So, it has changed my life.

Speaker 3: I was worried that you all have your nice hair, and I don't…
Speaker 5: Yes with chemo you see many women without hair, a lot, a lot, a lot.

Speaker 2: I am also not allowed to go into the sun,…

Speaker 3: Now my hand is, my fingers here are half-dead. They say it is because of the chemo, and my circulation to my legs, I don't know, they say it's because of the chemo…

Speaker 3 mentioned that she has developed a chronic cough due to the effects of the cancer on her lung tissue.

Speaker 3: Of course, I developed a cough, for years, for years, but then I asked them and they said the lymphoma on my lung probably did some damage…
Then she said, "No it is umm, it is, they can't fix it," and that I just have to live with that. No, it is nice if you can say that you are clean and to share that with other people I am happy.

Speakers 4 and 5 reported that because of their operations to remove cancer from their colons, they have experienced problems with regard to incontinence, which causes them embarrassment.

Speaker 5: And I must say, I've got this belief that I'm cured, but I've got one disadvantage that goes with colon cancer, which could be very embarrassing, terrible. You're either constipated or you've got diarrhoea, so that when you socialise you've got to be very, very careful. You cannot plan ahead. That is quite something to live with.

Speaker 4: The small intestine is a sensitive organ, it is very sensitive to some foods that you eat, yes, and you are a bit, umm it is not always easy for you to be in public,…

This is consistent with the assertion by Mullan (1985) that the phase of extended survival may involve physical problems resulting from the removal of bodily tissue, or side-effects of treatment.

4.1.3. Relationship with partner

Four main themes came out of the discussion around how the participants' relationships with their marital partners were affected after treatment. The husband of one of the participants is deceased and therefore, she did not contribute to the discussion on this topic.

4.1.3.1. Support

Four out of the five participants that contributed to the discussion reported that their husbands provided ongoing support.

Speaker 1: Right, umm my husband was always very supportive. He's been my rock. He's always been supportive…

Speaker 2: I have an unbelievable, a wonderful husband, and he was just there….He was just there for me umm, all the time,
…there was never an issue that he was too busy, and he is very busy…

Speaker 4: Yes, umm the support that I got from my husband, it was, it was terrific, umm and umm, I also think that he now realises that now that I am in remission, that support is umm is still important. It is not gone. It didn't disappear.

Speaker 5: Yes, I must say, my husband is very supportive, he was always there for me,…

The general trend of supportive experiences among the participants in this study goes against the trend reported in research conducted by Rabin (2003) of negative experiences with regard to participants' romantic partners.

4.1.3.2. The importance of support

Four of the five participants that took part in the discussion also mentioned that they are thankful for the support they received from their husbands, as they believe it would be very difficult if they did not have that support.

Speaker 2: That is a very important thing, that you really need that support…
Speaker 1: I was fortunate in the support that my husband gave me, and I say, I think it must be difficult for people, that had no support.
Speaker 5: Yes, I agree that it must be extremely difficult if you've got no support. I sometimes think about it and I wonder how people get through it, because with all of the love and the support you have and being closer to your husband it is still difficult, so I sometimes spare a thought for those who did not have what I have.
Speaker 4: …and you get that support that you always get, and been used to all those years, that you appreciate it much more than you realise.

Similar to these participants' statements, findings by Pistrang and Barker (1995) suggest that the partner plays an important role in the adaptation of their participants to breast cancer within a year after diagnosis.

4.1.3.3. Lack of support

Only one out of the five that took part in the discussion around their relationships with their marital partners reported that her husband has not been very supportive.

Speaker 6: I'm the odd one out… He was in denial from the start. He was very much in denial, still is not very supportive.
I wonder with me, with my husband or ex-husband that is in denial. I think it's people, it's the way they grew up as children and, and they find that very difficult. They don't have to say sorry or ask you how you're feeling or you know, they rather stay quiet.

The reported denial and withdrawal experienced by the husband of Speaker 6 relates to Barraclough's assertion (1999) that relationship problems may arise during the acute phase of survival because of communication barriers that impede open discussion about cancer. It seems that since Speaker 6 found out that she had cancer, her husband withdrew his support and was unable to talk about it, resulting in tension between them which has been carried through into the extended phase of survival.

Another possible explanation for the breakdown of communication in their relationship is that the husband of Speaker 6 might have experienced death salience, which appears to turn people inward to the inner challenges of their subconscious and unconscious minds (Little & Sayers, 2004).

4.1.3.4. Closer bond with partner

Three of the five participants reported that the experience of cancer has brought them closer to their husbands.

Speaker 4: We moved closer to each other…

Speaker 1: Umm, I think that also draws you closer, I mean that crisis draws you closer together with your husband. It did with me,…

Speaker 4: It's still there, it's as if umm we are closer to each other, and umm that he probably also realises that I could just as well not be there.

Speaker 5: …and being closer to your husband…

Two of the participants mentioned that their experience of cancer has resulted in a greater mutual appreciation between husband and wife.

Speaker 4: …much more appreciation for each other,…
We never know when is our time and we have to appreciate each other much more,…

Speaker 1: …this also again, again makes you appreciate the kind of husband you've got, and the support that you've got,…

These experiences relating to the development of a closer bond with a spouse after cancer survival relates to terror management theory that predicts that people who are made aware of their own mortality will seek to boost their self-esteem through strengthening their social bonds to buffer the anxiety they feel (Little & Sayers, 2004). Thus, mortality salience predicts that cancer survivors and those close to them would be driven to develop a closer bond (Little & Sayers, 2004).

The experiences of a closer bond and greater appreciation correspond with reports by Barraclough (1999) that her research participants gave accounts of taking responsibility for the fulfilment of their own goals in life and an increased appreciation for life.

4.1.4. Relationship with family

Various themes emanated from the discussion on how the participants' relationships with their families were affected after treatment.

4.1.4.1. Support

Five out of the six participants reported that their family was supportive.

Speaker 5: My whole family is really supportive.

Speaker 1: …they were very supportive you know, of the whole, whole thing,…

Speaker 5: Yes, I can honestly say in a time like this or a time like that, then you really thank God for a family.

Speaker 3: I had, they phoned me a lot to congratulate me. They came to congratulate me. It was very happy, you know, everybody was happy for me,…

Speaker 4: …umm you say thank you that you have family in this time.

Speaker 6 particularly mentioned that although her husband was not very supportive, her son provided her with emotional support.

Speaker 6: On the other hand, I have a son and he was with his mother all the time. It's one good thing, hey.

This is consistent with research by Lichtman, Taylor and Wood (1987) that found that approximately three quarters of the participants in their study reported that their relationships with family continued to be supportive and warm after the breast cancer episode.

4.1.4.2. Lack of support

In the case of Speaker 2, however, it was mentioned that her son was not very supportive and thus went against the trend of support in the families of the other participants.

Speaker 2: …he went in total denial, he didn't want to talk about it. It doesn't happen to his mother,…

It was so bad for him that he couldn't even ask me umm, how I feel, so he just ignored it.

…he was sort of in, you know total denial.

Both Speaker 2 and Speaker 6 agreed that it is difficult to live with a family member who is in denial.

Speaker 6: …it's, it's, it's hard to live with a person that is in denial, you know?
Speaker 2: Yes, for me it was very difficult…

Similarly, Lichtman, Taylor and Wood (1987) found that one quarter of their research participants reported at least one troubled relationship and that many more had the experience of instances of withdrawal or rejection. They further purported that within this group, strained communication was a common problem. Furthermore, reports from Speaker 2 and Speaker 6 that it is difficult to live with a family member who is in denial corresponds with research conducted by Manne and Glassman (2000) which reports that unsupportive responses from spouses and other family members can be associated with psychological distress in cancer patients who are undergoing treatment.

4.1.4.3. Closer family ties

Both Speaker 1 and Speaker 4 mentioned that their experience of cancer has resulted in them developing a closer bond with their family. Both of these participants earlier mentioned that they also moved closer to their husbands.

Speaker 4: …even, umm the children as well, umm there, there is a much closer bond now between the children and the mother and father. Umm there always was a good bond between all of us, but I think we moved a lot closer to each other.

Speaker 1: I think it definitely draws one closer together in a time of crisis like that, umm you know, with my sisters and my whole family it definitely draws you closer together as a family and I think it does improve your relationships with your family.

This finding is consistent with the results of research conducted by Zemore, Rinholm, Shepel and Richards (1989) which concluded that many breast cancer survivors in the acute and extended survival phases reported closer family ties. This also corresponds with work by Little and Sayers (2004) that purports that mortality salience predicts that cancer survivors and those close to them would be driven to greater closeness.

4.1.4.4. Open communication

Two out of the six participants mentioned that family members were more open about their experiences once the treatment ceased.

Speaker 2: He, he talks to me much easier now, much easier about everything.

Speaker 4: Umm yes, I think the children and the family, they had more courage to talk to you, you know, to talk to their mother, not that they didn't have it, but they just had more courage to talk personally, personally about mother's problems and stuff.

The lack of communication experienced during treatment corresponds to Barraclough's (1999) argument that relationship problems may arise because of communication barriers that hinder open discussion around cancer during treatment. Similarly, Rowland (1989) warns that a person who has a close family may find that support falls away during illness as stress felt by both the patient and the family may result in withdrawal of support and realignment of relationships, but that once the threat of cancer and the stress attached to it subsides, relationships may result in the subsiding of communication barriers and more open support.

4.1.5. Social support

4.1.5.1. Support from genuine friends

All of the participants agreed that their genuine friends had continued to support them throughout the treatment process and after the treatment ceased.

Speaker 2: I really got that support from day one…

Speaker 6: I have these wonderful people that… really there is a continuation of, of being there for you.
Speaker 2: I've found exactly the same with mine.

Speaker 1: …others were very supportive and those were the ones that you stuck to…

Speaker 4: Now that they know I am cured, it is still the same, still the same support, the same interest every day, to hear how it is going and so yes, no, it didn't change.

Speaker 3: …those that stood with me, they stayed with me all the way with my treatment and everything even when I was well.

Speaker 5: By the grace of God, all my genuine friends never changed, they are still the same. They are still as caring as they used to be.

This corresponds with research by Dunkel-Schetter (1984) that found that 95% of participants reported receiving the same amount of love, advice, assistance and approval during treatment as before treatment from the important people in their lives. Lichtman, Taylor and Wood (1987) found that approximately three quarters of their participants reported that their relationships with family continued to be supportive and warm even after their breast cancer episode, which supports the evidence above that support continued into extended survival.

4.1.5.2. The importance of social support

Four out of the six participants admitted that social support is crucial in helping them through their experiences.

Speaker 2: …and as speaker one said, you know there is definitely those people that are there for you, and I concentrate on them, but you need them, you need them, you absolutely need them,…

Speaker 5: …but all my friends are there and the support I got from them, I think that was the main thing that carried me through,…

Speaker 3: I can't complain. I have a lot of people that support me, many, many people. Strangers supported me, still support me and that is why I can carry on.

Speaker 1: I still think that the support and umm, which you get from, from friends is very important,…

These experiences are consistent with the results of a study conducted by Blanchard, Albrecht, Ruchdeschel and Grant (1995) which reviewed literature around the relationship between social support and psychosocial adaptation and survival in cancer patients between 1987 and 1993. This study found that social support was posited by many studies as having a buffering effect of cancer patients. Furthermore, Waxler-Morrison, Hislop, Mears and Kan (1991) similarly found that the number of supportive

friends as well as the extent of contact with friends is statistically important for cancer survival.

4.1.5.3. Closer relationship with friends

Two out of the six participants also mentioned that they are even closer to those friends who supported them through their experience of cancer.

Speaker 1: I think the friends that supported you, through the crisis, you are much closer to. Some friends, I, I wasn't that close to them, but they really stood by me through my treatment, and that's improved my relationship with those people. It's drawn me to, closer to, to certain friends,…

Speaker 4: Yes, umm the friends that stood with me through my time of crisis, did umm, are still just as close to me, even closer, umm still care just as much.

The experiences reported by these participants are consistent with the results of research conducted by Little and Sayers (2004) that purports that mortality salience predicts that cancer survivors and those close to them would be driven to greater closeness.

4.1.5.4. Avoidance during treatment but willingness to continue friendship after treatment

All of the participants agreed that a lot of friends avoided them when they had cancer, but now that they have completed treatment, these people are friendly again.

Speaker 1: …a lot of people avoided you… and when I went into remission they were fine you know, you're fine, you're well, you look okay, so we will go on with you.

Speaker 5: The old saying, the fair weather friends, applies. You certainly discover that very quickly - who are your genuine friends and who are not your genuine friends.
Speaker 1: …but when you're in remission everybody is your friend (laugh).
Group: Yes, yes, yes.

Additionally, they all agreed that they realise that the friends who avoided them feared approaching them because the subject of cancer scares them.

Speaker 2: They're really scared because they don't (laugh) know how to approach you, how to talk to you…
Speaker 6: It is, I know.

Speaker 1: Umm, as I've said earlier on, I found that friends, you scare them. I mean you scare them that you had cancer and they stayed away from you,…

Speaker 1: …and now that I am in remission everybody's friendly again.
Group: (Laugh) Yes.
Speaker 1: Because I don't scare them anymore.
Speaker 2: It's exactly that!
Speaker 1: Yes.
Speaker 5: Yes I can say the same,…
Group: Yes, yes.

Speaker 1: People who you thought were your friends and that, that you were friendly with - you can quickly see who can't handle a crisis.

Both Speaker 1 and Speaker 3 related that they can understand why their friends avoided them, but on the other hand they expressed resentment because of their friends abandoning them when they needed them most.

Speaker 1: And those, those friends that you thought would support you, and for whatever reason (look I, I understand the fear, you know, that they experienced) those ones that you thought would support you and didn't, I don't always feel the same about them.
Speaker 3: I agree with her. I also experienced it.

Speaker 1: …they are frightened of you even though they, they want to come and visit. They are frightened to come and visit you. They don't know what they're going to find and so I must say I understand that, but on the one hand you also resent them for that, because when you needed them, they were too scared to come and see you, but I do understand that they were scared.

These experiences are in line with claims by Rowland (1989) that close friends often avoid the patient and withdraw their support during illness. Similarly, Silver and Wortman (1980) report that although others are able to approach sick people, they

respond by avoiding them. The disappointment in withdrawal from friends is especially painful for these patients even when they can discern the reason for the response. The stress that is felt by both the patient and the friend during illness thus often results in realignment of interactions (Rowland, 1989). This is evident in the fact that although the participants realise that their friends avoided them out of fear and stress, now that they have survived cancer, they feel some resentment towards the friends who abandoned them and the relationship is no longer the way it used to be.

4.1.5.5. Unexpected reactions from people

One of the participants also mentioned that the reactions that she got from people were unexpected. Some friends whom she expected would support her did not and others, from whom she did not expect support, gave her support.

Speaker 1: But I did find socially that a lot of people, that I thought would come to my aid, didn't and strange enough it's people that you least expect. Strangers you know, they come to your aid, but the people that you actually think will, don't;…

The experience of unexpected reactions from people can be related to reports by Rowland (1989) that cancer patients are often surprised at unexpected sources of support that emerge during a crisis. She elaborates that sometimes a casual friend may provide powerful support that was expected from a close family member.

4.1.5.6. Stigma

The entire group agreed that there is a stigma attached to having cancer. Some people tended to gossip about what the participants might look like after the treatment, while others were surprised that the participants looked normal when seeing them after treatment.

Speaker 1: Umm, I found that with certain friends, they, they there is definitely a stigma attached to cancer…

Speaker 2: …there was a lot of stories going around…you know it was: my eyes are going black, I am totally blind, you couldn't believe it, it's like something out of a sci-fi film, you know. So people tend to…
Speaker 6: Yes they just add to that.
Group: Yes, yes, yes.
Speaker 6: They make a hell of a big thing of a…
Speaker 2: …of this small thing,…
Speaker 4: Yes, people see me and they are astonished, "Oh, but you look good" you know,…

Speaker 2: So there was quite a lot of people that told me, especially in Johannesburg umm, "We thought that you would look different."

All of the participants in this study agreed that they experienced problems related to the stigma of having had cancer. These experiences correspond to findings by Rabin (2003) that 50 breast cancer patients in the extended survival phase reported inadequate social support and stigmatisation and slightly less consistent with findings by Zemore, Rinholm, Shepel and Richards (1989) stating that less than 10% of breast cancer survivors in the acute and extended survival stages in their study experienced problems resulting from the stigmatising effects of cancer.

4.1.6. Social life

4.1.6.1. Less concern with trivial matters

All of the participants agreed that those people who are concerned with trivial matters tend to irritate them and they now prefer to spend time with people who have profundity and insight into meaningful things in life. This is because they realise that life is short and consequently they want to build a life that is as meaningful as possible.

Speaker 1: …socially I've also become more discerning with people. Umm before I got sick I was more prepared to spend time with umm people that didn't have any depth than what I am prepared to now. Now, I'm more discerning with people. I only, well I don't only but, I try and spend time with people that have depth and have meaning in my life, not vacuous airy fairy people because they irritate me more now.
Group: (Laugh) What can we say? Yes, yes.
Speaker 4: No I agree, I agree with her, it is like that. You, you try to spend more time with people, that umm which see the deeper things in life, be with them and spend more time with them. It is like that, like

she said, others irritate you, it's true, because there is deeper things in life, and life is short, just so short, and there is more important things in life, not just to let life pass you by.

These experiences correspond with reports by Barraclough (1999) that the majority of participants in her study of outlook on life during extended survival stated that since their survival of cancer, they have had less concern with trivial matters. This explains why the participants in the current study might have experienced irritation with those people who are indeed concerned with trivial matters.

4.1.7. Lifestyle

4.1.7.1. Trying to carry on as usual and feeling pressurised to do more

Four out of the six participants mentioned that they tried to carry on as normal after treatment, immediately trying to get back into the swing of things.

Speaker 4: Yes, my life goes on, like I said I live while I live.

Speaker 2: I just went on with my social life.

Speaker 5: …on my good days, yes I (laugh) go out and do the best I can.

Speaker 3: It's not always easy, but you go on.

Speaker 2: I went for a walk with the dog and started straight away with my classes, and went on with my life.

Three out of the six participants revealed that they have even tried to do more in their lives since they survived cancer because they feel they have to make the most out of the time they have.

Speaker 3: You know, then I realised, I can also do more, but you know it was very nice. I, I was never really a social person, you know, you didn't go everywhere, but I make the best of what I get.

Speaker 1: Umm socially I think I feel more, umm not under pressure, but I, I feel like I want to do more, whereas before you, you, you know, you were inclined to be, well, I was inclined to be a little more laid back. But now you feel almost under pressure. You must be doing things and I, I'm doing more things because you realise almost that there is, well not an urgency, but you want, you don't want to waste your life basically because you realise that life is short.

Speaker 4: …life is short, and I realised that you have to do what you can, enjoy what you can, every day, umm, umm what you can enjoy. You have to enjoy, and I do that. I think I do it now more (laugh), to enjoy life and to enjoy things and to do things, to go out and to come and go. They even tease me now. They say they never know when I am home. They don't know when to come and visit (laugh) because I am never at home anymore (laugh), but yes just as a joke, yes umm enjoy that, you have to enjoy it, every day.

…go and enjoy it; enjoy it like God would want you to enjoy it: conversations with people, enjoy people's presence and I realised that we need each other, we need each other in prayer, support, visits, make more time for each other, get together more often as a family for instance, enjoy each other while we are alive, we only live once, so enjoy it! …. you have to enjoy that what God gave you, every day!

This is consistent with findings by Barraclough (1999) which purports that the majority of breast cancer survivors in the expended phase in her study reported that they tend to take responsibility for the fulfilment of their own goals in life. However, it seems that the participants in the current study are taking the responsibility to carry on with life as soon as possible, with some undertaking to achieve more and do more, as they are acutely aware of their mortality and may feel pressurised to do as much as they can in the time they have. This can be related to literature on the topic of the Damocles Syndrome (Koocher & O'Malley, 1981) as it appears that the participants are driven by their anxiety that cancer might return at any time, possibly resulting in their death, thus imposing urgency to realise their goals and try to enjoy life every day.

4.1.7.2. Health consciousness and avoidance of stress

Three of the six participants mentioned that they are more health conscious after surviving cancer.

Speaker 1: Well I think I try to be more health conscious. You know, before you got sick, you didn't really, well I didn't really think about your diet or this or that, but since I've been sick, I, I, I think I definitely try to be more health conscious than what I used to be.

Speaker 4: Yes umm, I agree with the previous speaker that umm, umm you umm get more health conscious, and I got a lot more health conscious, I was actually very health conscious but I think I am much more careful about what I eat and what I consume, and what I am not allowed to eat, so yes, I am much more health conscious.
Speaker 3: I agree, I am also more conscious about what I eat. There was a time that I almost didn't eat. It was very hard to eat, but then I had umm, approached a doctor, that tells you what to eat and I ate more health consciously and I eat a lot better now and look at what I eat.

Three out of the six participants mentioned that since they have survived cancer, they have tried to avoid stress, although it is difficult to completely eradicate stress from their lives.

Speaker 4: …but also to put less stress on myself. I try to avoid things that cause stress. Yes, that is part of umm cancer, stress, so you try to avoid things that cause stress.
Speaker 5: That is very difficult (laugh)…

Speaker 4: It is not easy (laugh).
Group: (Laugh)
Speaker 4: It's not easy, but there is just some things that you sometimes stress too much over, unnecessarily attract, that you can try to umm, to avoid. You tell yourself, no you shouldn't draw it to yourself, but umm to live totally stress free is very hard (laugh).
Speaker 1: I agree, it is; you, you try to avoid stress, but somehow it does follow you around,…

These endeavours to be more health conscious and avoid stress correspond with experiences in the Reorientation Phase of Cullberg's (1975) crisis model where people who encountered a crisis like cancer re-evaluate their lives in the past and what they want from the rest of their lives after tests that reveal that they have survived cancer. It appears that the participants have re-evaluated their past stress and eating habits and would like to change these factors so as to avoid cancer in the future. This can also be related to the Damocles Syndrome (Koocher & O'Malley, 1981), as the participants

might be driven to avoid stress and become more health conscious because of anxiety that the cancer may return.

4.1.8. Religious experiences

4.1.8.1. Relationship with God

All of the participants agreed that they would not be able to get through their experiences during and after treatment without their relationship with God.

Speaker 1: I also think that if you don't believe in God, I really, I don't know how you go through with that…

Speaker 2: …I, I think, I never went through this without my religion. It would not be possible.

Speaker 3: …but with God's help, I went through it…

Speaker 4: …but with God nothing is impossible.

Speaker 5: …without God's help I would not have been able to do it,…

Speaker 6: …I agree with you if we don't have the Lord on our side there is no way we come through this,…

Speaker 3: Then afterwards I realised, I did not walk alone, I have these footprints in the sand you know what, I read it and then I said, I didn't walk alone, and it's funny; I accepted it.

Two out of the six participants also mentioned that they pity those who do not have any religious convictions, as they don't believe they would have coped if they did not have a relationship with God.

Speaker 1: …and I always look at the people when I go for my tests and when I was having treatment and always, always used to think if you haven't got God in your life, I don't, I don't think you'll make it.
Speaker 4: I want to agree with her. I can't think that you can walk this road without God. It, it, for me it is impossible, so I don't know, it's just that, it is impossible, but with Him on your side you can.

Speaker 1: I just think that umm cancer patients that don't have belief in God, in a higher power, they are really at a disadvantage. They don't know what they are missing.

These findings are contrary to research by Zebrack and Chesler (2002) who evaluated the quality of life in one hundred and seventy six permanent childhood cancer survivors. Overall, these survivors reported that their spiritual quality of life was lowest out of a number of different facets of their lives.

4.1.8.2. Finding meaning in illness through religion

Three out of the six participants demonstrated that they have found meaning in their illness by saying that they believe that there is a divine purpose in their having had cancer.

Speaker 4: …I know umm, God has a goal with that, umm to be witnesses for Him.

Speaker 2: Umm I was very busy, too busy. Sometimes I know, I know that I think God…it was the only way that He could get me to stand still and to listen to Him.

It was good for me and I think walking that path and believing, umm, that it is His will; that was very important for me to, that I'll be cured to go on with His work,…

Speaker 4: God put it on your road, "Why, I don't know?" I think it is to always be positive, to be more positive in your life, so people can see that and you can talk to them about it and that they can also be positive.

Speaker 2: …I know now that God knows that it was the best way to umm, give me a melanoma in my eye; not in another place, or another sort of cancer…and umm, I think it was the best way to get my attention.
Speaker 5: Absolutely,…

This corresponds with searching for the meaning in illness and the meaning of life in the Reorientation Phase of Cullberg's (1975) crisis model. It seems as though half of the participants in this study found meaning in their illness through religion, which has given them a purpose and an answer to what it is that they want to accomplish in their lives in

the future. It is possible that after future check-ups that they may experience a repeated work through experience where they will again engage in questioning in order to find meaning and purpose in their lives.

4.1.8.3. Social support from religious institutions and their members

The entire group revealed that they have a good social support structure, including churches and people at church whom they don't know very well.

Speaker 1: People that I didn't know asked me how I was and how it's going and the church was very supportive, so I've found the social structure was very supportive.
Speaker 6: I've found exactly the same, from strangers, church people that I don't know, different kind of churches, so I've had exactly the same.
Speaker 3: I also experienced the same as they did, churches, different church people that pray for me, my visits, it was great,…

Speaker 4: …everywhere where you go and if you talk to someone, they say, "Remember our group is praying for you," or "Our church is praying for you; every Sunday there is a prayer," so yes, there is a lot of good support over the whole country for people.
Speaker 2: …we belong to a cell group, and they really pray for me, you know, since the day of the diagnosis umm, onwards umm up to, to, to this time now…You're much better now but they still go on…
Group: Yes, yes.
Speaker 2: …and that is a very important thing.

The entire group also agreed that it is very important to them to receive social support and that the social support that they have received has had a positive impact on their lives.

Speaker 5: Yes, I think the fact that people still support you now and pray for you, makes a very big change in your life…
Group: Yes, yes, absolutely.

Speaker 2: So umm, that is a very important thing that people just go and never, there's, they never end in their praying for you.

The findings of the previous three themes of a "Relationship with God", "Finding Meaning in Illness through Religion" and "Social Support from Religious Institutions and their Members" are consistent with research that was undertaken by Gall and Cornblat (2002) which examined religious experiences of long-term breast cancer survivors. Similarly, the majority of the participants in the above-mentioned study discussed the positive role of a number of spiritual resources including a relationship with God, religious coping activities such as prayer, finding meaning through religion and social support.

4.1.9. Outlook on life

4.1.9.1. Positive outlook and finding meaning in illness

Three of the six participants elaborated that their experience of cancer has changed their outlook on life. Speaker 2 and Speaker 4 specifically mentioned that it led to a positive outcome and that they feel that there was some purpose in their having had cancer.

Speaker 4: It's not always true that if you have cancer it is your end. It might be a new beginning of life.

For me it became a better life, it's better for me. I have a better outlook on life, umm more positive, umm I try to make people more positive that are negative. I think that is it. I always say you, you…everything happens in your life for a reason. Nothing happens without a reason,…

Speaker 2: …if you smile to somebody, or talk to somebody, or just help somebody in any way while you have cancer, that is a mission, it's a mission for me.

Speaker 4: I think it is to always be positive, to be more positive in your life, so people can see that and you can talk to them about it and that they can also be positive. Nothing happens if it shouldn't,…

Speaker 2: So my outlook on life changed dramatically…
Speaker 1: All right, my outlook has changed, umm, I agree with speaker two.

This positive change in outlook is consistent with Barraclough's (1999) research, which points out that the experience of cancer can have a positive impact on the psychological and social well-being of the extended phase survivor. The majority of participants in her

research reported positive aspects in their outlook. This finding is also consistent with the results of research conducted by Zemore, Rinholm, Shepel and Richards (1989) which concluded that many breast cancer survivors in the acute and extended survival phases reported a more positive outlook on life.

The finding of meaning in their illness in the cases of Speakers 2 and 4 is consistent with the re-evaluation of life and the search for the meaning of life that patients experience in the Reorientation Phase of Cullberg's (1975) crisis model.

4.1.9.2. Focus on the present

Three out of the six participants said that ever since they survived cancer they are trying to live one day at a time, thus focussing on the present.

Speaker 1: I think one thing that's…you try and live one day at a time, but it's not always that easy.

Speaker 3: I can only live from day to day. I have to live from day to day.

Speaker 1: …basically you have to try live one day at a time, because you don't know what the future holds for you.

Speaker 4: …but yes, you live from day to day.

Barraclough (1999) points out that in her research on 155 breast cancer patients two years after diagnosis, the majority of the survivors reported that they had the ability to focus on living in the present. Similarly, half of the participants in this research study agreed that they try to live one day at a time.

4.1.9.3. Uncertainty of the future

Three out of the six participants mentioned that they could not plan ahead as they did not know what the future holds and certain physical ailments sometimes prevented them from doing what they would like to do. Speaker 1 specifically revealed that she had to let go of the life she had planned and that she experienced this as a loss in her life.

Speaker 5: You're either constipated or you've got diarrhoea, so that when you socialise you've got to be very, very careful. You cannot plan ahead. That is quite something to live with. You cannot plan ahead because the day when that comes to you, there is no way you can move out of your back door, never mind your front door.

Speaker 5: Yes, we cannot reserve a holiday a year ahead, because you are not sure what is going to happen in the coming year.
Speaker 3: I also don't plan ahead, because I can't.

Speaker 1: I had to let go of the life that I had planned…

Speaker 4: Yes, umm yes, you realise now that umm, you can't really plan ahead.

Speaker 1: And I think basically one of the hardest things for me was, you know, letting go of a life that you have planned, because you plan this and you plan that, retirement and this and now you realise, it brings into perspective, having an illness like cancer…

Barraclough (1999) states that cancer patients' experiences during the acute survival phase can be understood in terms of loss or threat of loss in the future. However, it seems as though this loss extends into the extended survival phase for some survivors. Half of the participants who took part in this study experienced a loss in the sense that they were unable to plan things in advance because of uncertainty about the future and because of the physical effects of the cancer. One participant also experienced a loss of the life she had planned because now she may not realise all her previous goals.

4.1.9.4. Greater appreciation of life

All of the participants mentioned that they have a greater appreciation of life. Speaker 2 particularly mentioned that she became more appreciative of life, because before her illness she was so busy that she tended to neglect things that were important to her. Speaker 1 mentioned that she began to notice and appreciate the smaller things in life. Speaker 5 specifically disclosed that she discovered things that she had overlooked in the past and that she learned to appreciate these things.

Speaker 2: You know it's just that rat race that you just got in and you just never realise that you got into that rat race and then it's a rat race. It, it's just a big part of your whole life. So my outlook on life changed dramatically, and when I said that it's small things, sometimes very small things, umm to look at my children, my family, to appreciate everything from the smallest to the biggest, much more; umm and I am actually very glad for that.

Speaker 1: …I agree with speaker two. I have an appreciation for the small things in life. I appreciate the moon and the sun shining, that kind of thing.

Speaker 5: Yes, I have discovered that this is still a wonderful world, with a lot of wonderful people in it, I think I've learned to smell the roses and you see what a beautiful colour they are.
…you really appreciate the little things you took for granted before.

Three out of the six participants elaborated that before their experience of cancer, they took important things for granted that they learned to appreciate, for example, family, holidays, nature and milestones in their lives. They also mentioned that in addition to being more appreciative of life, they were also more thankful to be alive.

Speaker 5: You know, tomorrow when you get up and you are alive, you say hallelujah, thank you that we are still alive.

Speaker 1: Yes, you definitely umm appreciate things more, because before you, before cancer you used to, I used to appreciate things but you take a lot for granted and I think once you get sick like that, you appreciate everything when we go on holiday I say thank you Lord that I am here. When my children come home for the weekend, I say thank you Lord that we can spend time together as a family, whereas before that, I took, well I think I took a lot for granted. It makes you not take things for granted, you definitely appreciate things more - holidays, and family, and little things that you never thought about before, that makes you think about that now.

Speaker 4: Yes, I agree with her, umm it is the things that we take for granted that we see now and appreciate every day, what we took for granted every day, the coming and going of children for example, to you for the weekend, togetherness of a family, umm you took it for granted. You are a family and you are together, but now you appreciate it much more. You think about that. It is a special day, it's a special day to be together as a family, umm and like she said also to go on holiday, umm yes its, its, its like that you always take everything for granted and yes after you have been diagnosed with cancer, you realise that it can just as well be taken away from you, and then you begin to appreciate every little thing in life and don't just take it for granted.

Speaker 1: Yes, no, you definitely appreciate milestones in your life, like before, you know, I mean you know how it is when you get this "Oh another birthday" but now I say, "Oh another birthday!" I'm so happy that I'm here for another birthday and you definitely appreciate birthdays and Christmas and anniversaries, whereas you, you, you used to take it for granted; you just thought it will always be there, but it makes you more aware of that.

Speaker 5: …you just thank the Lord at the same time that you feel better and that you can take part in life out there, as a couple of months before you weren't sure whether you were going to be able to live.
I see the Spring again, I love nature and love roses and I love flowers, beautiful trees and I just said thank you Lord I am here another Spring to see the green leaves on the willow trees, to see the roses bloom.

These experiences are consistent with Barraclough's (1999) assertion that the majority of her 155 research participants reported an increased appreciation for life and the taking of responsibility for the fulfilment of their goals of remembering not to take important things for granted.

4.2. Concluding discussion

The main findings of this study will now be presented and a critical discussion of the results will be conducted. As this study is exploratory in nature, many of the findings that are presented below are related to further research implications. This is because this particular field of study is young, especially in a South African context, and the lack of theory and theoretical concepts regarding the topic of cancer survival prevents an in-depth critique of literature.

It is interesting to note that even though the research questions focused on the post-treatment experiences of the participants, their post-treatment experiences seem to be inextricably intertwined with their experiences during treatment and as a result, the participants often related their experiences during treatment and would compare their post-treatment experiences with their experiences during treatment.

It seems that the current experiences of the research participants could not be told without placing them in the context of having been diagnosed with cancer and undergoing

treatment and these experiences cannot be understood without them being placed in this context. From this research, it appears that once people have been diagnosed with cancer and have undergone treatment, they will always identify themselves with cancer. This relates to the participants' reported experiences of never being able to forget that they had cancer. It appears that the cancer experience has had such a deep impact on their existence that it has become part of their identity. It is hoped that further hypothesising and research will shed more light onto this enigma.

This research revealed definite support for Kübler-Ross's (1967) stage of Acceptance as all of the participants reported reaching a feeling of acceptance of death towards the end of treatment. However, not all of the participants reported that they experienced all the stages in the model of Kübler-Ross, although they were facing the possibility of death from cancer. These findings are in line with criticism posed by Buckman (1999) which states that several patients experience only certain stages. Some emotional experiences out of the realm of Kübler-Ross's stage model were also reported by some of the participants which support claims by Buckman that certain emotions such as fear of dying and guilt are experienced. Yet again, not all of the participants experienced all of these emotions, which supports Buckman's assertion that patients experience a mixture of reactions which are characteristic of the patient and not of a particular stage in the process. However, although there is support for the claims that the stages set out by Kübler-Ross might not be as clear cut as was thought previously, her model did provide insight into many emotions experienced by the participants in the current study and as Barraclough (1999) points out, it seems clear that her model offers a useful framework for understanding certain important aspects of people's reactions to cancer.

A majority of the participants reported relief as well as mixed emotions ranging between elation, anxiousness and depressed feelings after discovering that they had survived cancer. This is consistent with research conducted by both Rabbin (2003) and Tibbs (2003) which revealed elevated anxiety and research by Tibbs (2003) reporting elevated depression, yet high levels of hope at the end of treatment. However, as these studies were conducted in the United States of America, further research is required pertaining to

the South African context which either supports or refutes this finding as this double bind of fluctuating emotion may pose a negative impact on the psychological well-being of post-treatment survivors and therefore may have implications for future South African interventions. A possible reason for these fluctuations in emotion after the news of cancer survival may be due to a need to rework through the intense emotions felt during the stages of terminal illness that were experienced before the news in order to make sense of one's identity and sense of future. Further research may shed some light on the reason for these fluctuating emotions.

A major finding of this research was that all of the participants have been experiencing anxiety that the cancer may recur. The majority also reported a loss of their sense of control. Such anxiety and loss of sense of control may carry on into the permanent survival phase afflicting serious psychological implications like Post Traumatic Stress Disorder as reported by Amir and Ramati (2002) or negative affect, significantly lower quality of life (Tomich and Helgeson, 2002).

The majority of the participants reported physical effects of the cancer, its removal or the treatment which have had a negative impact on their quality of life. It is imperative that interventions address not only the psychological aspects of cancer survival, but also the impact of the physical effects on the psychological state of cancer survivors and their quality of life.

Although the majority of the participants reported ample support from their partners and other family members, the importance of this support was highlighted. Also, a small segment of the participants reported a lack of support, which negatively impacted on coping ability. It is imperative that further research be undertaken to ascertain the impact of support from spouses and other family members on the psychological well-being of cancer survivors and what type of support is most needed by survivors. Due to the importance of support from family members being highlighted in this research and in other research studies such as that of Pistrang and Barker (1995), it is essential that

interventions be established that encourage spouses and other family members to be efficiently mobilised in helping the patient cope after treatment.

The entire group of participants admitted that their genuine friends remained supportive throughout treatment and after treatment ceased and two thirds mentioned that social support was vital in helping them through their experiences. Once again, the importance of support has been highlighted in this study, which affirms findings by Blanchard et al. (1995) and Waxler-Morrison et al.(1991) that support from friends has a buffering effect on cancer survivors. However, all of the participants in the current study reported that certain friends avoided them when they had cancer, but were willing to continue the friendship after treatment, which has inevitably impacted negatively on their friendship. The entire group also mentioned that they had negative social experiences due to the stigma attached to having cancer. It seems as though the negative social experiences of aversion during treatment and stigma may have a negative impact on the psychological well-being of cancer survivors. Further research in this area is required in order to validate these findings. If these findings are indeed validated, social intervention programmes aimed at people being able to understand and work through their avoidance tendencies and the stigma attached to cancer will be required in order to promote the psychosocial well-being of cancer survivors after treatment.

All of the participants reported that they preferred spending time with people who have insight into the meaning of life and that those who are concerned with trivial matters irritate them. This may result in resentment and the break-down of relationships. Further research is required to explore how relationships between cancer survivors and others may be impacted due to a lack of shared meaning and understanding regarding the experience of cancer.

All of the participants agreed that without their relationship with God, and the social support structure including churches and acquaintances at church, they would not be able to get through their experiences during and after treatment. These findings are contrary to research by Zebrack and Chesler (2002) about childhood cancer survivors who

reported that spiritual quality of life was lowest out of a number of different facets of their lives. A possibility for future research may be to evaluate the effects of cancer on the spiritual experiences of survivors of adulthood cancer in comparison to survivors of childhood and adolescent cancer, as well as reasons for the previously mentioned discrepancies among different age groups.

All of the participants mentioned that they now have a greater appreciation for life after having completed treatment and survived cancer. It is important that researchers consider ways of enhancing such positive outcomes of the experience of cancer and the creation of meaning in attempts to limit the negative psychological impact of cancer experiences.

CHAPTER 5

Conclusion

The current study aimed to explore the post-treatment experiences of female adult cancer patients and to identify possible patterns around these experiences.

5.1. Main findings

5.1.1. Emotional experiences

From the analysis of the emotional experiences of the participants, two main theme clusters were identified, the first cluster being emotional experiences during the acute phase of survival and the second cluster being emotional experiences during the extended phase of survival.

While a definite pattern of shock at the news of diagnosis emerged and the majority of the group experienced isolation, only a minor segment of the group reported experiencing anger, guilt and fear of death after diagnosis during the acute phase of survival. The majority of the group mentioned that they experienced depressed feelings during treatment. A distinct pattern of acceptance of eventual death towards the end of the acute phase of survival was discovered which continued into extended survival.

During the extended phase of survival, the majority of the participants reported relief as well as mixed emotions ranging from depressed feelings to elation after discovering they had survived cancer. A pattern of anxiety that cancer might recur was presented. The majority of the participants reported loss of their sense of control, while half of the participants mentioned that they make use of humour as a coping mechanism. Only one participant mentioned that she resents healthy people who abuse their bodies. Although

no direct literature could be found which pertains to this experience in cancer patients, this awareness of mortality and anxiety that cancer may return seems to have resulted in the resentment of others because of their ignorance of their own mortality and their lack of appreciation for life.

5.1.2. Physical effects

The majority of the participants mentioned that since they have survived cancer they have experienced certain physical effects; either as a consequence of the cancer or its removal or the treatment and that these physical effects have had an impact on their quality of life.

5.1.3. Relationship with partner

Four main themes came out of the discussion on how the participants' relationships with their marital partners were affected after treatment. The husband of one of the participants is deceased and as a result she did not contribute to the discussion on this topic. The majority of the participants reported ongoing support from their partners and the importance of support from one's partner. The minority of the group mentioned a lack of support. A majority of the group also mentioned a closer bond with their partners since surviving cancer.

5.1.4. Relationship with family

The majority of the group reported that their family has been continually supportive. However, it was mentioned that in the case of one participant, one family member was not very supportive and thus went against the trend of support in the families of the other participants. A third of the participants mentioned that their experience of cancer has resulted in them developing a closer bond with their family. Both of these participants mentioned earlier that they also moved closer to their husbands. A third of the participants mentioned that family members are now more open about their experiences since the treatment has ceased.

5.1.5. Social support

The entire group agreed that their genuine friends continued to support them throughout the treatment process and after the treatment ceased, which is indicative of a trend. Two thirds of the participants admitted that social support is crucial in helping them through their experiences. A third of the participants mentioned that they are even closer to those friends who supported them through their experience of cancer. A definite pattern emerged of friends avoiding the participants when they had cancer, but being friendly again after treatment. Only one of the participants mentioned that the reactions that she got from people were unexpected. A definite pattern of the stigma attached to cancer emerged.

5.1.6. Social life

A distinct pattern emerged in the participants' preference for spending time with people who have profundity and insight into meaningful things in life as those people who are concerned with trivial matters tend to irritate them.

5.1.7. Lifestyle

The majority of the participants mentioned that they tried to carry on as normal after treatment. Half of the participants revealed that they have even tried to do more in their lives since they survived cancer because they feel they have to make the most out of the time they have. Half of the participants also mentioned that they have tried to avoid stress and are more health conscious since surviving cancer.

5.1.8. Religious experiences

Two distinct patterns become apparent in the fact that all of the participants agreed that they would not be able to get through their experiences during and after treatment without their relationship with God and that they have a good social support structure which has been very helpful including churches and people at church whom they don't know very

well. Half of the participants demonstrated that they have found meaning in their illness by saying that they believe that there is a divine purpose in their having had cancer.

5.1.9. Outlook on life

Half of the participants stated that their experience of cancer has changed their outlook on life and that ever since they survived cancer they are trying to live one day at a time, thus focussing on the present. Half of the participants also mentioned that they cannot plan ahead as they don't know what the future holds and certain physical ailments sometimes prevent them from doing what they would like to do. A distinct pattern of a greater appreciation of life since surviving cancer emerged.

5.2. Limitations of the study

From a quantitative point of view, the use of qualitative research in this study might be considered to be too lacking in control and objectivity to be of any great significance (Schurink, 1998a).

A possible limitation of this research from a traditional (quantitative) point of view resulted because of the limited number of possible participants found who matched the participant criteria. No random selection of participants could take place, as all of the participants who suited the participant criteria and who were willing to take part in the study, did indeed take part in the study. As the sample is not representative of the total population of South African adult female cancer patients who completed their treatment less than four months ago, generalisations cannot be made from this research. However, the goal of this research was not to be able to generalise beyond the confines of the study, but rather to produce rich description of the subjective experiences of the participants. It is hoped that hypotheses may be formulated from this research, which in turn will be tested by other researchers in the endeavour to further scientific knowledge in this young area of research, especially in the South African context.

The exclusion of methods of substantiation of the participants' experiences through triangulation or corroboration by a third party of these experiences might have contributed to a limitation in this research. As this research report did not have the scope to fully investigate this, it could have impacted upon the results and the analysis.

A limitation of this study is that one of the participants who participated in the first focus group was unable to attend the second focus group. Were she able to attend the second focus group, further information on her part might have been gained and different group dynamics might have taken place.

The fact that the participants were aware that their responses would serve as research material, might have led to more socially appropriate experiences being reported in the group. Also, due to the sensitive nature of the subject of cancer survival some of the participants may not have been as open as they might have been if they had been asked to discuss a less sensitive topic. This may be regarded as a further limitation of this research.

A limitation of the focus group method was that it was at times difficult to prevent domination by certain participants, while at the same time encouraging passive respondents (Berg, 1995).

5.3. Implications for future research

This study may contribute to the field of psychology as it provides exploratory research through which countless hypotheses can be constructed for further research. The findings of this study have also contributed to the body of research that has previously been conducted on the topic of cancer survival and have strengthened certain findings by other researchers in regard to cancer survival. The highlighting of certain difficulties that are experienced by cancer survivors in both the acute and extended phases of survival in this research also have wider implications in terms of interventions for survivors in a South African context. It is hoped that further research will be conducted in regard to these

difficulties and that more effective interventions will be developed as a result. Specific research questions that may be explored include whether cancer survival results in different religious experiences in younger and older people and how these experiences might impact on psychological adjustment after treatment as well as how positive outcomes of cancer experiences can be utilised in restricting negative psychological effects of cancer survival.

This uniquely South African study may also stimulate further research into how culture, lifestyle and the environment affect the experiences of cancer survival of South Africans. As little research has been conducted from a South African perspective about experiences of cancer survivors, particularly in the extended survival phase, it is imperative that researchers explore South African experiences of cancer survival.

In conclusion, it is evident that the experiences of cancer survivors in the South African context necessitate further research. It is also apparent that an understanding of cancer survivors' experiences will continue to play a crucial role in the development of successful interventions for survivors, their families and the wider social community in regard to cancer.

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APPENDIX A

General Subject Information

Hello, my name is Lisa Ziegler. I am carrying out a research study in order to complete a Master of Arts In Community-Based Counselling Psychology degree at the University of the Witwatersrand.

I would like to invite you to participate in my research, which will be an exploration of the psychological and social experiences of post-treatment female adult cancer patients. Furthermore this study is aimed at possibly identifying patterns in the nature of these experiences. Participation in this study is not a requirement and if you refuse to participate or withdraw, it will not compromise you in any way.

Should you agree to participate in this study, you will be required to attend two focus group discussions on two separate days. In these focus group discussions, we will discuss your psychological and social experiences after cancer treatment.

If you agree to participate, you will be asked to sign a consent form (see CONSENT FORM), but you can still withdraw your participation at any time.

As focus group discussions will be conducted, confidentiality cannot be guaranteed.

Some of the information that is asked is of a personal nature, and therefore there is a possible risk that your participation in this research could affect your emotional state. If you are affected negatively in any way by the research, counselling services will be provided by me at the RAU Institute for Child and Adult Guidance at no extra cost to yourself.

You are reminded that you have the right to refuse to participate and withdraw your participation at any time. Please feel free to ask questions on anything you do not understand about the study.

Lisa Ziegler

APPENDIX B

Informed Consent Form

An exploration of the post-treatment psychosocial experiences of female adult cancer patients

I understand the aims of the study and the procedures involved. I understand that my participation in the study is voluntary and that I can withdraw at any time if I want to.

I understand that confidentiality cannot be guaranteed when a focus group is conducted.

I agree to take part in the study, by attending two focus group discussions on two separate days.

Some of the information that will be asked is of a personal nature, and therefore there is a possible risk that my participation in this research could affect my emotional state. I am aware that if I am affected negatively in any way by the research, counselling services will be provided to me by Lisa Ziegler at the RAU Institute for Child and Adult Guidance at no extra cost to myself.

Signature of participant:…….. Date: / /2004

You are in no way obliged to participate in this study. It is necessary for me to obtain informed consent from each participant before I begin the research. Your signature indicates that you understand and accept the above conditions.

I, Lisa Ziegler, have explained the procedures and the aims of the study to the best of my ability. I have assured the participant that participation in this study is voluntary and that the participant can withdraw at any time.

If the participant requires counselling due to anything that takes place in the study, I will gladly assist her.

Signature of researcher:……..…….. Date: / /2004

APPENDIX C

Informed Consent Form (Audio-taping)

An exploration of the post-treatment psychosocial experiences of female adult cancer patients

I understand the aims of the study and the procedures involved. I understand that the focus group discussions will be audio-taped and that transcripts will be typed from the audio-tape.

I agree to take part in the study, fully knowing that the focus group discussions will be audio-taped.

I understand that a research report will be written based on the information that has been audio-taped.

Some of the information that will be asked is of a personal nature, and therefore there is a possible risk that my participation in this research could affect my emotional state. I am aware that if I am affected negatively in any way by the research, counselling services will be provided to me by Lisa Ziegler at the RAU Institute for Child and Adult Guidance at no extra cost to myself.

Signature of participant:…….. Date: / /2004

You are in no way obliged to participate in this study if you are uncomfortable with the audio-taping. It is necessary for me to obtain informed consent from each participant before I begin the research. Your signature indicates that you understand and accept the above conditions.

I, Lisa Ziegler, have explained the procedures and the aims of the study to the best of my ability. I have assured the participant that participation in this study is voluntary and that the participant can withdraw at any time.

If the participant requires counselling due to anything that takes place in the study, I will gladly assist her.

Signature of researcher:……..... Date: / /2004

APPENDIX D

List of Questions for Focus Groups:

What type of cancer did you have and what kind of treatment did you undergo?

What made you decide to share your experiences about cancer with us?

What psychological experiences (emotional experiences) have you had since you discovered that you are in remission?

What specific emotions have you felt since your treatment ended?

How has your relationship with your partner been affected since your treatment ended?

How has your relationship with your family been affected since your treatment ended?

How has your relationship with your friends been affected since your treatment ended?

How has your social life been affected since your treatment ended?

How has your social support been affected since your treatment ended?

Is this an adequate summary? Is there anything that we left out that you would like to discuss?