

**Meaning-centeredness in adult cancer patients in remission**

Dissertation

Submitted for the fulfilment of the requirements for the degree

Master of Social Work

MSW

**by**

**Elma Hamilton**

in the

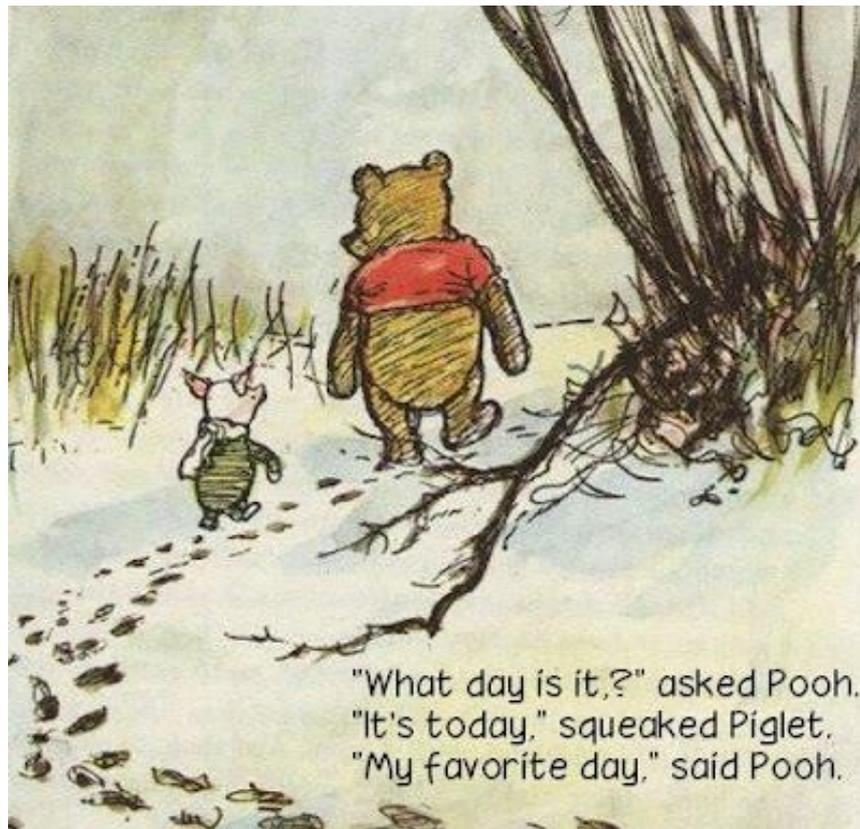
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*January 2014*



"What day is it,?" asked Pooh.  
"It's today," squeaked Piglet.  
"My favorite day," said Pooh.

*A.A. Milne - Pooh and Piglet*



# Declaration of originality

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Topic of dissertation:

Meaning-centeredness in adult cancer patients in remission

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## **ACKNOWLEDGEMENTS**

Completing this degree has set challenges, setting high demands on many levels of my life. In retrospect, this was, overall, a rewarding experience: it made me question my own worldviews, adding meaning to my life, and providing me with the satisfaction of fulfilling a goal. This would not have been possible without the support of the persons and institutes involved. Therefore, I would like to express my gratitude to:

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## **ABSTRACT**

Title: Meaning-centeredness in adult cancer patients in remission

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Degree: MSW

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This study explores how cancer patients in remission derive meaning in their lives. A need for social work intervention was identified with cancer survivors, especially those patients who are in remission and who have to continue their lives, in spite of the incurable status of their cancer. In line with literature, the researcher, in her role as social worker at a radiation oncology clinic, observed that patients often report that they find benefit in the cancer experience. The framework for conducting this study is based on the existential theory and the ultimate concern of human existence, that life has meaning under all circumstances. Meaning and meaning-centeredness is described. The role of a meaning-centered approach to oncology social work was argued. The Meaning-Centered Counselling and Therapy (MCCT) model was described from a literature perspective, and proposed as an intervention model. MCCT offers a model that includes the existential domain in interventions.

Within the context of this study, remission refers to the period that the cancer is under control. It may be that there is no indication of the cancer, but the cancer is expected to recur, or that some of the symptoms have disappeared, or that the progression of the cancer has slowed down. During remission, patients are under surveillance only, or on maintenance treatment. Thus, they do not have regular contact with the oncology team. Patients live with

uncertainty and ambiguity, resuming activities, responsibilities, careers and relationships that were influenced by the cancer diagnosis and treatments. The demands of living in remission are described.

This research study explores the quest for meaning in patients who are living with incurable, recurrent cancer. The goal of this research study was to explore meaning-centeredness in adult cancer patients who are in remission. This research study was guided by the following research question: “Does meaning-centeredness play a role in adult cancer patients’ coping with remission?”

The research population included oncology patients who are in remission, and have experienced one or more recurrences, and where the cancer has metastasised. A qualitative approach was followed, using the collective case study design. The research was conducted at the Radiation Clinic, Sandton Oncology Centre in Morningside, Johannesburg. Data was collected using an interview schedule to guide 4 focus group interviews, totalling 21 participants, who were selected by means of purposive sampling. All participants gave voluntary and informed consent to take part, and the focus group interviews were voice-recorded, with their permission. The researcher transcribed these recordings. Creswell’s steps for qualitative data analysis were implemented.

From the findings, the following themes and sub-themes were identified, demonstrating the search for meaning amongst these participants who are in remission and answering the research question:

Theme 1: Meaning-construal associated with attribution with the sub-themes of hope, spirituality, and death awareness and a foreshortened future.

Theme 2: Meaning-construal associated with appraisal, with the sub-themes of benefit finding, growth, relationships, and an increased appreciation of life, and prioritising.

Theme 3: Meaning-construal associated with reappraisals, with sub-themes of sense of self, sense of coherence, assumptive world, adapting to new normal, and transcendence.

The findings demonstrated that a perspective that provided the participants with the means to explore their unique meanings, purposes, and life tasks helped them to cope with remission and the fear or reality of recurrence or metastases. Participants were able to derive meaning in their lives despite living with incurable cancer. Participants, who had integrated the knowledge that their cancer is incurable and recurrent into their meaning-system, were able to adapt and adjust to living in remission. They had a sense of purpose and maintained realistic hope. Their hopes were proportional to the prognosis. They did not dwell on their own death, but focused on what life offers them each day. They developed a new normal that incorporates the knowledge of a foreshortened future, coping with side effects and late effects of treatment, and the uncertainty that the cancer is expected to recur or metastasise again. They were aware of their life tasks, and embraced life to the full.

Intervention strategies, based on the existential oriented proposition that life has meaning under all circumstances, were recommended. This included the Meaning-Centered Counselling and Therapy (MCCT) model for integration in oncology social work.

Recommendations in this study include enhancing the understanding of members of the transdisciplinary team regarding the needs and experiences of patients in remission. Furthermore, a better understanding of the role of meaning-centeredness intervention amongst oncology social workers can improve interventions, specifically for patients in remission.

## LIST OF KEY TERMS

Assumptive world

Cancer

Carcinoma

Coping

Distress

Health social work

Meaning

Meaning-centeredness

Meaning-construal

New normal

Oncology

Oncology social work

Posttraumatic growth

Remission

Sense of coherence

Survivor

Trauma and crisis

## **SAMEVATTING**

Titel: Betekenisvolheid in volwasse kankerpatiënte wat in remissie is

Kandidaat: Elma Hamilton

Departement: Maatskaplike Werk en Kriminologie

Graad: MMW

Studieleier: Dr C.L. Carbonatto

Hierdie studie ondersoek hoedanig kankerpatiënte wat in remissie is betekenisvolheid in hulle lewens skep. 'n Behoeftes is geïdentifiseer vir maatskaplike werk intervensie-programme vir mense wat kanker oorleef en voortgaan met hulle lewens, ten spyte van die wete dat die kanker ongeneesbaar is. Die navorser het, in haar rol as maatskaplike werker by 'n bestralingseenheid, waargeneem dat pasiënte dikwels opmerk dat hulle sekere voordele geput het uit die kankerervaring. Hierdie waarneming is in lyn met die literatuur. Die raamwerk waarbinne hierdie studie uitgevoer is, is gebaseer op die eksistensiële teorie, die grondbeginsel vir menslike bestaansreg, en die verskynsel dat die lewe onder alle omstandighede betekenis het. Betekenis en betekenisvolheid is omskryf. Die rol van 'n betekenisvolle benadering in onkologiese maatskaplike werk is beredeneer. Die Meaning-Centered Counselling and Therapy (MCCT)-model is vanuit 'n geesteswetenskaplike perspektief beskryf, en MCCT is voorgestel as 'n intervensiemodel. MCCT bied 'n model wat die eksistensiële domein insluit.

Binne die konteks van hierdie studie verwys remissie na die periode wat kanker gekontroleerd is. Dit mag wees dat, alhoewel daar geen aanduiding van die kanker is nie, die verwagting nogtans bestaan dat die kanker sal terugkeer of versprei. Gedurende remissie kan sommige van die simptome verdwyn, of die groei van die kanker is afgeskaal. Pasiënte is slegs onder

waarneming, of op instandhoudende behandeling gedurende remissie. Hulle het dus nie gereelde kontak met die onkologiespan nie. Pasiënte lewe in onsekerheid en vaagheid. Hulle hervat aktiwiteite, verantwoordelikhede, beroepe en verhoudings wat deur die kankerdiagnoses en -behandelings beïnvloed is. Die eise wat remissie stel, is omskryf.

Die doel van die navorsing was om betekenisvolheid in kankerpatiënte wat in remissie is te ondersoek. Die navorsingstudie is deur die volgende navorsingvraag gelei: **“Speel betekenisvolheid ‘n rol in pasiënte se hantering van remissie?”**

Die navorsingspopulasie bestaan uit pasiënte wat in remissie is en by wie die kanker voorheen teruggekeer het, en/of versprei het. ‘n Kwalitatiewe benadering, met gebruikmaking van kollektiewe gevallestudieontwerp, is gevolg. Die navorsing is uitgevoer by die Bestralingseenheid, Sandton Onkologiesentrum, Morningside, Johannesburg. ‘n Onderhoudskedule is gedurende die vier fokusgroep-byeenkomste gebruik om die onderhoude te lei en om data in te samel. Die 21 deelnemers is deur middel van ‘n waarskynlikheidsteekproefmetode geselekteer. Al die deelnemers het vrywillige en ingeligte toestemming gegee om aan die navorsing deel te neem, en die fokusgroeponderhoude is, met die deelnemers se toestemming, op band opgeneem. Die navorser het hierdie opnames getranskribeer. Creswell se stappe vir kwalitatiewe data-analise is geïmplementeer.

Vanuit die bevindinge is die volgende temas and subtemas geïdentifiseer. Temas demonstreer die deelnemers se soeke na betekenis, en beantwoord die navorsingsvraag.

Tema 1: Betekenisskepping wat geassosieer word met toeskrywing. Subtemas is hoop, spiritualiteit, bewustheid van die dood, en bewustheid van ‘n verkorte toekoms.

Tema 2: Betekenisgeving wat geassosieer word met waardasie. Subtemas is om voordeel in die kanker ervaring te vind, groei, verhoudinge, 'n toename in waardering van lewe, en voorkeurverlening.

Tema 3: Betekenisgeving wat geassosieer word met herwaardasie. Subtemas is 'n sin van self, 'n sin vir 'n gevoel van samehangendheid, aannames, aanpassing by nuwe normaal, en transendensie.

Die bevindinge demonstreer 'n perspektief wat deelnemers geleentheid gee om hulle unieke betekenis, doelstellings, en lewenstake te ondersoek, die deelnemers help om beter met remisie en die vrees of realiteit van herhalings (terugkerings) of verpreidings van die kanker te hanteer. Deelnemers is in staat om betekenisvolheid te beleef ten spyte daarvan dat hulle kanker ongeneesbaar is. Deelnemers het die wete gehad dat hul kanker ongeneesbaar en terugkerend is en het dit in hul betekenisstelsel geïntegreer. Dit het hulle beter in staat gestel om aan te pas by die eise wat remisie stel. Hulle is doelgerig en behou realistiese hoop. Hulle hoop is proporsioneel tot die prognose. Hulle konsentreer nie op hulle eie dood nie, maar fokus eerder op wat die lewe elke dag bied. Hulle ontwikkel 'n nuwe normaal wat die wete van 'n verkorte toekoms inkorporeer, hanteer die nuwe- en laateffekte van behandeling en hanteer die verwagting dat die kanker gaan terugkeer of versprei. Hulle is bewus van lewenstake, en lewe voluit.

Aanbevelings in die studie sluit in om lede van die transdissiplinêre span bewus te maak van die behoeftes en ervarings van pasiënte wat in remisie is. Beter begrip onder onkologiese maatskaplike werkers van die rol van betekenisgeoriënteerde intervensieprogramme, kan hierdie programme vir pasiënte wat in remisie is, verbeter.

## **SLEUTELTERME**

Aannames (assumptive world)

Kanker (cancer)

Karsinoom (carcinoma)

Hantering van (coping)

Kommer (distress)

Maatskaplike Werk in gesondheidsorg (health social work)

Betekenis (meaning)

Betekenisvollheid (meaning-centeredness)

Betekenis skepping (meaning-construal)

Nuwe normaal (new normal)

Onkologie (oncology)

Onkologiese Maatskaplike Werk (oncology social work)

Posttraumatiese groei (posttraumatic growth)

Remissie (remission)

Revel van samehangendheid (sense of coherence)

Oorleweraars (survivor)

Trauma en crises (trauma and crisis)

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## CHAPTER 1

### 1 GENERAL INTRODUCTION

#### 1.1 INTRODUCTION

Cancer is a complex disease and it affects the different levels of personhood, family and society. The World Health Organization Cancer Programme, as cited in Albrecht (2006:22), confirms that cancer is a public health problem worldwide. Referring to the incidence and prevalence of cancer, Blum, Clark and Marcusen (2001:45) indicate that a better awareness of cancer, coupled with advances in diagnostic tools and skills, has resulted in more people diagnosed with cancer. Jaftha (1995:161) adds that advances in cancer treatment modalities has saved many lives, and resulted in more patients living in remission. It has further ensured that patients, who cannot be cured, enjoy a greater quantity and quality of life.

The increase in the cancer survival rate has resulted in a shift in focus that includes survivorship. Currently the aim of oncology treatment is to keep survival rates high, while reducing the negative impact of treatment. Consequently, an interest in the psychological issues relating to cancer and survivorship has developed and a field for psychosocial intervention has been established (Holland & Lewis, 2000:196,197). In the context of this research, a survivor is defined as a person who has received treatment for cancer and where there is no active disease present. It thus includes concepts of cure and remission. This research focuses on survivors who are in remission. In the context of this study, the term remission indicates that a patient has an incurable cancer that is under control.

With reference to oncology social work Stearns, Lauria, Hermann, and Fogelberg (1993:1) observe that there has been a gradual shift in focus: from a speciality that dealt almost exclusively with terminal illness and chronicity, to one of coping with treatment and its side effects, and adapting to long-term survival. The goals of cancer treatment are cure, remission, symptom control

or end-of life care. Holland (1990:75) maintains that, with cancer, the medical facts to which patients must adjust include diagnosis, prognosis, treatment, and the events that will likely follow in the clinical course. With cancer, this may be total cure, a long-term disease-free state followed by recurrence, a chronic illness state with rehabilitation to counter dysfunction, or illness leading to death. It is the researcher's opinion that patients need to understand and come to terms with the goals of treatment. She observed that receiving treatment is often equated with cure; this misconception, caused by misinformation or misinterpretation of information can lead to a crisis when a cancer recurs. Wells and Turney (2001:38) observed that when a cancer recurs, patients could lose trust in the medical profession and/or their oncology team. In this regard, the researcher observed that afore-mentioned issues could result in patients making uninformed decisions regarding future treatment, or stopping treatment without exploring their options.

Mulcahy (2009) argues that although there is a growing awareness of the adjustment required and demands made on survivors, there is a lack of medical and psychosocial support for survivors and families. Christ (1993:91) observes that when treatment finishes, patients must recognise and cope with fears of having less medical surveillance; return to dealing with personal and work situations predating the cancer diagnosis; adapting to remaining physical impairment and psychological stress and change expectations of support from family and friends. Patients in remission need to continue to lead their lives despite the diagnosis of incurable cancer. The researcher observed that, in practice, a sense of meaning assists patients to shift their focus from quantity of life to quality of life. This reminds one of the philosopher Seneca's adage: "Life, if well lived, is long enough" (Egberg, 2009).

This study is based on the existential oriented proposition that life has meaning under all circumstances. Building on the seminal work of Frankl, and the contemporary work in meaning therapy, the researcher proposes that living with incurable cancer can initiate a quest for meaning. The researcher

posits that a perspective that provides the opportunity for patients to explore their unique meanings can help patients to cope with remission and the fear of recurrence. Therefore, the researcher proposes a meaning-centered model for intervention in oncology social work.

To determine the feasibility of this study, several experts, oncologists as well as social workers, were consulted to explore the anticipated value of this study. Referring to the specialisation in the field of social work, Strydom (2011a:239) recommends consultation with experts in the field. He states that the purpose of interviews with experts is to bring unknown perspective to the fore or to confirm or reject the researcher's own views. This can assist the researcher to delineate the problem more clearly and gain valuable information on the more technical and practical aspect of a research study. The researcher held a discussion forum, which was attended by Dr Nelia Drenth (2010), a social worker in private practice with experience in oncology work, and Mrs Wilna Burgers (2010), a social worker at the Mary Potter Oncology Centre, Little Company of Mary Hospital, with extensive experience in oncology social work. At this forum, it was agreed that this study addresses a gap in the field of oncology social work. The researcher also consulted Drs Robbie de Mûelenaere (2010), Sally Bairstow (2010) and Linda van Zyl (2010), partners and radiation oncologists at the Radiation Oncology Unit, Sandton Oncology Centre. These doctors, who are experts in the oncology field, are of the opinion that the knowledge gained from this study can be implemented in oncology social work. Thus, the need for this study was confirmed.

In this chapter, the researcher contextualises the prevalence of cancer and the phenomena of remission. A research problem indicates the problem or issue that leads to the need for a study (Creswell, 2014:108). The research problem becomes the foundation for the entire research process (Alpaslan & Mabutho, 2005:277) and, in this chapter, the research question is conceptualised. The rationale for the research study is also stated.

Additionally, this chapter considers some limitations of the study, and indicates the format of the research report.

In this report, the researcher uses the term 'client' and 'patient' interchangeably. This study is concerned with cancer patients; therefore, the researcher prefers to use the term 'patient'. Borrowing from the hardiness literature, the researcher, in the context of this study, conceptualises challenge as the way in which remission is perceived as a positive opportunity for personal growth, and is characterised by openness to the experience of living in remission, and willingness to re-examine one's views on life. Control refers to one's beliefs in one's self-efficacy, and accepting accountability for the consequence of one's behaviour (Linley, 2003:604), the choices one makes, and how this influences one's capacity to cope with remission.

The key terms that are defined in this chapter are cancer, meaning, meaning-centeredness, remission, and survivor.

## **1.2 KEY TERMS**

### **1.2.1 Cancer**

Rosenthal's (2001:1) definition of cancer reads, "Cancer is not one disease state but rather many, all characterized by the presence of an uncontrolled (for example malignant) proliferation of a certain cell in the body. There are numerous types of cells, so there are many types of cancer." The *Oxford Concise Medical Dictionary* (2007:107) expands this definition, defining cancer as:

Any malignant tumour, including carcinoma, lymphoma, leukaemia, and sarcoma. It arises from the abnormal, purposeless, and uncontrolled divisions of cells that then invades and destroy the surrounding tissues. Spread of cancer cells (metastasis) may occur via the bloodstream or the lymphatic channels or across cavities such as the pleural and peritoneal spaces, thus setting up secondary tumours (metastases) at sites distant from the original tumour.

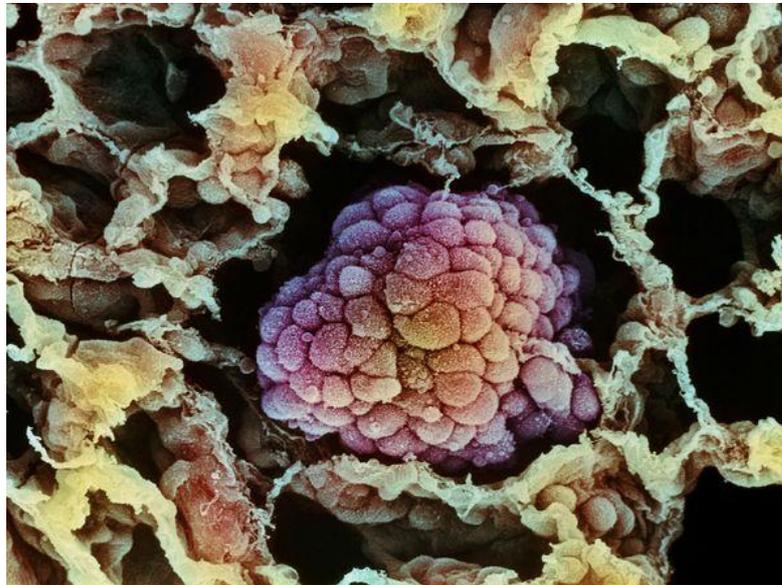
The term 'cancer' thus refers to the uncontrolled growth of cells that has the tendency to invade surrounding tissue and metastasise to distant body sites. Cell division and multiplication is a normal bodily function, but when abnormal changes to the cells occur, cancerous growth occurs. Cancer can thus manifest in any part of the body where the abnormal growth of cells causes the development of tumours. The term 'primary' cancer refers to the site where the cancer originated; for example, if the cells that divided abnormally originated in the breast, it is breast cancer; if it was a bone cell it will be a bone cancer, and so on (Daniel, 2005:45). When a primary breast cancer metastasises to the bone, it is referred to as metastasis of the breast cancer. The terms relapse and recurrence refer to the reappearance of cancer after a disease free period. Cancer can reappear at a distant site in the body or at the original site of the tumour (Stearns et al., 1993:334). The likely cause of a relapse (recurrence) is that a few of the original cancer cells survived initial treatment. Sometimes some cells escaped to other parts of the body because they were too small to be detected during any immediate follow up after treatment (*CureSearch for children's cancer*, [sa]).

During diagnosis, a pathologist examines the cells to determine if they are benign or malignant. If the cells are malignant, the pathologist determines the type of cancer. A pathologist can often determine the primary cancer from certain characteristics of the cells. If a person had been treated for cancer, a tumour found in another site is most likely a metastasis and tests will be done to confirm whether it is a metastasis of another primary (*NCCN: guidelines for patients*, [sa]).

A patient can have more than one primary cancer. Each individual primary tumour has its own pattern of local behaviour and spread; for example, bone metastases is very common in cancers of the breast, bronchus, thyroid, kidney, and prostate but less common in other tumours (*Oxford Concise Medical Dictionary*, 2007:107). The social worker must distinguish if a patient refers to another primary or to metastases.

The picture below is an image of lung cancer.

**Figure 1:** Lung cancer



*Figure 1: Lung Cancer (National Geographic: Cancer Photo Gallery. [sa])*

This image shows how the cancer cells, indicated by the purple colour in the image, have formed into a tumour. This is due to abnormal, uncontrolled cell growth. In this image, the size of the cancer cell can be compared to the surrounding healthy cells.

### **1.2.2 Meaning**

It is challenging to conceptualise the term “meaning” as it is characterised by a great deal of indistinctness and vagueness. Meaning is interpreted in the context it is used, for example, philosophical, theological, psychological, or colloquial (Klinger, 2012:Kindle location 1380). The *Oxford Advanced Learner’s Dictionary* (2006:914) defines meaning according to a sense of purpose and according to experience. Meaning is the quality or sense of purpose that makes one feel that one’s life is valuable. Meaning is the real importance of a feeling or experience.

The researcher conceptualises meaning as a one's pursuit to validate one's life and to live life to the full. Within the context of this study, the concept of meaning refers to a patient's ability to live a life focused on quality – to have the ability to make the cognitive and emotional shift to live with cancer rather than dying of cancer.

### **1.2.3 Meaning-centeredness**

Wong, (2006:246) observes that the meaning and purpose that one ascribes to life are rooted in values, virtues and beliefs. Lewis ([sa]: 4) infers that living a meaning-centered life, implies choosing beneficial attitudes. Attitudes are defined as consistent beliefs. From this observation, the researcher deduces that meaning-centeredness implies living a life based on positive core values, and choosing a positive attitude towards life. Meaning-centeredness refers to the sense of meaning and purpose that a person experiences and how this experience governs that person's life. Within the context of this study, meaning-centeredness implies that living in remission puts patients on a journey to discover or affirm their meanings.

### **1.2.4 Remission**

Remission is a cessation of the symptoms of a disorder or disease. The connotation of cure is entirely absent from this term, the disorder or disease is still assumed to be present though there are no apparent symptoms (Reber & Reber, 2001:623). The NCI: *Dictionary of cancer terms*, (reviewed 2010) defines remission as a decrease in, or disappearance of, signs and symptoms of cancer. Partial remission indicates that some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared. In the context of this study, remission refers to the time that the cancer is under control.

### 1.2.5 Survivor

The term survivor is ambiguous. The Oxford Advanced Learner's Dictionary (2006:1491) defines survivor as a person who continues to live, especially despite being nearly killed or experiencing great danger or difficulty. Within the oncology context, a survivor is defined as a person who completed treatment at least five years ago and has no sign of cancer (Holland & Lewis, 2000:195). A broader definition is that of the NCI: *Dictionary of cancer terms*, (reviewed 2010) that defines a survivor as:

One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered a survivor from the time of diagnosis until the end of life. In cancer, survivorship covers the physical, psychological, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience.

Advances in treatment contribute to the ambiguity of the term survivor. One view considers cancer survivors to be those patients who have completed the traditional treatments for cancer: radiation therapy, chemotherapy, or surgery. Advances in treatment have obscured when the survivor phase begins, because adjuvant care and treatments such as hormone therapy may now be administered to patients for years. The consequences of cancer screening further complicate the definition of survivors. Some cancers that would never have come to light clinically can be diagnosed after a positive screening test (so-called "latent disease") such as early-stage prostate cancer diagnosed following prostate-specific antigen (PSA) screening (Marcus, 2006).

In the context of this research, a survivor is defined as a person who has received treatment for cancer and where there is no active disease present, or where a person is on maintenance treatment to control the cancer, which is

when the cancer is viewed as a chronic illness. The term survivor thus includes concepts of cure and remission.

This research focuses on patients that are in remission.

### **1.3 LITERATURE REVIEW**

#### **1.3.1 Prevalence of cancer**

The latest global statistics, as reported in the World Cancer Report (2012), estimated the burden of cancer in terms of incidence (number of new cases occurring) and mortality (number of deaths). This report estimated that in 2012 there were 14.1 million new cancer cases and 8.1 million cancer deaths reported worldwide (On the sciencenet, 2014). More than half of cancer cases and about 60% of deaths occur in less-developed countries. Another concerning but significant observation in the report is that the global cancer burden has doubled in the last thirty years of the twentieth century; it is now estimated that it will double again between 2000 and 2020 and will nearly triple by 2030. This rapid increase in the cancer burden represents a crisis for public health and health systems, worldwide. The burden of cancer is immense for cancer patients and cancer survivors as well as for their social attachments. Furthermore, cancer poses considerable challenges for the health care systems in poor and rich countries alike (Boyle & Levin 2009). The GLOBOCAN 2008 statistics indicate that cancer is the leading cause of death in economically developed countries and the second leading cause of deaths in developing countries (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011:69). These statistics are compelling evidence for the need for social work interventions for cancer patients and their social attachments.

In South Africa, current cancer statistics are not readily available. The National Cancer Registry (NCR) statistics were compiled from data received from histology, haematology, and cytology laboratories in South Africa. Public and private laboratories, through a voluntary cancer notification system,

submitted data to the NCR (National Health Laboratory Services, reviewed 2013. Mqoqi, Kellet, Sitas & Jula. 2004). Issues surrounding patient confidentiality resulted in 2001, in many private pathology laboratories ceasing to submit cancer data to the NCR. Nevertheless, the latest 2000-2001 NCR report shows that males have a lifetime risk of 1 in 6 of developing cancer, as opposed to 1 in 4 in the previous report. The predominant cancers in men are prostate cancer (1 in 23), followed by lung (1 in 69), oesophagus (1 in 82) and colorectal cancer (1 in 97). In women, the lifetime risk of developing cancer is 1 in 8, as opposed to 1 in 6 in the previous report. The predominant cancers in women are breast (1 in 29) followed by cancer of the cervix (1 in 35), followed by uterine, colorectal and oesophageal cancers. The NCR report also highlighted suboptimal reporting of many cancers, due to a lack of tissue diagnosis (National Health Laboratory Services, reviewed 2013). After doing a comparative study of data from the South African Medical Research Council (MRC) and data from NCR, Albrecht (2006:11), an independent medical research consultant, found a discrepancy in the data. He suggests that this anomaly is due to an underreporting of cancer incidences. Dr Georgia Demetriou, spokesperson for the SA Oncology Consortium concurs, stating, "Our registry is pathology based, thus those patients who demise without a diagnosis or access to health care, are missed. There is every indication that cancer is probably underreported at this point and that as our health care services improve and we have an older population, the incidence of cancer will increase too" (Medical Chronicle: *New registry to give major boost to fight against cancer*, March 2011:20). We thus do not have an accurate view of the incidence of cancer in South Africa. The Medical Chronicle, (*New registry to give major boost to fight against cancer*, March 2011:20) also reports that the lack of an updated national cancer registry is currently being addressed by the Department of Health. Regulation that stipulates that health care facilities must submit reports to the NCR within three months of diagnosis, while laboratories must submit reports on a quarterly basis, is currently waiting to be signed by the Minister of Health. In terms of confidentiality, the regulation states that the register must maintain

the same standards of confidentiality as those that apply for doctor-patient confidentiality. The objectives of the NCR will be to collect, validate, store, analyse, interpret, and report data relating to cancer. The new regulation will also make provision for the establishment of a Population Based Cancer Registry (PBCR), which will have wider applications than the NCR because it will include cancer control, patient care, administrative and cancer research programmes.

Global statistics indicate that the disease burden of cancer continues to increase, largely because of the aging and growth of the world population and because of the greater incidence of cancer-associated lifestyles (Jemal et al., 2011:69). Many people of diverse backgrounds develop cancer over the course of their lifetime but many people survive for a substantial period following diagnosis and must therefore live with the aftermath of the disease. This indicates a global need for oncology social work services.

### **1.3.2 Social work in oncology**

With reference to oncology social work, Stearns et al. (1993:1) note that intervention programmes have broadened in focus. A shift occurred from interventions that focussed primarily on terminal illness and chronicity, to a multifaceted focus that includes the whole continuum of cancer care. Currently the field of oncology social work includes all the phases in the cancer continuum namely, diagnosis, treatment, survivorship, terminal and end-of- life care, and bereavement. Cordoba, Fobair, & Callan (1993:49,50) observe that patients in remission, who face the real possibility of recurrence and/or metastases, have to adjust their outlook on life, expectation of life, and views of mortality. In addition, patients in remission often have to adjust to the side effects of treatment on physical, emotional, and economic levels. Burton and Watson (1998:14) reiterate that cancer is a disease that is characterised by uncertainty and it is this uncertainty that can make the experience so stressful. Various researchers refer to the “Damocles syndrome”; the experience that cancer is a sword hanging over the survivors’ head, ever

present; ready to fall at any time (Cordoba et al., 1993:44; Holland & Lewis, 2000:194; Wells & Turney, 2001:37). The Damocles syndrome refers to the fear of recurrence blended with the relief that they no longer have to endure the rigors and hardships of treatment (Wells & Turney, 2001:37). The researcher observed that in addition, many patients are focussed on the treatment process during the treatment phase. Consequently, they process the experience more consciously after they have finished treatment. This is another indication for the need for social work intervention during remission.

Psychosocial intervention can help patients and survivors to explore their cancer experience and find benefit in the illness. Referring to various authors, Thornton (2002:153), and Wells and Turney (2001:30) confirm that the focus on dysfunction following cancer has limited the understanding of the psychological consequences of the illness. In addition, they confirm that psycho-oncological research that incorporates the positive outcomes, confirms that many cancer survivors find benefit in their illness (Andrykowski, Brady & Hunt, 1993; R.L. Collins, Taylor, & Skokan, 1990; Curbow, Somerfield, Baker, Wingard & Legro, 1993). The researcher proposes a perspective that provides the means for patients to explore their unique meanings, purposes, and life tasks that could help patients coping with remission and the fear of relapse or recurrence. When a patient realises that the cancer is incurable, it forces the patient to re-evaluate his or her life.

### **1.3.3 The focus on meaning**

Patients in remission need to continue to lead their lives as best they can, despite the diagnosis of incurable cancer. Deriving meaning in their lives while living with an incurable cancer can be accomplished by assigning some meaning to the illness, in order to maintain a sense of coherence and familiarity (Spira & Kenemore, 2002: 174). In response to their cancer, many patients re-evaluate their lives; reflect on their values and priorities and, often, they identify changes that are warranted (and perhaps even overdue) in their lifestyles and personal relationships (Kneier, Rosenbaum & Rosenbaum,

reviewed 2010). The researcher observed in practice that this reassessment of goals and values often motivates patients to explore what really matters for them and, in this way, contributes positively to a sense of personal integrity and fulfilment. Living in remission brings about a change in perceptions – from curable to incurable, from quantity of life, to quality of life.

Researchers that focussed on personal growth that might occur from the cancer experience, noted that individuals who have gone through a cancer diagnosis and treatment often report that, despite being harmed, they were positively changed by the experience (Wells & Turney, 2001:30). A cancer diagnosis is not always a traumatic event. Thornton (2002:153) argues that cancer neither is an unvaryingly devastating diagnosis nor are severe psychological problems normative responses to the diagnosis. Referring to various authors (Andrykowski, Brady & Hunt, 1993; Collins, Taylor & Skokan, 1990; Curbow, Somerfield, Baker, Wingard & Legro, 1993), Thornton (2001:153) noted that research employing a broader concept of the cancer experience, one seeking to describe both the positive and negative concomitants of this illness, confirms that many cancer survivors find benefit stemming from their experience. McMillen (1999:456-461) reports that research that focussed on the effects of adversity as it relates to a spectrum of experiences, including to cancer, revealed that the following positive categories were consistently and independently reported: changed life priorities; an increased sense of self-efficacy; an increased sensitivity to others; improved personal relationships and increased spirituality. In this regard, Tedeschi and Calhoun developed the construct of posttraumatic growth, which refers to the positive psychological change which results from individuals' struggle with challenging and adverse life events (Tedeschi & Calhoun, 2004:1). Schroevers, Helgeson, Sanderman, and Ranchor (2010:47) argue the experiences of stressful events may challenge personal goals and fundamental beliefs about oneself, one's future, and the world. How one appraises an experience, and re-evaluates and redefines beliefs and goals, can facilitate meaning-construal, which eventually results in the

perception of growth. In the researcher's opinion, a perception of growth contributes to patients' personal and unique sense of meaning-centeredness.

#### **1.4 THEORETICAL FRAMEWORK**

An important focus of the social work profession is the impact of adverse experiences on people, and how they cope with these new demands imposed on them by a specific experience. Historically, theory has emphasised how people were harmed by adverse experiences, but there has been a shift to theoretical models, based on these theories, which emphasise the human potential to find something positive in the face of adversity. These models include the strengths perspective (Saleebey, 1997), resilience (Fraser, 1997; Werner and Smith, 1992), hardiness (Kobasa, 1979), empowerment (Gutierrez, Parsons, and Cox, 1998), solution-focused approaches (De Jong & Miller, 1995), coping theory (Lazarus and Folkman, 1984), positive psychology (Seligman, 1998), logotherapy (Frankl, 1959), meaning-therapy (Reker and Wong, 1998), hope counselling (Scioli & Biller, 2010), and meaning-centered counselling and therapy (Wong, 2012).

In reaction to the nihilistic and mechanistic life-views present in Europe in the early 1900's, Viktor Frankl formulated Logotherapy. In his seminal work, *Man's Search for Meaning*, first published in 1946, Frankl argues that adverse circumstances can have a positive impact on personal development by providing opportunity for "a search for meaning", which he believes to be a basic human need. The premise of logotherapy is that life has unconditional meaning, which cannot vanish under any circumstance (Frankl, 1985:135; Lukas 1989:6).

Within the field of education, during the 1960's, interest developed in the experience of meaning. Theories included values clarification (Raths, Harmin, & Simon, 1966), and confluent education (Shapiro, 1976). Confluent education is method that can be employed to bridge the gap between cognitive and affective learning (Francke & Erkens, 1994:354). In the

humanistic atmosphere of the 1970's, Maddi (1967, 1970) constructed a theory about the developmental psychopathology of the existential sickness, and developed a theory about healthy development (Leath, 1999). Yalom (1980) is seen as a key figure in existentialism and the existential theory is based on the ultimate concerns in human existence being anxieties concerning death, freedom, isolation, and meaninglessness, and the implications these anxieties have in clinical work. Thus it is relevant to this study with the fear of death and search for meaning amongst persons who are in remission.

Reker and Wong (1988), in developing their concept of the "personal meaning system," have expanded Maddi's and Frankl's conceptualisations of personal meaning and combined them with Kelly's personal construct theory. The personal construct theory posits that throughout one's life, one tries to make sense of the world, constantly forming and testing one's worldviews. Kelly argues that this process develops one's personality. Kelly's proposes that one may or may not modify these worldviews when faced with contradictory information, and one has core beliefs that are unlikely to change (Stewart, 2004). Reker and Wong researched the motivation for the construction of the personal meaning system. This research investigated the breadth, depth, and the degree of differentiation and integration (complexity) of the personal meaning system; one's freedom of choice in the construction of one's meaning system, as well as the disintegration of the meaning system during a major change of the system. They hypothesised about the change in integration of the meaning system over the life span, as well as the difference in complexity between the meaning system of an individualist and that of a conformist (Leath, 1999).

Denne and Thompson (1991) examined the characteristics of the transition from the experience of meaninglessness to meaning in life. Debats, Drost, and Hansen (1995) examined the nature of the experience of meaninglessness and the experience of meaning. O'Connor and Chamberlain

(1996) extended the research of De Vogler and Ebersole (1981) on sources of meaning. Prager (1996, 1997) explored the types of experiences people find meaningful (Leath, 1999).

Much research in the area of meaning in life and existentialism has been completed since Frankl first published his ideas about logotherapy. Significant advances have been made in learning what people find meaningful in life, but little progress has been made in understanding what the nature of the experience of meaning actually is, such as how and why people think they experience meaning (Leath, 1999). Janoff-Bulman (1992), in her book *Shattered Assumptions*, argues that sufficiently stressful or traumatic events have the potential to challenge and disrupt the fundamentally positive, adaptive assumptions that most people hold about the world and their place in it. When these beliefs are challenged or disrupted by traumatic or stressful events, a central task for the victim is the restoration or rebuilding of this assumptive world. In re-evaluating and redefining beliefs and goals, people may be able to find meaning in the event (Schroevers et al., 2010:47). Reframing the experience and exploring avenues to meaning falls in the field of social work.

Perusing Frankl's work, Havenga-Coetzer (2003:56-58) purports that all reality has meaning and that life never ceases to have meaning. Being human means being confronted with meanings to fulfil, and values to realise. Furthermore, meaning is relative; it is related to a specific person who is entangled in a specific situation. Meanings are unique; they differ from person to person, from day to day, even from hour to hour. Meaning can also be found in accepting the unavoidable, and by turning it into a challenge, because life has potential meaning under all circumstances. The researcher interprets these observations as that living with cancer can offer patients the challenge to find and explore the meaning in their changed circumstances.

### **1.4.1 The role of meaning-centered therapy**

Psychosocial distress in cancer patients, including patients that are in remission, includes a broad spectrum of unpleasant experiences. These include mental, societal, and spiritual experiences that range from feelings of vulnerability, sadness and fear to severely restricting problems such as depression, anxiety disorders, panic disorders, social isolation, and existential crises (Koch & Mehnert, 2007). The meaning perspective hypothesises that distress prompts meaning-making efforts.

The meaning-making model proposes that: people possess orienting systems, referred to in the meaning literature as global meaning. Global meaning provides one with cognitive frameworks with which one interprets one's experiences. When one encounters adverse situations, which have the potential to challenge or disrupt one's global meaning, one appraises the situations and assigns meaning to them. The extent to which that appraised meaning is discrepant with one's global meaning, determines the extent to which one experiences distress. Distress caused by discrepancy initiates a process of meaning-making. Through meaning-making efforts, one attempts to reduce the discrepancy between appraised and global meaning, and restores a sense of the world as meaningful, and one's own lives as worthwhile. This process, when successful, leads to better adjustment to the stressful event (Park, 2010:257, 258).

Paul Wong (2012) has developed a comprehensive model for meaning-centered counselling in Canada, which he refers to as Meaning-Centered Counselling and Therapy (MCCT). MCCT is an integrative model that is open, flexible, and comprehensive. It assimilates cognitive-behavioural, narrative, cross-cultural, and positive therapies with its logotherapy and humanistic-existential roots (Wong, 2012c:Kindle location 16072), which proposes that "people have the intrinsic motivation for meaning; they are free to choose and live a meaningful life because meaning can be found in all circumstances (Wong, 2012c:Kindle location 15909). The quest for meaning represents a

primary intrinsic motivation for life expansion, as well as a powerful capacity for personal transformation (Wong, 2012c:Kindle location 15864). Fabry (1998:296,297) posits that life issues demands that one has to respond to, in order to derive meaning in life. He argues that it is the human spirit, which allows one to experience fulfilment: to be goal oriented; to be aware of a past from which one can learn, and a future for which one can plan. Fulfilment also derives from a self-transcending love that goes beyond physical needs and emotional drives, and the conscience that tells one, beyond instinctual responses, how to respond to the demands of life. Hoffman (2009) as cited in Wong (2012c:Kindle location 16077) explains that the value of meaning-centered therapy as follows:

The instillation of meaning is a primary component of all existential approaches to psychotherapy. The deepest forms of meaning can be experienced on the various realms of biological, behavioral, cognitive, emotional, and interpersonal; in other words, it is a holistic meaning. The attainment of meaning is one of the most central aspects of human existence and necessary to address in existential therapy.

Meaning therapy is an extension of logotherapy, and has its roots in existentialism and humanism. The meaning therapy model corresponds closely with the person-oriented approach. Humanists and existentialists contend that that peoples' behaviour is determined by their own free will (Meyer & Moore, 2003:7) and they choose freely between available options (Meyer, Moore, Viljoen, 2003:324). Shantall (2003:439) maintains, due to humans' spiritual dimension, that human beings are open systems, one can think about oneself and change oneself, and one can think about one's world and change one's world. Maddi (1998:19) infers that existential psychotherapy underscores the individuation lifestyle; it increases one's recognition of the inevitability of choices is life; the importance of choosing the future regularly, and the role of courage in mastering anxiety. In the context of this research study, it implies that patients in remission have choices: they can choose to focus on their approaching death, with an attitude that life

offers no promises and enjoyment; alternatively, they can choose to live the remainder of their lives to the full.

Meaning therapy integrates the positive psychology perspective. A tenet of the positive psychology is that positive affect and personal strengths are what make life worth living (Wong, 2012a:Kindle location 539). Positive psychology is concerned with well-being and optimal functioning. The positive psychology proposes that troubled persons want more from life than just the relief of their suffering. They want more satisfaction, contentment and joy, not just less sadness and joy. They want to build their strengths and not just correct their weaknesses. They want lives imbued with meaning and purpose (Duckworth, Steen, & Seligman, 2005:630). Social workers can however, also make use of this framework when working in the field of oncology.

The researcher proposes MCCT as an intervention strategy in social work for patients who are in remission. The MCCT model addresses existential and spiritual issues, it underscores the importance of transforming and transcending life crises and personal tragedies, and it equips people with the tools to succeed in their quest for a better and more fulfilling life (Wong, 2012c:Kindle location 16027). Appropriate consideration must be given to the diverse cultural, indigenous, and religious aspects which are unique to South Africa. The MCCT model is multicultural, and therefore appropriate for implementation. The MCCT model is discussed in detail in Chapter 5.

## **1.5 RATIONALE FOR RESEARCH AND PROBLEM FORMULATION**

The researcher's rationale for conducting this study is based on the existential oriented proposition that life has meaning under all circumstances. The thematic analysis in chapter 7 identifies the relevant experiences, attitudes, and insights that participants reported that enabled them to integrate the knowledge and demands of living with incurable cancer and derive meaning in their lives in spite of suffering and an awareness of the transitoriness of life. When a patient realises that a cancer is incurable, it forces the patient to re-

evaluate his or her life. Cordoba et al. (1993:52) posit that an awareness of the transitoriness of life, the importance of certain relationships, a future vision and a validation of one's own life are all common experiences in cancer patients. The researcher maintains that patients in remission need to explore their hopes, strengths and expectations of the future. The researcher further purports that, in validating himself or herself, patients are able to create quality of life. When patients derive meaning in their lives, they are able to focus on the quality of life, and do not become stuck or pre-occupied with the quantity of life.

The research topic derived from practice. The researcher is the social worker at the Radiation Clinic at the Sandton Oncology Centre in Morningside, Johannesburg. The pursuit of knowledge meshes with the researcher's career goals to improve her skills, competencies, and knowledge base (Fouché & De Vos, 2011a:82).

The researcher works exclusively with oncology patients. Over the past ten years, she observed a shift in her caseload, towards increased demand for services to survivors. The researcher observed that patients in remission spend significant less time with the oncology team during follow up consultations as patients that are on active treatment. Furthermore, follow up consultations focus on the medical aspects of survival and continued medical surveillance. This is possibly due to the situation that historically the focus, medical and psychosocial, was largely on the needs and experiences of patients and families during the stages of diagnosis, treatment and palliative or terminal care.

The researcher has observed in practice that those patients that derive meaning in their lives cope better with diagnosis, treatment, and survival. This poses the question - how do patients, knowing that they are in remission and not cured, derive meaning in their lives? The researcher is of opinion that meaning-centeredness, that awareness of one's meanings and purposes can empower patients to live a fulfilling and happy life whilst in remission. In the

case of oncology social work, the primary focus is on the adverse experiences surrounding cancer, and models have been developed to address these adverse experiences. Brennan (2001:3), referring to other authors (Taylor, 1983; Goodare, 1996; Schaefer and Moos, 1998), postulates that an adequate theory of adjustment to cancer must account for both the high degree of stress and psychopathology associated with cancer, as well as the experience of healthy personal development which patients report.

The longer survival period necessitates a variety of psychosocial interventions (Fawzy, Fawzy, Arndt & Pasnau, 1995:100). In South Africa, only a few oncology centres have social workers as part of the oncology team, with the result that psychosocial needs for the majority of patients and survivors are not addressed. Cancer involves a complex set of changing conditions that put demands on patients' coping capacities. Issues that need to be addressed are the threat to survival, the impact on one's assumptive world, and the social, financial, and physical resources relating to the cost of cancer, employment, discrimination, insurance, and negotiating the health care system (Cordoba et al., 1993:44).

Blum et al. (2001:45) observed that the psychosocial needs of cancer patients have become increasingly complex because most treatment modalities have shifted to the outpatient basis, and patients are spending significantly less time with the oncology team than in the past. The outcome of outpatient care is that patients and their significant others bear increasing more responsibility for managing care, for example, diet, constipation and diarrhoea. Patients are also presented with more treatment choices. With the improvement in symptom control, more patients continue to work during treatment and they maintain their daily routine. By focussing on awareness of these psychosocial needs of patients and significant others, social work intervention can contribute to reducing stress and helping patients, and their significant others, to become more confident in their ability to maintain a sense of control.

Historically, the focus in social work intervention has been to support patients and families with diagnosis, acute treatment, palliative care, and end-of life care. Consequently, there is little preparation and support available for patients that are in remission. When survivors receive the “good news”, the confirmation that they are cancer free or that the cancer is stable, they tend to refrain from asking questions. Few oncologists explore with survivors the psychosocial needs that derive from the treatment and side effects or late effects of the treatment or refer these patient and/or their significant others to an oncology social worker. Patients may be referred only after the patients mentioned a need or requested a referral. When a social worker is not part of the oncology team, oncologists or team members may not be aware of the contribution that social work intervention can offer. There is also a need to formulate guidelines for social work intervention in the field of psychosocial oncology.

## **1.6 THE RESEARCH QUESTION**

Within the South African context, a lack of statistics and a lack of literature regarding cancer survivors necessitate research and follow-up studies. The researcher observed that those patients who derive meaning in their lives cope better with diagnosis, treatment, and survival. It poses the question of how do patients, knowing that they are in remission and not cured, derive meaning in their lives? The researcher is of the opinion that meaning-centeredness, that awareness of one’s meanings and purposes can empower patients to live a fulfilling life, creating and experiencing quality of life, whilst they are in remission.

The research question was derived from observations of practice and theoretical perspectives that were surveyed during the preliminary literature study. Due to the exploratory nature of the study and the fact that it is a qualitative study, the researcher used a research question as opposed to a hypothesis. The research question formulated for this study is thus: “**Does**

**meaning-centeredness play a role in adult cancer patients in coping with remission?”**

## **1.7 GOAL AND OBJECTIVES**

The *Oxford Advanced Learner's Dictionary* (2006:638) defines a goal as something that you hope to achieve. Thus, the goal of a study gives direction to the study (Royse, 1995:267). Stated differently, Fouché and De Vos (2011b:94,) argue that the goal of a study indicates the intention of what the researcher aims to achieve. Research goals are categorised as either basic or applied, while the objectives of research are exploration, description, and explanation. The objectives of a research study are the steps a researcher takes at grass-roots level, within a certain time span, to reach the goal or goals of a study. It can thus be concluded that objectives specify what the researcher has to do to achieve the study goals.

This study falls within the scope of applied research. The researcher has employed exploratory research because there is little known on the subject of cancer patients living in remission and, more specifically, on how those patients derive meaning in their lives whilst in remission. The purpose of exploratory research is to gain a broader understanding of a situation, phenomenon, community, or person (Bless, Higson-Smith & Kagee, (2006:47). Information collected from this research may improve social workers understanding of the research topic and this may lead to the development of guidelines for improved social work intervention in the oncology field, specifically for cancer survivors who are in remission.

### **1.7.1 Goal**

The goal of this research study was to explore meaning-centeredness in adult cancer patients who are in remission.

### **1.7.2 Objectives**

The objectives of the study were:

- to contextualise cancer survivorship, specifically focussing on remission as a field of study
- to provide a broad theoretical overview of social work in oncology
- to explore meaning-centeredness in adult cancer patients in remission at the Radiation Oncology Unit, Sandton Oncology Centre
- to provide conclusions and recommendation to social workers for consideration during intervention with cancer patients who are in remission
- to provide conclusions and recommendation as well as to heighten the awareness of the oncology team regarding patients who are in remission, and
- to create awareness of the role of the oncology social worker.

### **1.8 RESEARCH METHODOLOGY**

Qualitative research aims to obtain participants' accounts of meaning, experience or their perception and interpretation of an experience (Fouché & Delport, 2011:64). Grinnell (1997:14) defines qualitative social work research as a structured inquiry that utilises acceptable methodology to solve human problems and create new knowledge that can contribute to an increase in the body of generalizable knowledge about social work concerns. The social work problem in this research refers to adjustments needed to live in remission. Lang (in Delport and de Vos, 2005:45) cautions that, the social work profession appears to have an imbalance between strategies that produce knowledge, and strategies that direct action. The deficit in knowledge development strategies makes the profession exceptionally vulnerable to borrowing and importing rather than developing its own special knowledge base with the result that potential knowledge in the social work domain is continuously unarticulated and lost. It is desirable that this imbalance be

corrected. This observation holds true concerning meaning therapy. The researcher had to consult literature in the fields of existentialism, meaning-therapy, logotherapy, and positive psychology. Roberts, BrintzenhofeSzoc, Zebrack, and Behar (2003:1) observe that social workers are contributing to the body of knowledge regarding cancer survivors. The researcher, however, observed that literature in the social work domain on the topic of living in remission in social work is limited. There is thus limited knowledge available to guide oncology social workers to develop intervention programs. As stated earlier, the shift in focus in oncology social work from palliative care to interventions that focus on treatment, side effects, and long-term survival (Stearns et al., 1993:1) further necessitates research. The high prevalence of cancer, the increasing number of patients in remission, the impact of cancer on patients, survivors, families, communities and societies, and the need to develop social work intervention strategies, call for research in the field of psychosocial oncology. The researcher is of the opinion that expansion of the knowledgebase concerning survivorship and remission is required.

The qualitative approach emphasises that people are experts concerning their own experiences and therefore they are in the best position to report how they experience a particular event or phenomena (Darlington & Scott 2002:2). Thornton (2002:156) argues that qualitative data provides researcher with a glimpse into participant's narrative that is relatively untainted by prior assumptions or biases on the part of the investigator.

The researcher implemented a case study design. Case study design is the study of a single individual, or a very small group, with the purpose of obtaining a detailed description of the experiences of an individual or small group (Gravetter & Forzano, 2009:373). Case study furthers the understanding of the researcher about a specific social issue or population (Mark 1996:19), because the researcher develops an in-depth analysis of a case (Creswell, 2014:14). With case studies, a researcher uses a variety of data collection procedures, which entail the observation of a process, an

activity event, a programme, or an individual bound within a specific time and setting (Creswell, 2014:14).

A collective case study design has been implemented in this study to examine groups of cases and concepts, and also to extend and validate existing theory (Fouchè & Schurinck, 2011:322). In this case study, the researcher used focus groups (groups of cases) to examine how these patients, who have received treatment at the Sandton Oncology Centre and who are in remission [place and time], derive meaning in their lives [concepts].

In order to obtain the subjective accounts of participants' experiences, the researcher used focus groups to collect data. Stewart, Shamdasani, and Rook (2007:39) state that focus groups as a data-collecting instrument produce a rich body of data as expressed by participants in their own words and within their own context. In this research study, the researcher acknowledged participants as self-knowing subjects, and used their subjective accounts to explore meaning-construal while living in remission. In this research study the nature of patients' social reality is that, they have to adjust to living with incurable cancer. According to Neuman (2006:105), human beings are social beings who create meaning and who constantly make sense of their world.

Focus groups rely on purposive sampling (Greeff, 2011:365). Participants were purposively chosen from the group of patients that had received treatment for cancer more than once, and who were in remission. No distinction was made between cancer type and the duration of disease. Four focus group sessions were conducted (comprising 5 or 6 participants per group), accumulating in 21 participants. Apart from these participants, 3 participants who were initially invited to participate withdrew because their cancer moved out of remission and they became too ill to take part in the study. One participant suffered a car accident on the way to the last focus group interview and thus excused herself.

The research methodology will be discussed in detail in chapter 6, together with the ethical considerations.

## **1.9 LIMITATIONS AND STRENGTHS OF RESEARCH STUDY**

Although this research is focused on cancer patients in remission, the researcher recognises that cancer affects the entire family. Abrams (1974), as cited in Blum et al. (2001:62), observes that spouses, parents, children, and siblings are affected by cancer, particularly when the cancer becomes a chronic illness, and the equilibrium of the family is disrupted for long periods.

Meaning theory is an emerging field that has received relatively little attention from researchers. Park (2010:262) observed that although, the meaning making model has been described and accepted by a number of theorist, empirical work is still lacking. The result is that there is a lack of standardised terminologies. There is also a lack of standardised measuring scales. The lack of measuring scales that focus on patients in remission, left this researcher with having to accept that the findings reported, come from participants as self-knowing subjects. Therefore, the reports are subjective. The lack of clarity in the terms meaning, meaning-centeredness, and remission influenced participants' responses; they often talked more about their experiences of living in remission. From these narratives, the researcher had to interpret how they derive meaning in their lives.

These limitations in the meaning literature will change due to the current exponential growth of positive psychology. Meaning is a cornerstone of positive psychology (Wong, 2012a:Kindle location 456). Since 2012, more literature has become available with regard to meaning therapy. This is due to a developing interest in meaning therapy, which has resulted in academic organisation such as The International Network on Personal Meaning (INPM), which is the professional branch of the multi- and interdisciplinary organisation for meaning therapy, known as the International Society for Existential Psychology and Psychotherapy. They publish scholarly, peer-

reviewed articles that focus on meaning (International Network on Personal Meaning, 2013). The INPM encourages and promotes advanced research and education in meaning therapy, resulting in more literature becoming available.

The wide conceptualisation of the term remission is confusing. Therefore, in the context of this study, remission refers to living with incurable cancer. Due to the growing incidence of cancer, and by implication the growing number of patients that are in remission, and the impact of cancer on patients, families, communities and society, it necessitates psychosocial intervention. Exploring the literature, the researcher observed that there is comparatively little literature available with regard to remission. Thus, the results of this study are limited in their generalisability.

In line with the findings of Park (2010:285), the researcher also observed the scarcity of research available that has examined meaning-construal. In addition, the extents to which meaning-making processes do lead to meanings made are also poorly researched. The exception is reports on posttraumatic growth, for which there is a reasonable amount of research on meaning-making as its determinant. The researcher's literature research confirms the findings of Park (2012:Kindle locations 13701), that to date, there is no research on cancer survivors which has fully assessed the components of the meaning-making process. Therefore, much remains to be learned about meaning and meaning-making in cancer survivorship. In order to fully understand the role of meaning in transitioning to longer periods of survivorship, much more attention must be given to both conceptual and measurement issues.

A better understanding of the ways by which survivors create meaning through their experiences with cancer holds great promise for better appreciating the ways in which individuals differ in their capacities to cope with cancer. Knowledge derived from this study could help to identify

individuals who need assistance in adjusting to survivorship, and to develop intervention strategies for those who may need social work interventions.

Participants were invited to participate voluntarily in the research study. In order to meet the sampling criteria, the researcher utilised, within a specific time frame of one month, non-probability purposive sampling to assemble the sample. This resulted in unequal ethnical diversity, small sample size, unequal gender distribution, unequal age distribution, and bias in terms of financial status, and educational qualifications. The research sample was biased in terms of demographics and of cancer type, recurrences, and disease progression. The research sample is not ethnically diverse and all participants were well educated and from upper to middle class socio-economic circumstances. Shuttleworth (2009) infers there is no problem with sampling bias, as long as the researcher is aware that the results cannot be extrapolated to the entire population.

The sample included only adults. The Sandton Oncology Centre treats mainly adults because the protocol for treating children differs, and therefore children are referred to a paediatric oncology unit. The unequal gender distribution is not representative of the cancer population. Statistics indicate that the male-female ratio on cancer prevalence is almost equal. Although this research sample is not representative of the whole of the South African population it is representative of the population of the Radiation Department of the Sandton Oncology Centre, where the research study was conducted. Due to the lack of South African cancer statistics, the researcher has no indication if the sample is representative of South African cancer survivors that are in remission.

In this research study, the researcher listened for the perspective of participants (emic perspective) rather than from the researcher's own perspective, and strived to maintain a non-judgemental stance. The researcher focussed on what participants are thinking, why they are thinking it, their assumptions, motives, reasons, goals and values. In qualitative

research, researcher subjectivity is important, because the results rely on the accounts of participants as self-knowing subjects. Qualitative research poses the risk of researcher bias. Shuttleworth (2009) depicts researcher bias as a process where the researcher influences the results. The researcher was the data-collecting instrument; therefore, a certain amount of subjectivity was unavoidable. The goal of this qualitative research was to understand (not prove) the complexity of the quest for meaning in patients living with incurable cancer. The researcher is the only social worker at the Radiation Clinic at the Sandton Oncology Centre, and had previous contact with participants. Therefore, interpretation of data could possibly be influenced by the researcher's knowledge of participants' circumstances. Trustworthiness, and how researcher strived towards maintaining trustworthiness, is addressed in chapter 7. Despite the limitation of this study, the study contributes to the body of knowledge related to meaning-construal while living with incurable cancer. It also created an awareness of the demands of living with incurable cancer. It appears that meaning-construal manifests independent of medical variables, and because meaning-construal is a basic human need, the findings of this research study reflect the viewpoint of this research sample, but cannot be generalised. It can give an indication of how the research population derives meaning, and the findings could be transferable to patients who are in remission.

The researcher argues that the findings of this research can be generalised to a similar population of patients diagnosed with a life threatening illness. The MCCT model would be appropriate for intervention with patients who face a life-threatening illness.

Focus group interviews were used as the data collecting instrument. This is a limitation because it is suggested that with regards to the case study design, data collection should involve multiple sources of information (Creswell, 2013:97). Future study designs should include multiple sources of data collecting,

## **1.10 CONTENTS OF THE RESEARCH REPORT**

### **Chapter 1: General Introduction**

An introduction of the study, which focuses on the problem formulation, the rationale, goal and objectives of the study, a brief discussion of the research methodology, the ethical considerations and definition of key concepts.

### **Chapter 2: Oncology**

This chapter offers brief descriptions of cancer and the generally applied treatment modalities. Some common side effects of treatment are discussed in order to create awareness for the demands imposed by treatment and remission.

### **Chapter 3: Remission**

Here, a definition of remission as applied in this research study is provided. The complexity of remission is discussed.

### **Chapter 4: Meaning, meaning-centeredness and meaning-construal**

The theoretical background is provided and meaning, meaning-centeredness, and meaning-construal.

### **Chapter 5: Oncology Social Work and a proposed intervention programme**

This chapter outlines the factors that call for oncology social work interventions. It aims to contribute to the explicit knowledgebase of oncology social work. Wong's (2012) Meaning-Centered Counselling and Therapy model is proposed as an intervention programme.

### **Chapter 6: Research Methodology**

The research methodology used in this study is described.

**Chapter 7:** Empirical findings of the study.

The research findings are discussed, firstly providing a biographic profile of participants and secondly a thematic analysis of the themes and sub-themes generated from the study.

**Chapter 8:** Summary, conclusions and recommendations

This chapter gives a summary of the study along with the researcher's conclusions and recommendations.

## CHAPTER 2

### 2 ONCOLOGY

#### 2.1 INTRODUCTION

The researcher observed in practice that patients, caregivers and their families all expressed a need for more information and/or help with interpreting information regarding their cancer or diagnosis. The value of health literacy, defined as “the capacity to seek, understand, and use health information to participate in decisions about health”, is increasingly recognised. It is central to a person’s participation in their health care knowing when to seek medical advice, communicate effectively with healthcare professionals, and to adhere to treatment (Jordan, Briggs, Brand & Osborne, 2008:S11). In the context of this research, health literacy refers to the provision of reliable and tailored information to the growing number of cancer survivors, and by implication, the growing number of patients who are in remission. Knowledge empowers patients to make informed decisions (Davies, 2010:32). Health literacy can facilitate better perception of control, which, in turn, reduces feelings of threat and anxiety, resulting in patients’ experiencing a better quality of life (Davies, Kinman, Thomas, & Bailey, 2008:1048). Good health literacy thus facilitates better adjustment to cancer and, by implication, to living in remission. Therefore, providing health information should be an on-going process throughout the cancer experience (Davies et al., 2008:1049). There is also strong evidence that patients, who are well-informed are more likely to comply with treatment and medication regimes (Coulter, 2003:1).

The need for patients to be involved in decision-making and illness management has been recognised. In the context of the South African multi-cultural population, McLaughlin (1994:1) emphasises the importance of providing accurate information in the appropriate language, at the appropriate time during the course of the treatment. Coleman (2006:2) states that the amount of information that each patient needs, differs. Adequate health

literacy empowers patients and their social attachments to understand the medical terminology as well as the scientific concepts behind the treatments, which, in turn, enables them to understand and interpret information better, and enables them to ask pertinent questions of the oncology team. They will therefore find the time spent with the oncologist and with the oncology team more valuable. There is also a need for patients, caregivers and families to explore information at their own pace and thus avoid information overload. Information overload manifests when patients and/or the social attachments perceive that they have lost control of their situation, because they are overwhelmed by the amount or complexity of information. The researcher infers that patients and their social attachments also need to know where to look for valid information.

Patients and their social attachments may be so overwhelmed by the cancer experience that they are unable to recognise and express their information needs, with the result that their information needs can go unrecognised (Davies et al., 2008:1048). Patients do not always know if the information they access is scientifically sound and they may find it difficult to interpret information. The objective of health literacy should be to ensure that patients and their social attachments receive accurate and adequate information that empowers them to develop insight about treatment and interventions that will motivate, support and promote adherence to treatment and medication regimes (Spies, 2007:8,9). Concerning the role of health literacy, Stovall, who has experienced a recurrence of cancer, concludes "...cancer is a lesser foe in the light of knowledge. With that knowledge come understanding; with understanding, fear diminishes, in the absence of fear, hope emerges; and in the presence of hope, anything is possible" (Coleman, 2006:XIV).

Oncology social workers often assist patients to make informed decisions about treatment, therefore they need to know what cancer is (and what it is not), and what treatment entails (Cordoba et al., 1993:43). Patients need to understand the specific treatment options available, the rationale behind a

prescribed treatment, the demand imposed by suggested treatment, the anticipated side effects and late-effects of suggested treatment and the anticipated outcome of the treatment. Understanding the rationale and impact of suggested treatments empowers patients to make informed decisions about their treatments.

This chapter aims to give a general introduction of cancer and the current treatment modalities that are employed generally, and the general anticipated side-effects of those treatments. The researcher infers that oncology social workers should have this basic knowledge in order to understand the demands of various treatments, or to be able to clarify and address misconceptions or patients' fear regarding treatment regimes. Oncology social workers should always confirm with the oncologist if the treatment is radical or palliative, in order to help patients and their significant others to build realistic hope. Side effects of cancer types are not discussed in this research study.

Key terms defined in this chapter are cancer, carcinoma, and oncology.

## **2.2 DEFINITION OF KEY TERMS**

### **2.2.1 Cancer**

The Merriam Webster Dictionary [sa] explains cancer as:

Any of a group of more than 100 distinct diseases that are characterised by the uncontrolled multiplication of abnormal cells. Cancerous cells and tissues have abnormal growth rates, shapes, sizes, and functioning. Cancer may progress in stages from a localised tumour (confined to the site of origin), to direct extension (spread into nearby tissue or lymph nodes), and metastasis (spread to more distant sites via the blood or lymphatic system). This malignant growth pattern distinguishes cancerous tumours from benign ones. Cancer is also classified by grade, the extent to which cell characteristics remain specific to their tissue of origin. Both stage and grade affect the chances of survival. Genetic factors and immune status affect susceptibility. Triggers include hormones, viruses, smoking,

diet, and radiation. Cancer can begin in almost any tissue, as well as in the blood and lymph.

Cancer is thus a malignant tumour. A tumour is described as a mass of abnormal tissue that arises from normal cells, has no useful function, and tends to grow. Cell abnormalities that occur are increased size of cells, or increased in numbers of cells. The abnormal cells also lose the characteristics of their tissue of origin. Cells in malignant tumours have a distorted size, shape, and/or structure. Less differentiated cells tend to grow faster. Malignant tumours invade tissues locally and spread (metastasise) in blood or lymph: the stronger the tendency to metastasise, the more malignant the tumour. Benign tumours remain as a solid mass that can be removed by surgery if accessible; they can consist of various tissues and may become malignant. Malignant tumours, though they may remain quiescent for a time, never become benign cancer (*The Merriam Webster Dictionary* [sa]).

*The National Library of Medicine* (2013) explains that cancer grows out of normal cells in the body. Normal cells multiply when the body needs them, and die when the body does not need them. Cancer appears to occur when the growth of cells in the body is out of control and cells divide too quickly. It can also occur when cells forget how to die. *The Free Medical Dictionary* [sa] explains further that cancer originates on a cellular level. It is a disease of the genes. Throughout people's lives, the cells in their bodies are growing, dividing, and replacing themselves. Many genes produce proteins that are involved in controlling the processes of cell growth and division. A mutation of the DNA molecules can disrupt the genes and produce faulty proteins. This causes a cell to become abnormal and lose its restraints on growth. The abnormal cells begin to divide uncontrollably and eventually form a neoplasm (tumour). In a healthy person, the immune system can recognise the neoplastic cells and destroy them before they get a chance to divide. However, some mutant cells may escape immune detection and survive to become tumours or cancers. The altered cells (neoplasm) pass on inappropriate genetic information to their progeny cells and begin to

proliferate in an abnormal and destructive way. As the cancer cells continue to proliferate, the mass of abnormal tissue that they form enlarges, ulcerates, and begins to shed cells that spread the disease locally or to distant sites. This migration is called metastasis. Some cells invade neighbouring tissues, destroying and displacing normal cells and taking their place. If cells enter the blood and lymphatic vessel, they are carried in the fluid to other parts of the body. Another way, in which cancer can metastasise, is by entering a body cavity by diffusion and coming into contact with a healthy organ.

Cancer is a cell that lost its control on cell growth and cell division. It has the tendency to metastasise. Oncology social workers need to understand whether a patient refers to a primary, metastasis, or another primary. The staging and grading of a cancer influences the prognosis and treatment options.

### **2.2.2 Carcinoma**

Sometimes the term 'carcinoma' is used to describe all cancers. A carcinoma is actually a type of cancer. An oncologist may refer, for example, to a carcinoma of the breast, indicating a cancer that originated in the breast tissues. Carcinomas are cancers that originate in the skin, or in the tissues that lines or covers internal organs. Malignancies that arise from the keratinised stratified squamous epithelium are known as squamous cell carcinomas. Adenocarcinoma arises in the ducts of glands or glandular tissue, basal cell carcinoma arises in the epidermis, and transitional cell carcinoma arises in the bladder (Cohen, 1995:31; Coleman, 2006:44; Gardner & Werner-Lin, 2012:500; Jaftha & Pervan, 1995:772).

The other common types of cancers are sarcomas, leukaemias, lymphomas, and central nerve system cancers. Sarcoma indicates cancers that originate in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukaemia indicates cancers that originate in blood-forming tissue such as the bone marrow, and cause large numbers of abnormal blood

cells to be produced, and to enter the blood. Lymphomas and myeloma refer to the cancers that originate in the cells of the immune system. Central nervous system cancers indicate the cancers that originate in the brain and spinal cord (Coleman, 2006:44; Gardner & Werner-Lin, 2012:500).

### **2.2.3 Oncology**

Oncology is a branch of medicine that specialises in the diagnosis and treatment of cancer. It includes medical oncology (the use of chemotherapy, hormone therapy, and other drugs to treat cancer), radiation, and surgical oncology (NCI: *Dictionary of cancer terms, reviewed 2010, [sa]*). *The Oxford Concise Medical Dictionary, 2007:505* defines oncology as “the study and practice of treating tumours. It is often subdivided into medical, surgical, and radiation oncology.”

The oncology team consist of an oncologist, other medical professional involved in the diagnosis and treatment of cancer, and the other disciplines involved in the physical and psychosocial care of the patient. Oncology social work focuses on the psychosocial aspects of oncology care.

## **2.3 CANCER**

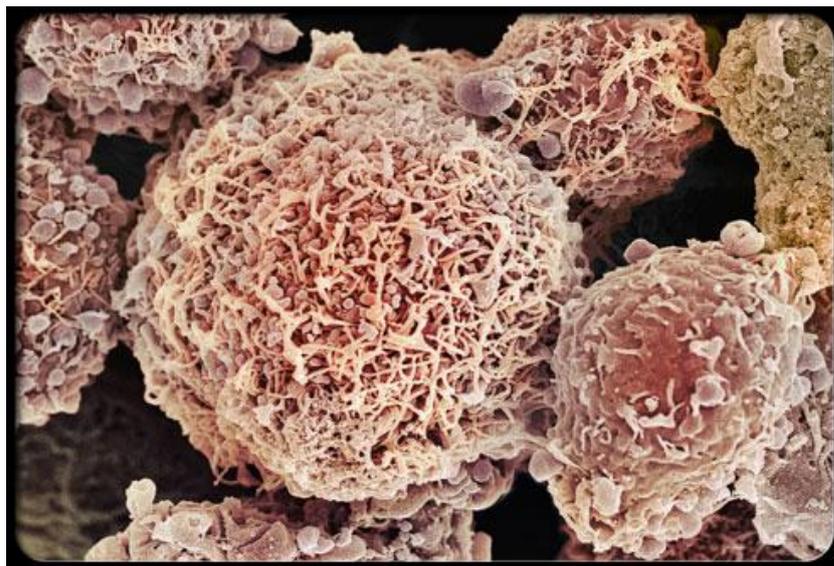
### **2.3.1 Description of cancer**

Cancer was defined in Chapter 1 and as a key term in this chapter. Originated in the fifth century, the word describes what the disease looks like. Hippocrates observed that a cancerous tumour has a hard centre with “claw-like projections” which reminded him of a crustacean. He named the disease *karkinos* or *karkinoma*, the Greek word for crab. The Latin version of the Greek word is *cancer* (Lyss, Fagundes & Corrigan, 2005:26).

In oncology, the term malignant describes a tumour that invades and destroys the tissue in which the tumour originates and has the potential to spread (metastasise) to other sites in the body via the bloodstream and lymphatic

system (*The Oxford Concise Medical Dictionary*, 2007:429). Highlighting the main characteristics of cancer as the uncontrollable growth of the cells in the human body coupled with the ability of these cells to metastasise, *The Free Medical Dictionary* [sa] warns that uncontrolled metastases can result in death. The term cancer thus refers to the uncontrolled growth of cells that has the tendency to invade surrounding tissue and metastasise to distant body sites. Ross and Deverell (2010:134) add that metastatic cancer impact on the prognosis, because metastatic tumours are rarely operable. Cancer tends to metastasise to different sites, and removal of all the cancer cells is virtually impossible. Furthermore, metastases are not always visible, further limiting surgery. Metastases require additional treatment in the form of chemotherapy or radiation therapy or, in some cases, changes in the treatment to either palliative or end-of-life care. In rare cases, a single metastasis may occur that is operable.

**Figure 2:** Image of cervical cancer.



*Figure 2: Image of a cervical cancer tumour (MedicineNet: Disease Prevention in Women, 2011)*

### 2.3.2 Pathophysiology of cancer

*The Free Medical Dictionary*, [sa], depicts the pathophysiology of cancer as follows:

Cancer is a disease of the genes because it originates on cellular level. A gene is a small part of DNA (deoxyribonucleic acid), which is the master molecule of the cell. Throughout one's life, one's cells continue to grow, divide, and replace themselves. Many genes produce proteins that are involved in controlling the processes of cell growth and division. If DNA molecules mutate, the genes produce faulty proteins which cause a cell to become abnormal and lose its restraints on growth. The mutated cells begin to divide uncontrollably and eventually form a tumour (neoplasm).

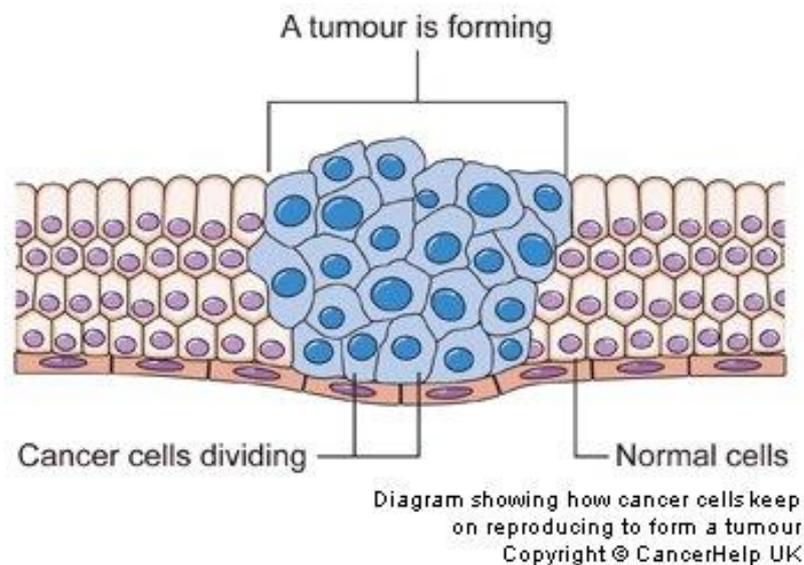
Normal cells do not divide randomly. A normal cell recognises its borders and stays in place. It recognises other cells next to it and respect the territory of the neighbouring cells. A normal cell stays where it should be until it dies, when another cell replaces it. Division occurs when a cell receives a signal instructing it to divide. One way in which cells receive the signal to divide is through hormones, growth factors and cytokines (Coleman, 2006:29). In a healthy person, the immune system recognises the neoplastic (abnormal) cells and destroys them before they start to divide. However, some mutant cells may escape immune surveillance and survive to develop into benign or malignant tumours. The altered cells pass on inappropriate genetic information to their progeny cells, causing these cells to lose constraints on growth. This starts a cycle where the altered cells proliferate in an abnormal and destructive way. As the cancer cells continue to proliferate, the mass of abnormal tissue that they form enlarges, ulcerates, and begins to shed cells that spread malignant cells locally or to distant sites. This migration to a distant site is called metastasis. Some malignant cells can invade neighbouring tissues, destroy and displace normal cells, and even replace the normal cells. Cancer cells can also spread via blood and lymphatic vessels. This enables the cancer to be carried to other parts of the body. Another way

in which cancer can metastasise is by entering a body cavity by diffusion and coming into contact with a healthy organ (Daniel, 2005:59; *The Free Medical Dictionary*, [sa]). If a malignant cell enters a body cavity, it can encounter healthy organs, and invade those organs, becoming a metastatic site. Cancer tends to metastasise to various sites. A benign tumour is not cancerous; benign tumours are often slow growing and tend not to metastasise or invade. Once a benign tumour is removed, it does not usually recur. A malignant tumour is cancerous (Daniel, 2005:59).

The Cancer Research Organisation (UK) (The Cancer Cell) provides the following informative diagrams:

Unlike normal cells, cancer cells do not stop reproducing after they have doubled 50 or 60 times. This means that a cancer cell will go on and on and on doubling. Thus, one cell becomes 2, then 4, then 8, then 16....

**Figure 3:** The cancer cell



*Figure 3: The cancer cell*

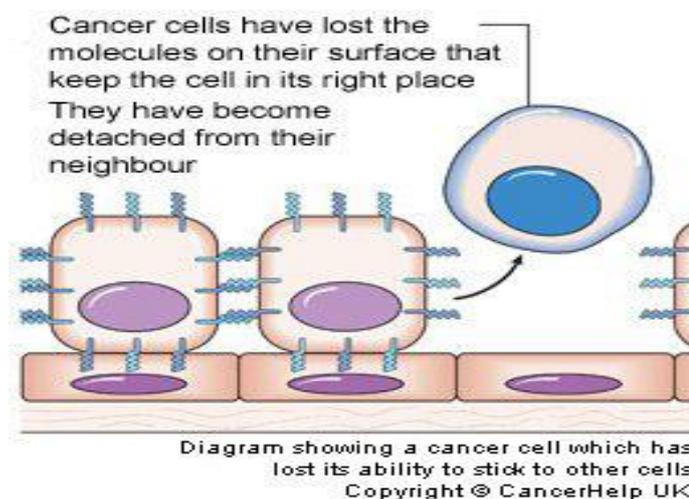
The cancer cells may be able to stop themselves self-destructing, or they may self-destruct more slowly than they reproduce, so that their numbers continue

to increase. Eventually a tumour is formed that is made up of billions of copies of the original cancerous cell. Scientists describe untreated cancer cells as being 'immortal'.

Something in the cancer cells overrides the normal signalling system. This may be because the genes that tell the cell to reproduce keep on and on sending signals, or, because the genes that normally tell the cell to stop reproducing have been damaged or lost. Therefore, the cancer cell keeps on doubling, regardless of the damage the extra cells cause to the part of the body where the cancer is growing.

Cancer cells can lose the molecules on their surface that keep normal cells in the right place. So they can become detached from their neighbours.

**Figure 4:** Cancer cells detaching from normal cells



*Figure 4: Cancer cells detaching from normal cells*

It is not always certain what causes cancer (Mcperson, 1999:82). The causes of cancer can be hereditary, environmental, dietary, habits, viral, or immunosuppressive. In the context of this research, environmental factors refer to factors outside a person's body. Exposure to a wide variety of natural and synthetic substances in the environment can cause cancer. Included in environmental causes are lifestyle choices, such as in smoking, excessive

alcohol consumption, poor diet, lack of exercise, excessive exposure to sunlight, and sexual behaviour that increases exposure to certain viruses. Viruses that can contribute to the development of cancer include the human papillomavirus (HPV), the hepatitis B (HBV) and hepatitis C (HCV), Epstein-Barr virus (EBV), and Kaposi's sarcoma-associated herpes virus (KSHV). Infection with the *Helicobacter pylori* bacterium can contribute to the development of stomach cancer (NCI: *Cancer and the environment*, 2003: 1,9,10). When environmental carcinogens cause cancer, these carcinogens cause the initial mutation in the DNA (Medical News Today: *What is cancer...* [sa]). Inherent factors, which make one more susceptible to develop cancer, include altered genes in the body's cells, abnormal hormone levels in the bloodstream, or a weakened immune system. When cancer has a genetic basis, it means one could inherit faulty DNA from one's parents, predisposing one to developing cancer. Cancers that are known to have a hereditary link are breast cancer, colon cancer, ovarian cancer, and uterine cancer. Certain physiological traits could make one more susceptible to cancer. For example, if a person with a fair skin is exposed to intensive sunlight for a prolonged period, such a person has an increased risk to develop cancer (*The Free Medical Dictionary*, [sa]). Environmental factors interact with a person's cells throughout their lives. Harmful exposure to environmental factors may cause gene alterations. Presently more than 300 genes have been identified, which, when altered, can cause cancer. A mutation in the oncogenes (growth-promoting genes) can signal the cell to divide out of control. A mutation in tumour suppressor genes will allow cells with damaged DNA to continue dividing, instead of repairing the DNA, or eliminating the injured cells. The uses of some medical drugs have shown an increased risk of the development of secondary cancers. Some immunosuppressant drugs are also associated with increased cancer risks (NCI: *Cancer and the environment*, 2003:2,4,5). The term immunosuppressive refers to any agent that suppresses the immune response of an individual (*The Free Medical Dictionary*, [sa]).

A basic knowledge of the physiology of cancer enables the social worker to explain the process of various treatment modalities. For example, different chemotherapy drugs exert their action in different stages of the cycle of a cell (Leon, De Jager & Toop. 1995:198).

### **2.3.3 Types of cancer**

An accurate diagnosis of the type of cancer is needed. Malignant cell types behave differently, and are treated differently (Gardner & Werner-Lin, 2012:500). A common way to classify cancers is according to the epithelial tumours (carcinomas), the mesenchymal tumours (sarcomas, lymphomas, and leukaemias), and germ cell tumours. A more expanded classification is to name cancers according to the organ or tissue in which the cancers originate.

**Table 1:** Classification according to cancer type

Type of cancer	Tissue or organ where the cancer originates
Carcinomas	
adenocarcinoma	cells lining the ducts of glands or cells from glandular tissue
Carcinoma	a general term for all cancers beginning in epithelial tissue
carcinoma in situ	an early cancer that occurs in a glandular or lining structure that have not invaded the surrounding tissue
Endometrial	uterus
Hepatoma	liver
non-small cell, small cell	lung, small cell cancers can occur at other sites, e.g. cervix
squamous carcinoma	cells on the surface of the body or cells that line internal structures such as the mouth, throat, bronchus, anal canal
transitional cell	bladder
Germ cell tumours	tumours arising from the testes or ovaries
Gliomas	
glioblastoma	brain
astrocytoma	brain
Leukaemia's	bone marrow, the soft tissue in the centre of bones where blood cells are manufactured
Lymphomas	cells in the lymph system which manufacture immune cells
Hodgkin's disease	
Non-Hodgkin's lymphoma	
Melanoma	pigmented cells, usually in the skin
Mesothelioma	tissue lining the lung or abdominal cavity
Multiple myeloma	antibody-producing immune cells
Sarcomas	bone or connective tissue such as muscle
Seminomas	germ cells in testes or ovary

*Table 1: Classification according to cancer type (Coleman, 2006: 44, 45)*

Prefixes have been assigned to the site where a cancer originates. Such a prefix is combined with the cancer type, which will indicate a specific cancer, for example, an osteosarcoma indicates a cancer of the bone.

**Table 2:** Common prefix

Prefix	Associated with
adeno-	gland
chondro-	cartilage
erythro-	red blood cells
hemangio-	blood vessels
hepato-	liver
lipo-	fat
lympho-	white blood cells
melano-	pigment cells
myelo-	bone marrow
myo-	muscle
osteo-	bone
uro-	bladder
retino-	eye

*Table 2: Common cancer prefixes (Medical News Today: What is cancer [sa])*

Social workers do not need voluminous or detailed information about cancer, but must know the basic facts about cancer types and expected side effects and late effects of treatment (Hermann, 1993:5). The type of cancer directs the medical management of the disease and gives an indication of the burden of treatment. Therefore, social workers need to develop an understanding of the type of cancer, where it originated from and if it has metastasised, in order to develop an understanding of how cancer or cancer metastases may affect a patient's functioning. As indicated by the *Oxford Concise Medical Dictionary* (2007:107) treatment of cancer is determined by the type and site of the original tumour, as well as the extent of metastases, for example, an endometrial cancer (carcinoma) that metastasised to the bone does not turn into a sarcoma. The researcher infers that patients and their social attachments need to understand that when a cancer has metastasised, the treatment will still fall within the regime of the primary tumour, for example the treatment for a metastasis to the lungs cannot be compared to the treatment of a primary lung cancer.

### **2.3.4 Primary cancer and metastases (secondaries)**

Virtually all cancers can form metastatic tumours. The type of the primary cancer indicates the anticipated behaviour and metastases, for example, bone metastases are very common in cancers of the breast, bronchus, thyroid, kidney, and prostate but less common in other tumours (*Oxford Concise Medical Dictionary, 2007:107*). A metastatic cancer contains the same type of cancer cells as the primary cancer. Therefore, a metastatic cancer is referred to by the same name as the primary cancer; for example, breast cancer that spreads to the lungs and forms a metastatic tumour is referred to as metastatic breast cancer and not lung cancer. Metastasis of blood and lymphatic system cancers (leukaemia, multiple myeloma, and lymphoma) to the lungs, the heart, the central nervous system, and other tissues are seldom reported (NCI: *Metastatic Cancer*, reviewed 2013).

Currently, a cure for metastatic cancer is only possible for a very small percentage of cancers. For metastatic cancers, which current treatments cannot cure, the option remains for palliative treatments. The primary goal of palliative treatment is to control the growth of cancer, and to relieve symptoms caused by cancer. Palliative treatments may help to prolong life; however, most people who die of cancer die of metastatic disease (NCI: *Metastatic Cancer*, reviewed 2013).

A patient can have more than one primary cancer. The social worker must distinguish if a patient refers to another primary cancer or to a metastasis.

### **2.3.5 Growth path of cancer**

Sometimes a cancer recurs. A recurrent cancer (recurrence or relapse) happens when some cancer cells were not destroyed in the initial treatment regime. Some tumours may have been so small that they were not observed in initial or follow-up examinations (NCI: *When cancer returns*, 2010). A

recurrence is classified by where the cancer recurs in relation to the primary tumour:

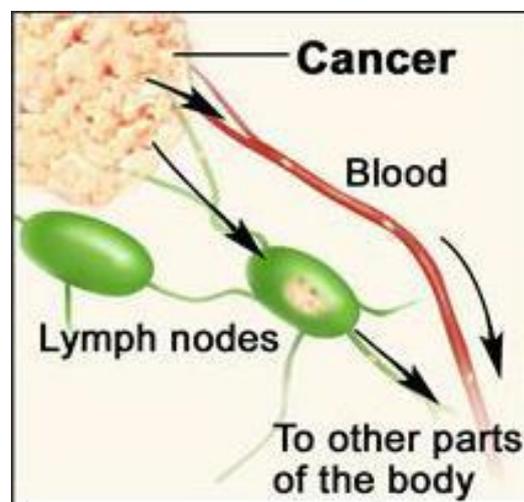
- a local recurrence implies that the cancer is in or very close to the original
- a regional recurrence is when the cancer recurs in the tissues or lymph nodes near the original cancer site
- a distance recurrence is where the cancer has metastasised to glands or organs beyond the original cancer site (Lyss et al., 2005:283).

The National Cancer Institute (*Metastatic Cancer*, reviewed 2013), gives a broader description of the steps involved in cancer metastasis:

Cancer cell metastasis usually involves the following steps:

- Local invasion: Cancer cells invade nearby normal tissue.
- Intravasation: Cancer cells invade and move through the walls of nearby lymph vessels or blood vessels.
- Circulation: Cancer cells move through the lymphatic system and the bloodstream to other parts of the body.

**Figure 5:** Invasion of lymph nodes



*Figure 5: Metastatic cancer cells invade lymph vessels and blood vessels*

Metastatic cancer cells invade lymph vessels and blood vessels near a tumour and migrate to other parts of the body (National Cancer Institute: *Metastatic Cancer*, reviewed 2013).

- Arrest and extravasation: The cancer cells stop moving when they reach the capillaries. They then invade the walls of the capillaries and migrate into the surrounding tissue.
- Proliferation: Cancer cells multiply at the distant location to form small tumours known as micro metastases.
- Angiogenesis: Micro metastases stimulate the growth of new blood vessels to obtain a blood supply. A blood supply is needed to obtain the oxygen and nutrients necessary for continued tumour growth.

**Table 3:** Common pathways of metastases

<b>Cancer type</b>	<b>Main sites of metastasis</b>
breast	lungs, liver, bones
colon	lungs, liver, bones
kidney	lungs, liver, bones
lungs	adrenal gland, liver,
melanoma	lungs, skin/muscle, liver
ovary	peritoneum, liver, lungs
pancreas	liver, lungs, peritoneum
prostate	bones, lungs, liver
rectum	liver, lungs, adrenal gland
stomach	liver, peritoneum, lungs
thyroid	lungs, liver, bones
uterus	liver, lungs, peritoneum

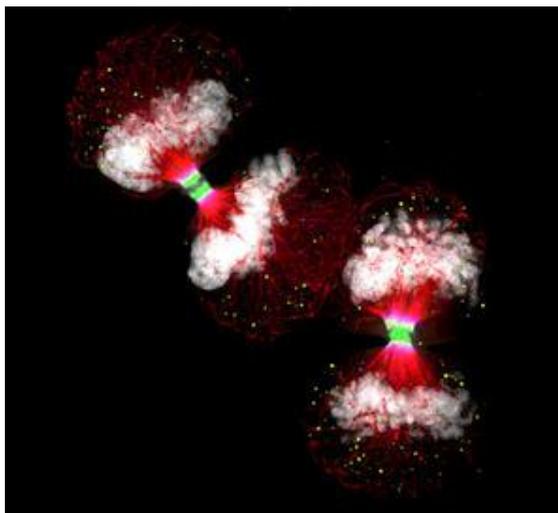
*Table 3: Common pathways of metastases (NCI Metastatic Cancer, reviewed 2013)*

The most common sites of cancer metastasis are the lungs, bones, and liver. Although most cancers have the ability to metastasise to many different sites, they usually metastasise to one site more often than to other sites. The table above shows the three most common sites of metastasis for several types of cancer: this table excludes any spread to the lymph nodes.

Understanding the growth path of cancer prevents cancer phobia, which occurs when minor symptoms are interpreted as signs of cancer; panic

attacks may ensue (*Oxford Concise Medical Dictionary*, 2007:107). Cancer patients refer to “cancerites,” an anxiety common within the first year after treatment when patients perceive every physical discomfort as an indication of cancer. Understanding the typical growth path of their specific cancer can put patients at ease about unrelated symptoms, when is it necessary to consult with the treatment team, or when another medical speciality is needed, for example, a dietician, or swallow therapist. Furthermore, understanding where specific cancers can spread to may help to prevent a patient from blame of overreacting, or being neurotic, or being a hypochondriac. For example, when a cancer metastasises to the brain, emotional or physical functioning may be impaired, and behaviour may manifest that is not expected when the focus is only on the site of the primary tumour.

**Figure 6:** Cancer cell dividing



*Figure 6: Microscopic snapshot of cancer cells multiplying (Chan, 2010)*

## 2.4 DIAGNOSIS OF CANCER

During diagnosis the cancer is named, the primary site is identified, and it is determined whether and whereto the cancer has metastasised (Coleman, 2006:11). The prognosis indicates a statistical estimate of the chance that a

patient will be alive at a certain point in time after treatment. Prognosis is based on average numbers for a large group of patients (Coleman, 2006:76). Prognosis is thus an estimate of how a cancer will respond to a specific treatment regime, and can therefore be interpreted as an estimate of a patient's life expectancy.

A biopsy is a procedure where cancer cells are extracted and investigated under a microscope. Currently, a biopsy is the only absolute way to diagnose cancer. Other modalities, which can be employed to diagnose cancer, include blood tests, imaging techniques, and molecular diagnostics. Imaging is a diagnostic procedure that utilises imaging equipment that will locate the site, stage, and grade of tumours. Molecular diagnostic tests analyse cell content for disease information. These tests may sequence specific regions of DNA to identify genetic mutations or quantify the levels of certain genetic materials which may be expressed by a bacterium, virus or cancer (Dombrauckas, [sa]). Physicians may analyse the body's sugars, fats, proteins, and DNA at the molecular level. For example, cancerous prostate cells release a higher level of a chemical called PSA (prostate-specific antigen) into the bloodstream, and that can be detected by a blood test (Medical News today: *What is cancer...* [sa]).

**Figure 7:** Illustration of a fine needle biopsy.



*Figure 7: Fine needle biopsy (MedicineNet: Breast cancer pictures [sa])*

Referring to the National Comprehensive Cancer Network (2012) the information booklet of AstraZeneca Oncology states:

In breast cancer the treatment choice is influenced by a number of factors: clinical and histopathological characteristics of the primary tumour and the axillary lymph node, the presence of hormonal receptors, the level of expression of the *HER 2/neu* gene, the presence of metastasis, associated co-morbidities, the patient's age, and the presence or absence of menopause. Therapy includes local treatment of the cancer with surgery, radiation therapy or both. In the presence of metastasis, treatment options are one or a combination of chemotherapy, hormone therapy, biological therapy. Radiation and surgery are often included in the treatment regime if there are metastases.

Blood tests are usually taken to assess blood counts and blood chemistries and to evaluate cancer markers. Not all cancers have a cancer marker. A complete blood count (CBC) serves as a baseline that enables the oncology team to monitor the effect of treatment by comparing the initial CBC with later CBC's. Blood chemistry tests measure whether organs such as the kidneys or

liver are functioning properly, because treatment can put additional strain on other organs. Biomarkers (tumour markers) are normally present in the blood in small amounts. When the amount of a particular biomarker is higher than normal, a cancer may be present. Elevated biomarkers do not necessarily indicate the presence of cancer, but can indicate the need for further investigations. Tests for biomarkers are often done during the course of treatment, to determine whether there are still tumour cells present (Coleman, 2006:48,49). Biomarkers are measurable biochemicals that are associated with a malignancy. They are either tumour derived (produced by tumour cells) or tumour associated (produced by the body in response to tumour cells). Biomarkers are typically substances that are released into the circulation and thus measured in the blood. There are a few exceptions to this. An example is when tissue-bound receptors from a solid tumour need to be measured in a biopsy (*The Free Medical Dictionary*, [sa]). Histology tests also indicate if, in certain cancers, adjuvant treatment is required, for example hormone manipulative treatment for hormone receptive cancer.

An understanding of the diagnostic procedures enables social workers to prepare a patient and social attachments for the medical steps that the patient is likely to undergo.

#### **2.4.1 Staging**

Following diagnosis, staging studies are performed. Staging is the process by which physicians determine how advanced the cancer is and what the prognosis is. It helps doctors determine what treatment to recommend (Lange & Adamec, 2003:70). Treatment is determined by the clinical (observed) changes and the pathological (structural and functional) changes that characterise a specific type of cancer. Clinical studies include blood tests and diagnostic imaging tests such as X-rays, nuclear medicine scans, ultrasonography, CT scans, and MRI scans. Pathological studies are performed when it is necessary to obtain additional biopsies of tissues such as lymph nodes or bone marrow, or of tissue near the tumour (Coleman,

2006:14,15). In summary, the staging of cancer is performed to determine the site of the cancer, the size of the tumour, if there are any metastases, and, if so, to where the cancer has metastasised, the treatments that are likely to be appropriate, and the prognosis - indicating how the disease is likely to respond to treatment (Coleman, 2006:14).

Some staging systems use numbers to identify the stage of a cancer. In all staging systems, a higher number indicates a greater volume of tissue that is involved in the cancer. Most commonly used is the 'TNM' system in which **T** refers to the size of the primary tumour, **N** indicates whether lymph nodes are involved, and **M** indicates whether the cancer has metastasised to another part of the body (Coleman, 2006:47).

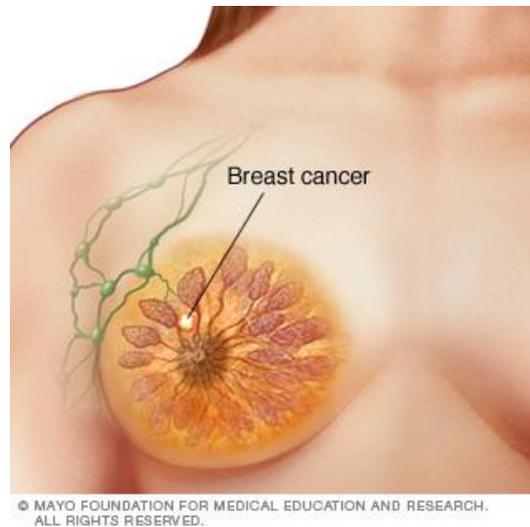
Another staging system commonly used is:

- **stage I** indicates a small tumour that has not spread to other organs, usually curable
- **stage II** likely means that the cancer has not spread, but the tumour is larger or has invaded deeper than a stage I tumour, or there may be cancer cells in the nearby lymph nodes
- **stage III** indicates that the tumour is even larger, and/or some lymph nodes are affected
- **stage IV** denotes that a tumour has metastasised to major organs in the body
- **stage 0** is sometimes used to indicate pre-cancerous (in situ) conditions (Lyss et al., 2005: 54; Sorenson & Metzger, 2000:79).

The following diagrams indicate how breast cancer is staged (Mayo Foundation for Medical Education and Research, Stages of breast cancer, [sa]).

**Figure 8:** Stage I breast cancer.

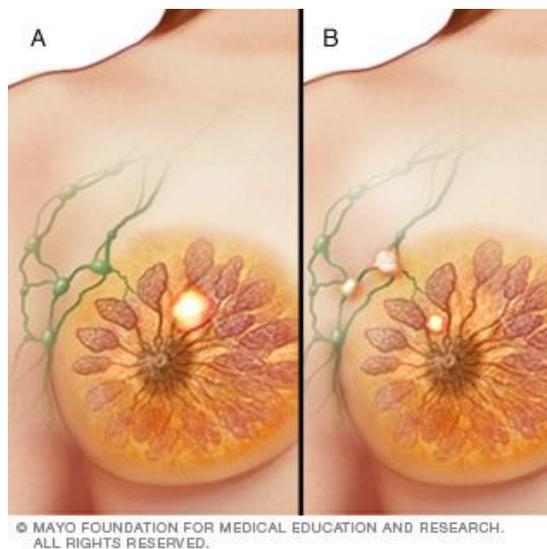
In a stage I cancer the cancer is less than 2 cm in size, and is still encapsulated in the breast.



*Figure 8: Stage I breast cancer*

**Figure 9** Stage II breast cancer.

In a stage II breast cancer The tumour is larger than a stage I tumour, but less than 5 cm in diameter, and the tumour has not metastasised to a distant part of the body (picture A) Stage II cancer is also indicated when the tumour has metastasised to no more than 3 axillary lymph nodes (picture B). Occasionally the primary tumour is not found in the breast, but breast cancer cells are detected in no more than 4 axillary lymph nodes.



*Figure 9: Stage II breast cancer*

### Figure 10: Stage III breast cancer

Stage III cancer is referred to as a locally or regionally advanced cancer. In this stage, the cancer has metastasised to axillary lymph nodes and the primary tumour is larger than 5 cm (picture A). Alternatively, the primary tumour is smaller than 5 cm, the tumours in the lymph nodes are growing into each other or the surrounding tissue (picture A), or the primary tumour has metastasised to lymph nodes above the collarbone.

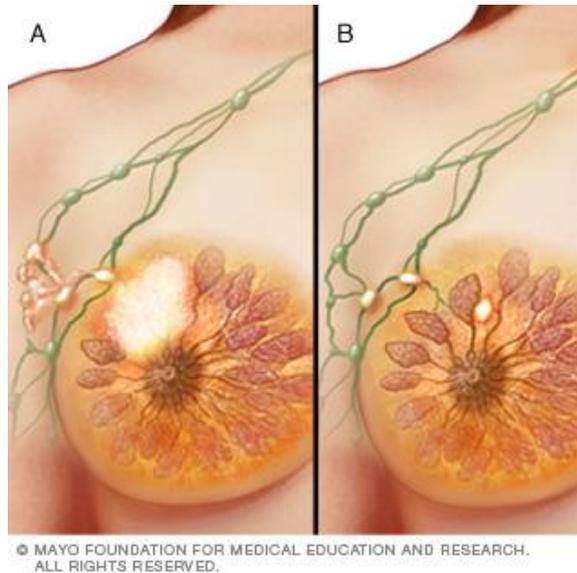


Figure 10: Stage III breast cancer

### Figure 11: Stage IV breast cancer

Stage IV is the most advanced form of cancer. It indicates that the cancer cells have spread to distant areas in the body.

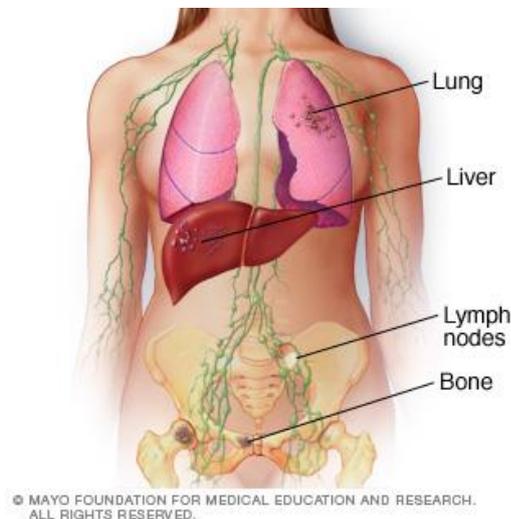


Figure 11: Stage IV breast cancer

### **2.4.2 Grading**

Pathologists assign a pathological grade to a tumour by examining the biopsy specimen under the microscope. The grade of cancer is useful in predicting the outcome of cancer. A high-grade tumour contains abnormal cells that have mutated greatly, grown rapidly, and have often spread throughout the body (Daniel, 2005:62). Tumour grades are expressed as well differentiated; moderately differentiated, poorly differentiated or undifferentiated (Coleman, 2006:53; Lange & Adamec, 2003:85). In undifferentiated cells, it may even be difficult to determine the tissue of origin (Jaftha & Pervan, 1995:776).

The staging and grading of cancer indicate the extent and aggressiveness of the tumour, which determine if the treatment is to be radical or palliative. The treatment of cancer is indicated by the type, stage, and grade of cancer, for example, the treatment and prognosis of metastatic, stage IV germ cell cancer differs from metastatic stage IV lung cancer. For example, the relative survival rate at 5 years following diagnosis for testicular cancer is 96% while the relative survival rate at 5 years following diagnosis for lung cancer is 16% (Biggs & Schwartz, [sa]:166). For efficient social work intervention, the social worker must understand the prognosis of a specific cancer and the stage to which the cancer has progressed.

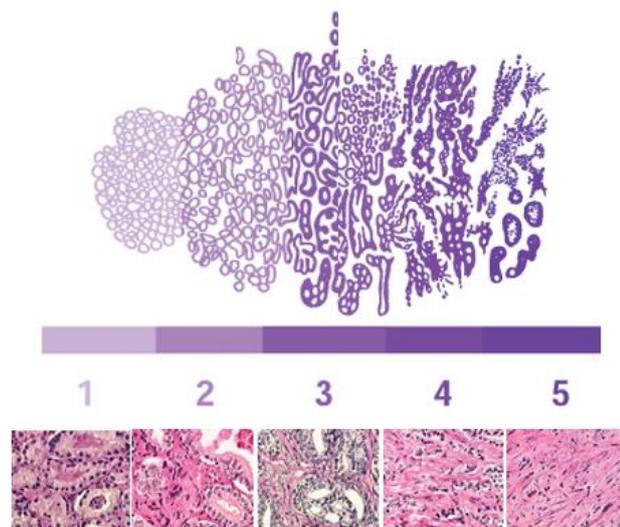
The information gained from staging and grading procedures are also important indicators to the combination of treatment modalities to be prescribed, for example, intracavitary brachytherapy as consolidation therapy to external beam therapy for certain gynaecological cancers.

The *UPMC Cancer Centre* [sa] provides the following description and diagram regarding grading of prostate cancer:

When prostate\_cancer is found in a biopsy, it will be graded to estimate how quickly it is likely to grow and spread. The most commonly used prostate cancer grading system, called *Gleason grading*, evaluates prostate cancer cells on a scale of 1 to 5, based on their pattern when viewed under a microscope

Cancer cells that still resemble healthy prostate cells have uniform patterns with well-defined boundaries are considered well-differentiated (Gleason grades 1 and 2). The more closely the cancer cells resemble prostate tissue, the more the cells will behave like normal prostate tissue and the less aggressive the cancer. Gleason grade 3, the most common grade, shows cells that are moderately differentiated, that is, still somewhat well-differentiated, but with boundaries that are not as well-defined. Poorly-differentiated cancer cells have random patterns with poorly defined boundaries and no longer resemble prostate tissue (Gleason grades 4 and 5), indicating a more aggressive cancer.

**Figure 12:** Grading of prostate cancer cells



*Figure 12: Grading of prostate cancer cells*

The schematic diagram of the Gleason grading system is courtesy of Dr D.F. Gleason, Minneapolis, Minnesota. The integrated design is courtesy of Pittsburgh Supercomputing Center.

## 2.5 CANCER TREATMENT

Depending on the type, stage, and grade of cancer, the objectives of cancer treatments are cure, remission, or palliation. Cancer is considered to be cured if the tumour could be completely surgically excised, or when treatment has killed the tumour. When remission is the objective of treatment, the goal of treatment is to prevent metastases, or to slow the metastases, and/or to destroy metastases. A complete remission occurs when the tumour(s) cannot be observed by examination, imaging, or histology, but because of the type and staging of the cancer, a recurrence is expected. A partial remission refers to when tumours, in response to treatment, have shrunk, but not disappeared. Sometimes, cure or remission is not possible and the focus of treatment shifts to palliative or end-of-life care. The goal of treatment in these cases is to reduce the symptoms, improve the patient's quality of life, while prolonging their lives. If a patient in remission experiences a good quality of life, then treatment may be administered in an effort to prolong life (Coleman, 2006:8; *Remission and goals of cancer therapy*, [sa]).

Normally, the first consideration is to remove the primary tumour surgically before it has spread, then to destroy any stray cells around the site of the primary tumour with radiation therapy, or to destroy a more distant cell spread with chemotherapy. With blood cancers, attempts are made to destroy the cancer cells in the blood with chemotherapy and then to remove the abnormal parent cell from the bone marrow (Daniel, 2005:50). Often preventative treatment (adjuvant treatment) in the form of chemotherapy or radiation therapy- is administered after surgery. Even if a tumour is removed, there may be the possibility that microscopic cancer cells are still in the body. These cancers can potentially be destroyed if adjuvant therapy is administered soon after surgery. It is often difficult for patients to understand the rationale for receiving adjuvant treatment for cancer when there is no indication that a cancer is still present. Adjuvant therapy may reduce the likelihood of a relapse (recurrence) of cancer (Ross & Deverel, 2010:134).

On occasion, preoperative treatment in the form of chemotherapy or radiation therapy is administered in order to shrink and contain the primary tumour before attempting to remove it surgically. Sometimes the primary or secondary tumour might be deemed inoperable; in which case the treatment offered is usually chemotherapy, or radiation therapy (Daniel, 2005:50; Pervan, 1995:704).

A cancer might be incurable, but treatable. This implies that the focus shifts from cure to symptom control. Patients may live for a very long time with a cancer where the growth is arrested or slowed down. These patients can have a good quality of life (Jaftha, 1995:161). An incurable cancer can be active or inactive. Active disease refers to the state when cancer is growing and patients normally receive treatment. Inactive indicates that the cancer growth has been arrested or slowed down - a state of remission. Remission is temporary, unpredictable and cancer type specific. Some incurable cancers can be interpreted as a chronic disease. A chronic disease is an illness that develops slowly and persistently over a long period, often the remainder of a person's life (*The Free Medical Dictionary* [sa]). The *Dictionary of Health Services Management* [sa] defines chronic disease as having "one or more of the following characteristics: it is permanent, leaves residual disability, is caused by non-reversible pathological alterations, requires special training of the patient for rehabilitation, or may be expected to require a long period of supervision, surveillance, or care".

The social worker should have a clear understanding of the objectives of the treatment, because the expected outcome of the treatment depends on the objectives of the treatment. Patients and their social attachments need to understand the objectives of treatment in order to build realistic hope, and adjust their expectations to the expected outcome of the treatment.

### **2.5.1 Treatment modalities**

The type and site of the primary tumour, as well as any secondary tumours, and the extent of metastasis, guide the choice of treatment (Oxford Concise Medical Dictionary, 2007:107). The basic management options for cancer are still surgery, radiation therapy, chemotherapy or biological therapy, or any combinations of these treatment modalities (Werner, 1995:13). Monotherapy (single-modality therapy) indicates that only one treatment modality was utilised, while the term combination therapies indicate that more than one treatment modality is utilised. Combination treatment can be administered simultaneously, sequentially or in alternating cycles (Coleman, 2006:85).

The increased use of advanced technology in the treatment of cancer challenges social workers to find ways to bridge the gap between complex technology and the human experiences of patients. Patients require help to integrate new information and in making informed decisions about undergoing innovative treatments (Christ, 1990:670). The treatment of cancer is a dynamic field with current treatment continuously expanding and with new treatment options emerging. This can result in a situation where the treatment team may not be able to answer all of the patient's, or social attachments', questions regarding treatment that is still in the development phase, or relating to some untested treatments. Coleman (2006:3) is of opinion that it may be helpful for a patient and/or significant other to know that because not all the facts of cancer have been discovered; some questions just cannot be answered.

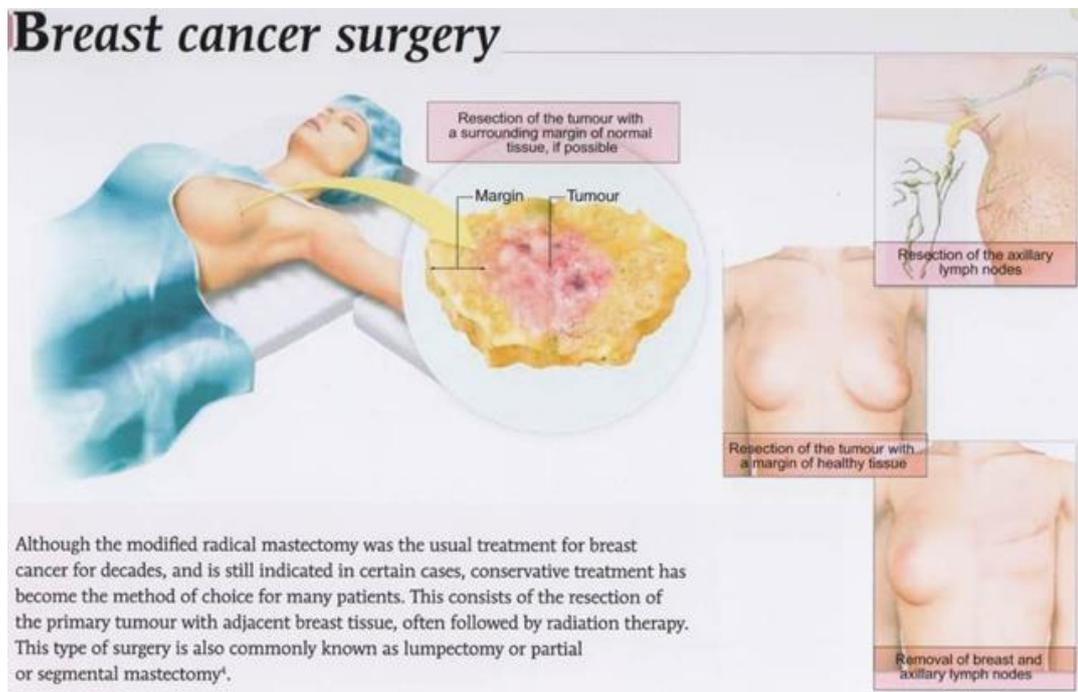
Social workers should have basic knowledge regarding the following common current treatment modalities in order to assist patients in their decisions making.

### 2.5.1.1 Surgery

Surgery is the oldest known treatment modality for cancer. The goal of cancer surgery is to remove the tumour while maintaining optimal functionality of the affected organ. If a cancer has not metastasised, a cure can be achieved by surgically excising the whole tumour. When a complete excision is not possible, debulking surgery is performed to remove most, but not the entire tumour. Surgery may contribute to symptom control, for example, correcting a bowel obstruction. Reconstructive surgery is performed to restore function to an organ that has been partially excised, or to insert an implant (prosthesis) that replaces an organ that has been completely excised (Coleman, 2006:87,88; Daniel, 2005:70; Medical News Today: *What is cancer...* [sa]). Surgery can be divided into five categories

- **definitive surgery** – to define the diagnosis and spread
- **staging surgery** – to stage the disease in order to decide on prognosis and treatment
- **curative surgery** – to remove all tissue that contains tumour
- **palliative surgery** – removal of a tumour to make the patient more comfortable and to enhance the quality of life
- **combination surgery** – to achieve two or more of the above goals (Jaftha & Brainers 1995 173).

**Figure 13:** Illustration of breast cancer surgery



*Figure 13: Illustration of breast cancer surgery (Medical Illustrations Dr Rual L Lepori)*

### 2.5.1.2 Chemotherapy

In cancer terminology, chemotherapy indicates the use of chemical agents (drugs) in the treatment of malignant diseases. Chemotherapy can be used as an initial treatment (as in leukaemia), in conjunction with surgical processes, or radiation therapy, or where surgery or radiation therapy are not possible (Leon et al., 1995:197). Chemotherapy is used as a curative treatment modality for some cancers, such as Hodgkin's disease and other lymphomas, acute leukaemia in children, and testicular cancer. As palliation, chemotherapy is effective in alleviating symptoms and it may prolong life. Chemotherapy as an adjuvant treatment before, during, or after local treatment (surgery and/or radiation therapy) aims to both eradicate metastases (Tannock & Goldenberg, 1998:392) and to destroy cancer cells that may have remained after surgery or radiation. As a neoadjuvant treatment, chemotherapy aims to shrink tumours before surgery or radiation

therapy. The aim of concomitant chemotherapy is to improve the effectiveness of radiotherapy and biological therapy. Chemotherapy can also be used to eliminate recurrent cells that have metastasised (NCI: *Chemotherapy and you: Support for people with cancer, 2007, The Free Medical Dictionary.* [sa]).

**Figure 14** Illustration of chemotherapy

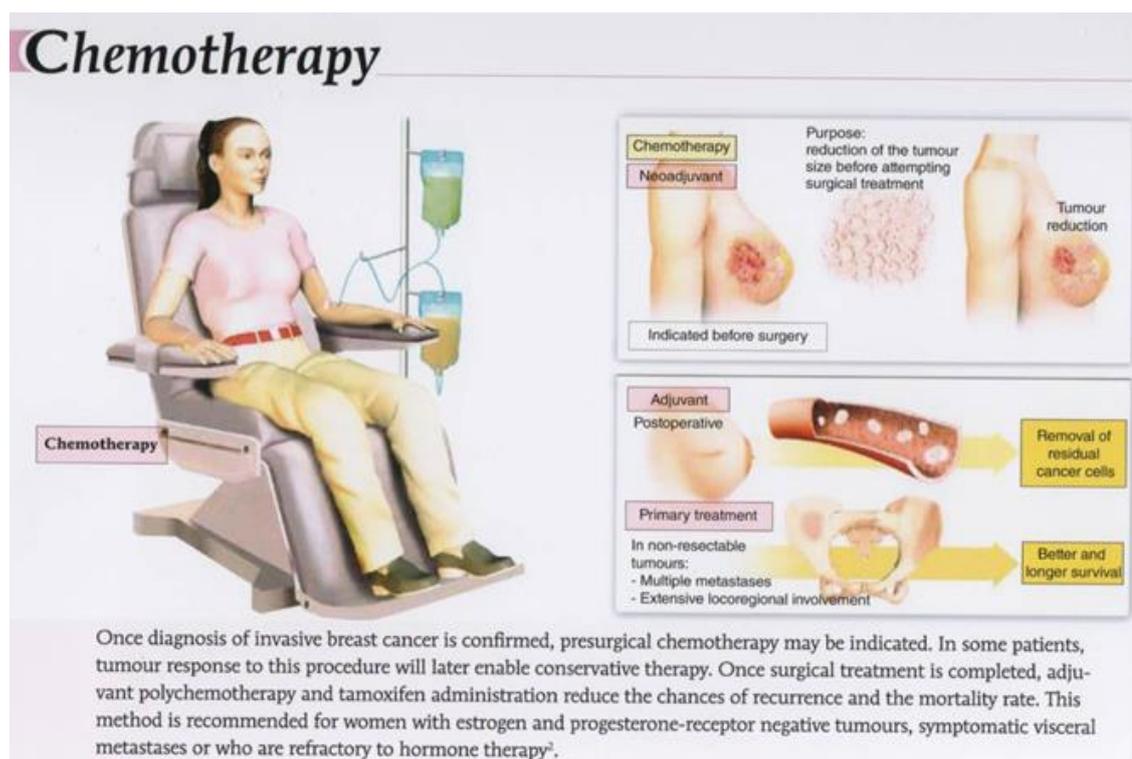


Figure 14: Illustration of chemotherapy (Medical Illustrations Dr Rual L Lepori)

Chemotherapeutic agents interfere with the cell division process (damaging proteins or DNA) in such a way that cancer cells die. It targets any rapidly dividing cells (not necessarily just cancer cells). Normal cells have an increased ability to recover from any chemical-induced damage. Chemotherapy is a systemic treatment (affecting the entire body) and is generally used to treat cancer that has metastasised, or have the potential to metastasise (Jaftha & Pervan, 1995:773; Medical News Today: *What is cancer...* [sa]). Most chemotherapy regimens consist of a cocktail of drugs.

These drug combinations are administered according to a clearly specified schedule (protocol) (Coleman, 2006:89). Drugs in the same class attack the same target within the cell and kill it. Most drug regimens are composed of drugs from different classes, because the different drugs work in different phases of cell division or have different targets. Some chemotherapy drugs are designed to enhance the efficacy of the more standard chemotherapy agents (modifiers or sensitizers), and others are designed to reduce the toxicity of treatment (protectors). Combination chemotherapy regimens are designed so that drugs will work in tandem, making it difficult for the cancer cells to become resistant to therapy (Coleman, 2006:90). Doctors prescribe a dose of chemotherapy that is high enough to optimise the chance that the tumour will respond. Chemotherapy regimens should be modified only for reasons having to do with the effectiveness or toxicity of treatment (Coleman, 2006:93). The most important factors underlying the successful use of drugs in combination chemotherapy are the ability to combine drugs as close to full tolerated doses to destroy tumours with little impact on normal tissue, and the expectation that the combinations will include at least one drug to which the tumour is sensitive (Tannock & Goldenberg, 1998:392).

The total amount of chemotherapy administered over a specified period is referred to as the regimen's dosage intensity (dose intensity), whereas the dose indicates the amount of drug that is administered at one time (Coleman, 2006:93). To cure a tumour it is occasionally necessary to use a dosage of drugs or radiation that may exceed the tolerance of an organ. As a result, the effected organ may malfunction for months or years afterwards. In some cases, the damage can be repaired by surgery. In other cases, the administration of a drug or hormone can replace a normal function (Coleman, 2006:94). Chemotherapy can also harm healthy cells that divide quickly, such as those that line the mouth and intestines or cause hair to grow. Damage to healthy cells may cause side effects, such as hair loss. Often, side effects improve or resolve after chemotherapy is completed (National Cancer Institute: *Chemotherapy and You: Support for People with Cancer*, 2007).

Treatment schedules for chemotherapy vary widely. Chemotherapy is normally administered in cycles. A cycle indicates the period during which the chemotherapy is administered as well as the rest period that follows, for instance in a four week cycle a patient may receive one week of chemotherapy followed by three weeks of rest. The rest period provides the body with an opportunity to replace damaged normal cells with new healthy cells. Cycles should not be interrupted, but due to side effects, the schedule may be altered (NCI: *Chemotherapy and you: Support for people with cancer*, 2007).

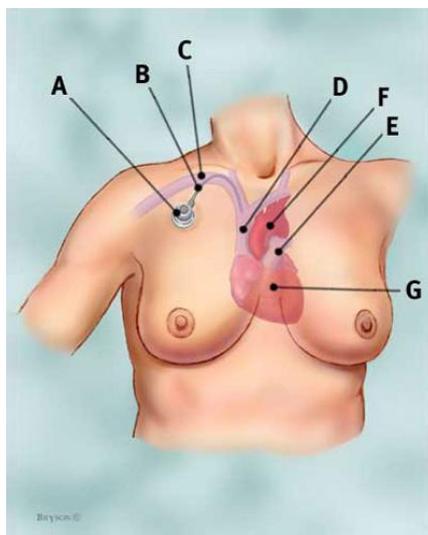
Chemotherapy is administered in various ways, but not all chemotherapy drugs are available in all the different methods of administration. The method chosen to administer chemotherapy depends on the particular cancer type and drug or combination of drugs prescribed. Chemotherapy can be administered via an injection or as pills or capsules, or in liquid form or as a cream administered to the skin. Chemotherapy can be injected in a variety of ways:

- **Intramuscularly** - when chemotherapy is injected in a muscle
- **subcutaneously** – when chemotherapy is injected under the skin
- **intra-lesion** – when chemotherapy is injected directly into the cancerous area of the skin
- **intra-arterial (IA)** – when chemotherapy is administered directly into the artery that feeds the cancer
- **intraperitoneal (IP)** – when chemotherapy is administered directly into the peritoneal cavity (the area that contains organs such as intestines, stomach, liver, and ovaries)
- **intrathecal** – sometimes chemotherapy is administered into the spinal fluid through a needle placed in the spinal column
- **intravenous (IV)** – when chemotherapy is administered directly into a vein

- **topically** – where chemotherapy is delivered as a cream that is rubbed into the skin
- **orally** – chemotherapy in the form of pills, capsules or liquids (Lyss et al., 2005:70 - 75; NCI: *Chemotherapy and you: Support for people with cancer*, 2007; Ross & Deverel, 2010:136).

Intravenous chemotherapy is mostly administered through a thin needle inserted in a vein in the hand or lower arm. Intravenous chemotherapy is administered through catheters, ports or pumps. A catheter is a thin, flexible tube of which one end is inserted into a large vein and the other end remains outside the body. Chemotherapy is then delivered directly through the tube. Sometimes the catheter is attached to a port. A port is a small plastic or metallic disc that is inserted just under the skin. Pumps control how much and how fast chemotherapy is administered; these can be internal or external and are often attached to catheters or ports (Lyss et al., 2005:70 - 75; NCI: *Chemotherapy and you: Support for people with cancer*, 2007).

**Figure 15:** Illustration of a chemotherapy port



*Figure 15: Port for chemotherapy*

**A** Port **B** Catheter [tubing] **C** Subclavian vein **D** Superior Vena cava **E** Pulmonary vein **F** Aorta **G** Heart.

The frequency and the duration of chemotherapy treatment is determined by the type and stage of the cancer, the goals of treatment, the type of chemotherapy, and how well the patient tolerates chemotherapy (NCI: *Chemotherapy and you: Support for people with cancer*, 2007).

In some instances, patients may be invited to participate in a clinical trial. A clinical trial tests new treatments to find more effective or ways to treat cancer. The objectives of many treatment trials are to compare a new treatment with a standard treatment. The standard treatment is the best treatment available at the time of the trial. The standard treatment is identified by evidence that indicates which treatment outcomes were the best at the time of the trial. Patients who participate in trials are randomly assigned to either the trial or the control group (Lyss et al., 2005:93,94,95)

### **2.5.1.3 Radiation therapy**

Within the oncology field, radiation treatment (radiotherapy) refers is the treatment of cancer with ionizing radiation. Ionizing radiation deposits energy that injures or destroys cells in the area being treated (target tissue) by damaging their genetic material, making it impossible for these cells to continue to replicate. Radiation can achieve this either directly (ionising within the DNA molecule) or indirectly (actions of free radicals (NCI: *Cancer Facts-Therapy*, [sa]; Ramiah, 2013:32). Although radiation damages both cancer cells and normal cells, the normal cells are able to repair themselves and function properly (NCI: *Cancer Facts-Therapy*, [sa]). Radiotherapy can be used as a monotherapy or as part of a combination therapy regime. Radiation therapy is mainly used to treat localised and solid tumours, but is also used occasionally to treat cancers of blood-forming cells and the lymphatic system (leukaemia and lymphoma) (Medical News Today: *What is cancer...* [sa]).

The treatment is planned before the actual treatment begins. The radiation oncologist, with the help of a radiation physicist and a radiation therapist, develops a plan designed to treat the tumour and the tissues around it. The

main aim of planning is to maximise the dose received by the tumour while minimising the damage to normal tissue within the field of irradiation. Treatment planning is done with the aid of a simulator, which uses lower-energy, diagnostic X-rays or with a CT scan, that enables accurate tumour localisation and identification of normal tissues within the radiation path. During the simulation process, the radiation oncologist uses the results of the diagnostic studies to identify the tissues that should be irradiated, including the local tumour site, the regional tissue (margins and lymph nodes), and possibly a prophylactic site. The term prophylactic radiation usually refers to preventative radiation therapy that is delivered to a site in the body where a tumour is not seen, but it is expected to recur (Coleman, 2006:101). The radiation oncologist determines the exact treatment area, the total radiation dose, how much dose will be allowed for the normal tissues around the tumour, dose tolerance, and the safest angles (paths) for radiation delivery, (NCI: *Radiation Therapy for Cancer*, 2010) and aim to salvage the tissue and organs around the tumour.

After the planning, the approved treatment plan is transferred to the linear accelerator (LINAC), which shapes the treatment field using a multileaf collimator. The precise numbers of treatments will depend on the total dosage of radiation that the radiation oncologist has prescribed. Treatment is usually given 5 days per week for 5 to 7 weeks, depending on the objective of the treatment. In many cases, the radiation field is relatively large during the initial treatments and later made smaller to avoid some of the surrounding normal tissue and to zero in on the tumour (cone-down field) (Coleman, 2006:101,102).

The term “fractionation” indicates the daily dosing schedule. Hyperfractionation indicates that a patient is scheduled to receive two or more doses per day. Each hyperfractionated dose is reduced so that less damage is produced in the normal tissues. Hypofractionation is used to treat a tumour in fewer but larger-sized fractions in order to reduce the time required for

treatment. The term “dose intensity” refers to the total dose divided by the total number of weeks. Accelerated fractionation refers to the concept that patients with some types of tumours should receive as much radiation as possible in the shortest possible time because the effectiveness of the treatment may depend on completing the treatment before the tumour begins growing again (Coleman, 2006:102,103).

The objective of radiation therapy is to cure, stop, or slow the growth of cancer. As palliation, radiation therapy is used to shrink tumours in order to reduce pressure. Radiation therapy can treat pain and bleeding or fungation of tumours. It can prevent or relieve blockage of organs such as the bowel, oesophagus, uterus, or spinal cord. Radiation does not immediately kill cancer cells; it takes days or weeks of treatment before cancer cells start to die. The cancer cells keep dying for weeks or months after radiation therapy ends (NCI: *Radiation Therapy for Cancer*, 2010).

As is the case with chemotherapy, radiation therapy may be administered before or after surgery. Radiotherapy may also be administered intraoperatively. Intraoperative radiation is administered during surgery to treat the cancer directly without passing through other normal tissues. The surgeon is able to move organs out of the way of radiation beams (NCI: *Radiation Therapy for Cancer*, 2010).

#### **2.5.1.3.1 Types of radiation therapy**

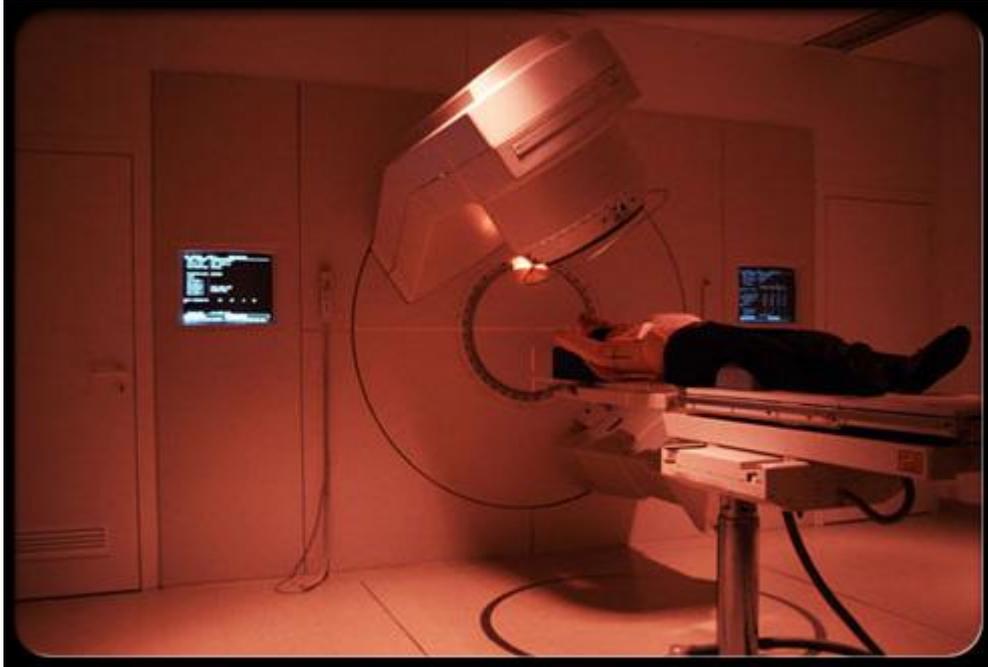
With external beam radiation therapy, the radiation is delivered by machine from outside the body. In the case of internal radiation therapy (brachytherapy), the radiation is delivered from radioactive material placed in the body near the cancer cells. Systemic radiation therapy uses radioactive substances, such as radioactive iodine, that are injected into the body to kill cancer cells (NCI: *Radiation Therapy for Cancer*, 2010). Radiation therapy can be delivered in sealed or unsealed radioactive sources. Unsealed source radiotherapy includes liquids, capsules, or ampoules that are administered

orally or by injection, normally in the nuclear medicine department. Sealed source radiation therapy includes pellets, grains, wires, pins or needles, which are inserted into the patient in the operating theatre or on the wards. Sealed sources may be left in place, but more commonly sealed sources are inserted for a prescribed length of time into a cavity to deliver a specified dose of radiation before withdrawal (Hart, 2006:53).

Newer radiation therapy technologies are coupled with advances in imaging using CT scans, MR images, PET scans, PET-CT scans and others, to allow increased precision. Such precision makes it possible for the radiation oncologist to deliver a higher dose to the tumour and a lower dose to normal tissues. The new technologies being used to do this include intensity modulated radiation therapy (IMRT), Tomography®, CyberKnife®, stereotactic radiotherapy (SRT), gated radiotherapy and stereotactic radiosurgery (SRS). Machines that use proton beams are able to focus the beam finely, which is particularly useful for small tumours. The use of computerised planning allows for this improved precision. It is essential to locate the tumour accurately in order to minimise, or account for, patient and internal organ movement (Coleman, 2006:102).

**Figure 16:** Radiation machine

A picture of external beam radiation therapy, delivered by an LINAC machine



*Figure 16: Radiation machine (MedicineNet: Understanding cancer of the colon (2011))*

**A. External beam radiotherapy (EBRT):**

Currently most radiation therapy is delivered with linear accelerators (LINAC). A LINAC delivers beams of both high-energy and low-energy photons and electrons. Other machines used in administering external beam radiotherapy include orthovoltage X-ray machines and cobalt 60 machines. Most cancers are treated with high-energy photon (X-ray) beam radiation. The aim is to destroy or shrink tumours, or to destroy any cancer in the area where a cancer was excised. Low-energy radiation is used to treat surface tumours. Electrons are charged particles, and are used to treat more superficial tumour sites such as lymph nodes in the neck, to boost treatment, or to treat skin cancer (Cohen, 2006; Lyss et al., 2005:8).

## Types of external beam radiotherapy

- 3D-CRT (three-dimensional conformal radiation therapy) uses computer software and advanced treatment machines to deliver radiation to precisely shaped target areas. A three-dimensional representation of the tumour is created. Multileaf collimators (blocks) match the radiation beams to the size and shape of the tumour. This allows for less radiation exposure to nearby normal tissue (Lyss et al., 2005:84).
- In IMRT (intensity modulated radiation therapy), the collimators can be stationary or can move during treatment, allowing the intensity of the radiation beams to change during treatment sessions. This kind of dose modulation allows different areas of a tumour or nearby tissues to receive different doses of radiation. The goal of IMRT is to increase the radiation dose to the areas that need it, and reduce the radiation exposure to specific sensitive areas surrounding normal tissues (Lyss et al., 2005:85; NCI: *Radiation Therapy for Cancer, 2010*).
- In IGRT (Image-guided radiation therapy), repeated imaging scans (CT, MRI, or PET) are performed before or during treatment to improve the precision and accuracy of the delivery radiation treatment. Machines that deliver radiation are equipped with imaging technology. These imaging scans are processed by computers to identify changes in a tumour's size and location that are caused by treatment, and to identify if there was organ and tumour motion during treatment. The radiation delivered can then be modified to take into account this movement, or the position of the patients can be altered (NCI: *Radiation Therapy for Cancer, 2010*).
- Tomotherapy is a type of image guided IMRT. The part of the tomography machine that delivers radiation for both imaging and treatment can rotate entirely around the patient. Tomography machines can capture CT images of a patient's tumour immediately before treatment sessions, to allow for very precise tumour targeting and

sparing of normal tissue (*Image-guided radiation therapy (IGRT)*, reviewed 2013; NCI: *Radiation Therapy for Cancer*, 2010).

- SRS (Stereotactic Radiosurgery) can deliver one or more high doses of radiation to a small tumour. SRS uses extremely accurate image-guided tumour targeting and patient positioning. Therefore, a high dose of radiation can be given without excess damage to normal tissue. It is most commonly used in the treatment of brain or spinal tumours and brain metastases from other types of cancer. SRS requires the use of a head frame or other device to immobilise the patient during treatment to ensure that the high dose of radiation is delivered accurately (NCI: *Radiation Therapy for Cancer*, 2010).
- SBRT (Stereotactic body radiation therapy) delivers radiation therapy in fewer sessions, using smaller total doses than 3D-CRT in most cases. SBRT treats tumours that lie outside of the brain and the spinal cord. Because these tumours are more likely to move with the normal motion of the body, SBRT is normally given in more than one dose. SBRT systems are commonly referred to by brand names for example, CyberKnife® (NCI: *Radiation Therapy for Cancer*, 2010).
- Particle beam therapy (proton beam radiation) uses protons, rather than X-rays to treat cancer. Proton therapy provides a sharper beam. Proton beam therapy is very costly, with the result worldwide only a few oncology centres have particle beam accelerators (Lyss et al., 2005:85).
- Neutron beam radiotherapy is used for tumours that are radio-resistant, or difficult to kill with conventional radiotherapy (Lyss et al., 2005:85).
- Electron beams are used to irradiate superficial tumours, such as skin cancer or tumours near the surface of the body, but they cannot travel very far through the tissue. Therefore, they cannot treat tumours that are deeply situated in the body (NCI: *Radiation Therapy for Cancer*, 2010).

## **B Internal radiation therapy**

Internal radiation therapies are delivered from a sealed or an unsealed radioactive source.

- **Brachytherapy**

Brachytherapy refers to “radioactive sealed sources near or in the tumour. This has the advantage of delivering high dose of radiation therapy to the cancer while sparing the surrounding normal tissue and organs.” Another advantage is that the treatment time is shorter and in some instances, it can be undertaken on an outpatient basis (Hart, 2006:55). Brachytherapy is normally prescribed for cancers of the head, neck, breast, uterus, cervix, prostate, gall bladder, oesophagus, eye, and lung. Liquid forms of internal radiation are most often used with people who have thyroid cancer or non-Hodgkin's lymphoma. Patients may receive internal radiation concurrent with other types of treatment, including external beam radiation, chemotherapy, or surgery (NCI: *Radiation Therapy and You: Support for People*, [sa]).

The National Cancer Institute, *Radiation Therapy and You: Support for People*, [sa], provides the following description of the better-known classification of brachytherapy:

- **Low-dose rate (LDR) implants:** In this type of brachytherapy, radiation stays in place for 1 to 7 days. Patients are likely to be in the hospital during this time. Once the treatment is finished, the oncologist removes the radiation sources and the catheter or applicator.
- **High-dose rate (HDR) implants:** In this type of brachytherapy, the radiation source is in place for 10 to 20 minutes at a time and then taken out. Treatment schedules vary; patients may have treatment twice a day for 2 to 5 days or once a week for 2 to 5 weeks, or twice a week. The schedule depends on the cancer type. During the course of treatment, the catheter or applicator may stay in place, or it may be put in place

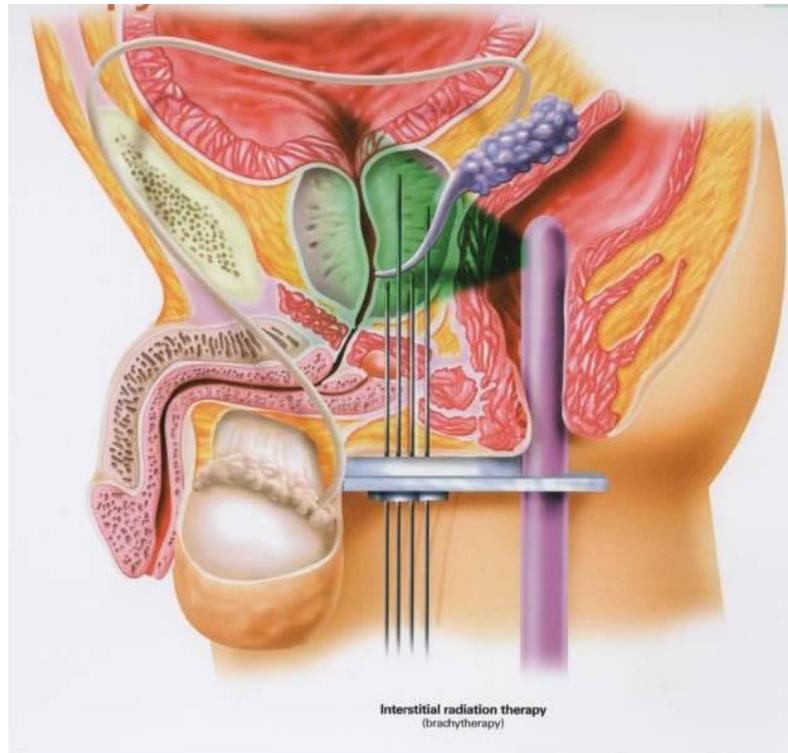
before each treatment. HDR is administered on an inpatient and outpatient basis.

- **Permanent implants:** After the radiation source is put in place, the catheter is removed. The implants always stay in the body, while the radiation gets weaker each day. As time goes by, almost all the radiation will go away, even though the implant stays in the body

Sometimes the following classification of brachytherapy is used:

- **Interstitial brachytherapy:** Isotopes (seeds) are implanted in the area of a tumour or a cancerous prostate. These isotopes may be inserted and removed on the same day and then reinserted within 46 to 48 hours. Sometimes the isotopes stay in the body permanently (Lyss et al., 2005:87). These implants can be employed alone or in conjunction with EBRT (Kunkler, 2003:336).
- **Intracavitary brachytherapy:** This is used to radiate the walls of a cavity in the body or nearby tissue. The isotopes are inserted with an applicator, and once the prescribed dose of radiation has been delivered, the applicator is removed (Lyss et al., 2005:87).
- **Episcleral brachytherapy:** This is used to treat melanomas inside the eye (NCI: *Radiation Therapy for Cancer*, 2010).

**Figure 17:** Illustration for brachytherapy for prostate cancer



*Figure 17: Illustration of brachytherapy for prostate cancer (Medical Illustration Dr Rual L Lepori [sa])*

Other forms of internal radiation therapy currently used include:

- **Intraoperative radiotherapy:** Radiation can be delivered during surgery. The benefits of intraoperative radiosurgery are that the oncologist can visualise the tumour bed directly, and organs which limit the dose of radiation can be moved out of the radiation field, or these organs can be shielded, which allows for higher doses of radiation to be delivered to the targeted area (Lyss et al., 2005:88; Ramiah, 2013:32).
- **Systemic radiation therapy:** Systemic treatment uses open source radiation treatment. The bloodstream carries the delivered radiation throughout the body. Some radioactive isotopes can be taken orally, given intravenously, or administered by injections. For example, radioactive iodine, that can be taken orally, is commonly used to treat thyroid cancer (Lyss et al., 2005:88).

- **Radioimmunotherapy:** Some types of antibodies can be manufactured in a laboratory and then attached to radioactive isotopes. The radioactive isotopes are injected into the body where they circulate in the bloodstream, hunting for cancer cells. The radiation in the antibodies combats the tumour antigens, destroying invading cells (Lyss et al., 2005:88).

## **C Nuclear medicine**

In the oncology context, nuclear medicine involves the use of radioactive isotopes (radiopharmaceuticals) in the diagnosis and treatment of cancer (Hart, 2006:52). The isotopes are administered into the body, and aim to destroy diseased tissue selectively (Errington, 2003:111).

### **2.5.1.4 Biological treatment**

#### **2.5.1.4.1 Immunotherapy**

Immunotherapy aims to stimulate the body's immune system to fight a tumour. One approach of immunotherapy is to kill cancer cells directly by using components of the body's immune system, including regulatory proteins (cytokines, lymphokines, or interleukins) that cells use to communicate with each other. Another approach is to use white blood cells (lymphocytes) that are specifically engineered to kill tumour cells. A third approach is to use monoclonal antibodies that either kill tumour cells directly or carry a poisonous substance or a radioactive particle to the tumour cell (Coleman, 2006:130). Local immunotherapy injects a treatment into an affected area to cause inflammation, which promotes tumour shrinkage. Systemic immunotherapy treats the whole body by administering an agent such as the protein interferon alpha that can shrink tumours. Non-specific immunotherapy improves cancer-fighting abilities by stimulating the entire immune system. Targeted immunotherapy specifically directs the immune system to destroy cancer cells. Bone marrow transplantation (hematopoietic stem cell

transplantation) can also be considered immunotherapy because the donor's immune cells will often attack the tumour or cancer cells that are present in the host (Medical News Today: *Definition of immunotherapy*, reviewed 2011; Medical News Today: *What is cancer...* [sa]).

#### **2.5.1.4.2 Hormone therapy**

Several cancers have been linked to some types of hormones, most notably breast and prostate cancer. Hormone therapy alters hormone production in the body. This reduced hormone production either causes cancer cells to stop growing or kill the cancer cells completely, for example, breast cancer hormone therapies, often focus on reducing oestrogen levels, and prostate cancer hormone therapies often focus on reducing testosterone levels. In addition, some leukaemia and lymphoma cases can be treated with the hormone cortisone (Medical News Today: *What is cancer...* [sa]).

#### **2.5.1.4.3 Gene therapy**

The goal of gene therapy is to replace damaged genes with genes that work to address a root cause of cancer. Some gene-based therapies focus on further damaging a cancer cell's DNA to the point where the cell commits suicide (Medical News Today: *What is cancer...* [sa]).

The researcher observed in practice that patients and their social attachments are too overwhelmed to interpret information during diagnosis and the first visit to their oncologist. During initial interviews with different medical specialists, patients and their social attachments are focussed on the availability of treatment, and the prognosis. Due to the real or perceived risk of metastases, patients may be eager to start treatment. Often they do not make another appointment with the oncologist to clarify procedures and handle unanswered questions. The social worker can assist to clarify uncertainties, explain the treatment in straightforward language, and address fears related to side effects.

#### **2.5.1.4.4 Bone Marrow Transplantation (BMT)**

Bone marrow transplantation is utilised to treat neoplastic and haematological diseases such as leukaemia, aplastic leukaemia, chronic myelocytic leukaemia, the lymphomas, and various others. Neoplastic disease refers to purposeless abnormal growth that is independent of the body's normal homeostatic growth-regulating pattern and where the growth continues after the initiating stimulus has been removed (*Oxford Concise Medical Dictionary*, 2007: 482). A haematological disease is a disease of the blood and blood-forming tissues (*Oxford Concise Medical Dictionary*, 2007:315). Bone marrow transplantation replaces bone marrow that has been destroyed by treatment (NCI: *Dictionary of cancer terms*. [sa]). Thus, in essence, bone marrow transplantation replenishes depleted bone marrow reserves.

The goal of BMT is that, over time, the transplanted stem cells will work towards restoring the bone marrow's ability to produce the blood cells a patient needs, and that, eventually, a healthy production schedule will be resumed. In certain instances, BMT allows the delivery of lethal high dose chemotherapy and total irradiation as a curative treatment for patients with resistant disease. Normally, the purpose of administering high doses of chemotherapy and radiation therapy before a bone marrow transplant (ablative or myeloablative treatment) is to eliminate diseased bone marrow, or to reduce the number of cancer cells in the body, or to suppress the immune system in order to prevent rejection of the bone marrow transplant (Lyss et al., 2005:108). A bone marrow transplant can be used either to treat one of the types of cancer commonly treated with bone marrow transplants, or in cases where a cancer is not responding to the standard treatment, or in the event that a cancer recurs (Lyss et al., 2005:107).

Bone marrow transplants depend on bone marrow donations. When bone marrow is harvested from a parent or sibling, it is referred to as an allogeneic donation. An autologous donation indicates that a patient's own marrow was harvested prior to chemoradiation and then "purged" of malignant cells by

additional chemotherapy. When bone marrow is harvested from an identical twin, it is referred to as a syngeneic donation.

Bone Marrow Stem cells are harvested from three sources:

- Stem cells are harvested directly out of the bone. During an autologous bone marrow transplant (rescue transplant), the harvested stem cells are replaced when chemotherapy or radiation therapy is completed. This procedure allows patients to receive high doses of chemotherapy and radiation therapy. With an allogeneic bone transplant, stem cells are harvested from a donor's bone marrow, and then transplanted to the patient.
- Apheresis is the procedure when stem cells are collected by filtering the blood for peripheral (circulating) blood cells (PBSC). The majority of marrow stem cell transplants use PBSC collected by apheresis, because this procedure has better results for both the donor and the recipient.
- During an umbilical cord blood transplant, stem cells are harvested directly after the delivery of an infant. These stem cells are tested, typed, counted, and frozen until they are needed for a transplant (MedicinePlus: *Bone marrow transplant*, reviewed 2012).

Bone marrow is the soft, sponge-like material found in the central cavity of bones. The marrow contains stem cells (immature cells) that produce blood cells. Blood consists of red blood cells (erythrocytes) which carry oxygen to your tissues, white blood cells (leukocytes) which fight infection, and platelets (thrombocytes) which help your blood clot (Lyss et al., 2005:108; Medicine Plus: *Bone marrow transplant*, reviewed 2012) The function of blood cells and platelets are to keep the immune system healthy.

During a BMT, stem cells are administered through a central venous catheter. These stem cells enter directly into the bloodstream and find their way to the bone marrow. The newly transplanted cells home to bone marrow, engraft, and then begin to produce healthy new blood cells. Peripheral blood stem

cells generally restore the bone marrow within about two weeks, but it can take up to five weeks if the stem cells come from the marrow itself. Restoring complete immune function can take several months in autologous transplants, and one to two years in allogeneic transplants. During the patient's recovery, doctors can determine whether the cancer has returned by taking blood samples or aspirating small amounts of bone marrow through a needle for a biopsy (NCI: *When cancer returns*, 2010).

Social work interventions in the milieu of bone marrow transplants have the added dimension of the donor and possible organ rejection. The patients and donors must be prepared for these possibilities, and supported if they occur. They must be aware that the procedure is irreversible. Patients and family must be prepared to the specific side effects of bone marrow transplants.

#### **2.5.1.5 Other therapies**

Research is continuing to find new and more effective treatments. Some therapies not often used include laser therapy, cryotherapy/cryosurgery, ultrasound and microwave therapy, percutaneous ethanol injection, and photodynamic therapy (Daniel, 2005:84 - 88).

**Laser therapy** uses high intensity light to shrink or destroy tumours or to relieve certain symptoms such as bleeding or obstructions. Laser therapy is most commonly used to treat superficial cancers, or in the very early stages of some cancers such as cervical, penile, vaginal, and non-small cell lung cancer (NCI: *Fact Sheet: Lasers in cancer treatment*, reviewed 2011).

**Cryotherapy or cryosurgery** is the use of extreme cold, produced by liquid nitrogen or argon gas to destroy abnormal tissue. Cryotherapy is used to treat external tumours, such as those on the skin. Cryosurgery is used to treat internal tumours and tumours in the bone. Cryosurgery is administered through a cryoprobe, which is placed in contact with the tumour, in order for liquid nitrogen or argon gas to be circulated through the cryoprobe to freeze

the targeted cells. Cryotherapy can be an effective treatment for certain prostate and liver tumours, retina-blastoma, early stage skin cancers, precancerous skin growths and precancerous conditions of the cervix (NCI: *Fact Sheet: Cryotherapy in Cancer treatment: questions and answers*, reviewed 2011).

**Ultrasound therapy** is the use of intensified ultrasound energy that can be directed at cancer cells to heat and destroy them. (NCI: *Prostate Cancer Treatment: Treatment options overview*, reviewed 2013).

**Hyperthermia** (microwave thermotherapy) is a procedure during which body tissue is exposed to high temperatures with the objective to damage and kill cancer cells, or to make cancer cells more sensitive to the effects of radiation and certain anticancer drugs. Currently, hyperthermia is still in clinical trials, and not widely available (NCI: *Fact Sheet: Hyperthermia in cancer treatment*, reviewed 2013).

**Percutaneous ethanol injection** (ethanol ablation) is a procedure when ethanol is injected through the skin directly into a tumour to kill cancer cells. The alcohol dehydrates the tumour, thereby altering the structure of the cellular proteins, which in turn, results in tumour destruction (American Cancer Society: *Liver cancer: percutaneous ethanol ablation*: MedicineNet: *Liver Cancer: Percutaneous ethanol injection*, reviewed 2007).

**Photodynamic therapy** indicates treatment with drugs (photosensitisers) that become active when exposed to light. A photosensitising agent is injected into the bloodstream and is absorbed by cells all over the body. A characteristic of a photosensitiser is that it stays in cancer cells longer than it stays in normal cells. Approximately 24 to 72 hours after a photosensitiser has been injected, when most of the photosensitiser has left the normal cells, but remains in the cancer cells, the tumour is exposed to light. The photosensitiser in the tumour absorbs the light and produces an active form of oxygen that destroys cancer cells. Photodynamic therapy can also be administered in an effort to shrink

tumours because a photosensitiser can damage blood vessels in the tumour and thereby preventing the tumour from receiving the necessary nutrients (NCI: *Fact sheet: Photodynamic therapy for cancer, reviewed 2011*).

Many cancer patients supplement conventional treatment with complimentary or alternative treatments (Gardner & Werner-Lin, 2012:502). Ross and Deverel (2010:141,142) postulate that when patients are confronted with the reality that treatment is not working, or that their health is declining, alternative treatments are often explored. Alternative treatments may be used in place of allopathic (conventional) oncology treatments. Generally, Western doctors do not recommend or value alternative therapies, because there is not sufficient scientific evidence of the safety and efficacy of these treatments. The promises of un-researched or poorly researched, alternative treatments may give patients false hope. Choosing to undergo alternative treatments may also cause a patient to decline conventional oncology treatments that have been proven to have beneficial effects.

Alternative therapies involve those therapies that may be used as an alternative to allopathic cancer treatments. Daniel (2005:7) divides alternative therapies in the following categories:

- **anti-cancer nutrients** to help combat cancer directly or to stimulate the body's immune system
- **herbal medicines** that are believed to have anti-cancer properties or that can inhibit tumour growth
- **neuro-endocrine** therapies aimed at rebalancing the body's hormones and neurotransmitters to inhibit tumour growth
- **physical therapies** in which heat, light or oxygen is used to combat cancer
- **body-mind approaches** that are used to restore immune function and direct tissue healing.

Complementary cancer therapies involve the use of natural medicines or therapies that can be used in a supportive context alongside allopathic oncology treatments. These therapies include:

- **touch therapies** such as massage, aromatherapy and reflexology
- **energy therapies** such as acupuncture, reiki healing, and spiritual healing
- **natural remedies** such as herbal medicines
- **mind-body symptom control** through hypnotherapy, visualization and relaxation
- **Nutritional** and immune support (Daniel, 2005:7).

The complementary therapies aim at improving well-being, and enhancing the body's ability to fight cancer. Many of these psychological approaches are already incorporated in the social workers competencies, for example, guided imagery. Holland (1990:515) concludes that alternative and complementary therapies are apt to continue until cancer is more generally treated successfully. Social workers need to be aware that some of the alternative treatments, particularly the metabolic and rigid dietary regimes, may carry hazardous risks to patients. Certain psychological approaches have negative effects when guilt is established for causation of cancer, or for disease progression. Social workers need a basic knowledge of contemporary and alternative approaches, combined with an approach to reduce the sense of helplessness and to re-establish realistic hope. For example, patients and significant others are cautioned that the quantity of supplements or the combination of supplements with oncology treatments, may cause negative side-effects, for example, nausea, constipation, blistering of the irradiated skin due to the applications of certain topical alternative ointments.

## **2.6 TREATMENT OUTCOMES**

In some cancers, the tumour growth is so slow that it negates the need for immediate treatment because, even without treatment, these cancers do not cause problems for many years. These untreated, slow-growing tumours must

be kept under surveillance. The rationale in oncology treatment protocol is that treatment is only justified if the outcome of treatment is anticipated to be better, compared to the anticipated outcome if the tumour is not treated (Coleman: 2006:15).

Treatment outcomes are described according to the tumour's response to treatment, the rate of response, the duration of response, the patient's chances of survival, whether the patient's symptoms are reduced, and if the patient's quality of life is improved (Coleman, 2006:59). Tumour response to treatment is described as:

- **Complete response** (remission) indicates that the tumour has disappeared completely – NED (no evidence of disease). This does not mean that the disease will never return, it means that now no disease can be detected.
- **Partial response** (remission) indicates that the tumour has shrunk to approximately half its original size. Sometimes further treatment will turn a partial response into a complete response.
- **Minor response** (remission) indicates that although the tumour has shrunk, it is still larger than half its original size. Some practitioners consider a 30% reduction in tumour size as a partial response.
- **Stable disease** indicates that the tumour did not shrink, but it did not grow any larger.
- **Progressive disease** indicates that the tumour has become at least 25% larger than what it was before treatment. If a patient has more than one tumour, the overall response is determined by the tumour with the worst response (Coleman, 2006:60,61).

Response rate refers to the likelihood that the tumour will either shrink or disappear after a specific treatment. Most studies determine how large groups of patients respond to a particular treatment (Coleman, 2006:61).

The duration of remission varies. Some remissions may be permanent, while others may last only a few months. Although partial remission and stable disease are usually not permanent, they are important because they can add time and comfort to a patient's life (Coleman, 2006:62; BC cancer agency; *What to expect when cancer progresses* [sa]). Social workers should explain to patients, and their social attachments, that incurable cancer is, in most cases, still treatable, because palliative care can provide quality of life. A patient's social network should understand that they should not judge the quality of a patient's life according to their own standards. Many patients' view on quality of life changes as the disease progresses.

Survival refers to how long a patient may live and the likelihood that the disease will return (recur). Overall survival indicates how many patients are likely to be alive at different time points. Disease free survival (freedom of tumour progression) is a measure of how many patients are alive and have no evidence of cancer at some point after treatment. Different grades of cancer have different rates of relapse. For some aggressive tumours (rapidly growing tumours) such as aggressive lymphomas, remission might last only a few years or less, whereas for slow growing tumours such as a low-grade lymphoma or low-grade prostate cancer, remission may last over many years (Coleman, 2006:63,64,65).

Blum (1993:107) declares that social work intervention must be based on an understanding of a patient's specific diagnosis, prognosis, and treatment plan, as well as the patient's emotional and social situation. The type of cancer, including the stage and prognosis, the patient's age, general health and other co-morbidities determine treatment outcomes. Cancers associated with high risks of mortality, and treatment that is more intensive, elicits a higher level of distress. The degree of disability caused by cancer and cancer treatment has consequences to the patient's and the family's lifestyle and quality of life. Patients need to be informed regarding the intensity and duration of treatment, the side-effects of treatment, and the possible late-effects of

treatment. The researcher observed in practice that, in most cases, when patients and their social attachments, understand the objectives of treatment they can prepare and adjust to the expected treatment outcomes.

## **2.7 COMMON SIDE EFFECTS OF TREATMENT**

### **2.7.1 Radiation therapy**

Within the context of this research, side effects are depicted as physical, emotional, cognitive, and spiritual problems that can occur as results of treatment. Side effects differ for each patient. Side effects of radiation therapy are due to damage of healthy cells. The most common side effects of radiation therapy are fatigue and skin changes. Other side effects depend on the part of the body that is irradiated. Skin changes may be dryness, itching, peeling, or blistering. These changes occur because radiation therapy damages the healthy skin cells that are in the radiation area (NCI: *Fact Sheet: Radiation therapy Side effects*, 2007).

Fatigue due to treatment for cancer is often described as feeling worn out or exhausted. Fatigue is the most frequently reported side effect of radiation therapy. It can be caused by radiation therapy, the effort of going to radiation therapy each day, or through stress. Anaemia, anxiety, depression, infection, lack of activity, or certain medicines can cause fatigue. Fatigue influences a patient's perception of his or her quality of life, self-esteem and productivity (NCI: *Radiation Therapy for Cancer*, reviewed 2010; Wells & Turney, 2001:33).

Depending on the part of the body that received radiation therapy, side effects could be diarrhoea, hair loss (alopecia) in the treated area, mouth problems, nausea and vomiting, sexual changes, swelling, trouble with swallowing, and urinary and bladder changes. Mouth problems include mouth sores, dry mouth (xerostomia), dry throat, loss of taste, tooth decay, changes in taste, infections of gums, teeth and tongue, jaw stiffness, bone changes, and thick

rope-like saliva. Nausea and vomiting can occur if radiation therapy is administered to the stomach, small intestines, colon, or parts of the brain. Radiation therapy can cause sexual and fertility changes which can include hormone changes and loss of libido, or loss of the ability to have sex. Urinary and bladder changes due to radiation therapy include burning or pain when beginning to urinate and after emptying the bladder, trouble starting to urinate, trouble emptying the bladder, frequent and urgent need to empty the bladder, incontinence, blood in urine, and bladder spasms. Oesophagitis occurs when the lining of the throat becomes inflamed (NCI: *Radiation Therapy for cancer*, reviewed 2010).

Most cancer patients do not develop adverse effects later in life as result of their radiation therapy, but some patients do eventually experience damage to an organ and, in few instances, patients develop a treatment-related secondary cancer (Coleman, 2006:72). Late side effects of radiation therapy may include infertility, joint problems, lymphoedema, mouth problems, organ damage, and secondary cancers (NCI: *Radiation Therapy for Cancer*, reviewed 2010).

### **2.7.2 Chemotherapy**

Common side effects of chemotherapy include: anaemia, appetite changes, blood clotting problems, constipation and diarrhoea, fatigue and sleep disruption, alopecia (hair loss), susceptibility to infections, memory changes (chemo brain), nausea and vomiting, mouth and throat changes, nerve changes, pain. In addition, sexual dysfunction, decreased libido and infertility changes are common side effects of chemotherapy. Skin and nail changes, swelling (fluid retention), weight loss or gain, and urinary changes are also common side effects of chemotherapy (Cancer Council Victoria: *Managing side effects of chemotherapy*, 2012; Wells & Turney, 2001:33).

The purpose of chemotherapy is to kill cancer cells. Chemotherapy drugs inevitably kill normal cells too. The most common side-effect from

chemotherapy is due to damage to the stem cells in the bone marrow, preventing the bone marrow from producing enough blood cells (Cancer Council Victoria: *Managing side-effects of chemotherapy*, 2012; Coleman, 2006:96), putting a patient at risk of developing infections. Some patients may need a transfusion of red blood cells or platelets (Cancer Council Victoria: *Managing side effects of chemotherapy*, 2012). Almost all chemotherapy agents produce side effects that can affect blood counts, and cause physical symptoms such as nausea and vomiting. Patients need to be aware that they will probably only experience few of the anticipated side effects. Patients also need assurance the chemotherapy is still effective, even if they don't experience any side effects.

### **2.7.3 Psycho-social side effects**

Emotional side effects of oncology treatments include mood swings and emotional turmoil caused by steroids and hormonal medications. Feelings of loss and control may occur due to treatment regimes that dictate daily schedules, restrictions, and limitations. Self-doubt or disillusionment may set in if the side effects of treatment are perceived to be more ravaging than the cancer itself. Anxiety, depression, and fears may also manifest (Wells & Turney, 2001:34).

Changes in lifestyle, routine, roles, and expectations and perspectives of the patient, family, and caregivers occur. Disruption or termination of employment and infringement of recreational activities are common side effects of oncology treatment. Increased dependence on family members and caregivers change the equilibrium within families. Patients prioritise their life and may experience a shift in their perspectives regarding values and relationships (Wells & Turney, 2001:35).

On the spiritual level, the realisation of the reality of the cancer, and/or the intensity of treatment, may lead to an exploration of spiritual foundations. An examining of one's spiritual beliefs can result in finding meaning in the cancer

experience. For some patients, the difficulties of treatment can challenge their beliefs and many individuals may feel conflicted as they face a perceived test of faith. Others may have strayed from a religious upbringing and feel guilt and self-blame about their illness because of this lapse (Wells & Turney, 2001:35).

## **2.8 SUMMARY**

This chapter started with a discussion of the value of health literacy. Cancer was defined as well as the different procedures involved in establishing a diagnosis, treatment plan, expected treatment outcomes, and the prognosis. This was followed by discussion of the objectives of treatment, discussion of different treatment modalities, including complementary and alternative therapies. The chapter concluded with a description of common side effects of treatment.

In order to render effective intervention programmes, social workers who deal with cancer patients should understand what cancer is, what the frequently used treatment modalities are and what the common side effects of treatments are. This will enable the social worker to assist a patient to explore and clarify the links between facts and fears associated with the patient's cancer.

The following chapter will focus on remission.

## CHAPTER 3

### 3 LIVING IN REMISSION

#### 3.1 INTRODUCTION

The objective of this chapter is to provide information on the experience of living in remission. An awareness of the demands imposed on patients who are in remission is needed in order to understand the role that a meaning-centred approach in psycho-oncology interventions. Meaning therapy proposes that the quest for meaning is a basic human need (Weinstein, Ryan & Deci, 2012:Kindle location 2861, Frankl, 1985:121), human beings have the capacity for meaning seeking (Wong, 2012a:Kindle location 791), and meaning can be found under all circumstances (Lukas, 2000:6). Based on these propositions, the researcher postulates that people can derive meaning in their lives while living in remission.

The increase in survival rates and the prevalence of cancer necessitates that intervention programs should include patients who are in remission. In this chapter, some variables associated with living in remission will be discussed.

The key terms that are defined in this chapter are: remission, distress, trauma and crisis, coping, posttraumatic growth, sense of coherence, assumptive world, new normal.

#### 3.2 DEFINITIONS OF KEY TERMS

##### 3.2.1 Remission

The term remission is vague and within the oncology context, and the context of this research study, remission refers to the temporary or partial disappearance of cancer. The American Cancer Society (*After diagnosis: A guide for patients and families*, reviewed 2013) describes remission as a period of time when the cancer is responding to treatment, or when the cancer is under control (*If you need more chemo*, 2012). The differences in

the conceptualisation of remission are associated with the concept of complete remission. A contradictory view of complete remission (*If you need more chemo*, 2012) is when all signs and symptoms of cancer are greatly reduced or are gone, but cancer may still exist in the body. The distinction between a complete remission and a partial remission is, according to this definition, in the degree to which the cancer has disappeared. Stated differently, remission indicates the degree to which the cancer has responded to treatment. Treatment responses are described in chapter 2. Remission is also described as the time when cancer becomes a chronic illness: sometimes the cancer may be controlled with treatment, meaning it might seem to go away or stay the same, and it doesn't grow or spread as long because the patients receive maintenance treatment. There is thus no tumour shrinkage. Other times treatment may shrink the cancer, and a patient can take a break from treatment until the cancer starts to grow again (*If you need more chemo*, 2012). A consolidating definition of remission is that it is a medical term ascribed to a cancer recovery; it means that a cancer has responded to a particular treatment favourably. It is not synonymous with a cure, nor does it mean the cancer cannot return. There are two kinds of remission in cancer:

- **A partial cancer remission** where the cancer decreases or shrinks, but does not disappear completely from the patient's body. It is still present, and is still malignant, but it is more manageable. The patient, in a sense, has bought more time for himself or herself.
- **A complete remission**, on the other hand, is the disappearance of the cancer; but the cancer may still return, but the patient is out of danger while in remission (*Chemotherapy Glossary*, reviewed 2012). This definition alludes to the fact that, even in complete remission, a recurrence is still expected.

The advances in treatment contribute to the ambiguity of the term remission, because advances in treatment obscure when patients enter remission

(Marcus, 2006:24). Adjuvant care and treatment such as hormone manipulation may now be administered for patients for many years. The effects of treatment and the side effects are dependent on type of cancer and treatment. The oncologist may also not be able to predict if, or when late effects will occur (Lifstrong Foundation: *Cancer survivorship after treatment* [sa]).

In the context of this study, the term remission indicates that a patient has incurable cancer that is under control, and it is expected that the cancer will recur.

### **3.2.2 Distress**

Holland and Lewis (2000:79) depict distress simply as unpleasant feelings that occur normally with cancer. In this research study, the stressor is living in remission, and patients and their social attachments responses are influenced by the cancer, the progress and prognosis of the cancer, side effects and late-effects of treatments, and individuals' unique coping styles, support systems and interpretation of their quality of life.

### **3.2.3 Crises and trauma**

The researcher uses the terms crisis and trauma interchangeably. In this research study, distress refers to those experiences that fall within the coping capacities of patients who are in remission, while crisis refers to experiences that demand coping skills from these individuals that are beyond their existing coping capacities.

Everly and Mitchell (2000:212) define crisis as a response to some adverse situation, when one's psychological homeostasis is disrupted, and one's usual coping mechanisms fail to re-establish homeostasis. The disruption will result in functional distress or impairment. One's response can be to an anticipated crisis, or as result of one's anticipation of a crisis. Van der Kolk, McFalane,

and Weisaeth (1996) as quoted in Shapiro (2013:153), define trauma as the result of exposure to an inescapable stressful event that overwhelms a person's coping mechanisms. These definitions highlight one's ability to cope with an event. From a psychiatric perspective, Klein and Schermer (2000) as quoted by Shapiro (2013:153) define trauma as a "situation specific, severe, and stressful violation or disruption that has serious psychiatric consequences for the individual". This definition highlights that trauma is associated with a specific event. Trauma is also associated with one's assumptive world. Janoff-Bulman (1992:51) hypothesises that much of the psychological trauma produced by traumatic events, derives from the shattering of the very basic assumption that one held about the operation of the world.

#### **3.2.4 Coping**

The researcher conceptualises the term coping as encompassing the constructs of resilience, self-efficacy, and coping strategies. Self-efficacy refers to one's sense of one's abilities and capacities to deal with a particular set of conditions that life puts before one (Reber & Reber, 2001:661). Self-efficacy is one's belief in one's abilities to succeed in specific situations. It plays a major role in how one sets goals, and approaches tasks and challenges (Cherry, 2011). In the context of this research, self-efficacy refers to patients' belief in their ability to cope with the demands and challenges of remission. Resilience refers to the ability to recover from unpleasant or damaging events (Word Power Dictionary, 1996:930). Grotberg (2003:1) defines resilience as "the human capacity to deal with, overcome, learn from, or even be transformed by inevitable adversities of life." Newman as quoted by Grotberg (2003:212) defines resilience as the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress. In this context of this research, resilience refers to patients' ability to recover from the effects of treatment and adapt to the psychosocial and physical demands of remission. Coping strategies refers to conscious, rational ways of dealing with the anxieties of life (Reber & Reber, 2001:157). In the

context of this study coping strategies refers to the methods and strategies a patient employs to deal with remission.

Social workers must be able to identify the coping strategies that a patient employs in order to evaluate if the coping strategies are effective. Furthermore, understanding how patients cope with remission, also indicates which approach or combination of approaches a social worker can follow, for example, meaning-centered and/or a solutogenic approach.

### **3.2.5 Posttraumatic growth (PTG)**

Tedeschi & Calhoun (2012:Kindle location 14568), who coined the term Posttraumatic Growth, describe PTG as positive psychological change that is experienced because of struggles with highly challenging life circumstances. They suggest that evidence of PTG can be found in five domains: appreciation for life, connection with others, personal strength, new possibilities, and spiritual growth. The core premise of Tedeschi and Calhoun's model is that PTG occurs when an adverse life event challenges or even shatters a person's cognitive schemas of the world and self, and one can reappraise the event positively. PTG is an outcome of the process of adapting to the event, and incorporating the experience into one's revised worldview (Tedeschi & Calhoun, 2004:5).

Social workers can assist patients to explore where PTG occurred. To facilitate PTG oncology social workers can:

- Assist patients to find ways to minimise tension and anxiety, for example, teaching patients relaxation techniques.
- Restore a sense of safety, for example, health literacy can help patients to build realistic hope.
- Reflection, for example, journaling can help patients to develop new perspectives.

- Create a life vision, assess the PTG and reflect how it can become a strategy for living in remission (ASCO: *Post Traumatic Growth and Cancer*, 2011).

### **3.2.6 Sense of Coherence (SOC)**

A sense of coherence represents an individual's generalised world view. It is enhanced by a feeling of high comprehensibility, manageability, and meaningfulness (Aspers, Moons, Goossens, Luyckx, Gewillig, Bogaerts, & Budts, 2013: 2). Lindström and Eriksson (2010:32) conceptualise a sense of coherence as a way of thinking, being and taking action: a life orientation which views life as coherent, structured, manageable and meaningful, and provides one with the ability to identify, use and reuse both internal and external resources. These definitions are associated with the construct of global meaning, which refers to one's assumptions and philosophies of how the world works. Wong (2012b:Kindle location 1050) conceptualises SOC as an activity of the cognitive (understanding) component of the PURE model. The PURE model is described in chapter 5. Antonovsky (1993), as quoted by Aspers et al. (2013:2), describes the sense of coherence as a personality characteristic consisting of aspects such as comprehensibility (cognitive), manageability (instrumental), and meaningfulness. Maintaining a SOC is a dynamic process, and related to one's physical and psychological health. A high SOC is needed because it protects one against anxiety, depression, burnout and hopelessness, and it provides one with optimism, hardiness, control, and coping.

Within the context of this research study, the researcher conceptualises SOC as the ability to make sense of the demands of remission, and the ability to adapt to and manage the demands of remission. It is difficult to identify what causes cancer, and nobody deserves to have cancer. A SOC provides a patient in remission with the belief that in spite of a living with incurable cancer, there is still things in life that is rewarding to do

(manageability/comprehensibility), and that there is opportunity to have these rewarding experiences. Sometimes these experiences, and deeper appreciation of life, are an outcome of the cancer experience, for example, strengthening of relationships.

### **3.2.7 Assumptive world**

Beder (2005:255,258) conceptualises the assumptive world as one's assumptions or beliefs that ground, secure, stabilise, and orient one. The assumptive world is one's core beliefs, reflecting all that one assumes to be true about the world and the self on the basis of previous experiences. In adversity, these beliefs are shattered and disorientation and even panic can enter the lives of those affected. In essence, the security of one's beliefs has been challenged.

Janoff-Bulman (1992), in her ground-breaking research on the assumptive world, suggests there are certain types of events that can threaten one's sense of safety to the extent that these events are traumatic to the individual. The reason why one perceives these events as threatening, however, is not so much the actual event, but rather, to what degree one perceives this event to be a threat to one's sense of self-preservation. Perceptions influence cognitive schemas. Cognitive schemas are networks or patterns that form one's beliefs. Often these schemas become so integrated that one no longer questions them. Janoff-Bulman (1992: 52,53) proposes that when an event shatters these fundamental and often unconscious schemas, it results in trauma (Joseph & Murphy, 2013:6).

Oncology social workers can intervene when patients have experienced a shattering of their assumptive frameworks. A cancer diagnosis or learning that a cancer is incurable can be such events. In the context of this research, patients have to rebuild their sense of the world, which includes living with incurable cancer.

### **3.2.8 New normal**

New normal is a commonly used expression amongst cancer patients and in the psycho-oncology literature (Sorenson & Metzger, 2002:232). It refers to the view patients have formed about their lives, as they had to adapt to the changes that cancer demands and integrate changes in values, goals, and priorities in their continued journey of living with cancer. Spira and Kenemore (2002:173) state that cancer changes one's life forever; a life transition that demands changes in self-perceptions, physically, emotionally and interpersonally.

## **3.3 LIVING IN REMISSION**

One of the key stress periods of the cancer experience is remission (Cordoba et al., 1993: 49,50). Living in remission imposes physical, emotional, cognitive, behavioural, and spiritual demands on cancer survivors and their social attachments. Wells and Turney (2001:42) observe that during each stage of cancer, which in this research study is remission, patients and their social attachments are confronted with issues and challenges. An individual's response to each stressor is unique and depends on an individual's interpretation of the event, coping style, and support system.

### **3.3.1 Coping with the diagnosis of incurable cancer**

When a patient is informed that a cancer is incurable, a common reaction to the diagnosis is to feel out of control and have a feeling of helplessness (Spira & Kenemore, 2002:173). Cordoba et al. (1993:45) indicate that in order to cope with the diagnosis of incurable cancer, patients have to face the reality of their illness. The researcher argues that the knowledge that a cancer is incurable implies giving up hope for a cure, and patients have to rebuild hope. For patients in remission, realistic hope implies hope that the cancer may be manageable, and that they can have quality of life, and that there is treatment available that can extend their life expectancy and/or add to their quality of

life. Remission implies that there is not an immediate threat to their life, as would be the case when patients enter the terminal phase of cancer.

During remission, patients have to make informed decisions about treatment; therefore, they need to be well informed. In a time that they have to process the knowledge that their cancer is incurable, they have to absorb new and complicated information. Patients need to engage their self-advocacy skills, because from the guidance and suggestions that the medical team provide, they have to decide on treatment, assessing how treatment is going to extend or affect the quality of their lives (Cordoba et al., 1993:45). Patients need to understand that although the cancer is incurable, maintenance treatment, or treatment when the cancer recurs, can still prolong their lives. Rosenbaum and Rosenbaum (1999) advise patients to choose a knowledgeable physician who projects confidence and is someone they can talk to. Kneier et al. (reviewed 2010) observe that some patients are able to ask pointed and brave questions about the seriousness of the cancer and the pros and cons of various treatments available for when needed. In this researcher's opinion, asking questions is an empowering approach that enables patients to make informed decisions about the available treatment options. Some patients explore treatment options available in other treatment centres, including centres in other countries. Some patients may also explore the options of complementary and alternative medicine. The researcher has observed that some patients are ambivalent about informing the oncology team if they have considered consulting or have consulted practitioners from the complementary or alternative fields. They seem to be concerned that members of the oncology team may disapprove, or even that the team may lose interest in them. The researcher believes that patients should be encouraged to discuss their complete treatment regime with the oncologist in order to eliminate contra-indication, for example, some medication may block the uptake of other medications.

Patients in remission have to mourn for the loss of their idea of themselves as healthy, and the loss of certainty and predictability in their lives, and the hope for cure (Hermann, 1993:15). Cordoba et al. (1993:49,50) elaborate, stating that patients have to adapt to changed circumstances and changed future vision. These include adapting to physical impairment and temporary or permanent side effects of treatment. Survivors who are in remission have to adjust to the idea that they will never be cured, or that the cancer could return without warning. Sometimes physical recovery does not progress as smoothly and quickly as a patient expects. The researcher infers that during this time social work intervention should include clarification of the objectives of treatment and expected side effects, exploring medical and psychological options for support to cope with side effects or slow progress of treatment, for example, referral to a lymphoedema therapist and/or relaxation exercises that the social worker can provide. Christ (1993:90) adds that patients respond to the sense of personal loss of good health in unique ways. They have to reassess their value of their own life and a shift is needed from a healthy individual to incorporate life altered by cancer. A process of validating themselves occurs. The researcher observed in practice that, for many patients, the realisation that cancer is incurable evokes feelings of being overwhelmed, anger, guilt, resentment, exhaustion, fear, and uncertainty. Other patients might retreat into a state of denial. Kneier et al. (reviewed 2010) state that for many patients denial is a way of coping; it enables a patient to face the reality of remission gradually, in a piecemeal manner, without feeling overwhelmed. They caution that denial can have a negative impact; it can prevent a patient from coming to terms with the cancer and getting on with other constructive ways of coping. The researcher observed that some patients in remission hold onto the hope that research might still find a cure, or find new treatments that could prolong their lives.

### 3.2.2 Coping with incurable cancer

When living with incurable cancer patients have to cope with the following:

- **The fear of recurrence:** Recurrence is a real possibility for patients who are in remission. Given cancer's potential to metastasise, many survivors are afraid that when their cancer recurs it will have metastasised. This will affect both the treatment and the prognosis, which, in turn, affects their ability to cope with both the recurrence and treatment. Certain events, such as follow up medical visits, unexplained pain, or particular sights and smells associated with treatment, can trigger bouts of anxiety and fear that are as debilitating as those that occurred during the treatment itself. Some survivors may become hyper-vigilant while others may go to the other extreme of avoiding necessary medical care (Christ, 1993:85).
- **Patients in remission live with ambiguity:** The course and the outcome of the disease are unpredictable for most patients. Cancer has been compared to the sword of Damocles, ever present, and ready to fall at any time (Cordoba et al., 1993:49). This is very true for patients living in remission. Some cancer survivors may become so fearful of what may befall them in the future that they can no longer enjoy life as they once did. They may have a hard time making major life decisions. The researcher infers that patients may feel that further treatment, or living itself, is futile. Therefore patients have to accept the reality of their cancer, be aware that treatment offers them time, and live in the moment. The researcher observed that when patients live life to the full, this ambiguity fades. At times of follow up visits to the oncology team and the accompanying medical investigations, this ambiguity comes to the fore.
- **Fatigue** is one of the most common legacies of cancer treatment and manifests as a persistent lack of energy or an overall weariness (Harvard Health Publications, 2008). The researcher infers that it is difficult to enjoy life when one is constantly tired. Another dimension is that patients become

fatigued with the constant medical appointments and investigations. Sumalla, Ochoa, and Blanco (2009:25) refer to this dimension as the internal stressor of cancer. Cancer is a stressor with an internal nature genesis, with an ongoing threat to one's life and well-being.

- **Stress responses:** Long-term effects of dealing with the stress of cancer diagnosis and treatment include difficulty sleeping and concentrating, physical symptoms such as heart palpitations, and fearfulness or hyper vigilance (Harvard Health Publications, 2008).
- Christ (1993:85-88) adds that survivors, including patients who are in remission, also face the tasks of recognising and coping with the fears of having less medical surveillance, returning to dealing with personal and work situations predating the cancer diagnosis, and changing their expectations of support from family and friends. The researcher is of opinion that survivorship is the time when patients are confronted with the impact that cancer has, and still will have, on their lives. During survivorship, patients are intensely aware that life as they knew it has changed forever, and they have to create a new normal. A meaning-centered approach can help patients to find meaning and purpose, in spite of having to live with incurable cancer.
- Patients in remission have to examine their **sense of a foreshortened future and loss of future memories.** Future memories refer to how one's sense of self accommodates one's perception of one's future. Sumalla et al. (2009:26) argue that future memories are more than one's plans and expectations; they include one's image of oneself in an imaginary or forward-looking way. These memories influence what one expects to be and ensures that one's life is coherently focused on the future. Cancer can fracture these 'future memories', curtailing any sense of continuity in the patient's life, for example, the ability to conceive children. Patients can perceive that cancer presents them with an ill-fated future, resulting in the inability of the patients to picture themselves over time. The researcher argues that patients can become so caught up in their treatment and/or disease, that they lose track of

the continuity of their lives since before the onset of the illness. Creating a future orientation, contributes to building meaning. Greenstein and Breitbart (2000:494, 495) suggest that the knowledge of the transitoriness of life may be partly responsible for the need that people have for a sense of meaning and purpose, and learning to cope with limitations is what allows one to appreciate what one does have. Furthermore, recognising the limitation of time, challenges people to make the most of the time they have. The researcher concludes that in order to cope with remission, survivors have to grieve for the losses that cancer brought, including the loss of health and the hope for cure. They have to cope with the stigma associated with incurable illness and especially those associated with cancer, for example, the misconception that remission implies that they are terminal. Patients in remission have to build a positive self-image with a new sense of self, develop a sense of competence, mastery, and control, continue building and maintaining satisfying relationships, regain a sense of normalcy, and integrate changes in values, goals, and priorities.

The following adjustments are required to cope with remission.

### **3.3.2.1 Finding activities**

Finding activities that foster one's own sense of wellbeing in a comfortable manner is essential. Cancer wellness implies being open to new possibilities and ways of looking at oneself and the world (Spira & Kenemore, 2002:176). This includes commencing activities that survivors tend to put off or postpone, taking up new hobbies and interests and letting go of unnecessary tasks. This focus on wellbeing may lead to the exploration of alternative or complementary therapies. Finding new activities contributes to creating a new normal. Spira and Kenemore (2002:177) infer that patients need to be aware that they have a life beyond cancer. The researcher infers that activities that crystallise for patients that they have a life beyond cancer, living with their cancer, contribute to meaning-construal.

### **3.3.2.2 Participatory stance**

Adopting a participatory stance in the cancer journey is an important skill because it results in patients engaging self-efficacy skills resulting in claiming back their autonomy and focus on empowering themselves. Kneier et al. (reviewed 2010) define self-efficacy as “the belief in yourself as an active and effective agent.” In line with these authors, the researcher observed in practice that patients in remission who implement a participatory stance ask about treatment options, alternative and complementary therapies and are compliant to treatment. They develop their own ideas to promote their wellbeing, for example dietary changes and stress management. This means that they have to assess their coping strategies, acknowledge which strategies are effective, and identify where improvement or new strategies are needed. This, in turn, enables them to measure their growth and fight helplessness and vulnerability. Self-efficacy skills must also be applied to obtain good pain and symptom control. In these ways, patients in remission are actively participating in efforts to maintain the best possible physical and psychological health. The researcher infers that activities that adopt a participatory stance contribute to meaning-construal because patients contribute actively in creating quality of life and prioritising what is important to them.

### **3.3.2.3 Support networks and support groups**

The building of support networks and reaching out for support imply that patients in remission need to be aware of and be able to identify their own needs. This enables them to ask for the type of support they need most (Kneier et al., reviewed 2010). Patients can misconstrue reaching out for support with giving up roles or giving up their independency.

Support groups play an important role and research has shown that such groups help patients to cope with and adjust to their illness. Group members have a great deal to offer each other in terms of mutual support and

encouragement, discussion of common problems and ways of coping, and with the sharing of medical information. Groups also offer a safe and supportive haven for confronting fears (Kneier et al., reviewed 2010). The researcher observed in practice that stress often causes patient to have little recall of information imparted by the oncology team. For patients in remission groups offer the opportunity where misconceptions can be corrected and/or patients become aware of what questions they still have to ask. Many patients are surprised by the prevalence of cancer. Support groups highlight for patients that they are part of a group, commonly referred to as the cancer family. Spira and Kenemore (2002:178) state that support groups and support networks provide patients with the continued opportunity to give to others. From a meaning perspective this phenomena is referred to as self-transcendence.

#### **3.3.2.4 Positive attitudes**

How patients in remission cope emotionally is closely correlated to their attitudes. Rosenbaum and Rosenbaum (1999) identify the following positive attitudes and behaviours in cancer survivors:

- they live in the present and accept that the past cannot be changed, but that one has the capacity to influence the quality of today and tomorrow,
- they accept new problems and attempt to solve them through introspection, understanding and sharing,
- they set reasonable and achievable goals, and
- they consciously try to downplay negative emotions and focus rather on feelings of love and hope; and surround themselves with supportive friends and family members.

Positive attributions, which are influenced by positive attitudes, allow patients to make sense of remission, by discovering the benefits in the cancer journey. As such, positive attribution contributes to meaning-construal.

### 3.3.2.5 Hope

Cancer confronts one with one's mortality. The threat of loss of life often challenges one spiritual perspective and/or one's relationship with Divinity (Spira & Kenemore, 2002:180). This influences one's ability to maintain hope. Patients in remission and their social attachments need to maintain realistic hope. Kneier et al. (reviewed 2010) postulate that patients need to keep balance and proportion, understanding that they will experience a degree of hope that is proportional to the positive survival chances that apply to the patient's individual situation, but will also experience a degree of worry that is proportional to the mortality rate in similar cases. In this way, positive and negative emotions can balance each other out, and one can avoid overreacting or under reacting to the medical realities, that one faces.

Realistic hope is a crucial component for successful adaptation to remission. The level of hope and ability to cope are interconnected (Cordoba et al., 1993:60). Weingarten (2010:7.--11) uses the term reasonable hope. She depicts reasonable hope as something both sensible and moderate. It directs one to set attainable goals, rather than wishing for the unattainable. As such, realistic hope softens the polarity between hope and despair, and hope and hopelessness. It allows individuals to put themselves within the category of the hopeful because reasonable hope is orientated towards the here and now. The quest for reasonable hope motivates one to work towards something better, to understand that the future is not determined, but influencable. Reasonable hope does not negate feelings of doubt, contradiction, and despair; it accommodates those feelings. Kneier et al. (reviewed 2010) adopt the view that if patients experience a degree of hope that is proportional to the positive survival rates applicable to the specific stage of the disease, then the degree of worry that patients' experience would be proportional to the mortality rates in similar cases. The researcher interprets this as that reasonable hope provides proportion and balance. Kneier et al. (reviewed 2010) conclude that patients who maintain proportion and balance enjoy

better psychological adjustment than patients who feel too optimistic or too pessimistic. They argue that the result is that patients feel that they are coping well with the ambiguity inherent in cancer, neither dwelling on nor denying their legitimate fears, whilst keeping their sights on getting better. The researcher conceptualises hope as a process. What might have started as hope for cure may during remission change to hope for more short-term goals, implying that their focus shifts to quality of life instead of quantity of life (Hedlund & Clark, 2001:309). Davidson (2003), as cited in Weingarten (2010:11), postulates that assisting people with formulating goals and exploring ways to goal achievement – doing reasonable hope – activates a neuro-chemical cascade that dampens fear and makes people feel more hopeful. This process activates the reward circuitry of the prefrontal cortex, setting in motion the complex chemical interplay between the prefrontal cortex and the amygdala.

Death is a universal experience, it is inescapable and could happen at any time, but one tends to deny the immediacy of the possibility (Spira & Kenemore, 2002: 179). Patients in remission live with the knowledge that cancer can return at any time, and a recurrence can mean that they have entered the terminal phase of cancer. Therefore, as Spiegel [sa] states, patients have to detoxify fears of death and dying. Discussing impending death helps to detoxify death. This is illustrated in Christina Middlebrook's (as quoted by Bowman, 1999:185), remark, "Talking about death will not kill me. And not talking about death will not save me." Greenstein and Breitbart (2000:49) argue that detoxifying death puts death in a larger context, as part of on-going life. Spiegel [sa] infers that anxiety about death is reduced when the possibility of death is faced in a direct and supportive manner. Most people fear the process of dying more than death itself. These fears include being in pain, being unable to make decisions about one's medical care, and/or being separated from one's loved ones.

Spirituality, faith, and prayer play an important role in the cancer patients' journey. Most people have some fundamental spiritual beliefs. Patients who call upon these beliefs experience a greater sense of peace and inner strength and they cope better. They show an improved psychological adjustment and better quality of life (Kneier et al., reviewed 2010b). Spirituality issues, which may vary significantly among different cultural and ethnic groups, may include anger at God (Divinity), loss of faith, finding faith, fatalism, and the notion of cancer as punishment. Remission demands that patients learn to live with the uncertainty that comes with cancer, and cope with their fear of death (Reuben, 2004:11).

Hope and spirituality are cornerstones in meaning-construal. Spirituality and hope are often employed to make meaning out of stressful events such as remission. Richards and Bergin (2005) as quoted in MacKinon, Milman, Smith, Henry, Berish, Copeland, Korner, Chochinov and Cohen (2012:222) differentiate between spirituality and religion. According to them, spirituality refers to the experiences, beliefs, and phenomena that go beyond specific religious affiliations and relate to the transcendent and existential aspects of life, whereas religion is concerned with theistic beliefs, values, practices, and feelings, often associated with organisational denominations. They conclude that the spiritual and religious paradigms offer individuals support, for example, clergy, scriptures, and communities of faith.

#### **3.3.2.6 Self-perception and self-esteem**

It is necessary to integrate the changes in self-perception that accompany living with incurable cancer. It is important to remain recognisable to oneself because the loss of a normal sense of self can be profound and unexpected. Patients who express their emotions and concerns benefit from a better psychological adjustment than those who suppress their feelings. Emotional expression provides an outlet for feelings, an opportunity to work through feelings and an opportunity to obtain better emotional support. Thus, patients can experience that their feelings are validated, and that they are understood.

Unfortunately, it is not uncommon for patients to hide their true feelings as a way of protecting their loved ones. This can cause isolation and lack of support (Spira & Kenemore, 2002).

Patients need to maintain their self-esteem, which can be threatened by cancer and the side effects of treatment. Patients must avoid defining themselves solely as cancer patients. Whilst living with cancer, patients are successful in certain roles and they are still needed. They must embrace each day and be aware of the contributions they make. They should be encouraged to create joy and fun whilst living with cancer (Kneier et al., reviewed 2010).

Thornton (2002:159) and Sumalla et al. (2009:25) perused several research studies in which participants (cancer survivors) reported positive changes in the self and changes in interpersonal relationships. Changes in the self incorporate increased inner strengths and independence, feeling stronger and feeling more self-assured, taking more time for themselves, learning to take care of their own needs, improved self-respect, and increased emotional maturity. Other aspects included in the sense of self are more satisfaction in terms of what they have accomplished in life, increased satisfaction with their ability to manage demands, and feeling more experienced and more able to face the future challenges. Changes in interpersonal relationships include strengthening of ties with other people and an increased need to share and express one's feelings.

In a study of breast cancer patients, some patients reported a perceived increase in their competence as their significant others recognised their struggle with adversity and viewed them as fighters or heroines. Being respected as a living person and not as a dying person was described as essential. Some participants viewed themselves as one of many people suffering from cancer, and knowing that illness was part of life (Kenne-Sarenmalm, Thorén-Jönsson, Faston-Johansson & Öhlén, 2009:1123). Patients who have high self-esteem and self-perception can adapt to the

demands of remission, and create a new normal that enables them to enjoy life, and derive meaning in their lives.

When a patient realises that a cancer is incurable, the patient is forced to re-evaluate his or her life. Cordoba et al. (1993:52) posit that an awareness of the transitoriness of life, a heightened sense of own vulnerability, the importance of certain relationships, a future vision and a validation of one's own life are common experiences in cancer patients. Some individuals experience trauma as a "wake-up call". Janoff-Bulman (1992:176) states that after trauma, "trauma survivors no longer move through life unmindful of existence; they can more readily relish the good, for they all too well know the bad". Kneier et al. (reviewed 2010) observed that patients prioritising of values, their lives and relationships, or establishing what quality of life in these changed circumstances implies, might also lead to drastic changes. Spira and Kenemore (2002) observe that often renegotiation of relationships occurs. The management of cancer and survivorship is done in the context of a complex network of relationships with family, friends, co-workers, clergy, doctors and other medical personnel. Kenne-Sarenmalm et al. (2009:1126) report that living with recurrent breast cancer also include adjusting to the symptoms related to changes in bodily state and adjusting to the disease progress. The respondents had to make sense of living with a lifelong threat, and cope with everyday life. They faced the challenge of dealing with loss of health, which they had previously taken for granted. They have to make sense of living in a world of healthy people. Living with a life-threatening disease is a life-altering experience that demands dealing with changes and accepting that life would never be the same. It also required making sense of the disruption of their perceived future biography. The researcher interprets these findings as that the respondents had to deal with shattered assumptions and rebuild their assumptive world, and adjust to physical changes resulting from cancer and treatment.

During the re-entry phase, patients in remission might be apprehensive or not motivated or excited by the idea of re-joining the rat race or returning to their old lifestyles. They may feel apprehensive about investing or reinvesting in life. Alternatively, patients that are in remission may also perceive that they have been given a second chance. Therefore, they are eager to embrace life and live life to the fullest (Cordoba et al., 1993:59).

Rowland (1990a:26) reviewed the impact of cancer on all life stages and divided the common disruptions of cancer into five categories: altered interpersonal relationships, dependence-independence, achievement disruption, body-sexual image and integrity, and existential issues. These disruptions have been simplified to “the five D’s”: distance, dependence, disability, disfigurement, and death. Cordoba et al. (1993:52) postulate that fears associated with these disruptions centre first on the threat to life and then the threat to quality of life. Individuals respond to these disruptions in unique ways. Holland and Lewis (2000:40) conclude that learning to live with uncertainty becomes the bottom line in dealing with cancer. Cordoba et al. (1993:59) and Kneier et al. (reviewed 2010) add that the patients prioritising of their lives, the so called “wake-up call”, or establishing what quality of life in these changed circumstances implies, can lead to drastic changes. They may not be motivated or excited by the idea of re-joining the rat race or a return to old lifestyles. Alternatively, patients may feel apprehensive about investing or reinvesting in life. Patients who are in remission may also experience that they were given a second chance. Therefore, they are eager to embrace life and live life to the fullest.

### **3.4 VARIABLES ASSOCIATED WITH LIVING IN REMISSION**

Illness entails threats to: life; bodily integrity; body image; self-concept; future plans; emotional equilibrium; social roles and activities (Cohn and Lazarus (1979) as cited in Brennan, 2001:6,7). Blum et al. (2001:46) explain that cancer differs from other illnesses in the sense that cancer evokes in one, one’s deepest fear about death, and it also provokes questions about the

meaning of life and the meaning of suffering. This researcher observes that this is evident in patients who are in remission. In addition, it presents the challenge of coping with side effects or late-effects of treatment, the prognosis, and progress of the cancer. Hermann (1993:15) infers that patients “mourn for the loss of their idea of themselves as healthy and the loss of certainty and predictability in their lives”. Patients in remission also have to make sense of living in a world of healthy people.

### **3.4.1 Distress**

During the cancer experience, distress at some level is expected universally. However, the intensity and degree of this distress depends on many variables, and distress is mastered with different levels of competencies and coping skills. The National Comprehensive Cancer Network (2013:*Clinical practice guidelines in oncology, Version 2.2013*), expands on the previous (1999) definition of distress in cancer, to one that reads:

Distress is multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional) social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

Taylor (2009:147) depicts stress, which the researcher conceptualises as distress, as a negative emotional experience accompanied by predictable biochemical, physiological, cognitive, and behavioural changes that are directed either towards altering the stressful event (in this research study, it is cancer), or accommodating its affects, (in this research study it is adapting to living with incurable cancer).

At different times of the cancer experience, cancer as a stressor can negatively influence a patient's functioning. The impact of remission can be far reaching. Remission impacts a patient's roles; the way a patient functions,

the ability to continue work or perform the same work, marital and family relationships, lifestyle, and value systems can be disrupted (Cordoba et al., 1993:43). During remission, the uncertain life expectancy, fear of recurrence, fear of availability and side effects of future treatment, and adjustments to late-effects or remaining physical impairment due to the cancer, can cause distress (Christ, 1993:86). Expectations of family, friends and colleagues can be unrealistic. The support that patients received during active treatment can also change or stop. Patients' lives as they knew it before the diagnosis that the cancer is incurable have changed irreversibly. This can cause distress.

In times of remission, when patients do not receive active treatment, it can evoke a sense of abandonment by the oncology team. Patients may be apprehensive about decreased contact with the oncology team and/or the support they received from other patients. They may also experience acute fears of recurrence (Cordoba et al., 1993:49).

The social worker must be able to distinguish whether a patient is distressed or traumatised, because the intervention approaches towards distress and trauma differ. Meaning-centered theory proposes that stressors can motivate individuals to search for meaning. The researcher proposes that patients can derive meaning in their lives whilst they are in remission.

### **3.4.2 Assumptive world**

The research of Beder (2004:255 - 258) on the assumptive world of a person reveals the following. The concept of assumptive world was first articulated by Parkes (1988) and built upon by others (Janoff-Bulman, 1992; Kauffman, 2002a). Parkes (1975) defines the assumptive world as one's view of reality, and defined it as a ". . . strongly held set of assumptions about the world and the self which is confidently maintained and used as a means of recognizing, planning, and acting...Assumptions such as these are learned and confirmed by the experience of many years" (Beder, 2004:258). Beder (2004:258) defines the assumptive world as an organised schema, reflecting all that one

assumes to be true about the world and the self, and is based on previous experiences. It refers to the assumptions, or beliefs, that ground, secure, and orient people, and that give a sense of reality, meaning, or purpose to life. These beliefs seem to lend a sense of meaningfulness to people; it is the lens through which they observe the world. When these beliefs are challenged or disrupted by traumatic or stressful events, a central task for the victim is the restoration or rebuilding of this assumptive world. In re-evaluating and redefining beliefs and goals, people may be able to find meaning in the event. Janoff-Bulman (1992:6) proposes that the three fundamental assumptions are: The world is benevolent. The world is meaningful. The self is worthy. Beder (2004:258) interprets these assumptions as follows: benevolence of the world refers to the notion that the world is a good place, people are essentially kind and well intentioned, and events eventually work out for the better. The assumption that the world is meaningful means that things make sense, and that there is a cause and effect relationship between events and outcomes. The notion of the self as worthy means that one perceives oneself as good, capable, and moral. In essence, one's assumptive world leads one to believe one is good and lives in a benevolent world where things make sense.

How patients handle possible stigmas associated with cancer is related to their assumptive worlds. Stahly (in Cordoba et al., 1993: 58,59) hypothesises that most people believe that the world is rational and fair and that people generally get what they deserve. Consequently, when something bad happens, the victim's character or behaviour is blamed. This assumption, expressed as a view that personality factors and stress play major roles in the etiology of cancer, is often reinforced by the popular press. Cordoba et al. (1993:59) reiterate that relationships between psychological states or traits and cancer outcomes have not been identified. Most psychological researchers hold that the disease itself is responsible for behaviour, not that personality causes the disease. Hermann (1993:16) adds that patients who grapple with self-blame and guilt have less emotional energy to devote to treatment and effective coping. Regardless of the true association between

cancer, behaviour, stress and coping, the tasks facing patients are acknowledging the lack of predictability and “fairness” in life.

Sufficiently stressful or traumatic events, such as remission, have the potential to challenge and disrupt the fundamentally positive, adaptive assumptions that most people hold about the world and their place in it (Thornton, 2002:154). Debats (1998:254) postulates that a health crisis may shatter one’s belief in one’s invulnerability, personal control, or in a just world. This can create a meaning crisis, evoking the need for deeper, more encompassing meanings. Beder (2004:255) cautions that if the assumptive world is shattered, disorientation and even panic can enter one’s life because the security of one’s beliefs is jeopardised. Conversely, when the assumptive world is successfully rebuilt, one can withstand future shocks to the system, coping effectively with adversity (Tedeschi & Calhoun, 2012:Kindle location 14457-14458). Updegraff, Silver and Holman (2008:710) argue that trauma challenges and disrupts people’s assumptive worlds.

Humans are dynamic beings whose life space is continually changing, so too, is their assumptive world being confirmed or disconfirmed, reinforced or altered in a continuous process of elaboration, refinement and adjustment (Brennan, 2001:2). Therefore humans have the potential to rebuild their assumptive worlds. PTG can occur when a person’s shatters assumptions are positively reconstructed. Wong (2012a:Kindle location 690) proposes that the key to PTG is the ability to reconstruct the assumptive world about the self and one’s life. This meaning-making ability allows one to create a new narrative that facilitates one’s positive change and growth. The discovery of new ways of perceiving life and negative events can lead to better adjustment. Tedeschi and Calhoun (2012:Kindle location 14457) state that a rebuilt assumptive world assists people to withstand future adverse events through processes of existential re-evaluation and psychological preparedness. The researcher infers that the way in which one copes influences one’s ability to reconstruct one’s assumptive world. Effective

coping skills such as positive reappraisal can assist patients to develop a healthy SOC. Living in remission demands from patients a reconstruction of assumptions, from - "I am dying of cancer" to "I am living with cancer".

### **3.4.3 Crisis and trauma**

The researcher uses the terms crisis and trauma interchangeably. In this research study, distress refers to those experiences that fall within the coping capacities of patients who are in remission, while crisis refers to experiences that demand coping skills from these individuals that are beyond their existing coping capacities.

Tedeschi and Calhoun (2004:1) define trauma as "sets of circumstances that represent significant challenges to the adaptive resources of the individual, and that represent significant challenges to individuals' ways of understanding the world and their place in it". Shmotkin and Shrira (2012:Kindle location 4613 - 4617) postulate that meaning is not easy to sustain in the aftermath of trauma. Trauma disrupts one's sense of normalcy by shattering one's core assumptions about the world as a benevolent, predictable place. The bad impact of the trauma may be stronger than that of many good experiences in the trauma survivor's life. In addition, because of imbalance caused by trauma, survivors' resources may be drained. Referring to various authors, Updegraff et al. (2008:710) state that traumas and other adverse events profoundly challenge one's core beliefs. Trauma can intensify feelings of vulnerability, or create feelings of vulnerability and erode self-worth. Accordingly, one of the major tasks that traumatised individuals face, is reconciling the harsh reality of adversity with previously held more benign assumptions about oneself and the world. The researcher observed in practice that many patients are surprised that cancer could happen to them. They have to come to terms with the unfairness of cancer; to the acceptance that bad things happen to good people. This result is the "Why Me?" question.

Living in remission confronts survivors with the transitoriness of life. Park (2012:Kindle location 13426-1342) concurs with Wong (2011) that meaning and meaning-making are important for all humans, but they are particularly salient for individuals who experience life-threatening experiences. Emmons, Colby and Kaiser (1998:164) note that in and of themselves, events have no meaning and are traumatic partly because they require fundamental changes in one's worldview (assumptions). Sumalla et al. (2009:24) confirm that the cancer experience is often viewed as a traumatic event. In the aftermath of trauma, cognitive rebuilding alters one's schemas, or core beliefs, and creates a new reality (Johnson, 2009). Tedeschi and Calhoun (2004:4,5) purport that cognitive rebuilding emerges due to changed realities of one's life after trauma, and it produces schemas that accept that trauma and positive events will occur in the future, and the new schemas are more resistant to being shattered. The researcher argues that when survivors find meaning in living with cancer, they can assimilate or accommodate the experience into their assumptive world and accommodate new information regarding the event and their coping capacities. This process helps them to regain homeostasis, with the result that their distress levels out.

Cancer often creates major discontinuity in patients' lives that causes lasting changes in the way they perceive themselves and their future (Christ, 1993:85). Traumatic events often precipitate a meaning crisis, raising questions reflecting on the meaning of life and the nature of suffering and justice in the world. Pertinent questions that arise are why the event occurred and what the implications will be for the future (Emmons et al., 1998:164). Maddi (1998:13) infers that to cope with changes, including distress and crisis, involves transforming these changes into opportunities by seeking broader perspectives, deeper understanding, and by taking decisive action. The researcher hypothesises that remission can trigger a quest for meaning. Thornton (2002:153), in line with various authors (Hoffman, Leigh, Loesner & Meyskens, 1989; Holland & Rowland, 1989; Meyerowitz, Leedham, & Hart, 1998), argues that trauma may manifest during survivorship. Survivors, and by

implication patients in remission, experiences may include depression, anxiety, confusion, anger, disrupted interpersonal relationships, vocational difficulties, worsened body image and sexual dysfunction. Survivors were, and might still be, confronted with their own mortality. They live with the possibility or certainty of recurrence or death, and have or may have to cope with toxic or disfiguring treatment. However, they still have to embrace life because they have to live beyond the illness. Christ (1993:85) postulates that the way survivors and their social attachments adjust to survivorship, is associated with the outcome of treatment. Wells and Turney (2001:37) reiterate that survivors with permanent disabilities and intense side effects from treatment therapies must deal with new realities as they shift focus from coping with treatment to adapting to life that may be permanently changed. The researcher postulates that in order for one to cope with living in remission (a traumatic life event) one must make sense of the experience by finding or creating meaning in living in remission.

Other terms for a traumatic event include adverse (Joseph & Linley, 2006:1041) disruptive (Benyaker, 2003) and extreme. Some of these negative events have been identified and grouped in diagnosis manuals and are referred to as posttraumatic stress disorder (PTSD). In the Diagnostic and Statistical Manual-IV, 1994) (DSM-IV 1994) cancer was explicitly regarded as a stressor capable of resulting in PTSD (Sumalla et al., 2009: 24). Trauma associated with cancer may be more to do with a threat that is located in the future than in the past (Brennan, 2001:6). Adversity can result in feeling scattered, fearful, worried, sad, tired, irritated, and confused. These feelings linger as PTSD, presenting as anxiety combined with a painful void where passion, care and love linger, and then slowly fade away (De La Lama [sa]). Survivors are vulnerable to acute as well as posttraumatic stress syndromes (Rosenbaum, Fobair & Spiegel, 2011).

Table 4: The differences between acute trauma and cancer as a traumatic event as summarised by Sumalla et al. (2009:25):

Topic	Acute trauma	Cancer	Examples
Stressor	Simple and direct nature;  The stressor is easily identifiable for the subject	Complex nature; the subject presents difficulties in identifying the stressor or set of stressors that produce the traumatic response	Stressors may be associated with the diagnosis of cancer, the aggressiveness of treatments, altered body image, a decrease in the level of functional autonomy, or role alterations
Source	Stressors generated in the external environment of the subject.	Stressors with an internal nature and genesis	Symptoms of avoidance associated with traumatic reaction are changed, since it is often impossible to erase the signs associated with the cancer (e.g. hospital visits, follow-up tests, illness control etc.)
Temporal dimension	Backward looking nature of the traumatic experience	Forward looking nature of the traumatic experience	In the oncology processes, most of the intrusive cognitions advance fears associated with future personal health and those of the subject's closest relatives. The emotional response to cancer is affected by the presence of adverse events related to treatment and illness outcomes
Temporal delimitation	Well established onset and termination of the traumatic event	On-going threat. Progressive presence of adverse events related to cancer. The individual has difficulties delimiting the onset and termination of the traumatic event	The expected on-going nature of cancer and cancer treatment is associated with several stressors over a period of time.
Perceived control	Scanty perception of control concerning the nature and consequences of the traumatic experience	There exists a major perception of control linked to the treatments, the clinical follow-up, and the preventive actions.	Patients have control over life-style changes when required

Table 4: Difference between acute trauma and cancer as a traumatic event

Steger (2012:Kindle location 5249-5250) cautions that there is also a correlation between meaning and psychological distress and psychopathology. Conversely, the crisis of a life event does not always result in trauma or psychopathology (Aldwin & Sutton, 1998; Brennan, 2001: 3; Frankl, 1959, 1985; Haybron, 2000). McMillen (1999:455 - 465) reviewed literature in several different fields on the effects of adversity as it relates to a spectrum of experiences including, but not limited to, cancer. These studies have revealed that the following positive categories were consistently and independently proposed: changed life priorities, increased sense of self-efficacy, enhanced sensitivity to others, improved personal relationships, and increased spirituality.

#### **3.4.4 Coping**

De Gruchy (1995:343) purports that during crisis one's patterns of coping are suddenly disturbed and are no longer adequate to deal with the new situation. Ideals and beliefs that were previously helpful are found to be wanting and are often discarded. In addition, during a crisis, one struggles to make sense of experiences, and to relate to the new experience in a meaningful way. Hoffman, Lent, and Rogue-Bogdan (2013:248) identify problem-focused coping and emotion-focused coping in the cancer domain. Problem-focused coping is aimed at managing or resolving the stressor. For cancer survivors, problem-focused coping may begin with seeking a diagnosis, gathering information, seeking second opinions, and making treatment decisions. Emotion-focused coping is aimed at managing the internal aspects of the stressor and may include distancing or distracting oneself or positively reappraising a stressor. For cancer survivors, emotion-focused coping may help to navigate emotional reactions (for example, distress), functional limitations, and changes in valued life roles. Patients need effective coping skills that will enable them to build the resilience needed to live with the demands of remission.

Meaning-making is a reappraisal coping strategy which Park (2010) defines as the recovery of meaning or making new meaning when facing highly stressful situations. In her integrative model of meaning-making Park (2010), explains that people rely on a global meaning-making (or orienting) system that serves as a cognitive framework for understanding their experiences. When facing stressful situations, such as experiencing cancer, people engage in an appraisal process in which they interpret the meaning of that experience compared to their global meaning system. Global meaning refers to one's assumptions, sense of purpose, goal striving and goal attainment, and one's sense of fulfilment. When there is a discrepancy between one's appraisal of an event, and one's global meaning, distress manifests. Meaning-making is the process of reducing the discrepancy between the appraised and global meaning. Meaning-making is hypothesised to result in improved adjustment through several mechanisms, such as acceptance, positive reappraisal, integrating the experience into one's identity or self-concept, or making positive changes in one's life.

Taylor (2009:174) defines coping as "...the thoughts and behaviors used to manage the internal and external demands of situations that are stressful." Effective coping is needed by patients and their social attachments in order to meet the demands of remission and deriving meaning in their lives. Effective coping facilitates the adjustments, altered lifestyles and changed perceptions that are required from patients to live with incurable cancer (Janoff-Bulman, 1992:201; Taylor, 2009:359). In this research study, the term 'coping' includes the constructs of coping style, coping strategy and coping capacity. Brennan (2001:3) defines coping as "the process of managing internal and external demands which are appraised as taxing or exceeding the resources of the individual. It is an interaction between the individual and the environment in which each affects the other." Coping style refers to how one characteristically appraises and responds to adversity, and coping strategies refers to "conscious, rational ways of dealing with the anxieties of life. The term is used for those strategies designed to deal with the source of the anxiety" (Reber &

Reber, 2001:157,180). Coping capacity refers to the extent to which one is able to mitigate the demand imposed by a specific life event. The researcher's perspective is that coping is interrelated with the emotional, spiritual, psychological, physical, social, and support resources available to patients and their social attachments. Coping is a process during which one employs one's abilities and competencies, as well as utilising the available resources to meet the demands imposed on one by a specific life event. Resource utilisation implies using known existing available resources, exploring to find available resources, or developing new resources.

Lukas (as quoted by Marshall, 2009:27) affirms that a person is in essence a spiritual being and cannot be divided. Her developmental view in the context of illness is: One is not indistinguishable from one's character, or illness. During one's life, one develops one's personality and this happens through upbringing, choices, and the successive realisation of one's potentials, which leads to patterns of behaviour. This influences how one responds to life events. The researcher conceptualises personality to be a contributing factor to whether a person experiences cancer and/or remission as a distress or a crisis. The coping style approach postulates that coping will reflect a relatively enduring attitudinal or behavioural style that is similar to a personality trait (Brennan 2001:3). Coping style in the oncology context refers to the attitudes and behaviours that individuals employ to maintain emotional well-being and to adjust to the stresses caused by cancer (Kneier et al., reviewed 2010).

Individuals and their social attachments need effective coping strategies to adjust to the demands imposed by cancer and cancer treatment. Effective coping is also needed to mitigate the negative emotions generated by the cancer and cancer treatment. The appraisal of threat is likely to vary according to the stage of the cancer and the treatment employed (Brennan, 2001:4). Kneier et al. (reviewed 2010) postulate that different people employ different coping strategies and that different coping strategies are required for different situations. Because of people's uniqueness and their different life

situations, people need their own strategies that will work for them in their unique and current life situation. Adjusting to and coping with cancer, and specifically incurable cancer, is a continuous process and patients use different strategies at different times, depending on the stage of their illness. Cordoba et al. (1993:44) reiterate that cancer involves a complex set of changing conditions that place demands on patients coping strategies. In the cancer continuum, this set of evolving conditions includes the threat to survival as well physical, emotional, and intimacy issues; possible manifestation of changes in values and outlook on life; social, financial and physical aspects, and the availability and affordability of treatment. Weissman, as quoted by Blum (1993:110), concluded that “Good coping means: (1) good solutions for old problems; (2) adequate solutions for new problems; and (3) resourceful solutions for unexpected problems.”

Cordoba et al. (1993:62) assert that the ability to reframe cancer into a more positive experience rather than solely a negative experience stems from the most sophisticated coping strategies available. Kneier et al. (reviewed 2010) observed that the value of effective coping with cancer and remission is improved emotional well-being, because patients are facing their illness squarely and working through its emotional impacts, whilst also keeping a perspective on it so that cancer does not define them or take over their life to validate the researcher’s observations. Effective coping assists patients in taking stock of their most cherished reasons for living, which, in turn strengthens and sustains them in their fight against cancer. It serves to clarify to them that their survival is not the only important objective: the quality of their lives and relationships, the values they live by and their spirituality are also deserving of attention and effort. They have the peace of knowing that their death from cancer, if it comes to that, will not obliterate the meaning, value and joy that their life has given to them and to their loved ones. The researcher postulates that coping is interrelated with each patient’s unique meanings and quality of life. Effective coping offers patients the opportunity to explore and challenge their meanings and to embrace life. It empowers

patients to maintain a healthy future orientation whilst living each day to the full, and brings patients the awareness that each day offers opportunities to actualise.

The researcher interprets meaning theory to propose that human beings are existential beings and therefore capable of finding meaning in the face of adversity. It is therefore possible to develop coping capacities and gain new perspectives.

### **3.4.5 Posttraumatic Growth**

In the oncology literature, meaning-making, and benefit-finding are virtually used synonymously to describe how many cancer survivors find something positive in their struggle with cancer. Various terminologies are used to refer to the benefits cited by survivors in the aftermath of major stressors. Some of these terms include “positive changes”, “benefit-finding”, “posttraumatic growth”, “stress-related-growth”, “thriving”, “finding meaning”, or “meaning-making” (Thornton, 2002:154). The positive changes associated with traumatic experiences have been conceptualised as posttraumatic growth (PTG). Tedeschi and Calhoun (1996) coined the term posttraumatic growth (Tedeschi & Calhoun, 2012:Kindle location 14568). They postulate that negative events can instigate growth and personal transformation because negative events (including trauma) can provoke changes in meaning (Wong, 2012a:Kindle location 689-690). They define PTG as “a change in people that goes beyond an ability to resist and not be damaged by highly stressful circumstances; it involves movement beyond pre-trauma levels of adaptation” (Tedeschi & Calhoun, 2004:4). PTG is associated with a person’s basic beliefs or main assumptions regarding the way they view the world, their relationship with others and their identity as individuals (Janoff-Bulman, 1992:144; Sumalla et al., 2009:5). Patients and their social attachments respond to and cope with a crisis, and then draw conclusions from that crisis. Some of these conclusions may be the source of PTG (Tedeschi et al., 1998

in Brennan, 2001:5). The researcher proposes that if patients in remission are able to experience PTG it can contribute to living a meaning-centered life.

#### **3.4.5.1 Characteristics of Posttraumatic Growth**

Vazques, Hervàs and Ho (2007), as quoted by Sumalla et al. (2009:25), posit that when PTG occurs, one undergoes a stage in one's personal development that extends beyond one's previous functional level, and PTG occurs concurrently with attempts to adapt to highly negative sets of circumstances that engender high levels of psychosocial distress. Furthermore, PTG occurs in a wide range of people, facing a variety of circumstances including cancer. De Gruchy (1995:343) maintains that the process of human growth is accompanied by tremendous emotional activity. The researcher observed that patients who experience PTG have accepted that life, as they knew it, has changed and they develop new assumptions about themselves and the world. A study by Kenne-Sarenmalm et al. (2007:1119) that explored the experiences of women with recurrent breast cancer reveals that when the respondents confronted the incurable nature of their cancer, a personal transition process set in. Respondents moved through a difficult and challenging time, into finding meaning and transcendence. They moved from suffering losses and fears to a healing process of easing distress and letting go of losses and eventually reached a stage of being reassured. Sumalla et al. (2009:26), purport that in cancer in general, as well as in certain specific forms of cancer, the dimensions of growth can be modified in a way that differs from the changes associated with other adverse events.

Zoelner and Maercker (2006:628) argue that the term 'posttraumatic growth' indicates that: this growth occurs after a traumatic event, PTG is not caused by other minor stresses, and PTG does not form part of a natural process of personal development. PTG refers to the positive changes that result from a struggle with a traumatic event, and not to the changes caused by the event itself. These positive changes include those associated with the emotions or cognitions related to trauma, and also encapsulate everything that can be

adaptively “fractured and reset” by the growth processes (Pèrez-Sales, 2006 in Sumalla et al., 2009:25; Tedeschi and Calhoun, (1995), as cited in Sumalla et al. (2009:25).

PTG influences a person’s assumptive world. Johnson (2009) asserts PTG does not occur through suffering itself, but through one’s struggle and reconstruction of shattered assumptions. Schroevers et al. (2010:47) state that the cognitive processing theory of PTG proposes that the experience of a highly stressful life event may challenge valued personal life goals and fundamental beliefs about oneself, the future, and the world. Through the use of cognitive processes, involving recurrent thinking about events and a re-evaluation and redefinition of beliefs and goals, people may be able to find meaning in the event, which eventually results in the perceptions of growth (Wong, 2102a:Kindle location 690).

PTG also has an affective component in the sense that individuals value the growth that they experience after trauma and that they recognise their strengths. Tedeschi and Calhoun (2004:4), differentiate between PTG and the concepts of resilience, hardiness, optimism, the sense of self, and sense of coherence, which they consider as personal characteristics that allow people to manage adversity, while PTG refers to the outcome of the struggle with adversity. Thornton’s (2002:153) research revealed that many survivors reported that experiencing cancer fostered an increase in their enjoyment and appreciation of life and “the small things” (Kennedy, Tellegen, Kennedy, & Havernick, 1976; Wyatt, Kurtz, & Liken, 1993). Many survivors also discussed ways in which cancer prompted them to revise their priorities (Carter, 1993; Fife, 1994; Nelson, 1996), alter their life philosophy, or become more spiritual (Ferrel et al., 1992; Wyatt et al., 1993). For some, the achievement of lifelong goals took precedence over career advancements (Mahoun & Casperson, 1997; Shanfield, 1980). A renewed awareness of the importance of emotional and physical well-being, including leading a healthy lifestyle was also reported (Ersek, Ferrel, Dow, & Melancon, 1997; Wyatt et al., 1993). The researcher

proposes that living in remission can result in an increased appreciation of life, changed priorities, and an awareness of new possibilities for taking one's life in a new direction. The researcher observed in practice that many patients express spiritual growth and a tendency to explore existential issues. Further observations include an awareness of the transitoriness of life, the importance of relationships, a reconstructed future vision and a process of self-validation, and that they were given a second chance. This is in line with the findings of Kenne-Sarenmalm et al (2007:1121), where respondents report that the ultimate loss is the loss of the sense of immortality. It is experienced as the loss of the lived life and a future life. The loss of the lived life was expressed as loss of life as it had been lived before, and the loss of a life that had been taken for granted. The loss of future life was described as dying a premature death, and not being part of the future. Respondents prioritised their lives and re-patterned their relationships. By being in the present, trying to live in the "now", not in the past, nor in the future, they found new ways of creating wellness.

Tedeschi and Calhoun (2004:6) purport that PTG builds self-efficacy. The term 'self-efficacy' was coined by Bandura and refers to one's sense of one's abilities, of one's capacity to deal with the particular sets and conditions that life puts before one (Reber & Reber, 2001: 661; Wong, 1998b:277). In the oncology context, self-efficacy refers to the patient's sense of and belief in his or her ability to cope with incurable cancer. Tedeschi and Calhoun (2004:4,5) observe that paradoxically, the identification of strengths in adverse circumstances often correlates with an increased sense of vulnerability. PTG is experienced as a combination of the knowledge that bad things can and do happen, but that one has the resources to mitigate the demands imposed by these life events. Wong's dual system model proposes that one's ability to achieve a balanced life depends on one's efficacy in coping with stresses, misfortunes, and negative emotions (Wong, 2012b:Kindle locations 923-924). Baumeister reiterates that self-efficacy is important in a person's sense of having a meaningful life (Klinger, 2012:Kindle location 1732).

Self-efficacy beliefs determine how people feel, think, and motivate themselves. Self-efficacy influences one's behaviour. Such beliefs include cognitive, motivational, affective, and selection processes. A strong sense of efficacy enhances one's sense of accomplishment and well-being. People who are confident of their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. They approach threatening situations with assurance that they can exercise control over them. Such beliefs produce awareness of personal accomplishments, reduce stress and lowers vulnerability to depression (Ramachaudran, 1998). In the context of this study, self-efficacy implies the survivors' perceptions and assessments of their own abilities will assist them in coping with remission.

The controversy associated with the nature of PTG centres primarily on the following question: is the fact that some people appear to grow after suffering cancer real or illusory? The growth referred to in PTG, could be proved real if apparent changes can be proved, such as a change in the way some survivors perceive themselves, others and the world in general. By contrast, this growth could prove to be merely illusory if PTG was shown to be the use of defensive mechanisms to reduce the emotional distress associated with the diagnosis of the illness and its treatment so as to keep the subjects' sense of identity intact (Sumalla et al., 2009:25,26). The researcher postulates that many cancer patients and cancer survivors experience PTG and that their experiences are not defence mechanisms. A defence mechanism refers to the intended ways one plans to prepare and respond to anxieties and defence strategies refer to any number strategies that one employs to defend oneself from anxiety (Reber & Reber, 2001:179). PTG results from an adverse event, whilst defence mechanism refers to an action or attitude that one intends to employ to defend oneself against anxiety caused by a negative event. Some patients may search for benefit in the experience, but do not know what benefits may come out of the experience. Johnson (2009) infers that trauma survivors often do not intentionally search for meaning or consciously seek for

benefits. Often PTG is the result of attempts to re-establish some basic cognitive guides for living.

### **3.4.6 Resilience**

In this study, the term 'resilience' refers to psychological resilience, and not to physical resilience. Resilience refers to "the ability to recover from unpleasant or damaging events" (Word Power Dictionary, 1996:930). Tedeschi and Calhoun (2004:4) define resilience as an ability to continue with life after hardship and adversity, or to continue to live a purposeful life after experiencing hardship and adversity. Grotberg (2003:1) expands on this definition, depicting resilience as the human capacity to deal with; overcome; learn from, or even be transformed by the inevitable adversities of life. Within the oncology context, resilience refers to the ability of patients to recover from or adapt to unpleasant and/or damaging events that stem from suffering cancer. O'Gorman (2004:14-17) asserts that cancer patients need resilience to maintain their emotional and physical well-being, and to adjust to the stresses caused by cancer and cancer treatment. Resilience helps patients to cope with cancer, cancer treatment, side effects of treatment and the demands of remission. It facilitates the adjustments, altered lifestyles and changed perceptions that are required from patients in order to live a meaningful life whilst in remission, and it impacts on all aspects of the self: emotion, intellect and spirit. How individuals experience resilience, and how resilience manifests itself, depends upon the individual's hardiness, sense of self and optimism. Paradoxically, being challenged does not mean individuals are not resilient. Effective coping with adverse events, builds resilience.

Goldstein (2002:30) depicts resilience as the hardiness and pliability of the human spirit. Resilience requires from patients and survivors hope as well as grieving for what they were (Bowman, 1999:187). It provides patients and survivors an opportunity to align themselves with their strengths and to recognize their personal power. Resilience is the power to know what is needed, and the strength to act on that knowledge (O'Gorman, 2004:14 - 17).

It consists of tendencies towards commitment, control and challenge (Tedeschi & Calhoun, 2004:4).

Various authors categorise the psychological characteristics of resilience. When dealing with adversity, these characteristics are used in combination, drawing from each category (Grotberg, 2003:27). Everybody has the potential to develop resilience and individuals may develop any one or a number of these characteristics as they struggle with the challenges of their lives (Saleebey, 2002:85). Resilience enables patients to become aware of their inner strengths, internal and external support systems, and enable them to believe in their ability to cope with remission.

A number of researchers identified the following characteristics of resilience:

Table 5: Characteristics of resilience

<b>Charney in Rosenbaum C, 2005: 6)</b>	<b>Saleebey(2002)</b>	<b>Grotberg (2003)</b>	<b>Erickson (1985 in Grotberg, 2003: 5)</b>
Optimism	Insight	I have (external support)	Trust
Altruism	Independence	I am (inner strengths)	Autonomy
Faith and spirituality	Initiative	I can (interpersonal and problem solving skills)	Initiative
Having a moral compass or set of beliefs that cannot be shattered	Morality		Industry
Humour	Humour		Identity
Having a role model	Creativity		Intimacy
Social support	Relationships		Generativity
Facing fear			
Having a mission or meaning in life			
Training			

*Table 5: Characteristics of Resilience*

Wong and Wong (2012:Kindle location 15181 - 15222) identified seven types of resilience.

**Cognitive resilience** refers to one's interpretation of events and determines how we cope. Cognitive resilience contributes to meaning-construal because it contributes to cognitive reframing and retraining of one's attribution or explanatory styles.

**Transactional resilience** refers to how one negotiates changing circumstances and daily stressors in a way that allows one to survive and flourish. It involves one's appraisal of events and influences the coping strategies one adopts. Transactional resilience contributes to meaning-construal because it includes existential coping. According to the transactional model (Lazarus & Folkman, 1984) and the resource-congruence model (Wong, 1993, 1995; Wong, Reker, & Peacock, 2006), resilience depends on having sufficient resources and effective coping strategies.

**Behavioural resilience** refers to one's abilities to persist and endure when confronted with failure and obstacles. It involves goal striving. Behavioural resilience can be learned through reinforcement and practice. Goal satisfaction contributes to a sense of living a meaningful life.

**Motivational resilience** involves commitment to a life goal or a higher purpose. A sense of purpose and commitment in pursuing a life goal contribute to meaning-construal. Frankl (1946/1985) infers that the will to live is dependent on the will to meaning.

Motivational resilience becomes **existential or spiritual resilience** when one considers the ultimate meaning and purpose of human existence. Existential resilience becomes spiritual resilience when the person resorts to religious or spiritual perspectives to answer life's big

questions. Existential or spiritual resilience is also related to the quest for meaning and purpose.

**Relational resilience** is derived from secure attachment, from bonding or close relationships between adults, and self-transcendence and altruism. Relational resilience implies that one draws strengths and support from others.

There are three styles of **emotional resilience**. The first is based on one's ability to form secure attachments, to tolerate rejections and negative emotions. Second is one's ability to maintain some level of self-confidence, hopefulness, and emotional stability through mental toughness or hardiness. Lastly, emotional resilience also comes from one's ability to confront and overcome existential anxieties through existential or spiritual experience. From a meaning perspective, emotional resilience implies that one is able to hold on to an anchor or find refuge when one feels overwhelmed and devastated.

From a meaning-centered approach, Wong developed the ABCDE model which for meaning-construal provides and emphasises the elements related to resilience (Wong & Wong, 2012:Kindle location 15400).

Table 6: The ABCDE model of resilience

<b>ABCDE</b>	<b>Description</b>
<b>Acceptance:</b> accepting what cannot be changed	Accepting reality, limitations, loss, trauma, existential givens
<b>Beliefs:</b> affirming one's ideals and core values	Recognising the intrinsic value and meaning of life Receiving support and help from others Turning to a personal god or a higher power Growing and striving for positive transformation Believing in an eventual triumph of good over evil Recognising the worthiness and authenticity of one's mission Recognising and using one's competencies and abilities
<b>Commitment:</b> moving forward and carrying out one's responsibility with determination	Doing what needs to be done regardless of feelings or circumstances Striving to fulfil one's responsibility, no matter what. Enduring hardship and pain for your cause Problem solving and effective coping Avoiding errors and temptations Practicing the pure principle Pursuing realistic goals Re-authorising one's life
<b>Discovery:</b> learning something new about the self and life	Digging deeper, exploring farther, and seeking higher Discovering one's hidden courage and strengths Discovering the power of faith and spiritual resources Grasping the complexities of life and people
<b>Enjoyment or evaluation:</b> savouring positive outcomes or reassessing one's progress	Feeling relief that the worst is over Savouring the moment of success Reflecting and reviewing one's life Receiving feedback from others Conducting assessment and making adjustments

*Table 6: The ABCDE model of resilience*

Acceptance builds resilience because it recognises one's limitations and vulnerability as well as the transitoriness of life (Wong & Wong, 2012:Kindle location 15405). Beliefs gives people hope, sustain goal striving, and provide the motivation to change. From a meaning perspective, the belief that life has meaning, leads to efforts to discover one's purpose and passion (Wong & Wong, 2012:Kindle location 15414). Commitment builds resilience because it

provides one with persistence and resourcefulness (Wong & Wong, 2012:Kindle location 15420). Discovery guides one to become aware of one's courage and strengths (Wong & Wong, 2012:Kindle location 15429). Evaluation motivates one to make adjustments when needed (Wong & Wong, 2012:Kindle Location 15432).

Resilience includes the social constructs of self-efficacy, coherence, coping strategies and sense of self. Reber and Reber (2001:658,659) define self as one of the more dominant aspects of human experience and it is the compelling sense of one's existence. Kneier et al. (reviewed 2010) propose that one's sense of self is based on various mental representations or ways in which one sees oneself in one's own mind – these involve roles, activities, relationships, and identities. In this researcher's opinion, this sense of uniqueness and autonomy contributes to a patient's self-validation and the meaningfulness of his or her life. Patients need to maintain their sense of self and not allow cancer to substitute their identity, for example, "I have cancer" not "I am cancer". It is the sense of self that encourages patients to move from the perception of a cancer victim, to that of a cancer survivor.

### **3.4.7 Sense of Coherence**

Antonovsky (1987) created the sense of coherence construct in order to understand why certain individuals respond better than others in stressful life events do. A sense of coherence (SOC) refers to the comprehensibility, manageability, and meaningfulness of events. Antonovsky (1987) as cited by Leath (1999) defines the sense of coherence as:

a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.

Antonovsky (in Leath, 1999) identified three components of SOC.

The **comprehensibility component** refers to the degree in which one perceives the demands imposed on oneself as predictable, ordered and making “cognitive sense”, that life is not completely random and unpredictable. Without a sense of coherence, life is incomprehensible, unpredictable, and unsettling. Without a sense of order and understanding of how the world works, one would have difficulty cultivating hardiness. Without a clear sense of self-identity, one would not know what to do with one’s life. The pursuit of self-understanding and self-knowledge is important for self-control (Wong & Wong, 2012:Kindle location 15341-15344).

The **manageability component** refers to the extent one perceives one has the personal and social resources to confront and cope with the demands imposed on one. Manageability does not imply that one needs to have absolute control over one’s environment: simply, that one either has control over enough of one’s environment, or that one does not believe one needs control over one’s environment, for example, "God has control, and my faith is in Him". Successful coping strengthens one’s sense of manageability as well as the SOC. The most significant component of SOC is meaningfulness, the emotional counterpart of comprehensibility.

The **meaningfulness component** refers to the degree to which one’s life makes emotional sense and that the demands which one confronts are perceived as being worthy of energy investment and commitment. It depicts the degree of one’s motivation in life. In general, if one’s experiences are characterised by participatory decision making, in which one is free to select the outcome, a strong sense of meaningfulness develops. However, when one has no say in the matter, one is at risk of viewing life devoid of meaning. Without meaningfulness, manifestations of comprehensibility and manageability are likely to be poor. This in turn, will affect negatively on coping.

The ability to manage resources is contingent on being able to make cognitive sense out of a live event. If one does not believe one has the resources to deal with a stressor, the manageability component, the impact of meaningfulness is threatened and coping is weakened (Korotkov, 1998: 55, 56; Leath, 1999). Meaning is also important in one's search for understanding and coherence in the face of uncertainty, chaos, and absurdity. One's views about people and the world are essentially our generalized and crystallized experiences and understandings about human existence. Self-concept and identity are based on (a) one's interpretation of how others treat us and (b) one's own evaluation of what really matters in life, and what one is meant to be. The meaning one attributes to an event is more important than the event itself. (Wong, 2012c:Kindle location, 16252 - 16256).

Leath (1999) argues that the SOC construct is primarily concerned with "coherence," - do things make sense? He argues that if Antonovsky's sense of coherence construct is altered to read "Do I feel capable of getting rewarding emotional experience in life?" (manageability), and, "Do I feel that I have an understanding of what is important to me for achieving rewarding emotional experience?" (comprehensibility), then the third part of the whole "sense of coherence" would be simply how rewarding an individual finds living to be (meaningfulness). Korotkov (1998:56) infers that coping is dependent on all three components of the SOC. Researcher interprets that within the contexts of this research study, a sense of coherence implies that patients in remission can hold onto the hope that when the cancer recurs there will still be treatment available, or that there will be new treatment available. Alternatively, when the cancer has progressed and radical treatment is no longer an option, then palliative care can provide them with good symptom control and dignity.

### **3.5 SUMMARY**

In this chapter, the demand of living in remission was discussed, and variables associated with remission were defined and discussed.

Life imposes challenges to which one has to respond. One's responses to challenges are dependent on many variables. For a vast number of cancer survivors the outcome of treatment is remission. Patients who are in remission have to assimilate and accommodate the knowledge that their cancer is incurable and they have to adjust to a life of living with cancer. The challenge of living in remission presents as a psychosocial process, which includes positive experiences, for example, posttraumatic growth, and/or negative experiences, for example, trauma. For patients in remission life as they knew it has changed. The duration of remission is unpredictable resulting in living with uncertainty, and adjusting to the side effects or late effects of treatment. Living in remission demands from patients a cognitive shift from "I am dying of cancer" to "I am living with cancer". Ideally, patients coping capacities should empower them to construe meaning through a processes such as posttraumatic growth, rebuilding their assumptive worlds, strengthening of their sense of coherence, strengthening of their sense of self, creating a new normal, and building positive attitudes. Adjustments to remission include finding activities, maintaining a participatory stance, building support networks, building, and maintaining positive attitudes, maintaining realistic hope, and building high self-perception and self-esteem.

The next chapter provides a literature review on the constructs of meaning, meaning-construal, and meaning-centeredness.

## CHAPTER 4

### 4 MEANING, MEANING-CENTEREDNESS AND MEANING-CONSTRUAL

#### 4.1 INTRODUCTION

The objective of this chapter is to explore the constructs of meaning as well as the process of meaning-construal and the theoretical framework from which meaning theory stems. There is currently an anecdotal and unstructured body of literature available, which demonstrates the meaning-construal efforts of cancer survivors. People seek meaning in general (Shmotkin & Shrira, 2012:Kindle location 4562), and the quest for meaning derives from positive experiences and human flourishing (Shmotkin & Shrira, 2012:Kindle location 4488) as well as facing adversity (Frankl 1985:135; Ryff, 2012:Kindle location 6845). Shantall, Moore, and Rapmund (2002:33) confirm that meaning manifests in circumstances of destitution as well as in circumstances of plenty. The researcher proposes that the temporal nature of remission, the confrontation with the finiteness of life, as well as the demands that cancer and cancer treatment impose on survivors and their social attachments, can trigger a quest for meaning.

The main impetus for research on the meaning of life originated with Frankl's (1959) logotherapy (Klinger, 1998:29). The premise of logotherapy is that life has unconditional meaning, which cannot vanish under any circumstance (Frankl, 1958: 135; Leath, 1999; Lukas, 2000:6). This also stems from existentialism (Yalom, 1980). Wong and Fry (1998) published the first major research on the meaning of life and its vital role in well-being, resilience, and psychotherapy (Wong, 2012a:Kindle location 452). Interest in meaning theory is the result of the exponential growth of positive psychology, which identifies what makes life worth living as one of the cornerstones of this new movement (Seligman & Csikszentmihalyi, 2000 in Wong 2012a:Kindle location 456). There are contradictory reports regarding meaning-making in cancer efforts. Referring to various authors, Park (2012:Kindle location 13560,13577) notes

that, for cancer survivors, efforts to make meaning out of their cancer experience are a near universal experience. Yet some research reports that search for meaning and cognitive and emotional processing are typically related to poorer adjustments, whilst other studies failed to find any relationship between searching for meaning and adjustment following cancer. Park (2012:Kindle location 13590) proposes that the lack of support for meaning-making may be the result of methodological or conceptual issues. Park (2012:Kindle location 16313) clarifies that meaning-making efforts may be helpful to the extent that it is related to actual meaning-construal, whereas a search for meaning without successfully finding it, may simply signify a lack of resolution or finding satisfactory meaning. The researcher observed the majority of patients with recurrent cancer focus on the positive aspects of their lives. They go through a process of accepting that their cancer is incurable, and focus on what life still offers them. The researcher proposes that patients are able to reach a point of acceptance, that they live beyond their cancer, because they live meaning-centered lives. This observation motivated the researcher to explore the construct of meaning and the process of meaning-construal.

Currently the main impetus for psychological research on the meaning of life is from Canada. Dr Paul Wong, a Canadian academic, clinical psychologist, and founder of the Meaning-Centered Counselling Institute, International Network on Personal Meaning (INPM), and the International Society for Existential Psychology and Psychotherapy (ISEPP) ([www.drpaulwong.com](http://www.drpaulwong.com)) developed the MCCT model. Built on the tenets of Logotherapy, and rooted in existentialism, Wong developed a comprehensive and conceptual meaning-centered counselling model that emphasises the central role of personal meaning in the process of adaptation and personal growth (Wong, 1998a:403). Meaning-centered counselling lacked satisfactory empirical testing. Researchers have addressed these shortcomings, with the result that meaning therapy evolved into MCCT. MCCT is an integrative therapy informed by advances in psychological research and new insights (Wong,

2012c:Kindle Location 16049). The researcher proposes the MCCT model as an intervention model in oncology social work. This model is described in chapter 5.

Psychosocial distress in cancer patients, including patients that are in remission, includes a broad spectrum of unpleasant experiences from a mental, societal or spiritual kind that range from feelings of vulnerability, sadness and fear to severely restricting problems such as depression, anxiety disorders, panic disorders, social isolation and existential crises (Koch & Mehnert, 2007). The meaning perspective hypothesises that distress prompts meaning-making efforts. The meaning-making model proposes that people possess orienting systems, referred to in the meaning literature as global meaning. Global meaning provides one with cognitive frameworks with which one interprets one's experiences. When one encounters adverse situations, which have the potential to challenge or stress one's global meaning one appraises the situations and assigns meaning to them. The extent to which that appraised meaning is discrepant with one's global meaning, determines the extent to which one experiences distress. Distress caused by discrepancy initiates a process of meaning-making. Through meaning-making efforts, one attempts to reduce the discrepancy between appraised and global meaning and restores a sense of the world as meaningful and one's own lives as worthwhile. This process, when successful, leads to better adjustment to the stressful event (Park, 2010:257,258). In the context of health psychology, the meaning-making model posits that the degree to which a patients perceives his or her illness as discrepant from his or her global beliefs, determines the extent to which the illness is distressing (Park, 2013:43). Park (2013:43) postulates that meaning-making is essential to serious illness, because it assists patients to either assimilate the illness into their pre-illness global meaning or help them to change their global meaning to accommodate it. This is evident in the researcher's practice, for example, when patients who perceive that they live healthy lifestyles, are diagnosed with cancer. This disrupts the global belief that a healthy lifestyle will protect them against

serious illness. Park (2013:43) advises one to address such issues, because the extent to which patients' appraisals of their cancer violate their beliefs in a just world, predicts a poorer psychological well-being.

The researcher's rationale for conducting this study is rooted in the existential oriented proposition that life has meaning under all circumstances. The thematic analysis in chapter 7, identified the relevant experiences, attitudes and insights that participants reported that enables them to integrate the knowledge and demands of living with incurable cancer, and derive meaning in their lives in spite of suffering, and their awareness of a foreshortened future. When a patient realises that a cancer is incurable, it encourages the patient to re-evaluate and prioritise his or her life. Cordoba et al. (1993:52) posit that an awareness of the transitoriness of life, the importance of certain relationships, a future vision and a validation of one's own life are common experiences in cancer patients. The researcher maintains that patients in remission need to explore their hopes, strengths, and expectations of the future. The researcher further purports that in validating themselves, patients are able to create quality of life. The researcher argues that when patients derive meaning in their lives, they can focus on the quality of life, and do not become stuck or pre-occupied with the quantity of life. The researcher proposes MCCT as an intervention strategy in social work interventions for patients who are in remission.

The key terms defined in this chapter are meaning, meaning-centeredness, and meaning-construal.

## **4.2 DEFINITION OF KEY TERMS**

### **4.2.1 Meaning**

Krause (2012:Kindle location 10834) points out that there is currently no agreed-upon definition of meaning. Meaning is interpreted in the context it is used, for example, philosophical, theological, psychological, or colloquial

(Klinger, 1998:27). From a psychological perspective, meaning is defined from different perspectives. These perspectives include perspectives regarding the ability to construe meaning, the process of meaning-construal and benefit finding; the ability to and process of adjustment; attributional and explanatory processes; one's general life orientation, and a sense of purpose in life (Thornton, 2002:154,155). The researcher postulates that a meaning-centered approach to the phenomena of living in remission will include all the mentioned psychological approaches.

Wong's (2010:89) descriptions of meaning are applicable in this research study. Wong's conceptualisation of meaning encompasses the human quest for meaning, purpose, and understanding, as well as the human capacity to discover and create meaning out of the perplexities of life experiences. He adds (in McDonald, Wong & Gingras, 2012:Kindle location 9737) that meaning is an "individually constructed cognitive system which endows life with personal significance." The meaning system consist of five components: affective, motivational, relational, cognitive, and personal (McDonald et al., 2012:Kindle location 9739). He argues that meaning is important in one's search for comprehension and sense making when one is confronted with uncertainty, chaos and absurdity (Wong, 2010:89). The researcher argues that a sense of meaning will provide patients living in remission with a sense that their lives have purpose, and that there is a reason for their existence and suffering. It is a sense of meaning that assist patients with recurrent cancer to accept the incurable status of their cancer.

#### **4.2.2 Meaning-centeredness**

Meaning-centeredness refers to the sense of meaning and purpose that a person experiences and how this experience governs their life. It refers to how patients validate themselves and how remission governs their lives. It refers to Shantall's (2002) concept of meaning-orientatedness, and Frankl's (1985) will to meaning. Nietzsche's aphorism "He who has a 'why' for living, will surmount almost every 'how'." (Graber 2003:28) and Jung's hypothesises that

“Man can withstand the most incredible hardships when he is convinced that they make sense” contribute to the researcher’s concept of meaning-centeredness. Meaning-centeredness provides an answer to the question “how does one derive meaning in life?” Thornton (2002:154), conceptualises meaning-centeredness as

a set of assumptions that includes the belief that life is instilled with meaning, order, and purpose, the sense that the self is worthy, and the idea that the world is essentially just and predictable. These beliefs seem to lend a sense of meaningfulness to people and represent a cognitive schema through which events are interpreted.

#### **4.2.3 Meaning-construal**

Meaning-construal refers to the efforts and processes in one’s quest for meaning. Meaning-construal includes the concept of meaning management. Meaning-management refers to how one manages one’s inner life, such as feelings, desires, perceptions, thoughts, and interpretation of life experiences. The quality of one’s inner life depends on how one manages the basic processes of meaning, meaning seeking, meaning-making, and meaning reconstruction (Wong, 2011). Patients who take charge of their thoughts, acknowledge and process their feelings, and clarify their understanding of the disease process, are able to take their focus away from the “why me?” question. They focus on what life still offers them. For many patients the objective of treatments is not only to prolong of life but also to maintain quality of life. The evaluation of quality of life is subjective, and is associated with patients’ characteristics, their diagnosis, the quality of life they experience, how they tolerated previous treatment and their expectation of how they will tolerate future treatments. During the time that patient with recurrent cancer are in remission, those patients who live meaning-centered lives, focus on living in the moment. The fear of recurrence does not stop them from living their lives to the full.

From a meaning perspective, Frankl (1959), as quoted in Shantall (2002:24) proposes that meaning can be experienced in three principle ways: The first way is what people give to the world in terms of their tasks, duties, and creations. Cancer treatments have move primarily to an outpatient basis. This enabled many patients to continue with their careers, and contribute to their sense of purpose. During remission, they can take their full workload on. For many patients who, due to late-effects or side effects, cannot continue with their careers, experience it as a loss, for example, loss of voice. Some patients re-evaluate their lives. If they become proactive after identifying a lifestyle change, for example, smoking cessation, they perceive this decision as taking control. Oncology social workers should explore with patients if a decision to change jobs is warranted. At times, a change within a current job is a better option for patients.

The second way to experience meaning is in what people receive or take from the world in terms of their encounters and experience (Shantall, 2002:24). Many patients report that the cancer experience contributed positively to their sense of self, and they experienced posttraumatic growth.

The third way, in which people experience meaning, is the stand that they take in the face of predicaments and sufferings. Many patients with recurrent cancer are aware of the impact that their cancer has on their family. They consciously try to minimise this impact, by trying to maintain realistic hope and a positive attitude.

### **4.3 MEANING**

One may not always be able to perceive the meaning of a situation or experience (Marshall, 2009:9), but it does not imply that life is meaningless in these circumstances. Some patients response to the “why me?” question is to believe that the Deity that they believe in will provide them with an answer in the after-life.

#### **4.3.1 Overview of the historical interest in meaning and development of measuring scales.**

One of the most prominent perspectives on meaning in life is that of Frankl (1959,1984). Frankl does not define meaning; he describes the experience of meaning (Shantall, 2002:18). He uses the term 'Logos,' the Greek word indicating the meaning of life. Frankl argues that Logos provides the reason for being (Graber, 2003:48). Frankl describes meaning in life as having found a reason for living and a feeling or experience that one's life is of significance. In Frankl's view, meaning in life refers to a sense of being committed to, and fulfilling, a higher purpose in life. This purposefulness provides one with a reason for living (the term purpose is often used as a synonym for meaning). It makes life more than just a survival quest, but rather an experience of one's life as having made or being able to make a difference in the world (De Klerk, Boshoff & van Wyk, 2009:315). From a meaning perspective meaning is perceived as unique, experiential, future oriented, and spiritual. Living in remission does not obliterate any of these variables.

Existential theory is a theoretical framework of psychology, focussing on meaning, (Yalom, 1980) and it is based on the ultimate concerns in human existence being anxieties concerning death, freedom, isolation, and meaninglessness. These ultimate concerns can have implications in clinical work. This theory is relevant to this study, as persons in remission have a constant fear of death, and search for meaning in their lives.

Marks (1972) provides the following précis of meaning in life, and how meaning is attained: According to Erich Fromm, one makes one's life meaningful by living productively, and by using one's powers of love and reason to their fullest capacity. Abraham Maslow postulates that meaning is experienced by the self-actualised, resulting in a growth-motivated person who delights in using one's creative powers for one's own sake, and who can affirm oneself and simultaneously transcend oneself through peak experiences. Rollo May purports that meaning is experienced by one

centered in oneself, who is able to live by one's highest values, who knows one's own intentionality, feels the power of one's will to choose, and is able to love. Krishnamurti argues that the world is experienced as most meaningful when, through the knowledge of self-gained self-observation, one frees oneself of the self and attains a state of passive awareness and self-forgetfulness, which is love. Paul Tillich infers one can choose to make one's life meaningful by surrendering in faith and love to Jesus. By opening to Jesus and experiencing His acceptance and forgiveness, one experiences the joy and freedom of "new being" and the courage to be oneself. Abraham Heschel proposes that one experiences one's life as meaningful when one lives in God's presence - not simply by encountering God in the world, but primarily by serving God in everyday life, infusing every moment with the spirit of God, and by dedicating oneself to ends outside oneself. Finally, for Viktor Frankl, meaning is experienced by responding to the demands of the situation at hand, discovering, and committing oneself to one's own unique task in life, and by allowing oneself to experience or trust in an ultimate meaning - which one may or may not call God.

The development of instruments to measure meaning in life, is disadvantaged by the difficulty in operationally defining the meaning construct. It seems that variables such as stage of life, coping capacity, worldviews, spirituality, and religiosity all influence how meaning is experienced (McDonald et al., 2012:Kindle location 9735).

Based on Frankl's theories of logotherapy, Crumbaugh and Maholick (1964) developed the Purpose in Life scale [PIL] that measures the purpose dimension of meaning in life. Criticism to the PIL scale is that it did not include control for the effects of social desirability and denial, and there was not clarity about the assumptions that a person who experiences meaning in life would endorse (Leath 1999; Wong, 2011; McDonald et al., 2012:Kindle location 9784). In order to address these criticisms, Harlow, Newcomb and Bentler (1986), have approached the concept of meaning in life using latent

variable and structural models and developed a revised version for use in their research (Leath, 1999). Battista and Almond (1973) explored different theories about the development of the experiences of a meaningful life, and constructed, the Life Regard Index [LRI]. The LRI consist of two subscales. The framework scale measures if an individual has the needed framework to develop life goals, whilst the fulfilment scale measures to what degree goals are fulfilled (Leath, 1999; Wong, 2011). The Life Attitude Profile (LAP) developed by Reker and Peacock (1981), Reker, Peacock and Wong (1987) and the Seeking of Noetic Goals (SONG), which was developed by Crumbaugh, (1977), were based on Frankl's concepts of will to meaning and the existential vacuum (McDonald et al., 2012:Kindle location 9786).

Reker and Wong developed measures for many of the aspects of their personal meaning system theory: The Sources of Meaning Profile [SOMP] that tests the depth, breadth, and complexity of an individual's meaning system, is delivered to determine both the structure and complexity of an individual's meaning system. Based on Frankl's theory, they developed the Life Attitude Profile [LAP] questionnaire. This questionnaire has seven dimensions: Life Purpose, Existential Vacuum, Life Control, Death Acceptance, Will to Meaning, Goal Seeking, and Future Meaning (Leath, 1999). Leath (1999) proposes the POREE (perception of opportunities for rewarding emotional experiences) scale.

Ryff and Keyes (1995) developed the Psychological Well-Being Purpose subscale (SWBW-P) that measures meaning from a well-being perspective. It is based on several dimensions of well-being: self-acceptance, personal growth, purpose in life, environmental mastery, autonomy, and positive relationships with others (McDonald et al., 2012:Kindle locations 9887).

Edwards (2007) developed the Multidimensional Life Meaning Scale (MLMS) based on factor analysis of several existing scales. It identifies 10 factors that contribute to meaning of life. Schnell (2009) developed the Meaning and

Meaning in life Questionnaire (SoMe) which identifies 26 sources of meaning (McDonald et al., 2012:Kindle locations 9800-10053).

The most current measuring scale that the researcher is aware of is Wong's Personal Meaning Profile (PMP). It was developed in 1998 and is continuously expanded upon. The PMP is a 57-item instrument that measures people's perception of meaning in their lives. The main reason for the broad appeal of the PMP is that it incorporates all major sources of meaning. The PMP-B, can be used as a quick assessment tool. The PMP-B is employed for research and clinical purposes if a researcher is interested in discovering the key components of meaning systems and their psychological correlates in different populations. The main advantages of the updated PMP (2012) are that it identifies the sources of meaning seeking, covers the components of well-being and happiness, and provides at least four indices of meaning seeking (McDonald et al., 2012:Kindle locations 10048-10053).

Coming from the field of sociology, Antonovsky has developed a Sense of Coherence (SOC) questionnaire. The SOC scale measures the understanding component of the meaning of life (Leath, 1999; Wong 2011). Steger (2012:Kindle location 5118), argues that the SOC is not a measure of meaning in life. "The objectives of the SOC questionnaire are to assess basic coping dispositions that indicate how individuals respond to stressors and challenges in an effective and proactive manner."

During the 1990's, researchers began looking at what personal growth might occur from the cancer experience. Researchers observed that individuals who have gone through a cancer diagnosis and treatment often report that, despite being harmed, they were positively changed by the experience (Wells & Turney, 2001:30). Thornton (2002:153) argues that cancer neither is an unvaryingly devastating diagnosis, nor are severe psychological problems normative responses to the diagnosis. Referring to various authors (Andrykowski, Brady & Hunt, 1993; Collins, Taylor & Skokan, 1990; Curbow, Somerfield, Baker, Wingard & Legro, 1993), Thornton (2001:153) noted that

research employing a broader concept of the cancer experience, one seeking to describe both the positive and negative concomitants of this illness, confirms that many cancer survivors find benefit stemming from their experience. McMillen (1999:456 - 461) reports that researchers in several different fields have studied the effects of adversity as it relates to a spectrum of experiences including but not limited to cancer. These studies revealed that the following positive categories were reported consistently and independently: Changed life priorities; an increased sense of self-efficacy; an increased sensitivity to others; improved personal relationships; and increased spirituality. In this regard, Tedeschi and Calhoun developed the construct of posttraumatic growth. They use the term to refer to “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004:1). Schroevers et al. (2010:47) argue that the concept of posttraumatic growth is a cognitive processing theory that proposes that the experiences of stressful events may challenge personal goals and fundamental beliefs about oneself, one’s future, and the world. When people think intermittently about an experience, and re-evaluate and redefine beliefs and goals, they may be able to find meaning in the event, which eventually results in the perception of growth. In the researcher’s opinion, a perception of growth contributes to patients’ personal and unique sense of meaning-centeredness.

De Klerk et al. (2009:305) note that meaning research is also found in the field of organisational behaviour. They report that research on meaning in life has focused mainly on the relationship between meaning in life and aspects of personality and psychological well-being. Studies have consistently shown correlations between meaning in life and positive life affects such as internal locus of control (Phillips, 1980), self-esteem and self-concept (Chamberlain & Zika, 1987), positive life experiences and well-being (Jaarsma, Pool, Ranchor, & Sanderman, 2007; Scannell, Allen, & Burton, 2002; Yockey, 2006), successful life changes, coping and resistance to stress (Edwards & Holden, 2001; Jaarsma et al., 2007; Mascaro & Rosen, 2006; Moomal, 1999), dealing

with traumatic events (Krause, 2005), dealing emotionally with cancer (Jaarsma et al., 2007; Jim & Andersen, 2007; Prince-Paul, 2008; Thompson, 2007), and successful ageing and acceptance of death (Debats, Drost, & Hansen, 1995; Krause, 2004; Savage-Stevens, 2003). Meaning in life is also an essential element of spiritual well-being (Cash, 2000; De Klerk et al., 2009:315). Spiritual well-being is interrelated with psychological well-being (Temane & Wissing, 2006).

Referring to the uniqueness of meaning, Shantall et al. (2002:24) infer that the unique demands of particular situations over the course of one's life have a moral imperative, namely personal responsibility. In logotherapy, a distinction is made between responsibility and responsibility. Responsibility is interpreted as imposed from outside "I should." Responsibility is interpreted as "a freely chosen response to an inner knowing "I ought" (Graber, 2003:67). When one responds to this responsibility, one is drawn to self-transcendence, which results in growth. (Shantall, 2002:20). Frankl (1985:131) infers that that one has one's own specific vocation or mission in life to carry out a concrete assignment that demands fulfillment. Therein, one can neither be replaced, nor can one's life be repeated. He proposes that one should not focus on what one wants from life, but on what life wants from one.

The gestalt therapy indicates that every situation possesses a demand character; the meaning, that the person who is facing the situation has to fulfil and that the 'demands of the situation' are to be approached as 'objective qualities' (Frankl's will to meaning). The gestalt therapy describes the "will to meaning" construct as "the original human ability to discover the meaning character not only in actualities, but also in possibilities" (Lukas, 2000:6).

Frankl argued that meanings are discovered, not invented (Shantall et al., 2002: 25). Reker and Wong (2012:Kindle location 11523) support this view, stating that a deeper sense of meaning can be discovered only when one moves towards a self-transcendent state. Havenga-Coetzer (1003:89) depicts self-transcendence as the human characteristic of elating and being directed

to something other than oneself. It is the ability to look away from the self, from one's pain, circumstances, suffering, or grief. It is the ability to reach out to someone else, or to realise and ideal, fulfil a task, and to reach out to a Higher Being. Research by Reker (1991) evidenced that individuals who experience meaning at deeper levels through collectivism and self-transcendence, score higher on a measure of global meaning, are more fulfilled and satisfied with life compared to the score of individuals who experience meaning through self-preoccupation and individualism (Reker & Wong, 2012:Kindle location 11520 - 1152).

A meaning-centered life can thus assist patients to take their focus away from the demands of remission, and focus on what life still offers in each patient's unique circumstances. It implies that patients can choose their attitude towards their circumstances of living in remission, and can create a mind-set of 'living with cancer' instead of 'dying of cancer'. The researcher observed in practice that some patients, when they receive treatments for the first time, state that if the cancer recurs, they will not undergo treatment again. When the cancer recurs, they investigate treatments available, evaluate their strengths and past coping, and then enrol for treatment again. This indicates that patients have changed their mind-set, and are able to prioritise. They experience their lives as meaningful.

From a future oriented perspective Steger (2012:Kindle location 5028) defines meaning as

...the web of connections, understandings, and interpretations that help us comprehend our experience and formulate plans directing our energies to the achievement of our desired future. Meaning provides us with the sense that our lives matter, that they make sense, and are more than the sum of our seconds, days, and years.

The future-oriented dimension of meaning, suggests that one has a sense of purpose when one perceives that one's current behaviours are linked to future, desired outcomes (Sommer & Baumeister, 1998:146; Sommer,

Baumeister, & Stillman, 2012:Kindle location 8333). Frankl (1985:120) describes it as “meaning to be fulfilled by the patient in his future”. It implies that life challenges individuals with demands to which they have to respond to if they endeavour to derive meaning in life (Fabry, 1998:295). Reker and Peacock (1981) in (Reker, Birren & Svenson, 2012:Kindle location 10349) conceptualise future meaning as the acceptance of future potentialities and the determination to make the future meaningful. According to Reker et al. (2012:Kindle location 10533) future meaning refers “to future fulfilment, the acceptance of future potentialities, and positive expectations concerning oneself and one’s future life”. The researcher interprets the future meaning dimension as that patients have the potential to experience growth, build reasonable hope, and restructure their assumptive world, which would result in living a meaning-centered life. Patients often have to rebuild a future vision that is proportional to the prognosis of the cancer and the outcomes of the treatment. Frankl (2000:141) depicts it as “becoming aware of possibilities against the background of reality”. The researcher agrees with Krause (2012:Kindle location 11073) that patients need plans and goals in order to construct meaning.

Spirituality refers to transcendence and a connection to something larger than one’s self, and to a pursuit of what is sacred in life (Steger, 2012:Kindle location 5246). The human spirit enables one to take a stand against the limitations imposed by adversity. Although humans are driven by the psyche, they are the drivers in the dimension of the spirit (Fabry, 1998:297). Frankl proposes that the human spirit is one’s healthy core, it presents the basic yearning and capacity for meaning and spirituality (Wong, 2012c:Kindle location 15883). Emblem’s system model proposes that life events and changes trigger an adjustment process. The spiritual belief system held by one serves as a stabilising function and produces religious practices according to one’s cultural and religious orientation (Wong, 1998a:396). Not all patients turn to religion. Patients often report a deepening in their spirituality or faith. They report an awareness of their inner strengths, of what

their anchors in life are, and what guides them in life. It builds their awareness of their ability to cope with the demands of living in remission. Canda (2002:69) observed that illness enables people to find meaning within and beyond the physical aspects of illness.

Shantall (2002:26) defines meaning from an experiential, purpose-driven perspective. She offers the following description of meaning:

...meaning is experienced in having ideals, values, goals or a vocation or mission in life – all which have an inspiring and uplifting effect upon us: as being beyond and ahead of us, thus leading us outside the circle of narrow self-concern, thereby enlarging and enriching us, giving us a sense of direction towards the future that we feel is awaiting us; as not arbitrarily assigned to events but found in doing or experiencing what each occasion seems to be demanding from us; as addressing our consciences in calling us to act in a morally accountable way; above all, as experienced by us all in a highly personal way through the unique tasks, experiences and choices presented to each of us.

Shantall (2002:27) add that meaning is discovered, not assigned. It addresses one's consciences in calling one to act in a morally accountable way. Meaning presenting itself in a personal way through the unique tasks, experiences, and choices offered to one every day. Frankl, as cited in Reker and Wong, (2012:Kindle location 22523) states that a deeper sense of meaning can be discovered when a person moves towards a self-transcendence state.

Living with incurable cancer, puts patients on a journey to discover their meanings. This process is interpreted as that patients have validated themselves and are aware of the unique roles they still play. Patients are in charge of the attitude they adopt towards cancer, treatment, and life, and are aware of the sanctity of their lives.

### **4.3.2 Psychological interest in meaning**

Psychologists have explored the meaning of human existence, for example, Adler, 1931/1958; Frankl, 1963/1985; May, 1958. However, empirical studies of meaning have been very recent, for example, Wong and Fry, 1998 (McDonald et al., 2012:Kindle location 9731), Wong, (2012), and Park, (2013).

Fabry (1987), as cited in Graber (2002:24), reiterates that all reality has meaning (logos) and that life never ceases to have meaning for anyone. Meaning is very specific and changes from person to person and for each person from moment to moment. Each person is unique and each life contains a series of unique demands that have to be discovered and responded to. The response to these life demands provides meaning. Happiness, contentment, peace of mind, and self-actualisation are mere side products in the search for meaning, it is the “will to meaning” that provides motivation for living. The researcher infers that the survival instinct is closely related to the will to meaning. When patients live meaning-centered lives, they cope with the rigors of treatments and the side effects and late-effects of treatment.

Greenstein and Breitbart (2000:493,494) infer that Frankl suggested three basic sources for meaning: creative values, experiential values and attitudinal values. The actualisation of creative values is similar to Erikson’s concept of generativity. This includes artistic pursuits as well as advocacy for a cause. Experiential values refer to the experience of relationships and beauty. Social support is one of the most important variables associated with good adjustment to cancer. The support of family and friends facilitates coping with cancer and the outcome of treatment. Patients endorse deepening relationships as the most frequent positive aspect of their illness. The third source of meaning is the attitude with which one bears unavoidable suffering. The initial reaction to encountering a crisis, such as cancer, is likely to appraise if anything can be done to alleviate the situation. If the situation is

unchangeable or severely limited in its modifiability, one can exert control through adapting one's attitude to this new reality. Frankl suggested that the one freedom left to the individual is the freedom to choose one's attitude in bearing one's suffering.

Gould (1993:XII) argues that one has the freedom to find meaning in how one thinks and what one does. Freedom of will implies that one can choose one's own values and purposes. He conceptualises the will to meaning as the "principle motivating force of the self". The final tenet of the meaning analysis theory is that suffering has meaning. Referring to Frankl's proposition that suffering is a basic component of life but not necessary in order to find meaning, Gould concurs that meaning may be found through suffering, but not because of suffering (Gould, 1993:XII,11,13,77). De Klerk et al. (2009:315) state that research has consistently shown a sense of meaning in life to be a significant correlate of mental health and well-being, evidencing that a sense of meaning in one's life correlates with almost every aspect of psychological wellness, whereas meaninglessness consistently correlates with psychological illnesses. Frankl describes meaning in life as having found a reason for living and a feeling or experience that one's life is of significance. In Frankl's view, meaning in life refers to a sense of being committed to, and fulfilling, a higher purpose in life. This purposefulness provides one with a reason for living (the term purpose is often used as a synonym for meaning). Purposefulness makes life more than just a survival quest, but rather an experience of one's life as having made a difference, or that one is able to make a difference in the world. Thus, for oncology social work, this implies that patients who experience a sense of purpose, who are aware that they have life-tasks to fulfil, integrate a sense of meaning into their lives.

De Klerk et al. (2009:315), report that research on meaning in life has focused mainly on the relationship between meaning in life and aspects of personality and psychological well-being. Studies have consistently shown correlations between meaning in life and positive life affects such as internal locus of

control, self-esteem and self-concept, positive life experiences and well-being, successful life changes, coping and resistance to stress, dealing with traumatic events, dealing emotionally with cancer, and successful ageing and acceptance of death. Meaning in life is also an essential element of spiritual well-being. Spiritual well-being is interrelated with psychological well-being. In contrast, a lack of meaning (meaninglessness) has consistently been shown to correlate with a lack of psychological well-being and the presence of psychopathologies. Meaninglessness is related to anxiety, stress, depression, suicidal ideations, alcoholism and substance abuse, and neuroticism. Oncology social workers should therefore explore and, if needed, address existential anxiety.

Meaning and benefit finding are intimately connected. Thornton's research reveals that a sense of meaningfulness in life has been ascribed as a marker of mental health and a basic human need. Cancer survivors who report higher levels of a sense of meaning and purpose in life also tend to report lower levels of anxiety, hostility, and stress. The search for meaning is proposed to be a central task for individuals adjusting to threatening life events, including cancer. Although it is not clear that all individuals who report having a sense of meaningfulness in life have actively undertaken a search for meaning, it seems reasonable to assume that people who report that they are searching for meaning do so because they experience some absence of meaning in their lives (Thornton, 2002:154).

Drawing on Seligman's (2002) work, the positive psychology proposes that people who experience meaning in their lives feel connected to something external, and larger than themselves (Peterson & Park 2012:Kindle location 7849). Baumeister (1991) posits that a meaning-centered life is dependent on satisfying the need for a sense of purpose, and feelings of efficacy. Additionally people want to view their actions as having positive value or as being morally justified, and people want a sense of positive self-worth (Klinger, 2012:Kindle location 1609; Sommer et al., 2012:Kindle location 8330). In addition, people

must also find ways to make sense of events, especially if the implications of the events challenge their perception of what makes life meaningful (Sommer et al., 2012:Kindle location 8338). A common result of successful adjustment to adverse experiences is finding meaning in the experience (Taylor, 2009:390). Breast cancer and prostate cancer patients often report that their diagnosis prompted family members and friends to go for mammograms or PSA tests. This leaves patients with a feeling that their diagnosis had some value to those people that they care for.

Wong's meaning-making theory emphasises the unique human need and capacity to seek, construct and manage meanings in one's adaptation to an ever changing world. Wong is in agreement with Hoffman (2009) that meaning is one of the most central aspects of human existence. Meaning is a coping mechanism as well as a basic human need (Wong, 2010:86,89). The Meaning management perspective explores how one manage one's inner life (feelings, desires, perceptions, thoughts, and interpretation of life experiences). Wong (2011) argues that the quality of one's inner life depends on how one manages the basic processes of meaning, meaning seeking, meaning-making, and meaning-reconstruction. He conceptualises meaning management as "a meaning-centered self-regulating or self-determination theory."

In her examination of the meaning literature Park (2010:263 – 281), refers to meaning focused research with cancer patients, but not to any research that focus on patients who are in remission. The researcher agrees with the opinion of Park (2012:Kindle location 13544) that it is likely that different types of cancer and the specifics of a patients cancer (for example, prognosis) would influence the situational meaning given and the extent of the discrepancy with global meaning. Situational meaning and global meaning are described later in this chapter. The researcher could also not find any research relating to meaning and cancer patients who are in remission.

#### 4.4 THE ROLE OF MEANING

Meaning is a basic human need, and the quest for meaning is an “innate part of the human mind” (Sommer et al., 2012:Kindle Location 8313). Frankl (1985: 121), in his seminal work *Man’s Search for Meaning*, states that man’s search for meaning is primary force in his life and not a ‘secondary rationalization’ of instinctual drives. Gould (1993:XII) argues that the search for meaning is one’s central quest as a human. He infers that life has meaning, and proposes that one has the will to find meaning. This quest for meaning is one’s central motivation for living. Baumeister (1991) posits four needs for meaning: the need for purpose, value, efficacy, and self-worth (Sommer & Baumeister, 1998:144). Canda (2002:71) infers that when patients approach life as presenting opportunities for insight and growth, it provides a sense of integrity, worth, and significance to life.

Table 7: The psychological markers of the four needs for meaning

<b>Need</b>	<b>Psychological markers</b>
Purpose: objective goals and subjective fulfilments	Forming new goals when old goals are reached; linking negative events to future, positive fulfilment states –such as greater appreciation for life; Reflecting on one’s accomplishments
Efficacy and control	Perceiving a link between present behaviours and future outcomes; maintaining “illusions of control” over uncontrollable events; reporting success in overcoming difficult obstacles in one’s past
Value and justification	Downplaying the consequences of, or externalising responsibility for, immoral or hurtful actions; Reporting good and admirable intentions; Claiming the victim status
Self-worth	Comparing self with fortunate others; Reiterating one’s appeal to others; Regulating personal failures to the past; Assuming credit for successes but not failures; Asserting superiority over others

*Table 7: The psychological markers of the four needs for meaning*

(Sommer & Baumeister, 1998:144).

A sense of purpose provides one with a belief that one is here for a reason, and motivates people to attain objective goals and pursue fulfilment (Sommer & Baumeister, 1998:146,149). It implies that in spite of living with incurable cancer, patients still have reasons for living. Efficacy reinforces the belief that one can achieve goals. These authors conceptualise purpose as “the need to view one’s actions as related to future outcomes” and efficacy as “the perception that one can achieve these outcomes”. Findings from research reveal that a sense of efficacy facilitates adaptation to difficult life circumstances, and efficacy facilitates healthy emotional adaptation to adverse events (Sommer & Baumeister, 1998:149,151). It implies that patients have the ability to adjust to the demands of living with incurable cancer, for example adjusting to the demands of late-effects of treatment. Taylor’s research on cognitive adaptation with breast cancer patients, as cited by Sommer and Baumeister (1998:148), reveals that patients reported that cancer caused them to reappraise their lives (prioritising). It included increase in self-knowledge and a tendency to derive greater satisfaction from current relationships. Taylor concludes that negative setbacks appear to threaten one’s sense of purpose, which instigated the need to link misfortune to future positive outcomes. This is in line with the researcher’s observations that when patients are out of remission, their awareness of their self-efficacy motivates them to cope with the demands of treatment. Patients also report that if, before the diagnosis of cancer, they were asked if they would cope with the rigors of living with cancer, they would have categorically denied it. Yet, they do cope, and, enjoy life.

People are by nature meaning-making creatures: one has beliefs about how things are and expectations about how they should be, and one tries to make sense of one’s world when reality differs from one’s expectations (Sommer et al., 2012:Kindle locations 8340-8341). When there are discrepancies between one’s expectations and one’s experiences, this results in negative effect (Slattery & Park, 2012:Kindle Location 12911), because traumatic or distressing events violate many of the basic assumptions people have about

themselves and the world (Updegraff et al., 2008). Janoff-Bulman (1992) describes such experiences as the shattering of one's assumptive world (Thornton 2002:154). This dimension of meaning relates to patients adjustments of hope for cure to realistic hope for quality of life. Frankl (2000:13) posits that when one faces a fate that cannot be changed, one can still turn one's predicament into an achievement and accomplishment. (Shmotkin & Shrira, 2012:Kindle location 4562) argue that meaning systems are geared to process information into schemas that direct behaviour; this provides one with purpose, coherence, and justification. (Wong, 2012c:Kindle location 15950) argues that suffering is an inescapable aspect of human existence; therefore, it is important to discover meaning in suffering. Park (2012:Kindle location 13491) infers that meaning systems encompass the lens through which cancer patients and survivors interpret, evaluate and respond to their experiences.

Havenga-Coetzer (2003:56 - 58) infers that all reality has meaning and that life never ceases to have meaning. Being human means being confronted with meanings to fulfill and values to realise. Meaning is relative in that it is related to a specific person who is entangled in a specific situation. It differs from person to person, from day to day, even from hour to hour. Meanings are also unique; they are fundamental components of the meaning of human life. Meaning can also be found in accepting the unavoidable, and by turning it into a challenge, because life has potential meaning under all circumstances. The researcher interprets these observations that living with recurrent cancer can offer to patients the challenge to find and explore the meaning in their changed circumstances.

To appreciate the role of meaning one has to be aware of the meaning of suffering because suffering is an inevitable aspect of human existence. Shantall (2002:48), examination of the meaning of suffering has revealed the following:

...suffering has a confrontational character; it brings us into the reality of the immediate moment; we feel called to responsibility; we are presented with the reality of choice; things that are precious to us are presented to us as tasks, as things we ought to preserve and appreciate; our realisation of such values in our lives sustain us; our lives take on more spiritual content and meaning; living on a dimension of meaning, we experience a sense of true destiny with peak moments of triumph and joy.

Wong (2012c:Kindle location 16009 - 16010), observes, "...suffering is not a necessary condition for meaning, but suffering tends to trigger the quest for meaning. Paradoxically, our ability to embrace and transform suffering is essential for authentic happiness." Deriving meaning from a life event makes suffering more bearable and provides reasons for living, but unnecessary suffering should be avoided. Frankl (2000:123) rejects masochism, which refers to accepting unnecessary suffering; he promotes deriving meaning from unavoidable suffering. Shantall et al. (2002:44) postulate that when suffering has a reason, it loses its unbearable quality and becomes an opportunity to achieve moral greatness. The researcher advocates that patients have the right and responsibility to avoid physical, psychological, emotional, and spiritual suffering. Patients need to be aware of, and motivated to utilise available resources.

## **4.5 MEANING SYSTEM**

Wong explains meaning by describing the different types, the structure, and its function. Structurally a meaning system consist of components, and functionally these components interdependently contribute to meaning-construal. Life would not be meaningful in the absence of any of these components (Wong, 2012a Kindle location 469).

### **4.5.1 The structure and function of meaning**

Wong operationally defines meaning according to his PURE model. The PURE model consist four components: **p**urpose, **u**nderstanding, **r**esponsible action, and **e**njoyment or evaluation (Wong, 2012a:Kindle location 469 - 480).

Functionally, these components serve four major psychological processes: motivational (purpose), cognitive (understanding), social and moral (responsibility), and affective (enjoyment or evaluation). In the context of this study, processes refer to the psychological mechanisms or adaptive efforts in the quest for meaning (Wong, 2012a:Kindle location 497,498), whilst living in remission. Baumeister (1991) argues that these components serve to meet four basic needs: purpose, efficacy or control, value and justification, and self-worth. The need for purpose comprises meeting goals and reaching a state of subjective fulfilment. The need for efficacy refers to one's desire to have control, and the desire to make a difference or a contribution. People have a need to perceive their actions as having positive value or as being morally justified. Lastly, people desire a sense of positive self-worth (Sommer et al., 2012:Kindle location 8332). Needs that are related to hope contribute to a sense of meaning. The sense of meaning is emphasised when needs drive the fulfilling of a purpose, where the purpose is to achieve future goals and personal significant goals (McDonald et al., 2012:Kindle location 9752). This again emphasises the need for realistic hope and realistic future expectations.

Wong (2011) proposes that meaning serves at least three important functions. Meaning contributes to well-being through effective coping. Meaning is a protective and preventative factor. It enhances one's well-being through meaning reconstruction and the development of psychological resources. Another function of meaning is that it serves as the basis for hope in a hopeless situation. When people are going through difficult times, meaning, rather than positive emotions, becomes more important in maintaining levels of well-being. This is in line with theories of suffering. Meaning in life enables one to make sense of one's existence despite guilt, suffering, injustice, seeming chaos, and the inevitability of death. It provides new perspectives. All the dimensions of being human, physical, emotional, psychological, and spiritual, should be taken care of. The meaning analysis theory advocates that the human spirit should be the key resource for recapturing health and wholeness. It emphasises the importance of being value-bearers, of being

able to learn from the past, to live responsibly in the present, and to plan hopefully for the future (Gould, 1993:XII,11,13,77).

The researcher's interpretation is that, from a function and structure perspective, meaning contributes to developing a sense of coherence and creates a sense of belonging (attachment). When facing adversity, meaning assist in creating some level of well-being (Frankl, 1985; Wong, 2010, 2011). Wong (2011) identifies four ways in which meaning can contribute to effective coping and stress reduction.

**Adaptive attribution and explanation** can contribute to hope and success (Seligman, 1990; Weiner, 1985; Wong & Weiner, 1981 in Wong, 2011).

**Existential coping** strategies such as acceptance and seeing the positive potential of negative events are important in coping with situation beyond one's control (Wong, Reker & Peacock, 2006 in Wong 2011).

Having a **sense of meaning and purpose** contributes to the will to live in extreme situations (Frankl, 1985; Wong 2009 in Wong, 2011).

The **resource congruence** model also assist is preventative coping in terms of cultivating coping resources (Wong, 2011).

Meaning is an integrating factor for people because it pulls together people's ideas about who they are, the kind of world they live in, and how they relate to the people and to the environment around them (Steger, 2012:Kindle location 5024).

#### **4.5.2 The components of meaning**

The **purpose component** is an important component in the meaning structure because it serves several functions (Wong, 2012:Kindle location

1039). The purpose component includes goals, directions, incentive objects, values, aspirations, and objectives. It is concerned with such questions as these: What does life demand of me? What should I do with my life? What really matters in life? What is the point of working so hard? (Wong, 2012c:Kindle location 16279). It links with the development and pursuit of goals (Steger 2012:Kindle location 5084). People are not only products or victims of the past and the present; they have prospects and quests for the future. Sommer et al. (2012:Kindle location 8332) argue that people need a sense of purpose and goal striving in their lives in order to experience meaning. These authors depict the purpose component as follows. "To believe in life's purpose is to believe that one is here for a reason, whether that reason is chosen by oneself, assigned by society, or decreed by divine powers. People have a sense of purpose in life when they perceive that their current behaviours are linked to future, desired outcomes". (Wong, 2012b:Kindle location 1038) concludes that "a clear sense of purpose and significance can increase the motivation for goal striving". The striving to find meaning in one's life is a primary motivational force in man (Graber, 2003:65). Recurrent cancer does not repudiate a sense of purpose. Patients may need to re-appraise their sense of purpose, and adjust it to living with recurrent cancer, but they have the ability to build and maintain the purpose component.

The purpose (motivational) component also refers to the significance of the event in terms of philosophical and spiritual implication, and the existential consequences of the event (Janoff-Bulman & Frantz, 1997 in Sumalla et al., 2009:27). If one assigns high significance to an event then the event is internalised and it can result as negative psychopathology or as PTG (Sumalla et al., 2009:27). A sense of purpose provides people who live with recurrent cancer with goals and motivates them to do the suggested lifestyle changes. They engage in a prioritising process and adapt positive attitudinal values.

The **understanding component** encapsulates cognitive activities, a sense of coherence, making sense of situations, understanding one's own identity and other people, and effectively communicating and building relationships (Wong, 2012b:Kindle location 1049).

The **cognitive component** refers to the comprehensibility of the adverse event, including efforts to comprehend the reasons why it has taken place (Sumalla et al., 2009:27). Therefore, meaning of life is characterised as "being comprised of people's perception of the world around them and their investment in a self-concordant purpose". Meanings draw association and connect things, and thereby influence one's perception. It refers to one's comprehension that one has the capacity for growth and development, and is grounded in one's comprehension of one's self, world, and niche (Steger, 2012:Kindle location 5049). Baumeister (1991) postulates that meaning involves "shared mental representations of possible relationships among things, events, and relationships.... without meaning, behaviour is guided by impulse and instinct" (Klinger 2012:Kindle Location 1423). Steger (2012:Kindle location 5024) broadens this description, stating that meaning is an "integrative factor in people's lives, drawing together the threads of their efforts to achieve happiness, withstand distress, and attain transcendence beyond their solitary selves." The cognitive component is viewed as the most essential component (Greenstein & Breitbart, 2000:491). One's comprehension of one's own meaning in life provides one with a foundation for coping with life events (Steger, 2012:Kindle location 5025). In turn, effective coping assists in building self-efficacy, enabling one to forge links between old and new experiences, and "integrating new experiences into the web of associations", and in bringing unity in one's life. Wong (2012b:Kindle location 1049) infers that this component is concerned with questions such as: What has happened? What does it mean? How do I make sense of the world? What am I doing here? Who am I? A life with understanding is a life with clarity and coherence. Steger (2012:Kindle location 5030) argues that comprehending life events assist people in nurturing well-being, building

resilience, and cultivating an existential domain. It emphasises the sense that one's life matters, articulating valued and overarching goals, and the feeling that one's life makes sense. A sense that one's life matters, implicates satisfaction, self-esteem and self-worth. This statement underscores the importance to focus on what life offers, and not just on the demands of remission. The true demand of remission is living beyond cancer.

Within the oncology context, understanding refers to understanding the reasons underlying one's feelings (Park, 2012:Kindle location 13580), and not the causal factors relating to cancer. Therefore, oncology social workers explore with patients their feelings associated with living in remission. Patients with recurrent cancer need to understand that recurrence often evokes stronger emotions than the initial diagnosis. This is because a recurrence emphasises the prognosis, and patients have to change their hope for cure, to hope for quality of life, and that there will be treatments available that can prolong their lives.

Attributing the cause of cancer to lifestyle is associated with poorer adjustments. Patients are confronted with the consequences of poor choices, for example, smoking. For many patients these lifestyles were ways in which they handled stress. After diagnosis, they are under pressure to immediately change their lifestyle. This often increases their stress levels, especially if they perceive that well-intentioned family, friends, and colleagues judge and police them.

**Responsible action**, referred to as the behavioural component, includes appropriate reactions and actions, doing what is morally right, finding the right solutions, making amends. It is concerned with such questions as these: What is my responsibility in this situation? What is the right thing to do? What options do I have? What choices should I make? A worthy life is based on the responsible exercise of human freedom and personal agency. Frankl (1946/1985) emphasises the need to be aware of the demand of each situation. A meaning mind-set will predispose individuals to do what is right

and behave responsibly in the face of pressures and temptations (Wong, 2012b:Kindle locations 1060-1063). Frankl (1985:98) purports that what really matter is not what one wants from life, but what life expect from one. He explains, “Life ultimately means taking responsibility to find the right answer to its problems and to fulfil the tasks which is constantly sets for each individual. These tasks, and therefore the meaning of life, differ from man to man, and from moment to moment.”

This component underscores the importance of health literacy. Health literacy assists patients to make informed decisions. Patients need to consider how their behaviour impacts on their lives and those of their social networks. Recurrent cancer results in a perception of a fractured future and a loss of future memories, but it still offers opportunities to transcendence. It opens patients’ minds to appreciate all that life offers.

The **evaluative component** (affective component) refers to one’s evaluation of life, including assessing a degree of satisfaction or dissatisfaction with the situation or life as a whole. It is concerned with such questions as these: Have I achieved what I set out to do? Am I happy with how I have lived my life? If this is love? (Wong 2012c:Kindle location 16288). Oncology social workers can guide patients to reframe their perceptions from being a cancer victim, to being a cancer survivor, to living a full life in spite of recurrent cancer. Patients need to be aware of their strengths, good coping capacities and the resources available to them.

Within the context of this study, these components are associated with patients’ comprehension of remission, the investment they make in living with recurrent cancer, creating realistic future orientations, and their validation processes. It focuses on patients’ awareness of their purpose in their current situation and environment. Patients’ comprehension and appraisal of life events contribute to them living a meaning-centered life.

In line with literature, the researcher experience that patients often report that they found benefit in the cancer experience. The benefits reported include improved relationships, higher levels of spirituality, improved sense of self, increased sense of self-efficacy, and increase in transcendence. These contribute to patients reinterpreting cancer in a more positive light.

#### **4.5.3 Types of meaning**

The meaning model distinguishes between situational meaning and global meaning. Reker and Wong (1988) postulate that life contains only meanings that are actualised through specific activities, quests, and goals. To achieve personal meaning, specific sources (for example, situational meaning) need to be integrated into a larger and higher purpose (for example, global meaning) (Reker & Wong 2012:Kindle location 11494-11498). The conceptualisation of situational and global meaning differs according to the paradigm used, for example the stress and coping perspective and the appraisal perspective.

Wong prefers the term **global meaning** to other terminologies such as existential meaning, ultimate meaning, meaningfulness, purpose in life, or meaning as comprehensibility (Reker & Wong, 2012:Kindle location 11434). Global meaning refers to one's philosophy of life and worldviews to make sense of life (Wong, 2012a:Kindle location 470). Stated differently, global meaning refers to the existential belief that life has purpose and coherence whereby the individual attempts to understand how life events fit into a larger context. It addresses the experience of meaning and asks such questions as "What is worth living for?" and "What is the purpose in life?" (Reker & Wong, 2012:Kindle locations 11437). Within the existential paradigm, Reker and Wong (2012:Kindle location 11455), depict global meaning as the awareness of order, coherence, and purpose in one's existence; the quest and attainment of worthwhile goals and the accompanying sense of fulfilment. They propose a model that structurally depicts global meaning as consisting cognitive, motivational and affective components. The cognitive components

of global meaning are one's beliefs, worldview and value schemas. The motivational components consist of wants, needs, and goal striving leads to satisfaction, fulfilment and happiness. A person high on global meaning has a clear life purpose, has a sense of direction, strives for goals consistent with life purpose, feels satisfied with achievements, and is determined to make the future meaningful. (Reker & Wong, 2012:Kindle location 11466).

**Situational meaning** refers to the attachment of personal significance to specific experiences in life whereby the individual tries to make sense of that experience. It involves the process of assigning or structuring meaning and addresses the meaning of experience, such as the meaning of growing old, or, in the context of this study, as living in remission. Situational or provisional meaning refers to attempts to understand the value and purpose of specific encounters and experiences in life that occur on a day-to-day basis. The ongoing quest to extract the "meaning of the moment" serves as a source for the attainment of a higher, ultimate, or global meaning. For Frankl (1963), meaning stems from three broad sources: (a) creative, or what one accomplishes from creative work; (b) experiential, or what one derives from beauty, truth, or love; and (c) attitudinal, or what one derives from reflections on such aspects of life as pain and suffering (Reker & Wong, 2012:Kindle locations 11472). Situational meaning is the preferred term over such other labels such as provisional meaning, meaning of the moment, definitional meaning, or meaning-as-significance (Reker & Wong, 2012:Kindle Locations 11441).

Global meaning addresses the experience of meaning, whereas situational meaning focuses on the meaning of experience. Research findings reveal that both situational meaning and global meaning play an important role in the recovery and adjustment processes of individuals who are challenged by traumatic life events (Reker & Wong (2012:Kindle location 11649). Oncology social workers explore with patients how their global meaning integrate with their experience of living with recurrent cancer.

#### **4.5.4 The content of meaning**

Another approach to understanding meaning in life is to focus on content of meaning and the process of meaning-construal. Wong (2012a:Kindle location 493) defines the content of meaning as the “experiences, activities, goals, and emotional states that imbue life with meaning”, and to the process of meaning as “the psychological mechanisms of adaptive efforts in the quest for meaning.” In the context of this study, it manifests in the activation of coping capacities to adapt to the demands of living in remission, which enables patients to experience their lives as meaningful.

#### **4.6 MEANING-CONSTRUAL**

Wong proposes the PURE model that provides a comprehensive framework to assess meaning-construal. The ABCDE strategy aims to transform negative experiences and life events into positive experiences. An additional aim is to make suffering more bearable.” ABCDE stands for acceptance, belief, commitment, discovery, and evaluation/enjoyment (Wong, 2011). This model is based on the deep-and-wide theory, which posits that repeated encounters with obstacles will compel one to dig deeper into one’s inner resources and explore more broadly for solutions and options. It thus enhances resilience (Wong 2012b:Kindle location 1194). These models are described in chapter 5.

##### **4.6.1 A typology for meaning-construal**

A typology for benefit finding, which was created by Thornton (2002:157,158,159) will be used to describe meaning-construal.

##### **4.6.1.1 Meaning-construal associated with life perspective including spirituality (changes in spirituality/philosophy of life)**

Thornton (2002:157) observed in phenomenological and qualitative research reports that it is relatively common for cancer survivors to report revising their

life perspective and priorities. This is evidence that cancer leads to a shift in an individual's sense of themselves and their world (assumptive world) (Taylor, 1983; Janoff-Bulman, 1992 in Brennan, 2001:2). One's life experiences accumulate in one's assumptive world. The assumptive world permits classification and prediction of the world and one's experiences in order to safely negotiate it and satisfy one's needs. Because humans are dynamic beings, whose life space is continually changing, their assumptive world is confirmed or disconfirmed, reinforced or altered in a continuous process of elaboration, refinement and adjustment. Whether an experience is appraised as positive or negative, pleasant or unpleasant, it involves the certainty that people will either adaptively 'assimilate', for example, merge new information into existing assumptions, or 'accommodate' the change, for example, modify existing assumptions about the world in order to incorporate the new information (Brennan, 2001:5,7; Sumalla et al., 2009:27). The ability to make sense of events in one's life has held a central role in theories of adaptation to adversity (Updegraff et al., 2008).

Theories that incorporate the potential for positive outcome following crises, propose that sufficiently stressful or traumatic events have the potential to challenge and disrupt the fundamentally positive, adaptive assumptions that most people hold about the world and their place in it. When these beliefs are challenged or disrupted by traumatic or stressful events, thereby exposing one to one's mortality and the fragility of life, a central task for the victim is the restoration or rebuilding of this assumptive world (Janoff-Bulman, 1989 in Thornton, 2002:154).

At the core of the assumptive world are abstract beliefs about the self, the external world, and the relationship between oneself and the world. Extreme life events, such as having cancer, shatter the assumption that the world is benevolent, that the world is meaningful, and that the self is worthy (Janoff-Bulman, 1992 in Brennan, 2001:7). Park (2013:42) adds that serious illness, such as cancer, can violate important global beliefs in the predictability of

one's life and one's sense of invulnerability and personal control. Cancer poses challenges to the adaptive resources of individuals and that presents challenges to individuals' way of understanding the world and their place in it (Janoff-Bulman 1992 in Tedeschi and Calhoun 2004:1). Some individuals respond to crises by adaptively re-examining and restructuring the core constructs by which they have lived their lives (Tedeschi, Park and Calhoun, 1998 in Brennan, 2001:7). The assumptive world of an adult contains knowledge and assumptions that have been derived from the information-rich cultural and social environment experienced during their development. Janoff-Bulman (1992) proposes that to adjust core assumptions involves huge amounts of cognitive processing and emotional distress, largely because human information processing is biased towards cognitive conservatism and a tendency to maintain existing deeply held assumptions (Brennan, 2001:7,9). The researcher observes that patients who are in remission assimilate and accommodate the knowledge that the cancer is incurable and adjust to a life of living with recurrent cancer.

Adversity, including illness, can disrupt or shatter fundamental assumptions and positive skewed worldviews, thereby exposing an individual to their mortality and the fragility of life. Such exposure confronts one with a meaninglessness world, thereby propelling a search for meaning and triggering meaning reconstruction or 'meaning-making' processes that may lead one to develop explanations for (sense making), and find benefits in (benefit finding), their adversity. Sense making and benefit finding are multi-dimensional in nature, evidencing differential relations with both demographic and illness variables, and domains of positive and negative adjustment (Lowry, [sa]).

In accordance with various researchers, the research of Thornton (2002:157,158) revealed that many survivors report that having cancer fostered an increase in their enjoyment and appreciation of life and the "small things", leading to less concern with trivial matters. Cancer prompted them to

revise their priorities, alter their life philosophy, or become more spiritual. For respondents, the achievement of lifelong goals took precedence over career advancement. Respondents reported a new awareness of the importance of emotional and physical well-being, including leading a healthy lifestyle. Sumalla et al. (2009:25) add that an appreciation of life enabled respondents to distinguish between what is important and what is of secondary importance. This resulted in a change in their scale of values. Thornton (2002:157,158) reports that it is relatively common for survivors to report revising their life perspective and priorities following cancer and having a greater appreciation for life. Benefit-construal is common, and cancer survivors' reports of positive changes in life perspective may be distinguished from control groups in terms of their frequency, magnitude, and pattern. Sumalla et al. (2009:25), report that when one increasingly appreciates what one has, it empowers one to distinguish between what is really important, and what is of secondary importance, resulting in a change in one's scale of values.

Scioli and Biller (2010:66) postulate: "Hope is often spiritual, not necessarily in a religious sense, but in terms of having faith, a sense of meaning in life, a connection to something greater, a belief in a benign universe". They add that some kind of faith is necessary for hope. Faith does not have to involve a divine being or a higher power. Spiritual beliefs give people a sense that there is something inside and around them that is more potent than any present or future danger. It provides them with a larger worldview that imparts meaning to their stressful life events. For those who are not religious or even spiritual, control, predictability and meaning may still be derived from memories of successful past coping efforts, from stories of others who have weathered the unexpected difficulties of life, or through the adoption of specific stress management techniques (Scioli & Biller 2010:66).

Living with recurrent cancer invariably violates patients' goals and plans for their lives and for the future. For example, the researcher observed that

patients are reluctant to move away from their oncology team. This impact on many patients' retirement plans. In situations where children have emigrated, the children are anxious about care for the patient, and their inability to provide physical support.

Spirituality provides patients with a sense that their lives matters, that there is still a plan for their lives, even if they cannot comprehend it at the time. They rebuild their assumptive world to accommodate new goals, and adjust their global meaning to accommodate situational meaning. Their evaluation of their lives provides them with a sense that they matter and that they are worthy. This is in line with the proposition of Park (2013:42.43), that spirituality can inform all aspects of global meaning, informing global beliefs (for example, the nature of God and humanity, control, destiny, karma) and provide motivation and goals for living. Spirituality provides guidelines for achieving goals, and provides cancer patients with a sense of purpose and mattering. The meaning that patients assign to cancer, predict their coping and subsequent adjustment, which in the context of this research is living with recurrent cancer.

#### **4.6.1.2 Meaning-construal associated with interpersonal relationships**

Interpersonal relationships include those of survivors with their partner/spouse, children, and friends. The impact on interpersonal relationships is twofold: the cancer survivor's relationships with their partner/spouse, children, and friends, and vice versa. The research of Thornton (2002:158) revealed that survivors report that their family became closer and more caring. The most prevalent positive changes included investing more time and energy into relationships, and increased sympathy, compassion, and sensitivity for others. Cancer survivors perceived that aspects of their marital relationship had improved since the cancer episode. Many cancer survivors perceive cancer as having a significantly more positive than negative impact on their relationship with, and love for, their spouse or partner.

An increased emphasis on the family appears to be an especially important feature of the cancer survivor's experience (Thornton 2009:158). Meaning-construal associated with interpersonal relationships stems from the basic longings of humanity, including the need for a sense of connection and trust, as well as the longing for the love and care that is required to achieve our potential as human beings. During remission, patients often express their gratitude for family and friends. They describe how support from family and friends motivated them to cope with the demands of treatment and remission.

Patients' own experiences created more compassion and sensitivity to the need of others. The researcher observed that patients, and especially patients in remission, reach out to other patients. This act of transcendence, reaching out to soften the suffering of other cancer patients, gives meaning to their lives. Patients reach out in different ways: via a support group, via a church, or informally when they meet with newly diagnosed patients. Patients tend to invest into meaningful relationships and distance themselves from toxic or stressful, draining relationships. Patients focus less on trivial matters, time matters for them.

The research data of Thornton (2002:158) and Sumalla et al. (2009:25) suggests that the benefits perceived by cancer survivors are distinguishable from controls in this domain as well. Cancer survivors showed better social adjustment in some areas, and reported greater emotional support relationship. Cancer patients also reported an increase in their need to share and express their feelings towards family and friends.

#### **4.6.1.3 Meaning-construal associated with the self**

The way in which patients adjust to cancer can contribute to personal growth. Adjustment in the social or psychological context implies that one is involved in a rich, on-going process of developing one's potential, reacting to, and in turn changing the environment in a healthy, effective manner (Reber & Reber, 2001:12). Brennan (2001:1-6), notes that in the psycho-oncology field,

adjustment refers to the psychological processes that occur over time as one, and one's social attachments, manage, learn from, and adapt to the multitude of changes which have been precipitated by the illness and its treatment, and includes the cognitive and behavioural responses to cancer. Adjustments to illness include the resolution of threats or incongruence with existing assumptions about world. Illness entails threat to life; bodily integrity and comforts; self-concept and future plans; emotional equilibrium; social roles and activities, and threats involving the need to adjust to the social or physical environments. Social-cognitive theorists propose that adjustment includes intrapsychic and interpersonal processes during which individuals strive to negotiate the adjustment demands and which results in a 'personal transition' or shift in the individual's core assumptions.

Rinaldis, Pakenham, and Lynch (2010:260) postulate that the ability to make a transition from meaning-making to developing a sense of an event's value and significance in the context of one's life may be essentially an adaptive process. They refer to an increasing body of literature that indicates that patients have found benefits from a wide range of medical problems, including cancer. The benefits most frequently reported include greater appreciation of life, improved relationships with family and friends, changes in life priorities, increased spirituality, and personal growth (feeling stronger and more compassionate). Theoretical conceptualisations of benefit finding vary. Taylor (1983) suggests that the positive evaluation on one's circumstances through benefit finding minimises or mitigates the negative implications and is necessary to maintain self-worth. Benefit finding has been regarded as an appraisal, in that it is a selective cognitive process involved in the evaluation of a situation, which minimises victimisation by appraising benefits to help individuals adapt. Benefit finding has also been construed as a cognitive reappraisal coping strategy, conceptualised as part of the meaning-making process within the extended transactional model of stress.

The research of Kenne-Sarenmalm et al. (2009:1123 - 1127) explored the personal transition process by which the women with recurrent breast cancer created meaning as they adjusted to living with a persistent, and in some cases an impending, death threat. The return of breast cancer was experienced as a devastating, life-altering event, and the women had to deal with a chronic illness and the major concerns created by suffering, disabilities, and difficult losses. Participants described various ways in which they experienced and made sense of their illness. Meaning was created in the context of a threat to life, and the women were forced to reconsider their life world as they faced the challenge of coming to terms with living with recurrent breast cancer. Changes in attitudes and relationships, and rediscovering important life values created possibilities for transformation and personal growth. They postulate that cancer may be viewed as a psychosocial transitional event that alters an individual's presumptive world view, and has the potential to engender both positive and negative outcomes. The researcher postulates that meaning-making efforts and the process of personal transition continue during remission.

Greenstein and Breitbart (2000:491-493) infer that the attitude taken toward a situation that can potentially not change, could imply different things. A sense of meaning can be derived from the fact of being able to cope with a crisis in a way that is considered dignified or heroic. The belief that one has some control over one's emotional reactions, rather than the ability to control the course of the illness, was related to successful coping. Gould (1993:77) agrees with Frankl's logotherapy principle that one has the freedom to choose one's attitude. It is one's attitude that determines what one focuses on and how one focuses on what is important determines the one's future thoughts and actions.

Alluding again to Nietzsche's aphorism: "He who has a *why* to live for can bear almost any *how*," Greenstein and Breitbart (2000:49) hypothesise that the why originates from one's values, both realised and not, as well as one's

goals. Recognising that one has already achieved some goals can be a buffer against despair. Telling one's story (narrative) connects one with the people around the narrator. Thinking about their narrative assist patients to reflect back on what they have found meaningful or joyful, clarifying which tasks they have undertaken and which tasks remain to be undertaken. Meaning can be found in the very act of bearing witness to the events of one's life. The key element of such tasks is that they must be meaningful to the person setting out to fulfil these tasks. The researcher proposes that these tasks can help patients to validate themselves.

Meaning-construal also requires that beliefs be explored in order to maintain rational beliefs. Beliefs, whether rational or irrational, yield great power over one. Gandhi stated: "Your beliefs become your thoughts. Your thoughts become your words. Your words become your actions. Your actions become your habits. Your habits become your values. Your values become your destiny" (Scioli & Biller, 2010:146). A patient's beliefs regarding his or her ability to adapt to living with incurable cancer, guide them in their meaning-making process.

The researcher postulates that Scioli and Biller's (2010) interpretation for hope construal is also applicable for meaning-construal. Scioli and Biller (2010:63-66), infer that reasonable hope (and by implication meaning-centeredness) helps people to develop a sense of empowerment, a feeling of strength, and assists people to take an honest inventory of who they are, what they can do, and what is important to them, and they use this information to forge a sense of purpose in life. They postulate that more hopeful individuals (and by implication individuals who are meaning-centered) are able to stay more centered when experiencing adversity. This shows that they can remain emotionally self-regulated, regardless of external pressures. They retain a sense of control, predictability and meaning. Hopeful individuals (and by implication meaning-centered individuals) feel empowered, connected, and centered, regardless of what is happening in the here and now. When

confronted by obstacles, they remain confident and goal oriented. When separated in space or time from loved ones, they remain at one with their families, their friends, or a higher power. When faced with loss, an injury, or any other form of threat, they are not overcome by fear. They believe that there are always adequate resources within and around them to meet any challenge, and they never stop looking for options and alternatives. No matter how difficult, lonely, or stressful the journeys, the hopeful individual is able to find a purpose and a reason for living. One can always find, build and strengthen hope. All circumstances offer options, and options offer the ability to choose one's attitude in all circumstances. Reasonable hope (and by implication meaning-centeredness) is about mastery. Mastery is a feeling of empowerment, and a sense of purpose. Reasonable hope (and by implication meaning-centeredness) helps people to develop a sense of empowerment, a feeling of strength, and it assists people in developing clear priorities; implying that people then take an honest inventory of who they are, what they can do, what is important to them, and they use this information to forge a sense of purpose in life.

Changes to self that survivors perceive include feeling stronger, more self-assured, more experienced, and more able to face future challenges (Sumalla et al., 2009:25). Thornton (2002:159) refers to various authors who report that positive changes in the self include increased inner strength, independence, and improved self-respect. Reports from different research projects indicate that making positive changes such as taking more time for oneself and learning to care for one's own needs; led to improved self-respect; woman survivors affirmed that they matured; and some cancer survivors reported more satisfaction in terms of what they are accomplishing in life and their ability to manage problems. Furthermore, some individuals acknowledge increases in vulnerability and damage to their self-concept following traumatic events, whilst at the same time report improvements in their ability to manage and cope with stressors, or have the sense that they have learned something about themselves because of the damage that they have sustained.

Thornton (2002:159) refers to several studies that have attempted to determine whether cancer survivors can be distinguished from presumably less-stressed groups in terms of these benefits. In the areas of life perspective and relationships with others, it appears that cancer survivors' reports of benefits may be distinguishable from controls in both frequency and magnitude. With respect to benefits in terms of self, less data are available and comparison and non-cancer samples are inconclusive. Benefit finding was unrelated to gender, income, or employment status. In addition, the research indicated that a better prognosis was associated with positive changes in certain domains. The majority of research indicates that time since diagnosis is unrelated.

Cancer survivors integrate the cancer experience into their self-concept, and develop a sense of living through and beyond cancer. It is referred to as a process of identity reconstruction (Park, 2012:Kindle location 13658). This process assists patients to create a new normal. Patients also make more time for themselves, and they have learned to take care of their own needs.

#### **4.7 SUMMARY**

The meaning theoretical framework was explored and it was found that meaning is a broad description referring to one's response to life tasks, how one make sense out of the perplexities and calamities of life, actualises one's potential in a given situation, take accountability for one's actions and decisions, and one's appraisal of life event. The confrontation of the knowledge that the cancer is incurable and recurrent, often leads to a disruption of patients' global meaning. This initiates a quest for meaning, which encompasses a cognitive meaning-construal process, and efforts to rebuild the meaning system. This entails that patients have to integrate the knowledge that their cancer is incurable and adapt to the demands set by remission. They create balance between global meaning and situational meaning. This is an on-going process influenced by disease progression, ability to tolerate treatment, and availability of treatments. Several authors

cautioned that meaning seeking could be maladaptive if the process devolves into brooding when satisfactory meaning cannot be constructed. This risk underscores the role of oncology social work.

Meaning-construal leaves one with the conviction that life is meant to be, and that meaning can be discovered in all circumstances, if not immediately, then in retrospect. For patients who live with incurable cancer, deriving meaning in their lives holds the promise and opportunity to embrace life, to gain new insights and perspectives, and to prioritise their values. One of the life tasks is to integrate the experience of living in remission into their lives. Remission challenges patients with facing their vulnerability. Meaning offers them a sense of purpose and realistic hope.

Patients report positive and negative experiences from living in remission. Meaning-construal does not disregard the impact of negative experiences. Meaning-construal is an integrating factor in patients who live with incurable cancer. Meaning provides them with a feeling that their lives matter, that they have roles to fulfil, that they are loved, and that they are able to give love. Patients living in remission are able to find meaning and live fulfilled lives, and that they are more than the sum of their seconds, days and years. Research confirms that patients are able to live with the ramifications of cancer remission. Meaning-construal helps patients to restore purpose. Faith and hope empowers them to overcome adversities and make life worth living. This is in line with the researcher's observations that patients often report a greater appreciation for life.

In the next chapter, the researcher discusses oncology social work and proposes the Meaning-Centered Counselling and Therapy Model.

## **CHAPTER 5**

### **5 ONCOLOGY SOCIAL WORK AND MEANING-CENTERED THERAPY AS A PROPOSED INTERVENTION MODEL**

#### **5.1 INTRODUCTION**

There is a growing awareness among survivors, psycho-oncology professionals and the medical profession that the psychosocial challenges associated with cancer survivorship should be addressed (Fawzy et al., 1995:100). Cancer can cause anxiety, distress, or trauma. Feelings of helplessness, hopelessness, and worthlessness can manifest during any time of the cancer continuum (Holland & Gooen-Piels, 2000). This study focuses on the specific psychosocial needs of patients who are in remission. This study derived from the researcher's observation in practice that, during the treatment phase, patients and their social attachments are mainly focussed on coping with the demands of treatment. Few patients have the emotional reserve to address psychosocial issues. These psychosocial issues then tend to present during the survival phase. Social workers have much to contribute in helping people in remission. Many aspects of the role of the social worker have been referred to in previous chapters. This chapter will add and give a broader description of social work in health care and specifically the specialised field of oncology social work. Oncology social work is sometimes referred to as psycho-oncology. The researcher conceptualises oncology social work as a discipline within the spectrum of psycho-oncology.

Few oncology centres in South Africa manage to retain social workers as part of the oncology team. This is possibly due to the cost involved in employing an oncology social worker, the difficulty in claiming from medical schemes for social work services, the fact that not all medical schemes cover social work services, and a lack of understanding of the value that a social worker can add to the oncology team. Consequently, there is little preparation and support available for patients that are in remission. There is also a need to formulate guidelines for social work intervention in the field of psychosocial

oncology. A perspective that provides the opportunity for patients to explore their understanding and assumptions towards their unique meanings, purposes and life tasks, and support patients to accept the realities of remission, could help patients to cope more effectively with the physical and psychological demands of remission. The researcher proposes the Meaning-Centered Counselling and Therapy model as an intervention model.

The key terms defined in this chapter are health social work, and oncology social work.

## **5.2 HEALTH SOCIAL WORK**

Fundamental to intervention and research in health psychology is the definition of health. The World Health Organisation, in a definition that has not changed since 1948, defines health as “a complete state of physical, mental, and social well-being, and not merely the absence of disease or infirmity” (Taylor, 2009:3; WHO definition of health, [sa]). Taylor (2009:3) defines health as a balance between physical, mental and social well-being. She infers that the term ‘well-being’ refers to a balanced optimum state of health. Cassel (1982) as quoted in Rosenblatt, Lakoma and Alexander (2004:51) infers that the primary goal of medicine should be to identify and help alleviate all aspects of suffering, not just physical pain and suffering. An awareness of the links between psychological and social factors, and health and disease, led to the emergence of the discipline of health psychology (Ross & Deverell, 20105). Taylor (2009:3;418) describes health psychology as a specialization area of psychology that focusing on understanding psychological influences on how people stay healthy, why they become ill, and how they respond when they get ill. Health psychology also incorporates the psychological origins and the impacts of health policy and health interventions. Psychiatry and psychoanalysis emerged in medicine after health social work (hospital social work, medical social work) became established as a field in health care (Gehlert, 2012:3). Auslander (2001), as cited in Fobair et al. (2009:160), notes that over the last 100 years, health social work has achieved recognition and

legitimacy, effecting a change in the models of illness and health, contributed to the knowledgebase, developed intervention programmes, and advocated and developed culturally appropriate intervention programmes.

Currently, it is suggested that health social workers follow a biopsychosocial approach to healthcare. The biopsychosocial model acknowledges that nonmedical determinants collaborate with biological components to cause disease (Browne, 2012:20) and health (Taylor, 2009:70). The advantages of the biopsychosocial model is that in addition to biomedical intervention, it focuses on the prevention, management, and rehabilitation of illness; it encourages people to become active participants in their health care, it is culturally sensitive, and it has adopted the systems theory (Browne, 2012:14; Ross & Deverell; 2010:14; Taylor, 2009:6). Systems theory maintains that all levels of organisation in an entity are linked to each other in a hierarchical order, and that change on one level will effect change in other levels. In the healthcare context, it implies that “both macro level processes (such as the existence of social support or the presence of depression) and micro level processes (such as cellular disorders or chemical imbalances) interact to produce a state of health or illness” (Taylor, 2009:7). The biopsychosocial perspective integrates the strength perspective of social work practice (NASW, 2005:9). The strength perspective acknowledges ones strengths and abilities to cope with problems, it is in line with the social work principle of enhancing clients’ personal strengths and resources, helping clients solve both interpersonal and environmental problems, and encouraging clients to mobilise for change (NASW, 2005:9; Saleeby, 2002:1).

Taylor (2009:3) purports that health psychology is concerned with all aspects health and illness across the life span, and health psychologists examine the psychological and social factors that led to the enhancement of health, the prevention and treatment of illness, and the evaluation and modification of health policies that influence health care. This is in line with the objectives of health social work. Browne (2012:21) describes the roles of health social

workers as “directly address the social, behavioural, and emotional concerns of individuals and their social support network as well as develop and administer policies and programmes and conduct research that are attuned to the psychosocial needs of individuals”.

### **5.2.1 Definition of health social work**

A current view of social work describes social work practice as a problem-solving process. The social work perspective is a contemporary, holistic growth-oriented approach to helping others (Turner, 2003 in Fobair et al., 2011:160). Burgers (1993:62) postulates that the primary aim of medical social work is to reduce stress in order to enable patients, within the patients' own unique abilities, to utilise medical services effectively. The American Association of Hospital Social Workers (1928), as cited in Gehlert (2012:12), observes that historically, the role of health social workers, then referred to as hospital social workers, was conceptualised as securing of information to enable an adequate understanding of the general health problems of the patient. The social worker's role was to interpret the patient's health problems to himself, his family and community welfare agencies, and the mobilising of measures for the relief of the patients and his social network. This description focuses on the correlation between disease and social maladjustment. A current description of role of health social worker reads:

Provide individuals, families, and groups with the psychosocial support needed to cope with chronic, acute, or terminal illnesses. Services include advising family caregivers, providing patient education and counseling, and making referrals for other services. May also provide care and case management or interventions designed to promote health, prevent disease, and address barriers to access to healthcare (*Summary report for healthcare social workers*, updated 2010).

The researcher conceptualises health social work as a specialisation area in social work, delivering services from diagnosis of an illness, through treatment, re-entry phase, post treatment, terminal care, and bereavement. Health social workers assess the psychosocial functioning of patients and

their social attachments, and intervene when necessary. Interventions may include connecting patients and social attachments to necessary resources in the community; providing psychotherapy, supportive counselling, or grief counselling, or helping a patient and social attachments to expand and strengthen their support network. Health social workers typically work in a transdisciplinary team. From these definitions, it seems that health social work distinguishes itself from health psychology in the sense that health social work includes the family, social network and community in service delivery. Cannon (1923) as cited in Fobair et al. (2009:160) stated that health social workers seek to remove obstacles either in the patient's surroundings or in his mental attitude that interfere with successful treatment, thus freeing the patient to aid in his own recovery.

### **5.2.2 Principles of health social work**

Health social workers will probably encounter ethical dilemmas in their practice. Ethical dilemmas refer to situations when health social workers cannot adhere to professional values, or when adhering to one ethical principle contradicts another ethical principle. Principles inform social work practice and offer a reference point for the development of even more specific standards (Sparks, 2012:42,44). The purpose of an ethical code is to protect the public and the profession, prevent internal strife, and protect practitioners from lawsuits (Lowenberg & Dolgoff, 1996 in Sparks, 2012:42). The ethical principles applicable to this research study are described in chapter 6.

The controversy around the right to die debate highlights the ethical responsibility of health social workers to advocate for, and document advanced directives as expressed by patients. In this regard, it is important for social workers to be aware of their own values. If a social worker's own values conflict with the wishes of the patient, it may interfere with the social workers ability to engage in meaningful discussion (Sparks, 2012:44).

Ethics guide health social workers in assisting patients to make informed decisions. Health social workers, must integrate personal values, and be aware of collegial, institutional, and societal influences. Health social workers need current knowledge regarding ethical theory and decision-making models; social work theory, research, and practice standards; social work and other professional ethical codes; relevant agency policy; applicable laws and regulations. The health social worker evaluates the impact of decisions on patients and their social network, on the health social worker, and the transdisciplinary team (Sparks, 2012:44). Health social workers encourage patients to be independent. The goal is for patients to live a normal and satisfying life within family and community. In this regard, health literacy and support are important in assisting patients and their social attachments to make informed decisions (Ross & Deverell, 2010:20).

Core values that health social workers should adhere to include respect for human worth and dignity, service to others, confidentiality and privacy, genuineness, acceptance and unconditional regard, non-judgmental attitude, controlled emotional behaviour, individualism, culturally sensitive practice and respect for diversity, purposeful expression of feelings, and patients' right to self-determination. In addition, health social workers should adhere to values that promote patients well-being, value the individual's capacity for growth, value the individual's capacity to grow and change, and recognises the individual's responsibility to develop self-awareness. Health social workers take responsibility for continuing professional development, for sharing knowledge and skills with others, and their accountability for their conduct (Ross & Deverell, 2010:63 – 67). Core values are the foundation of the social work practice (NASW, 2005:15).

The scope of emancipatory values goes beyond the individualism of core values. Emancipatory values include democracy, social justice and equity, citizenship, empowerment, partnerships, and the independence of people

(Ross & Deverell, 2010:68,69). The NASW (2005:16) echoes that health social workers have an ethical obligation to address health disparities.

Health social workers should be guided by the NASW standard for cultural competence in social work practice (2001) to deliver culturally sensitive and competent services (NASW, 2005:17). The NASW (National Association of Social Workers) is an international organisation. The objectives of the NASW include promoting continual professional development of social workers, the creation and maintenance of professional standards for social work, and the advancement of sound social policies (NASW, [sa]). In South Africa, social workers are guided by the guidelines and ethical codes as set by the South African Council for Social Service Professions (1986) (Strydom, 2005c:68). Underscoring the core values of SACPP, the NASW SA (National Association of Social Workers – South Africa) objectives are (a) to assure a qualified and culturally competent social work labour force by expanding members skills and knowledge in social work practice within the South African multicultural context, and (b) to assure high standards of social work practice by promoting professional and ethical social work practice (NASW SA, Reviewed 2012). Organisations such as The South African Association of Social Workers in Private Practice (1979) set guidelines for social workers in private practice (South African Association of Social Workers in Private Practice, [sa]).

### **5.2.3 Role of health social work**

Social work is a diverse profession (Social work and primary health care, [sa]). Health social workers operate in a variety of environments and assume numerous roles in the design, delivery, and evaluation of care (Browne, 2012:20). Historically, the role of the health social worker entailed services to the health team, serviced to patients, and services to the community. Cannon (1923) as cited in Gehlert (2012:9) observed:

While she [health social worker] must have an understanding of the patient's physical condition, the physical condition is only one aspect of the patient to which she must account. As the

physician sees the disease organ as not isolated but as possibly affecting the whole body, so the hospital [health] social worker sees the patients not merely as an isolated, unfortunate person occupying a hospital bed, but as a member belonging to a family or community group that is altered because of his ill health. Physicians and nurses seek to strengthen the general physical state of the patient so that he can combat disease. The social worker seeks to remove those obstacles, either in the patient surroundings or in his mental attitude, that interfere with successful treatment, thus freeing the patient to aid his own recovery

The *Summary Report for Healthcare Social Workers* (updated 2010) in the USA conceptualises the roles of health social workers as follows:

- advocating for patients to resolve crises
- collaborating with other professionals to evaluate patients' medical or physical condition and to assess the patient's needs
- when needed, referring patients and/or social attachments to community resources, and providing access to services such as financial assistance, legal aid, housing, job placement, or education
- counselling patients and/or social attachments in individual and group sessions to help them overcome dependencies, recover from illness, and adjust to life
- utilising consultation data and social work experience to plan and coordinate patient care and rehabilitation, following through to ensure service efficacy
- discharge planning from care facility to the patient's home or other care facility
- organising support groups or counselling social attachments to assist them in understanding, dealing with, and supporting the patient
- modifying treatment plans to comply with changes in the patient's status (this is always done in collaboration with the medical professional who is the primary caregiver to the patient)
- monitoring, evaluating, and recording patient progress according to measurable goals described in treatment and care plan

- identifying environmental impediments to patient progress through interviews and review of patient records (Summary report for healthcare social; work, updated 2010).

Similarly, Browne (2012:25 - 28) identifies the following roles of health social workers:

- assess patients and members of their social support team in order to identify assets and potential barriers to care
- develop and implement interventions that addressed the identified needs of patients and/or their social attachments
- facilitate effective communication between patients, social attachments, and health team
- assist patients and their social network to gain access to available resources
- provide counselling to patients and social attachments to cope with diagnosis, illness and treatment
- provide health literacy to motivate patients to comply with prescribed treatment regiment
- intervene during terminal and end-of-life stage. These interventions include bereavement therapy
- design and implement community health programmes and initiatives
- conduct research to influence policy, community and public health, and clinical practice.

Within the context of health social work, communication also includes providing information to patients and the social attachments regarding the disease or disability, as well as information relevant to treatment, treatment options, side effects, and late-effects of treatment (Ross & Deverell, 2010:80). Health social workers need to assess the extent and depth to which patients and their significant others want to receive information, including to what extent patients and significant others have processed and integrated information. It is this researcher's experience that information often has to be

repeated in follow-up interviews, because patients and the significant others need time to process the information. Health social workers must be aware with which family members, friends, and carers patients are prepared to share information. For example, a patient may want a homecare nursing aid only to have information regarding physical care, whilst they may want the home care agency or nursing sister to be informed regarding the treatment and prognosis of the disease. Ross and Deverell (2010:81) add that a minority of patients prefer not to be informed about a poor prognosis (bad news).

The researcher also emphasises the role of the health social worker during the re-entry phase, when treatment is completed and patients have to integrate in old or adjusted roles.

#### **5.2.4 Knowledge, skills and competencies of health social workers**

Health social workers form an integral part of the transdisciplinary team that endeavours to provide comprehensive patient care. Browne (2012:35) reiterates that health social workers fulfil a critical role in health care.

As mentioned, health social workers must assess the patients need for information because evidence suggests that pro-active patients comply with treatment, and are generally more satisfied and psychologically well-adjusted than those patients who are passive in clinical consultation. Health social workers need to assess patients' need for information, and address patients' fear of asking questions. Effective communication with team members provides patients with a sense of control, even if there is no real control, because patients experience that they have been included in the decision-making process (Ross & Deverell, 2010:82).

Health social workers must have an understanding of the patient's physical condition, and have basic knowledge of the disease. This knowledge should include physiological aspects of disease as well as the impact on psychosocial functioning (NASW, 2001:19).

Health social workers must be culturally sensitive. Cultural sensitivity promotes understanding of how patients perceive an event and how they want to address a problem. Cultural sensitive practice enables professionals to understand the meanings that patients and their social networks, attach to particular events or situations. It also assists professionals to understand how cultural ritual, traditions, and practices can help patients and/or their social networks to find solace and comfort. Cultural issues that health social workers should keep in mind include social class, race and ethnicity, religion, gender, age, beliefs about health, illness, and disability, views regarding traditional and allopathic medicine, and communication style (Ross & Deverell, 2012:26-42).

Assessment is a fundamental role in social work practice. Health social workers provide on-going assessments, including gathering comprehensive information to use in developing intervention programmes (NASW, 2005:20). Meyer (1993) as cited in Engstrom, (2012:167) define assessment as “the thinking process that seeks out the meaning of case situations, puts the particulars of the case in some order, and leads to appropriate intervention.” Health social work embraces the systems theory therefore; it needs to follow an approach that includes the microsystems, the macrosystems, the exosystems, and the mesosystems. The microsystem (for example, individual activities, roles, physical and mental status) broadens to the mesosystem (for example, relationships with family, social networks), then to the exosystem (for example, work, neighbourhood, community), and finally to the macrosystem (for example, cultural and dominant patterned processes, including politics, government, education, and law) (Engstrom, 2012:169). Health care social workers increasingly follow a biopsychosocial approach (Browne, 2012:20). This approach, (sometimes referred to as the social model, or the psycho-socio-environmental model), focuses on the promotion and maintenance of health through socio-environmental and behavioural changes. This model underscores the role of people’s behaviour, what work

they do, how they lead their lives, where they live, and what their access to health services are (Ross & Deverell, 2010:14).

The NASW (2005:21) underscore that comprehensive health care assessments shall address the unique needs relevant to special populations, including children, people with severe and persistent mental illness, immigrants and refugees, people with substance use disorders, victims of violence or trauma, homeless people, and people with physical or psychiatric disabilities.

One's cultural context informs one's frame of reference and influences how one will identify and label problems, including views on disease, disability and death (Engstrom, 2012: 169; NASW, 2005:21). Thus, health social workers need to assess patients and the social attachments cultural views regarding physical and mental health, because it assists health social workers to recognise normative coping. Beliefs facilitate a sense of coherence, meaning, and control. One's worldview can influence health positively by creating and maintaining healthy lifestyles (for example, diet, exercise, smoking cessation), promoting social integration and support (for example, shared beliefs, expanding social networks, health literacy), and providing comfort (for example emotional support, religious rituals for assistance in difficult times, source of hope) (Engstrom, 2012:170,171). Kleinman, Eisenberg, and Good (1978), as cited in Engstrom (2012:171), suggest the following questions to assess patients' views on their disease:

- What do you think caused your problems?
- Why do you think it started when it did?
- What do you think your sickness does to you? How does it work?
- How severe is your sickness? Will it have a short or a long course?
- What kind of treatment do you think you should receive?
- What are the most important results that you hope to receive from this treatment?

- What are the main problems that this sickness caused for you?
- What do you fear most about your sickness?

Intervention programmes ought to be developed in collaboration with the patients, their social network, and transdisciplinary team. Health social workers aim to implement intervention programmes that promote patient well-being and ensure a continuum of care. Health social workers adapt practice techniques to meet patients' needs within their health care setting to work, across lifespan, with different ethnicities, cultures, religions, socio-economic and educational backgrounds, and across the range of mental health and disability conditions. Intervention programmes include: strategies to address needs identified in the assessment, information, referral, individual, family, or group counselling, vocational, educational, and supportive counselling, psycho-educational support groups, financial counselling, case management, discharge planning, interdisciplinary care planning and collaboration, client and systems advocacy (NASW, 2005:21,22).

In order to avoid burnout and overloading of health social workers, NASW (2005:26,27) emphasises that health social workers have a responsibility to maintain a workload that allows for efficient and quality social work service delivery. A workload consists of any social work function performed for the purpose of the social work position, including direct practice, administration, policy, research, or education.

Health social workers have the responsibility to maintain records or documentation of social work services. The importance of clear, concise, and organised documentation reflects the hallmark of quality social work services and often serves as the mode of communication between a social worker and other professionals and patients.

The elements and responsibilities of thorough and comprehensive documentation include the following:

- comprehensive assessment and services delivered to the patient and patient systems, including the development of a plan of care
- on-going assessments, interventions, and treatment planning
- goals and planning that reflect an explicit statement of agreement with patient, patient systems, and team input
- referral sources and collaborations
- dates, times, and descriptions of patient and patient system contacts
- documentation of outcomes
- reason for case closure or transfer
- written permission to release and obtain information, where appropriate
- documentation of compliance with confidentiality rights and responsibilities, and
- documentation of receipts and disbursements (NASW, 2005:27,28).

As a specialisation field in social work, a social work degree from an accredited university is a prerequisite. Health social workers have a responsibility to be familiar with the literature crucial to their area of practice. As professionals, social workers in all settings should strive to improve the knowledge of the field, and this can best be accomplished through participation in research activities. To improve practice and competencies, health care social workers evaluate their practice on a continuing basis to assess quality and appropriateness of services. Furthermore, to stay in touch with development in the health social work field, social workers assume responsibility for their own continued professional development. It is strongly advised that health social workers have access to computer technology and the Internet, as the need to communicate electronically and to seek information on the Web for purposes of education, networking, and resources is essential for efficient and productive practice. Another suggestion to improve service delivery is that health social workers have access to

supervision. The purpose of supervision is to enhance social workers professional skills and knowledge, to enhance competence in providing quality patient care. Supervision aids in professional growth and development and improves clinical outcomes (NASW, 2005:28 - 33).

Health social workers should always uphold the ethical principles and codes of the profession. NASW (2005:30) underscores the importance for health social workers to follow guidelines for privacy with regard to confidential information of the patient, social networks or health care providers, as set by the health care organisation where the health social worker practices.

Health social workers have a responsibility to provide leadership to patients to ensure access to care and to improve and maintain the quality of care provided by an agency or institution. Social work leaders typically demonstrate knowledge, skills, and abilities in the following areas:

- management and administration, which includes supervision, consultation, negotiation and monitoring
- specialised knowledge of how to function within care teams in which various disciplines are involved
- research and education
- legal, ethical, and professional standards applicable to health social work practice
- including standards of documentation (paper and computer) and quality improvement activities
- the ability to prioritize needs for social work services and to recommend adjustments to staffing levels accordingly based on current literature and industry standards
- social work qualifications, productivity, and continuing education
- policies and regulations that affect social work practice, and patient and family care

- information on access to health care for the underserved and marginalised populations
- consultation to social workers and allied health professionals on relative health social work practice issues
- development of and adherence to organisational policies, procedures, and regulations by staff (NASW, 2005:33,34).

The above summary of the role of health social work implies competencies and skills needed by health social workers. Social workers can help patients and their social networks to cope with, process the experience, and integrate disease in their lives. Illness can influence a patient's personhood, and coping capacities. Depending on the illness, severity of the illness, and effects of illness, patients may need assistance to process and adapt to an illness.

In the South African multicultural context, health social workers should explore, within the cultural context of a patient, the patient's perceptions of causality, consequences, and expected outcomes of illness and treatment. Availability and access to health resources must always be brought to the attention of the health team, for example, patients in rural area, who live far away from health facilities, may not have the resources to come for monthly check-ups.

### **5.3 ONCOLOGY SOCIAL WORK**

One of the areas of specialisation in social work in health care is oncology social work, which is supported by Fobair et al. (2009:159), who states that Oncology social work evolved as a specialty within health social work. The AOSW (Association of Oncology Social Work) (2012), states that oncology social work is the primary profession that provides psychosocial services to cancer patients and their social attachments. They argue that the scope of oncology social work includes clinical practice, education, advocacy, policy and research. Christ (1990:670) notes that the prolonged survival of cancer patients has increased the number of patients who need social work services.

Social workers must therefore develop intervention strategies that include supporting patients and their social attachments.

Biomedical advances resulted in the current situation that for many patients cancer was transformed from a terminal disease to a chronic disease (Gardner & Werner-Lin, 2012:498). This result in patients living longer with cancer, which, in turn, poses long-term issues of psychosocial adjustment and issues of quality of life. Survivors need to learn to live, and need guidance on how to live a life to the full. Oncology social workers play a role in disease management. Disease management involves “a team of professionals that integrates and co-ordinates care across an array of services to maintain optimal patient functioning and quality of life” (Claiborne & Vandenburg, 2001 in Gehlert, 2012:15).

In the United States of America, oncology social work is acknowledged as a fully developed profession with a national organisation. The Association of Oncology Social Work (AOSW) is a non-profit, international organisation dedicated to the enhancement of psychosocial services to people with cancer and their families. The AOSW developed standards of care, assessment tools, and interventions for the quality of survival of cancer patients, which covers the full cancer continuum. Longer survival necessitated intervention to cancer survivors, and a cancer survivorship movement was created (Fobair et al., 2009: 156,167,169).

### **5.3.1 Definition of oncology social work**

Psycho-oncology is described as the field in oncology care that is concerned with the effects of cancer on a person's psychological health as well as the social and behavioural factors that may affect the disease process. It is an area of transdisciplinary interest and has boundaries with major specialties in oncology: the clinical disciplines - surgery, medicine, paediatrics, radiotherapy, epidemiology, immunology, endocrinology, biology, pathology, bioethics, palliative care, rehabilitation medicine, clinical trials research and

decision-making, as well as psychiatry and psychology (Delbrück, 2007:20). Another description of psycho-oncology states that psycho-oncology is a broad-based approach to cancer care that treats the emotional, social, and spiritual distress which often accompanies cancer. This description adds to the psycho-oncology team bioethicists, social workers, clergy, palliative care specialists, and volunteers (Gale Encyclopaedia of Cancer [sa]). The transdisciplinary field of psycho-oncology aims to develop and evaluate interventions that alleviate distress, increase support, and maximise quality of life among cancer patients and their social attachments (Gardner & Werner-Lin, 2012:504). The researcher is in agreement with those theorists that position oncology social work as a discipline within the spectrum of psycho-oncology.

The AOSW (2001) defines oncology social work as a profession “designed to promote the patient’s best utilization of the health care system, the optimal development of coping strategies and the mobilization of community resources to support maximum functioning” (Fobair et al., 2009:157). A more recent definition of the AOSW (2011) reads “oncology social work is the primary professional discipline providing psychosocial services to patients, families and caregivers facing the impact of cancer diagnosis and treatment” (Association of Oncology Social Work: 2012 Partnership Prospectus).

The researcher conceptualises oncology social work as a speciality field in the social work profession that provides social work services to cancer patients, their social attachments, the community, and to society.

### **5.3.2 Principles of oncology social work**

The values and practices from health social work inform oncology social work. Values include advocacy for the patient’s point of view within the medical system and in the community, the understanding the cancer disease process, and participating as a team-member within the transdisciplinary team. AOSW develop standards of practice (AOSW, 2001a:170).

Blum et al. (2001:53) and the AOSW (2012) identify the following basic principles of oncology social work: Oncology social work services must be based on an understanding of the patient's specific cancer diagnosis and treatment plan, and tailored to the patient's energy levels. Oncology social work services should be available and accessible to cancer patients and their social attachments. Oncology social workers should identify and address barriers to care and resources. Interventions should focus on helping patients and their social attachments to cope with the medical, emotional, and social problems they encounter at different points in the cancer continuum. Cancer patients are a diverse group and oncology social workers should therefore be sensitive to cultural diversity. This principle is particularly applicable in the multi-cultural South African population.

Patients need to make informed decisions about treatment, and surveillance programs. Oncology social workers should assess the level of interest of patients and social attachments in participating in decision-making. This assessment should be communicated to the concerning oncology team members. Oncology social workers assist patients with decision making by informing them about options, clarifying their misunderstandings, and encouraging them to evaluate different choices. Oncology social workers help patients to understand, acknowledge, and accept the outcomes of their choices (Christ, 1990:672). Patients may require help in integrating new information and in making informed decisions about maintenance treatments, or undergoing treatment when there is a recurrence. There is also a need to inform patients if new and innovative treatments are available that were not available at the time of their previous treatments. Anxiety often interferes with patients' retention and interpretation of information, therefore, oncology social workers must evaluate patients' interpretations and understanding of information. Patients also need to understand the rules and implications of participating in clinical trials (Christ, 1990:672).

The education component of oncology social work focuses on helping patients and their families understand the cancer diagnosis, use medical care effectively, and obtain access to the resources of their community. Education is needed because treatment has shifted to an outpatient base, resulting in less contact with the oncology team, reducing access to team members' knowledge. Patients are offered more treatment options, and thus need more information in order to make informed decisions regarding treatments. Another consequence of outpatient base care is that patients and their social attachments have to take increasing responsibility for managing care regimes. Furthermore, improved symptom control enables more patients to continue to work and maintain consistency in their daily routines. Patients need to know when to consult with the oncology team in managing the treatment effects (Blum et al., 2001:63).

### **5.3.3 Role of oncology social work**

Herman and Carter (1994) as cited in Gardner and Werner-Lin (2012:504) describes the role of oncology social work as providing comprehensive psychosocial assessment, case management, and support to patients and their social networks in individual and group interventions. Support interventions include support to patients, families, employers and staff in the oncology department, facilitating support groups, care to the dying, and bereavement counselling (van Schalkwyk, 1995:651,652). Oncology social worker draws upon knowledge from health social work and psycho-oncology. Addressing the medical and psychosocial difficulties associated with the treatment of cancer and the side effects of treatment is an integral part of cancer care (Coleman 2006:4). Psychosocial interventions with cancer patients contribute to their physical and psychological health outcomes. These benefits include patients showing a higher level of compliance with medical regimens; they feel more in control, and less helpless and hopeless (Fawzy et al., 1995:100). Social work interventions include awareness programmes that focus on cancer prevention, treatment options, survivorship,

and terminal care. Another aspect is to create awareness of the role of the oncology social worker, specifically regarding the transdisciplinary team. The social worker may have the most up-to-date knowledge of support groups and complementary resources in the community, to which survivors could be referred, for example, art therapy, exercise, Wings of Hope.

With reference to oncology social work, Stearns et al. (1993:1) postulate that there has been a gradual shift of focus: from a specialty that dealt almost exclusively with terminal illness and chronicity, to one of coping with treatment and its side effects, and adapting to long term survival. Holland and Reznik (2005:2624 - 2632) point out that to identify survivors at risk, or patients who do experience a crisis [distress], and then implementing psychosocial interventions, is not “pathologizing” patients. They identified three groups of cancer survivors who may require follow up psychosocial care:

- Survivors with physical sequelae, resulting in significant neuropsychological and physical consequences. The side effects or late-effects include concerns about sexuality and infertility, amputation or disability, body or facial changes, lymphoedema, and chronic fatigue.
- Survivors with psychological sequelae or psychiatric disorders that interfere with their functioning and quality of life. Concerns about body image manifest in distress over scars, a diminished sense of attractiveness, avoidance of wearing revealing clothes, and a reduced participation in leisure activities.
- Survivors with subsyndromal symptoms, for example, the symptoms do not reach the criteria for a psychiatric diagnosis, or patients who have no identified physical or psychiatric sequelae, but who may need help to integrate the cancer experience into their lives to increase a sense of purpose, direction, and well-being. This group of survivors may have no physical symptoms or formal psychiatric disorders but may experience a diminished sense of purpose and direction in life. They may not be able to attach a tolerable meaning to the experience, and may have

diminished resilience, which manifest subsyndromal symptoms. For this group of cancer survivors, referral to psychosocial care may increase resilience, reduce vulnerability to exacerbated distress, and facilitate posttraumatic growth. The main psychosocial rehabilitation task for this group of survivors is integration of their cancer experience into their personal identity. Kathleen Conway, a survivor, wrote about her experience of recurrent cancer “The hard task for me and my family is to integrate each of our experiences of cancer into who we are” (Holland & Reznik, 2005:2632).

Some oncology social workers become administrators and/or educators influencing the institutions in which they work and providing services to their community and profession (Fobair et al., 2009:157).

With the passage of time, survivors become less integrated into the medical system and may need monitoring of their psychosocial distress levels during and between their infrequently scheduled visits (Holland & Reznik, 2005:2624). During treatment, patients should be prepared for survivorship, and support networks should specifically be developed for survivors. Blaney, an oncologist, advocated for a “transition visit” as a bridge between the treatment and survivorship phases of cancer. He questions if an oncologist is the correct person to conduct this task and suggests that during the “transition visit,” survivors be counselled in aspects such as exercise, bone health, smoking cessation, sexual health, and management of stress (Mulcahy, 2009). Oncology social workers have the skills to provide this counselling.

Health social work intervention enables patients and families to adjust and function within the changed circumstances resulting from illness. Thus, oncology social workers assist patients to obtain optimal physical (motivate to adhere to medical regimes), social, psychological, and vocational functioning within the limits created by cancer and treatment. Patients in remission live with ambiguity and often have to cope with side effects or late effects of treatment. Oncology social workers should acknowledge the negative

consequences of the disease and help patients to reframe their experiences. As such, patients can develop a different perspective, find their own meaning in the situation, and integrate the experience into their lives (Schroevers & Teo, 2008:1245).

According to Fawzy et al. (1995:100 - 108), four categories of intervention are frequently described in literature, namely educational techniques, behavioural training, individual psychotherapy and group interventions. The overall goal of education is to reduce the sense of helplessness and inadequacy due to uncertainty and lack of knowledge. It seeks to replace helplessness with a sense of mastery and control. Behavioural training can contribute to reduce stress and psychological complications that often stem from cancer treatment. It encompasses a wide variety of techniques for example, progressive muscle relaxation, hypnosis (self-hypnosis or therapist-induced hypnosis), deep breathing, meditation, biofeedback, passive relaxation, and guided imagery. Psychotherapy provides empathy, support, and compassion. Group interventions can help patients and families to talk about fears, face fears, gain information, and learn from other patients' experiences. Group therapy contributes to patients feeling less isolated and more supported. As a clinical practitioner, the oncology social worker draws upon knowledge from medical and psychosocial oncology. Cordoba et al. (1993:44) infer that on a clinical level, the following issues in the cancer continuum need to be addressed:

- threats to survival and the physical, emotional, and intimacy issues related to cancer and treatment
- changes in values and outlook on life that may result from the cancer experience
- social, financial, and physical issues regarding the costs of cancer, employment, discrimination, insurance, and the health care system.

Oncology social workers rely on a broad spectrum of counselling modalities and therapeutic techniques, including individual, group, and family therapy,

education, behaviour modification, crisis intervention, supportive techniques, advocacy, and insight-oriented interventions (Christ, 1990:671). Fobair et al. (2009:57) depict the roles of oncology social workers as follows:

- providing advocacy to patients and their social attachments
- providing clinical services to patients and their social attachments
- working as team members with other health professions
- providing education and mentoring for younger social work professionals
- assessing the needs of patients and their social attachments
- assessing available care, or the need for care, and
- developing and providing intervention programs that assist patients and their social attachments to work towards solutions that address these identified needs on a physical, intrapsychic, interpersonal, and environmental level.

Blum et al. (2001:66) include effective screening and sound psychosocial assessment, linkage to community resources, bereavement therapy, and discharge planning. Cordoba et al. (1993:73) postulate that when social workers understand the common experiences of, and the demands and tasks imposed on cancer patients, then it enables social workers to shore up patients' personal strengths and sustain them as they struggle to successfully manage the cancer experience.

Patients, their social attachments, and caregivers face a myriad issues and challenges when confronted with cancer. Side effects of treatment contribute to their concerns and stresses. Cancer myths are incorrect beliefs and attitudes that interfere with their understanding of cancer and a patient's specific cancer. Consequently, these myths interfere with a patient's ability to manage cancer. These myths also influence families and friends, and thus the way in which they offer support. What a patient believes about cancer is based on a variety of factors including family history, personal experience with a loved one that has or had cancer, education, cultural and religious factors,

and previous responses to illness. Patients combine these influences and their physical symptomatology (or absence of it) with what they have heard from medical professionals to construct a perception of their situation (Herman, 1993:5). The researcher observed that perceptions about cancer are not based on facts, but often on fears, and what a person believes is not dependent on a person's intelligence. Patients and their social attachments often do not realise that their beliefs and perceptions are incorrect or distorted, with the result that they do not question the treatment team. It is therefore necessary for social workers to assess patients and the families understanding of cancer, as well as the specific diagnosis, prognosis, and treatment prescriptions for the patient (Hermann, 1993: 5).

Research indicates that provision of realistic information in a supportive, collaborative environment is hope nurturing (Clayton, Hancock, Parker, Butow, Walder, Carrick, Currow, Ghersi, Glare, Hagerty, Olver, & Tattersall, 2007: 643). Oncology social workers need to be knowledgeable about cancer and the disease process. This knowledge includes an understanding of the biological aspects of cancer, the continuum of the disease experience, and the differences in how patients and family members react to each stage of the disease and each aspect of treatment. Referring to the social worker's role relating to health literacy, Brandt (2009) suggests that social workers should provide patients with information regarding cancer surveillance, recommendations on the timing of follow up exams, tests and imaging, providing information regarding cancer screening recommendations, and providing information regarding immunisations and additional health monitoring, for example, influenza and pneumococcal vaccinations.

Interventions also include counselling regarding health promotion, wellness and lifestyle, guidance to attain information regarding the management of late effects of disease or treatment, for example, chronic diarrhoea or incontinence. Patients in remission should be provided with clear information regarding possible preparation for transfer of care to a primary physician. This

information from the oncologist should provide the primary care physician with specific information regarding the cancer, and with a summary of the treatment delivered, the possible clinical course including timing of long-term and late treatment consequences, surveillance recommendations, appropriate timing of transfer of care, and specific responsibilities of the oncologist and the primary care physician.

Bellet and Maloney as quoted in Burton and Watson (1998:3) emphasise the role of communication. Oncology social workers can assist patients and their social attachments to build and develop effective communication skills among themselves and with the oncology team. Effective communication will help prevent some psychological morbidity and, in particular, help to reduce anxiety. Patients should be able to communicate their fears, skills, and questions to the oncology team. Christ (1990:670 - 672) posits that oncology social workers should assist patients to attain information about their options. Patients need support and information to clarify misconceptions and misunderstandings, and encouragement to evaluate the outcomes of different choices. Oncology social workers support patients to identify and mitigate barriers to decision making, facilitate family communication about the patient's decisions, and help patients understand, accept and adapt to the outcomes of their choices, for example, certain treatments impact fertility and declining other treatments can improve the risks of recurrence if patients had a hormone related cancer.

During the treatment phase, oncology social workers prepare patients and their social attachments for the re-entry phase. Patients may need assistance in coping with uncertainty and fear of recurrence. Patients in remission need to understand that their cancer has a tendency to recur or metastasise, and therefore surveillance and/or maintenance treatment is essential. They need to make a cognitive shift that in spite of the incurable status of their cancer, they should focus on living with cancer, instead of perceiving remission as a time of dying of cancer. Patients need to understand that they are in

remission and not in the terminal stage of cancer. For patients in the terminal phase the objectives of treatment are symptom control. For patients in remission, treatment is often prophylactic, aimed at prolonging life, or preventing or delaying recurrences or metastases. Preparation for remission should also include support to cope with and adjust to side effects and late-effects of treatment, for example, adjusting to a stoma bag. Patients should also be prepared to reintegrate roles, for example, family, work, and the community. They should be prepared for, and adapt to less support from family, friends, and work colleagues. Patients may not have the same energy levels as pre the cancer diagnosis and treatment, recovering might be slower than anticipated, or patients' life philosophies might have changed and that can influence their ambitions and priorities. To summarise, during remission, patients need to regain a normalcy lens, they have to adjust to what is now normal for them. This new normal involves adjusting to changed roles and expectations of supporters, and cope with post treatment stress (posttraumatic stress). It is also suggested that survivors strive to find some benefit in the cancer experience (post traumatic growth, benefit finding), explore and find meaning in the experience, and embrace life tasks. Furthermore, patients also have to gain knowledge relating to side effects of treatments, comply with medical follow-up regimes, and cope with anxiety and decision-making when patients move out of remission.

Manicom (2010:56) observed that cancer is currently recognised as a chronic disease in countries with advanced health care. In South Africa, in line with international research findings, a range of physical, emotional, and social challenges accompanies the extended survival profile. These challenges include:

- role changes in the household, especially in terms of parenting functions
- social isolation and difficulty re-entering into social or community circles
- impact on decisions made around family size for patients of childbearing age
- questions about potential genetic links in the case of particular cancers
- adjustment to changed appearance, possibly with body image issues
- altered body functioning that may affect intimate relationships
- uncertainty about resuming employment (due to fatigue and/or workload)
- disruption or interruption on a career path
- potential prejudice when returning to the workplace, particularly when seeking new employment
- potential long-term loss or reduction of income
- financial depletion due to treatment, possible environmental modifications or equipment required
- regular encounters with social stigma
- possible psychological disorder, for example, depression, and/or anxiety disorder and, in some instances, posttraumatic stress disorder (PTSD)
- uncertainty about personal life expectancy, which can make future planning difficult
- emotional exhaustion and/or emotional withdrawal by carers, family and friends who find it difficult to sustain high levels of compassion for prolonged periods.

The above-mentioned challenges can be addressed in oncology social work interventions.

Patients in remission also need support to redefine realistic hope. Grieving occurs at many points of the illness experience for both patients and families. During remission, patients grieve for the loss of predictability and certainty of their lives (Blum et al., 2001:62). Patients need to build realistic hope. Realistic hope is proportional to their disease status (Kneier et al., reviewed

2010). Social workers must also assess what patients' perceptions of the treatments outcomes are. Misconceptions can cause distress, for example, patients who misconstrue remission as a cure, or who believe that they received a miracle, may be devastated when the cancer recurs. Their faith may be shattered, or they may believe that they failed their deity, or that they failed in keeping a positive attitude. Patients need support to adjust to changed circumstances, which may include debilitating side effects or late-effects. They need to create a new normal, reconstruct a future vision, and to maintain realistic hope.

Patients may need to be referred to other counselling services, for example, sex therapy, swallow therapy, psychiatric consultation. If a treatment centre does not offer appropriate support, patients can be referred to support groups, for example, PLWC (people living with cancer), CanSir (support group for prostate cancer). Group interventions can decrease feelings of alienation. Talking to other patients in similar situations, can reduce anxiety about the treatments, clarify misperceptions and misinformation, and lessen feelings of isolation, helplessness, and being neglected by others (Holland in Fawzy et al., 1995:100). Patients who do not want to participate in or do not have access to group intervention may benefit from talking to survivors or other patients in similar situations. Oncology social workers can instigate contact with other patients who are also in remission.

#### **5.3.4 Knowledge, skills and competencies of oncology social workers**

The knowledge, skills, and competencies of oncology social workers are the same as those described for health social workers. The AOSW (2012) advocates that oncology social workers should have a Masters in Social Work degree in order to practice as an oncology social worker. Oncology social workers should have knowledge of the disease process, understanding of the biological aspect of cancer, the continuum of the disease experience, and the differences in how patients and family members to react to each stage of the

disease and each aspect of treatment (Christ, 1990:671). Furthermore, oncology social workers should have basic knowledge of the frequently used treatment modalities, including the common side effects of treatments. There are rapid advances in the treatment modalities. Oncology social workers need to keep up to date with these advances in order to assist patients to make informed decisions relating to treatment options. The AOSW provides education and support to members. Adequate knowledge will enable oncology social workers to assist the patient to explore and clarify the links between the facts and fears associated with cancer.

The researcher is in agreement with the roles of oncology social work as described in this section. A number of oncology social workers fulfil the described roles, or an oncology social worker can fulfil some of these roles during different times of interventions. As the only oncology social worker in an oncology unit it is the researcher's experience that the oncology social worker needs to decide which roles are needed, and which roles she can fulfil. These decisions are guided by the oncology social worker's patient load, and organisational policies. These decisions around role-clarifications need to be communicated to the oncology team and the management team. Furthermore, the oncology social worker needs to be flexible regarding the roles, because development and change within the organisation or treatment protocols can change. Oncology social workers must strive to keep their duties within the scope of oncology social work, for example, not wasting time confirming doctors-appointments with patients. In addition, the oncology social worker must be aware when a psychosocial problem fall outside the scope of oncology social work, for example, a family member of a patient who abuses drugs should be referred to appropriate facilities. The description of the knowledge, skills and competencies required to practice as an oncology social worker, underscores the importance of continues professional development.

#### **5.4 THE FUTURE DEVELOPMENT OF ONCOLOGY SOCIAL WORK**

The research of Manicom (2010:58) indicates that in Europe and North America, the need for cancer survivorship care plans is gaining attention. She reiterates that such plans should be tailored to the needs of individuals and help survivors to understand the continued medical care and surveillance recommended after completion of treatment, the survivor's own responsibility in terms of recommended lifestyle or lifestyle changes, and the linkage to relevant resources for on-going support and education.

Research is often a neglected role in social work. The primary objective of social work research in oncology is to contribute to the existing knowledge base and enhance the understanding of processes such as adaptation and the provision of support in a way that will improve clinical practice and delivery of services to patients and families (Christ, 1990:673). The prevalence of cancer, together with the impact of cancer on the different levels of personhood, family and society, underscore the need for research that will contribute to effective intervention programmes.

Oncology social workers assist with maintaining good staff morale. Cancer evokes our deepest fears about death and the questions related to the meaning of life (Blum et al., 2001:46), therefore the potential for burnout is high, and requires supportive services to the oncology team (Christ, 1990:674). Support services reach beyond the oncology team, and need to include the administrative, cleaning, and security staff, because these staff members often observe disease progress in patients, or hear about patients' deaths. This confrontation with the transitoriness of life, and the awareness of suffering, may cause distress. The oncology social worker has the skills to address the distress.

Oncology social workers can derive benefit from working in the field of oncology. Oncology social workers can share in the patients' struggle and potential mastery of problems and this provides tremendous satisfaction for

oncology social workers. The work also generates a process of self-discovery and growth because it challenges oncology social workers to examine their philosophy of life, their spirituality and personal and professional attitudes, and value systems. The social work commitment to self-exploration, and social workers insight in, and appreciation of client growth offers additional benefits to patients and professionals (Lauria et al., 2001:XII,XIII).

The researcher promotes the concept of oncology social work as a specialisation field within health social work. There is a need in South Africa for guidelines for oncology social work. Currently, the Association of Oncology Social Workers in South Africa suggests that the guidelines as set by the international Association of Oncology Social Workers be followed. Membership to these associations is voluntary. Not all social workers working with oncology patients are aware of and/or are members of these associations. Currently, membership to the Association of Oncology Social Workers provides member free access to the professional journal *Psycho-Oncology*.

When oncology patients are only part of a health social worker's patient-load, interventions seem to be crises-oriented. This result in a lack of assessment of oncology patients and many patients' needs are not addressed. It is not fitting that patients and their social networks meet for the first time with an oncology social workers, during a crisis, or at the terminal or end-of-life phase of cancer. Previous contact with an oncology social worker can make the transition to hospice care smoother. It is important that patients and the social attachments understand that referral to a hospice facility is guided by the principle to act in the patient's best interest, in this situation, referring patients to a specialist in terminal care. This prevents that patients feel abandoned during the terminal phase of cancer.

## **5.5 A MEANING-CENTRED APPROACH TO SOCIAL WORK INTERVENTION WITH CANCER PATIENTS IN REMISSION**

Currently, a meaning oriented approach to mental and community health is gaining currency (Fabry, 1968; Frankl, 1992; May & Yalom, 1989; Wong, 1989, 1991; Yalom 1980; in Wong, 1998:396 - 401). Several themes of the humanistic/existential psychology directly bear on personal meaning. The theme of personal growth recognises that life is more than survival and pleasure seeking; it acknowledges a basic motivation that directs humans towards self-actualisation. Another theme is purpose and goal orientation. Allport (1955) differentiates between deficiency and growth motives. This corresponds with Maslow's (1970) differentiation between needs and meta-needs. In Maslow's opinion, self-actualisation is the ultimate goal. One of the qualities of self-actualised people is self-acceptance. There is meaning inherent in the act of self-acceptance. The theme of self-acceptance is also prominent in Rogers's (1951) writings. Rogers asserts that the purpose of life is to discover and actualise the true self – to become what one is meant to be by design or choice. Religious belief is another theme in meaning fulfilment, because the “essence of religion is the belief that something matters – the pre-supposition that life has meaning” May (1940) emphasised the importance of making choices and being authentic as ways to meaning-construal (May, 1940 in Wong 1998a:400,401). All these themes are integrated in a meaning oriented approach.

The researcher argues that within the field of oncology social work, patients should be guided to find meaning in the cancer experience. Psychosocial problems, when manifest, should always be addressed in social work interventions. Oncology patients are confrontation with their own mortality, and therefore, oncology social work offers the opportunity for meaning-centered interventions. The researcher proposes the Meaning-Centered Counselling and Therapy (MCCT) model that Wong (2012) developed in Canada for interventions with patients who are in remission. Cancer can

cause anxiety, distress, or trauma. Feelings of helplessness, hopelessness, and worthlessness can manifest during any time of the cancer continuum (Holland & Gooien-Piels, 2000). A perspective that provides the opportunity for patients to explore their understanding and assumptions towards their unique meanings, purposes and life tasks, and support patients to accept the realities of remission, could help patients to cope more effectively with the physical and psychological components of remission.

Wong (2012) published the MCCT model during 2012, with the result that there is currently little scientific review and commentary available on it. MCCT is an integrative therapy informed by advances in psychological research and new insights, and emphasises the central role of personal meaning in the process of adaptation and personal growth (Wong 2012c:Kindle location 16049). In the South African context, it is important to take our unique circumstances and multi-culturism into consideration, but this model does make provision for this and is thus appropriate.

Wong explains MCCT as follows:

For MCCT, the key organizing construct is meaning, which is central to understanding culture and society (Bruner, 1990; Wong & Wong, 2006), physical and mental health (Wong & Fry, 1998), spirituality and religion (Wong, 1998), and death and dying (Wong, 2008). Various constructs in cognitive and social psychology, among them cognitive reframing, existential and spiritual coping, attribution, stress appraisal, and life review, are also incorporated in MCCT (Wong, 1998). Consistent with all existentially oriented therapies, MCCT is primarily concerned with the meaning and quality of human existence, and it emphasises the importance of understanding what it means to be fully alive and how to live vitally in spite of suffering and the finiteness of life. MCCT helps people acquire existential insight and psychological skills to transform and transcend unavoidable predicaments and pursue worthy life goals. Consistent with most faith traditions and the tenets of logotherapy, MCCT believes that the terminal value of self-centred pursuits of personal happiness and success, often lead to disillusion and misery, whereas the ultimate concern of actualising one's mission, leads to authentic

happiness and fulfilment. This unconditional affirmation of meaning constitutes the bedrock foundation for MCCT.

MCCT deals with the salient aspects of human existence, such as people's existential anxieties, their ultimate concerns, the meanings of life, death, work, and love, and their inner resources (Wong, 1998a:413,415). Patients who are in remission have to assimilate and accommodate the knowledge that cancer is incurable and still embrace life. The researcher proposes the MCCT intervention model because it is positive and growth oriented, rather than problem focused. It is more concerned with individuals' potential for growth and actualisation than with their deficiencies and problems. In line with the existential perspective, a tenet of MCCT is that life has meaning under all conditions, but one has to discover it for oneself (Wong, 1998a:398). Thus, by implication, patients who are in remission can derive meaning in their lives. MCCT proposes that if a person is motivated by the prospect of fulfilling life goals, many problems will either disappear or become tolerable. Wong (2012c:Kindle location 16343) explains that existential therapy focuses on reducing existential anxieties, especially death anxiety, whereas MCCT focuses on what makes life worth living. For patients in remission MCCT offers opportunity to explore their strengths, validate themselves, and evaluate the growth that resulted from the cancer experience, and build realistic future orientation.

### **5.5.1 The role of meaning-centered counselling in social work interventions**

Psychosocial practitioners are divided regarding the role of meaning-centered interventions. There is a tendency to ascribe the human quest for meaning to the domain of philosophy, declaring that questions about meaning and purpose are too subjective and philosophical to be answered scientifically. Building on logotherapy, meaning therapy offers an affirmative viewpoint: meaning can be found in all circumstances and meaning matters. The existential quest for meaning is rooted in basic human needs: the need for

order and coherence in the midst of chaos, the need for personal significance and self-worth in the face of entropy and death, and the need for positive meanings in spite of negative life events that often overwhelm. In times of adversity, the search for meaning becomes more authentic. Today, a meaning-oriented approach to mental and community health is gaining currency (Wong, 1998a:396 - 399).

Referring to various authors (Coward, 1997; Lepore and Helgeson 1998; O'Connor et al., 1990; Greer and Moorey, 1997; Foster and McLellan, 2000), White (2004:469,470) postulates, that meaning is a concept that has relevance from a number of perspectives in understanding the psychology of cancer. Cancer challenges people's views of the world as meaningful, purposeful and coherent – 'what it all means' - is a common focus of thinking. The experiences associated with cancer, including living in remission, can result in 'severe spiritual disequilibrium', resulting in a search for meaning. By integrating the cancer experience into a pre-existing mental model, patients could promote psychological adjustment. The process of searching for meaning entails asking questions about the personal significance of a life event, such as remission, in order to give the experience purpose, and to place the life event in the context of a total life pattern. Understanding the personal meaning of remission is also crucial for patients in order to understand possible underlying cancer-related distress. Cancer care professionals should endeavour to assess the meaning derived from a person's cancer experience, including living in remission, because this can assist professionals to facilitate possible clarification of the patients' experiences of cancer and remission, or assist patients to challenge misappraisals.

The quest for meaning is considered a primary and basic human motive, and a specific need, not reducible to other needs and, to a greater or lesser extent, it is present in all human beings. Maslow refers to it as 'man's primary concern'. The main goal in life is not pleasure or power, but to find meaning

and value in life. Individuals are willing to endure adversity if that suffering has meaning (Wong, 1998a:397). Patients in remission have the capacity to deal with, overcome, learn from, or even transformed by, inevitable adversities of life. They have the resilience to recover from cancer diagnosis and treatment and adapt to the demand imposed by remission. They are able to explore the meaning of the experience, including exploring the meaning of their sufferings.

Frankl believed that the meaning of life is unique for each person, that there is potential for meaning for every human being, and that the quality of life can best be maintained by fulfilling personal meaning. Therefore, the researcher infers that patients living with recurrent, incurable cancer can derive meaning in their lives.

From a meaning-centered perspective, the quest for meaning consists of two psychological processes: the motivation to seek the core meaning of a specific life situation, and the motivation to seek purpose and significance for life goals (Wong, 1998a:398,403). By maintaining an optimistic, accepting attitude, one can turn suffering into something meaningful. May (1940) (in Wong 1998a:401), in his writings on meaning and purpose, eloquently affirmed that life has meaning:

The creative person can affirm life in three dimensions – affirm himself, affirm his fellow men and affirm his destiny. To him life has meaning. He is warmed by the friendships of his fellows and cheered by the confidence that he is of worth to them. Love can be supreme pleasure to him precisely because it is more than pleasure. His work can be satisfying precisely because it is part of a creative purpose larger than any particular work. All of which means that life's fundamental question deserves a positive answer: the person has confidence in meaning in his destiny.

In the context of this research, it implies that patients are able to prioritise, maintain reasonable hope, reconstruct shattered assumptions, and focus on

quality of life. Breitbart, Gibson, Poppito, and Berg (2004:367) propose that when patients understand the meanings associated with their suffering, they may mobilise their feelings into active responses to living. Patients who feel that they do not live up to the expectations of others, may, when understanding the meaning associated with their sufferings, shift to realistic evaluation of own needs, and focus on fulfilling their own potential.

In MCCT, meaning is not prescribed (Wong, 2012c:Kindle location 15970). The oncology social worker assists patients to gain a new perspective on life and explore new ways to finding meaning. In this regard, Shavrat (2011:50) describes the counsellor's role in proposing possible meanings as facilitating the exploration of a patient's perceptions, emotions, and thoughts in helping them gain deeper awareness of the unique meaning of their subjective experiences, in this context, living in remission. This will assist a patient in remission to integrate his or her life into a meaningful whole. The researcher has observed in practice that patients in remission sometimes feel that they failed because the treatment was unsuccessful, or that they failed in their loved ones expectations. They also sometimes experience disappointment because, due to side effects or late-effect of treatment, they cannot return to the same level of functioning as they experienced pre-diagnosis. They need to create a new normalcy, adjusting to the demands of living with incurable cancer, and they need to explore the potential and opportunities offered in this life phase.

Lukas (2000:61-71) cautions that therapists should be aware of not imposing their values and meaning, or their perceptions of what meanings patients should derive from specific life events. As in other models of therapy, meaning-orientated therapy aims at establishing an empathetic, rapport-building climate of communication and requires that the therapist unconditionally accepts the person in the patient, and the person's own genuineness. Accepting the person in the patient, offers the opportunity for therapists to examine the patient's perceptions and interpretations of a life

event with the patient in a reflective manner. This, in turn, offers the opportunity for patients to discover meaning in the event as well as the opportunity to identify and correct cognitive distortions. Referring to the role of the personal qualities of the counsellor, Wong (2012c:Kindle location 16108) argues that therapeutic change necessarily involves some form of exchange of life, resulting in reciprocal change in both parties in the counselling setting. The counsellor is the most important instrument in the therapeutic process. MCCT seeks to enhance patients' positive meanings through relationships, and the therapeutic relationship offers to patients' opportunity to learn to trust, to be accepted, and contribute to building relationships in other domains of their lives. Therefore, a MCCT practitioner needs to be a secure, centered person, who possesses the personal qualities of genuineness, empathy, and unconditional positive regard, as emphasised by Carl Rogers. These personal qualities are incorporated in the practice of mindful-presence: openness, compassion, empathy, acceptance, and non-judgment. Mindful-presence means that the oncology social worker is psychologically and spiritually present, and that the social worker is relationally and emotionally, attuned to the client. The therapeutic relationship is necessary to building rapport, trust, and therapeutic alliance. Mindful-presence provides a model for new ways of relating and demonstrates the importance of self-regulating skills and mindful-awareness.

In order to derive meaning from a life event, the capacity for inner growth is required. Lukas (2000:54,55) introduces the concept of 'dealing with oneself' describing it as an awareness aiming beyond the self, which is self-discipline, to achieve inner control and inner growth. Self-awareness only leads to a readiness for self-revelation, whilst dealing with the self leads to the capacity for self-distancing and self-transcendence. Self-transcendence is defined as "the act or condition of going or being beyond ego or egoity, usually as a result of love, service, non-egoic discipline, or undivided attention for another" or "an evolutive practice or technique which involves moving beyond prior conceptual, presumptive, or behavioral limitations". Self-transcendence is

essential for spiritual and psychological progress (Soulprogress, [sa]). The online medical dictionary defines self-transcendence as “the ability to focus attention on doing something for the sake of others, as opposed to self-actualization, in which doing something for oneself is an end goal” (*thefreedictionary.com*). Self-transcendence thus refers to altruism. Within a meaning-centred context, Havenga-Coetzer (2003:88,89) conceptualises self-transcendence as an ability to look away from the self, from one’s own pain, circumstances, suffering, or grief. It is the ability to reach out to someone else, to realise an ideal, or fulfil a task, or to reach out to a higher being. In this process, one forgets about oneself. Self-transcendence can facilitate one to overcome focusing too much on the self and, in the process, prevent one from becoming egocentric. Self-distancing is the ability to detach oneself from oneself. By virtue of self-distancing one can find a new attitude towards one’s circumstances, adversity, or symptoms and thus change them. Lukas (2000:55) elaborated, stating that: “finding oneself is achieved only by way of a detour to find meaning.” By maintaining authenticity and creating normalcy in their lives, patients in remission can invest in life and gain empathy for other people who experience adversity.

Based on the research of Thornton (2002:161) regarding the role of psychological intervention in stressful events, the researcher postulates that meaning-oriented intervention has the potential to help patients in remission to find benefit in the cancer experience and remission. This goal can be achieved by focusing the attention of patients in remission to the positive in addition to negative experiences following cancer diagnosis, treatment, and remission and focusing on exploring the possibility of growth from the cancer experience. Oncology social workers support patients in remission in finding benefits, and creating positive outcomes, by reinforcing reasonable positive interpretations made by the patients, by helping them to achieve a balance between acceptance and change, and by working with patients to develop a narrative of the event. Working within the patient in remission’s time frame

and belief system is important in order to avoid creating expectations for growth that may be premature and insensitive.

Folkman and Greer (2000:17) purport that it is beneficial for cancer survivors to talk about the experience with supportive others, because it may facilitate processing of the event and lead to benefit finding. As in the situation when working with clients that faced adversity, oncology social workers should be aware that patients have the potential, and in the researcher's experience, often report finding benefit in the cancer experience. Reframing the event as a challenge, and seeking out opportunities to help others may also introduce survivors to new possibilities in life and foster personal growth. The researcher argues that the process of finding benefit contributes to meaning-construal. Whilst assisting patients in remission to clarify their goals, the oncology social worker has to keep in mind that, often, a lot of trial and error process occurs and patients have to replace and restructure goals. Cancer often implies that patients were dealt with circumstances in which they had to choose and select goals that they never thought acceptable.

Interventions that explore and develop resilience in patients endeavour to empower those patients in maintaining as much control over their lives as possible and to live a meaningful life whilst in remission. Social work intervention can assist patients in assessing their own resilience and sense of meaning. Such intervention programs, based on the MCCT model, could empower patients to live a life enriched by quality and meaning. The objectives of intervention are to mobilise patients' strengths (talents, knowledge, capacities and resources) in order to help them reach their potential and have a better quality of life (Saleebey, 2002:1). According to O'Gorman (2004), interventions focusing on developing resiliency assist patients to develop a vocabulary of their own unique personal strengths, demonstrate to patients that they already rely on their resilience, find examples of when patients used their resilience in the past, and assist patients in consciously using their resilience to deal with the challenge that

they are currently facing. Wong (2010:87) asserts that the human spirit offers a basis for recovery and resilience.

Understanding a patient's or a survivor's hope is crucial for meaning-construal. Oncology social workers need to ask questions about what patients and survivors hope for. Asking these questions may assist patients to express what matters to them in their new reality, what they value, and what they hanker for during the coming months. Such meaning clarification assists the process of goal-revision and paves the way to building hope (Folkman, 2010:906). It is important to ensure that individuals from the social attachment group do not put pressure on the patients, or survivors, to maintain unrealistic hope. Oncology social workers should both avoid giving false or unrealistic hope and evaluate if false hope is present. As Scioli and Biller (2009:13) caution, false hope can promote wishful thinking in the face of certain unavoidable realities. Oncology social workers should focus on mobilising hope in patients in remission; exploring what the patient is prepared to do to realise hope, what is needed to realise that hope, and what the patient has to do in order to realise that hope. MCCT seeks to bring about fundamental changes, by equipping patients with the tools that enable them to see themselves in a new and positive light and to pursue their lives in a responsible, purposeful and hopeful manner (Wong 2010:88).

Oncology social work interventions focus on quality of life, psychosocial well-being and functioning associated with self, life perspectives, and interpersonal relationships. The researcher argues that MCCT provides a theoretical framework to address cancer patients, who are in remission, capacity for self-awareness, freedom and responsibility, relationships, anxiety as a condition for living and the quest for meaning. Breitbart et al. (2004:369) propose that meaning-oriented intervention can guide patients to become aware that they are finite, yet have the potential to continually grow and actualise, can make commitments to authenticity and responsibility, have the courage to be, as well as of aloneness and relatedness. Van Deurzen (in

Breitbart, et. al., 2004) reiterates that meaning may change over time due to changing circumstances. Although one may not have control over one's various circumstances, one still has the freedom to choose one's attitude toward adversity. Lichtenhall and Breitbart (2012: in press) emphasise that patients are the creators on meaning in their lives. Lichtenhall and Breitbart (2012: in press) reiterate that suffering should be avoided; only when suffering is inevitable, it becomes acceptable. In circumstances where suffering cannot be avoided, one still has the freedom to choose one's attitude towards the suffering. The researcher argues that MCCT provides a model to making choices and decisions, setting realistic goals, and guiding patients to live a meaning-centered life. The MCCT approach provides a theoretical framework to evaluate and integrate life experiences in order to resolve conflict and achieve a sustainable sense of meaning whilst in remission.

The researcher accepts the existential premise that meaning is a basic human need, and Frankl's proposition that the meaning of life is unique for each person, and that there is potential for meaning for every human being, and that the quality of life can best be maintained by fulfilling personal meaning. The researcher infers that the MCCT model provides an intervention that can assist patients to find within their unique situations, a more credible and meaningful alternative to being a cancer victim. An objective of MCCT is to guide patients to live in the moment. Lukas (2000:69) observes that counsellors can assist "the ambivalent person only when he comprehends, besides the truism that everything has a light and a shadowy side; that the brighter side is literally more natural, is more prospective for him, for whose sake he endures that which is tied up in the shadow." The oncology social worker assists patients to make attitude changes, moving away from the perception of being a hapless victim, to taking control of his or her own attitude.

The researcher argues that an awareness of self-efficacy strengthens patients' coping capacity and sense of self. From the perspective of this

research study, interventions that endeavour to find benefit in the cancer experience, assist patients to find balance and proportion, create a new normal, and motivate patients to adjust to the demands of cancer. It assists patients to live every day to the full.

### **5.5.2 Meaning-construal**

A premise of meaning-centred counselling is that anxieties are an inevitable part of life, and that people have the freedom of choice and the capacity to transcend environmental influences. Wong (1998a:408 - 411) identifies five categories of human motivation that are useful in meaning-centred counselling. One's beliefs and value system dictate which source of motivation is one's primary driving force.

The **survival** principle presumes that to stay alive is the key to receiving all that life offers. However, the survival instinct on its own may not be enough motivation to stay alive, and then other levels of motivation come to play. People are motivated to seek **pleasure** and avoid pain. However, research on meaning indicated that very few people indicated hedonistic pleasure as a source of meaning. It is evident from the existential psychology that if one seeks happiness as the primary goal of their lives, happiness eludes one. However, if one pursues meaning, happiness will be attainable (Frankl, 1959, Yalom, 1980 in Wong, 1998a:409). Human beings are spiritual beings who seek a higher purpose to endow their lives with meaning. The quest for **meaning** is twofold: an active seek to make sense of one's experiences, and search for a higher purpose and significance in life. The meaning principle is linked to spirituality because the quest for ultimate meaning of life deals with many of the same issues as religion. Goal-directed behaviour will only endure when it is **reinforced**. Wong (1998a:410) postulates that people are not only made for meaning, but are also born for success.

Because of the social nature of human beings, people need meaningful relationships and social **validation**. One needs affirmation from others that

one's life has worth and significance. Wong distinguishes between social validation and need for approval. An authentic person has the courage to follow personal convictions (Rogers 1961). The authentic person does not need the approval for others for decision-making (need for approval), but needs social connectivity (social validity). One's sense of self-worth depends on social validation (Wong, 1998a:410, 411).

The motivational component is an important structure in meaning intervention strategies. Therefore, oncology social workers must assess the category of motivation that is dominant in a patient's life, and guide patients to find balance between the different categories of motivation. Understanding the interaction between the different categories of meaning provides an oncology social worker with information that can assisted in reframing the cancer experience for patients.

### **5.5.3 Characteristics of MCCT**

#### **5.5.3.1 MCCT is integrative/holistic**

Referring to the therapist's intention, Wong (2012c:Kindle location 16074) proposes that the therapist integrate his or her clinical knowledge into a meaning-centered framework. An integrative and holistic approach recognises the patient as a complete human being in a specific cultural context. In the context of this study, it is living in remission in the multi-cultural South African population. MCCT is inherently integrative because of the holistic nature of meaning (Wong, 2010:86). Hofmann in (Wong, 2012c:Kindle location 16074) observes:

The instillation of meaning is a primary component of all existential approaches to psychotherapy. The deepest forms of meaning can be experienced on the various realms of biological, behavioural, cognitive, emotional, and interpersonal; in other words, it is a holistic meaning. The attainment of meaning is one of the most central aspects of human existence and necessary to address in existential therapy.

In MCCT, whenever possible, the philosophical insights of existential psychology are translated into cognitive/behavioural processes and key concepts are operationalised. It emphasises the central role of personal meaning in the process of adaptation and personal growth. (Wong, 1998a:403). It offers an integrative and positive existential perspective, which capitalises on the uniquely human capacity to discover and create meanings and values out of raw and often painful life experiences. It affirms the hope of finding meaning and purpose, even when one suffers from overwhelming difficulties and intractable problems (Wong, 2010:85).

### **5.5.3.2 MCCT is existential/spiritual**

Meaning oriented counselling is part of the humanistic existential paradigm, which emphasises the importance of addressing existential anxieties as well as the human need for meaning and authenticity. MCCT incorporates spirituality, and it focuses on the human responsibility to live meaningfully and purposefully in every situation, on a daily basis, in order to become *what* one is meant to be (Wong, 2010: 86). Spiritual beliefs shape one's worldviews. One's worldviews enables one to make sense of life and life's calamities, and provides one with the values by which one lives (Wong, 2012c:Kindle location 16097). According to Frankl (in Wong, 2010:86,87), three factors characterise human existence: spirituality, freedom, and responsibility. The spiritual dimension is the very core of one's humanness, the essence of humanity. The defiant power of the human spirit refers to the human capacity to tap into the spiritual dimension in order to transcend the detrimental effects of stressful situations, chronic illness or the burdens of the past.

Wong (1998a:400) observes that several themes of the humanistic/existential psychology directly bear on personal meaning. The theme of personal growth recognises that life is more than survival and pleasure seeking; it acknowledges a basic motivation that directs humans towards self-actualisation. Another theme is purpose and goal orientation. Allport (1955) differentiates between deficiency and growth motives. Growth motives include

long-range purposes and striving towards distance and goals. This corresponds with Maslow's (1970) differentiation between needs and meta-needs. In Maslow's opinion, self-actualisation is the ultimate goal.

MCCT attempts to make people aware of the importance of spirituality, freedom and responsibility in the processes of recovery and personal growth. MCCT recognises that when one experiences an existential vacuum, all behaviour is aimed at filling that vacuum (Wong, 2012c:Kindle location 16097). Havenga-Coetzer (2003:38) defines the existential vacuum as one's "feeling of inner emptiness, of doubting that life has any meaning at all, of having a feeling of ultimate absurdity." Living with incurable cancer can evoke an existential vacuum. A meaning-centered approach can assist patients to fill the existential vacuum with a sense of purpose, and create awareness of the opportunities that still awaits them.

One of the qualities of self-actualised people is self-acceptance (Wong, 1998a:401). Wong (2012c:Kindle location 15405) asserts, "...just as wisdom is needed for living an authentic life, a worthwhile life comes from the wisdom of self-acceptance. Acceptance moves us beyond the immature defence mechanisms of denials and repression, and enables us to face the new reality to which we must adapt." Meaning is inherent in the act of self-acceptance.

Religious beliefs and spirituality are core themes in meaning fulfilment, because the "essence of religion is the belief that something matters – the pre-supposition that life has meaning" (May, 1940 in Wong 1998a:401). Social validation provides an avenue meaning-construal (Wong, 1998a:400,401). Frankl (in Havenga-Coetzer, 2003:40,41) emphasises the importance of choices with the logotherapy tenet of the freedom of will. The freedom of will premise infers that one is under all circumstances free to change one's attitude towards that which cannot be changed. The freedom to choose is not unlimited, but in those circumstances where one has no say, where one is powerless against an inevitable fate, one is still free to change oneself and

one's responses. In the meaning-oriented context, freedom of will is the concept that the human being has the capacity of free choice.

Humans are finite beings and human freedom is restricted by circumstances. Graber (2003:53) cautions that the freedom referred to is not the freedom from conditions, but the freedom to choose one's attitude to whatever conditions exist. Humans are free to choose how a given situation will be regarded, with what meaning, or if meaning will be founded in the circumstances and life events. Translated into the context of living in remission it implies that patients do not choose to live with incurable cancer, but they have the freedom to choose their attitude toward living with incurable cancer. They can choose to stay their authentic self, or choose to be defined by cancer.

An objective of MCCT is to facilitate patients' and survivors' adjustments to their attitude and to assist them to find within their unique situation the more credible and meaningful attitude. The meaning oriented therapist explores with patients the options and implications of different attitudes towards cancer, remission, and survivorship, and guides them to comprehend that each situation possesses within it the meaning of the moment (Lukas, 2000:67 - 69).

### **5.5.3.3 MCCT is relational**

A basic assumption of MCCT is that humans are relational creatures with the basic need for belonging and attachment. Therefore, relationships provide a basis for assessment, intervention, and building a better future. Relationships include the therapeutic relationship (Wong, 2010:87). Relationships are central to healing, meaning, and well-being (Wong, 2012c:Kindle location 16107).

The therapeutic relationship is a fundamental part of MCCT. A premise of MCCT is that therapeutic change necessarily involves some form of exchange

of life, resulting in reciprocal change in both parties in the counselling setting. Each counselling session constitutes a genuine existential encounter. In this here-and-now encounter, information and energy flow back and forth between two human beings; thus, the messenger is more important than the message, and the therapist more important than the therapy. In fact, the therapist is the most important instrument in the therapeutic process. In addition to addressing interpersonal issues experienced by patients, MCCT aims to create awareness of meaning (Wong, 2012c:Kindle location 16108).

#### **5.5.3.4 MCCT is positively oriented**

MCCT is a meaning-oriented positive psychotherapy, which taps into people's capacities for imagination, meaning-making, responsible action, and personal growth (Wong 2010:88). MCCT emphasises that there is always something worth living for and that one has almost unlimited potential for meaning-construal, independent of life events (Wong, 2012c:Kindle location 16128).

Frankl refers to this human quality as the defiant power of the human spirit. Havenga-Coetzer (2003:29) depicts the defiant power of the human spirit as the belief that one is not the helpless victim of one's drives, environment, or circumstances. One has the capacity to take a stand and the ability to choose one's attitude. The concept of the defiant power of the human spirit is closely related to Frankl's concept of tragic optimism. Tragic optimism refers to the kind of hope that can weather storms and disasters (Wong, 2010:88), and includes acceptance, affirmation, courage, faith, and self-transcendence (Wong 2012c:Kindle location 16125). Havenga-Coetzer (2003:100) interprets tragic optimism as the human capacity to turn suffering into a human achievement, to an accomplishment; the capacity to derive from guilt the opportunity of changing oneself for the better; and deriving from life's transitoriness and incentive the ability to take responsible action.

Another supposition of MCCT is that one has unlimited capacity to construct meanings that both protects one from adversity, and empowers one to make

life worth living in the worst of times (Wong, 2010:88). MCCT addresses existential and spiritual issues, emphasises the importance and the skills of transforming and transcending life crises and personal tragedies, and equips patients with the tools to succeed in their quest for a better and more fulfilling life (Wong: 2012c:Kindle location 16147).

MCCT recognises both the downsides of positives and the upsides of negatives. Positive assumptions include a belief that meaning and hope, can be found in the most helpless and hopeless situations, and that one is capable of self-transcendence. Positive assumptions affirm that one has the freedom and responsibility to choose one's own destiny, that one has the potential for growth regardless of internal and external limitations, that negatives can be transformed into positives, and that existential crises are opportunities for personal transformation (Wong: 2012c:Kindle location 16154).

#### **5.5.3.5 MCCT is multicultural**

MCCT is inherently multicultural in its orientation. Meaning systems are shaped by one's historical-social-cultural background and culture has a profound and pervasive influence on one's behaviour and attitudes. MCCT counsellors must be sensitive to cultural diversity of patients. MCCT incorporates macro counselling skills because behaviour is always situated in macro-systems which include culture, race, gender, history and the human condition; and in a multicultural society, personal meaning systems necessarily evolve through a struggle of navigating the cross-currents of different cultures (Wong, 2012c:Kindle location 16173). Working with a model that is cultural sensitive, is important in the multi-cultural South African context.

#### **5.5.3.6 MCCT is narrative**

MCCT assumes that meaning is best understood, expressed and constructed in narratives. Sarbin (1986 in Wong, 2012c:Kindle location 16189) refers to this characteristic as the “storied nature of human conduct”. To achieve the therapeutic goals MCCT uses local and meta-narratives. Narratives motivate patients to construct a preferred future. This characteristic of MCCT is associated with the *why* question. Exploring the “*why*” of life events is important because it provides patients with the opportunity to verbalise their perceptions of life events, which in turn develop important conceptions of living, including their intentional understanding of life (Wong 2010:89).

#### **5.5.3.7 MCCT is psycho-educational**

MCCT advocates a psycho-educational approach. A psycho-educational approach facilitates explaining to clients the change process and the tools and strategies employed in achieving positive change (Wong, 2012c:Kindle location 16203). A psycho-educational approach support the emotional and cognitive processing of information, and may assist people with developing a psychosocial understanding of the conditions, in this research remission, and it meaning in their lives (Rolland, 1994 in Engstrom, 2012:200). As with MCCT, an objective of social work interventions are to make relationships work in the counselling room and in real life situations, and how to make decisions and pursue what really matters in making life better, in spite of inevitable setbacks. Therapy is essentially a learning process, because it involves learning new ways of looking at life and new ways of living. The MCCT approach provides important guidelines and tools for living a life filled with meaning, purpose, and responsibility. Once clients master these tools and strategies, they can employ them effectively in real-life situations, even long after termination of therapy (Wong, 2012c:Kindle location 16203).

#### **5.5.4 The therapeutic goals of MCCT**

Wong (1998a:413,414) observed that from the perspective of meaning-oriented therapy, thus by implication also MCCT, regardless of whether a problem is cognitive, behavioural or affective in origin, it is considered to be related to issues of meaning. Meaning therapy focuses on existential issues. Existential issues are concerned with gaining a deeper understanding of personal problems, and developing a more adaptive and fulfilling meaning system. One's meaning system serves as a foundation upon which to build a fulfilling and productive life, realising meaningful life tasks, and providing social validation to facilitate the process of meaning actualisation. Wong (2012c:Kindle location 16056) depicts the goals of MCCT as follows:

- MCCT is primarily concerned with the meaning and quality of human existence. It emphasizes the importance of understanding what it means to be fully alive and how to live vitally in spite of suffering and the finiteness of life. It helps people acquire existential insight and psychological skills to transform and transcend unavoidable predicaments and pursue worthy life goals.
- MCCT fosters an individuation lifestyle through increasing the patient's responsibility in making choices, creating future orientation, and expanding coping capacities. Maddi emphasizes the importance to build resilience (Maddi, 2012:Kindle location 2589). A MCCT approach is useful when depression, meaninglessness and hopelessness mount to a point where "behavioural vigor and future oriented decision making is jeopardized" (Maddi, 2012:Kindle location 2658).
- MCCT also addresses coping with adversity. Krause (2012:Kindle location 11202), agrees with McMillen that adversity forges one to develop new coping skills, or one realises that one has coping skills that one was not aware one possessed. In addition, stressful events contribute to one being more empathic to the plight of others who are in need, thereby motivating one to assist individuals who have experienced

similar kinds of difficulties. Finally, adversity may evoke more appreciation of the help one has received from social attachments, thereby strengthening informal support networks.

- MCCT addresses existential and spiritual issues, emphasises the importance and the skills of transforming and transcending life crises and personal tragedies, and equips patients with the tools to succeed in their quest for a better and more fulfilling life. MCCT taps into people's innate capacities for self-reflection, meaning construction, responsible action, and personal growth (Wong, 2012c:Kindle location 16147).

Individuals tend to seek counselling because they are unhappy with their life situation, feel dissatisfied with the way that their lives are unfolding, and have difficulty coping with the demands of life (Wong, 1998a:403). The objectives of counselling are thus solutogenic and problem focussed. The focus of MCCT is existential. The objectives are to guide patients to understand their meaning systems, and the impact that an experience has on both their global and situational meaning system. This, in turn, assists patients to become aware of life tasks, and integrate the experience into their meaning system. MCCT address invalid meaning systems, provide techniques to rebuild shattered global beliefs and integrate situational meaning with global meaning system.

#### **5.5.5 Techniques of MCCT**

Techniques from various approaches, for example, positive psychology, existential psychology, strengths perspective, cognitive behavioural therapy, are incorporated in MCCT framework. Wong (1998a:415-422) notes that the following techniques are of particular importance in meaning oriented approaches.

### **5.5.5.1 Contextualising the problem**

Contextualisation is the technique whereby the problem is placed in the context of the patient's overall life situation. Contextualising goes beyond reframing and cognitive restructuring, it consists of placing the problem in the larger context of life as a whole, and placing the problem in the cultural context. It also emphasises the finiteness and transitoriness of life. This technique encourages clients to switch from tunnel vision regarding a specific problem to the global vision of new opportunities and from the intense, pessimistic view of a victim to the rational, optimistic view of a victor (Wong 1998a:406).

Contextualising a problem is similar to the technique of situational reconstruction that is employed in hardiness training. Situational reconstruction involves assisting patients to distinguish between small, large, chronic and acute circumstances and then imagining a scenario that can be better or worse. This reflecting encourages patients to put the life event into a broader perspective (Maddi, 2012:Kindle location 2617).

The value of contextualising is that the problem may become less disturbing when it is placed into a proper context. It also offers opportunity for the meaning-centred counsellor to become aware of the other problems the patient is facing and helps the counsellor to understand why the presenting problems can cause such a strong reaction. The patient is more likely to develop a balanced view through viewing problems from different perspectives. When looking at the larger picture, the presenting problem may become insignificant in the context of the patient's ultimate concerns. Patients realise they have freedom and choice to change for the better. When patients learn to look at things from a completely different perspective, it is possible that the old problems dissipate and life becomes an exciting new adventure (Wong, 1998a:416).

### **5.5.5.2 Attributional probing**

This technique takes an inside view. The social worker looks at the life event from the patients' frame of reference in order to understand "their personal concerns and their idiosyncratic ways of thinking and processing information". The social worker moves beyond emphatic listening, and tries to understand the logic behind causal and existential attributions. Patients are often interested in understanding the cause of a problem because that understanding can contribute to problem solving. Attributional probing moves a step further into the area of reasons, meaning, and purpose. Useful questions that the social worker can ask include: What is your reason for doing this? To what end? Have you thought of alternative ways to address the problem? (Wong, 1998a:416).

Wong (1998a:417) cautions that counsellors and clients need to realise that there need not be a reason for everything. Sometimes the reason is not immediately clear and, at times, there may not be an explanation for the occurrence of a life event.

The value of attributional probing is that it reveals the deeper reason for the patient's problems such as faulty assumptions, distorted logic, self-defeating attitudes, and unresolved existential conflict. It enables the counsellor to challenge specific irrational beliefs and to question some specific aspects of the meaning structure. It paves the way for attributional re-training – it helps the patient to take ownership of the problems (Wong, 1998a:417).

### **5.5.5.3 Life review and playing back**

This technique entails reviewing the past in order to shed light on the current presenting problem. An individual's habitual patterns of actions and thoughts, and coping styles are products of past learning. It is difficult to achieve self-understanding without understanding the forces that have shaped the contour and the content of the self. If patients feel very anxious in certain situations,

playing back allows them to discover recurrent patterns in similar situations. Life review is a more systematic view of looking at the past; it is a powerful tool to achieve self-acceptance, self-affirmation, and self-integration. Positive meanings can be discovered through reviewing past experiences and rewriting of life stories (Wong, 1998a:418).

Life review is a tool to bring out the adaptive attitude – people cannot change the past, but they can learn to accept and live with the past. Concerning perceptions, Adler's (1963) individual psychology emphasised early childhood memory. He believed mistaken meanings given to a situation in childhood could have important implications for present and future behaviours. Individuals do not suffer from trauma as much as from the meanings they give to traumatic experiences. Early childhood memories are the key to understanding mistaken meanings and faulty assumptions, both of which shape the whole personality (Wong: 1998a:418).

The feedback technique of hardiness training refers to patients own reactions, feedback received from social attachments and others, and the effect of the actions taken to cope with a life event (Maddi, 2012:Kindle location 2633).

#### **5.5.5.4 Fast forwarding**

The fast forwarding technique uses questioning and word pictures to depict likely scenarios given to particular choices. Life is a series of choices and clients need to be made aware of the irreversible consequences of some of their decisions. Suggested questions to ask during the problem-solving and goal-setting stage of counselling include: Are you sure this is what you really want to do? Why is....so important that you are willing to....? Suppose you are able to get what you want, what will happen? What difference will it make to your life? (Wong, 1998a:419).

Because people have freedom to choose, they have to take responsibility for the consequences of their decisions (Wong, 1998:419).

Fast forwarding also incorporates the notion of paradoxical intention (Frankl). Through the process of asking patients to visualise the worst possible scenario, they learn that their worst fear is actually not so terrible (Wong, 1998a:419).

#### **5.5.5.5 Magical thinking**

Most of the time, people are so preoccupied with their own limitations and pressing problems that they cannot see opportunities. Magical thinking enables them to transcend current situations and to consider new possibilities. The three miracle questions to ask are: If you had the choice without limitations what would you like to do right now? If God (a higher power) granted you three wishes, what would your top three wishes be? If you were able to decide your future, what would an ideal life situation be in five years down the line? These questions open patients' eyes to possibilities without having to worry about realities. The first question focuses on daily activities that are intrinsically valuable or enjoyable in their own right. The second question is concerned with an individual's utmost concerns and most cherished dreams. The third question has to do with wishes for the near future. These questions reveal what patients really want and what would make life worth living. When answers all point in the same direction then the counsellor can be sure that the patient has a pretty good idea of what he or she wants and how to get there (Wong, 1998a:419).

Magical thinking promotes personal optimism or "future self-transcendence" (Sahakian, 1985). It incorporates the Frankl's notion of dereflection because when patients change their mind-set, and focus on the positive things in life, they are often able to solve or tolerate their present problems. By combining fast forwarding and magical thinking, the oncology social worker can help patients gain insight to what they really desire from life. These techniques can assist patients to become aware when, or determine whether, their values and life goals are self-defeating (Wong, 1998a:419).

#### 5.5.5.6 Constructing a personal meaning profile

This technique helps patients to achieve a better understanding of what will make their lives more meaningful. Wong developed the personal meaning profile (PMP), which can be used to identify the scope and depth of meaning in the clients' or patients' present situation. This exercise will reveal if patients live a balanced life (Wong, 1998a:420).

Frankl identified three modalities of meaning:

- **activity:** the three types of meaning-providing activities are:
  - activities that are intrinsically valuable and interesting
  - activities that are instrumental in attaining significant goals
  - activities that are self-transcendent and direct at serving others
- **experience:** the experience of beauty, truth, and love can give a sense of meaning to people. Wong caution that people need to develop a certain level of sensitivity in order to be surprised by epiphanies of meaning in common life situations
- **attitude:** in the face of adversity, having the right attitude is often all that can be done (Wong, 1998a:420).

#### 5.5.5.7 Targeting and contracting

The social worker targets with patients some specific changes to be made before a next session. These goals should be attainable and consistent with the patient's meaning system and life tasks. The value of contracting for change is that it demonstrates the client's good faith and seriousness in making desirable changes. The social worker provides encouragement and coaching to ensure success; however, if patients repeatedly fail to fulfil their part of the contract, counselling should be terminated, as social worker cannot help patients who do not help themselves and have no intention to change (Wong, 1998:421).

#### **5.5.5.8 Effective coping**

An objective of meaning-centred intervention is to assist clients (patients) to acquire effective coping strategies. The focus is twofold: meeting the demands of everyday life and fulfilling meaningful life goals. Although different problems require different coping skills, the following techniques are emphasised:

- the resource congruent model: Wong's resource congruent model focuses on the need to cultivate internal and external coping resources and adopt coping strategies that are congruent with the nature of the problem
- the principle of existential coping – learning to accept the realities of life and learning to see positive meaning in negative life events, clients (patients) are encouraged to direct their energies to live a meaningful and productive life in spite of uncontrollable negative feelings and negative circumstances (Wong, 1998a:421).

The MCCT techniques of targeting and coping, and effective coping, reflects elements of hardiness training, specifically the techniques of situational reconstruction and focussing. Focussing is used to explore emotion around stressful life events. Transformational coping refers to the action plan, aiming at transforming the stressful life event to advantages through future oriented decision. If a life-event is a facticity, then therapy moves towards compensatory efforts (Maddi, 2012:Kindle location 2620). Compensatory coping refers to accepting a situation and addressing the situation (Maddi, 2012:Kindle location 2570).

#### **5.5.5.9 Overcoming the Achilles heel**

An individual can be his or her own worst enemy. A single character defect, or one bad habit, can undo the best of intentions and efforts. Contrarily, denial and other defence mechanisms can make patients blind to their own flaws.

A counsellor can detect the Achilles heel by detecting the recurrent pattern of personal difficulties. Once a flaw is identified, attempts can be made to understand its origin and implement an appropriate plan of intervention, which typically involves developing new attitudes, adopting a more adaptive meaning system and learning new ways of reacting to temptations (Wong,1998a:421,422).

The researcher purports that these techniques can be successfully adapted to the oncology arena. Oncology social worker can adapt the questions to be appropriate to a patient's circumstances. It requires a shift in approaches, from a problem focussed approach to an existential meaning-centered approach. Social workers know these techniques, and oncology social workers have to adapt it to the oncology arena.

#### **5.5.6 Conceptual framework of MCCT**

The conceptual framework of MCCT is expressed in two complementary theoretical models: the dual-systems model and the meaning-management theory (MMT) (Wong, 2012c:Kindle location 16212).

##### **5.5.6.1 The dual system (S-SM)**

The dual system is concerned with the “how to adapt to a life event” aspect. The dual system model uses the approach and avoidance systems to strengthen coping and attaining life goals (Wong, 2011). It highlights the simplicity and the complexity of meaning therapy. Simplicity infers that adaptive attempts originate from approach or avoidance systems. Complexity refers to the psychological processes involved and the fact that the approach and avoidance system interact with each other. The dual-system model advocates that it is more effective to employ both appraisal and avoidance systems, than focusing on either one alone (Wong, 2010:90). The dual systems model hypothesises that all negative conditions contain seeds for personal growth and all positive conditions contain hidden dangers. It

integrates the meaning processes in a dualistic framework because it addresses adversity as well as facilitating the quest for happiness (Wong, 2011).

The dual systems model is based on three kinds of meaning-centered self-regulation: The approach system of life expansion, the avoidance systems of life protection, and the awareness system of regulation of one's attention and emotional responses (Wong, 2011). Stated differently, the dual systems model concerned with the following questions: what one really wants and how to achieve one's life goals, what one fears and how to overcome one's anxieties, and how one makes sense of the predicaments and paradoxes of life. Addressing the first two issues is related on one's philosophy of life, whereas the last issue is philosophical and spiritual in nature, having to do with how one makes sense of the self and one's place in the world (Wong, 2012b:Kindle location 897).

Wong (2012b:Kindle location 1139-1236) proposes the following hypotheses for the dual-systems model:

- Mindful-awareness: The mindful-awareness system is primarily concerned with the self-regulation of attention and emotional reactions whilst one is not actively engaged in approach or avoidance activities. Mindful-awareness develops one's ability to prioritise (Wong, 2011). Siegel (2007 in Wong 2012b:Kindle location1140) delineates the following components of mindful-awareness: openness, compassion, empathy acceptance, and non-judgment (OCEAN).
- Duality hypothesis: According to the duality hypothesis, one should move beyond "pitching the positive against the negative". Meaning oriented interventions should focus on how to make positives and negatives, work together to yield optimal results (Wong, 2011).
- Deep-and-Wide hypothesis: Professionals working in the paradigm of meaning therapy do not recognise the full extent of adaptive potentials from

confronting and overcoming negative conditions. Wong notes that his earlier research has identified at least four ways whereby frustration can contribute to adaptive success and personal growth (Wong, 1979, 1995): Setbacks or failure can arouse an individual or team members to give their all in order to achieve success. Desperation can lead to ingenuity and resourcefulness. When one is confronted with a seemingly intractable problem, one tends to dig deeper into one's inner resources resulting in creating ingenious solutions. Prolonged frustration can result in a broader search for alternatives and a major change of life direction. Lastly, the experience of overcoming progressively more difficult tasks or enduring increasing levels of frustration can result in higher frustration tolerance or a higher breaking point.

- **Breaking-point hypothesis:** Both the duality hypothesis and the deep-and-wide hypothesis imply the existence of a breaking point beyond which negativity is no longer beneficial. When the deep and wide coping strategy fails, learned helplessness will set in. Acknowledging that everyone has a breaking point, Wong reiterates that individuals vary a great deal, in how much they can tolerate.
- **Meaning-mind-set hypothesis:** The meaning mind-set focuses on the person (Maslow, 1962; Rogers, 1995) as meaning-seeking and meaning-making creatures. It also capitalizes on the human capacity for reflection and awakening. A meaning mind-set implies living a balanced life. The meaning mind-set is of fundamental because it reflects one's philosophy of life, ultimate concern, core values, and worldview and is the overarching motivation in one's life. This mind-set is related to character strengths, personal meaning, passion for excellence, moral judgment, altruism, volunteerism, business ethics, religiosity, spirituality, pro-social behaviours, resilience, and all kinds of good things that make life worth living (Wong, 2012b:Kindle location 1220).

#### **5.5.6.2 Meaning-management theory (MMT)**

Meaning manifests itself in thoughts, emotions, and actions. Meaning management is about managing and regulating one's life successfully through

meaning (Wong, 2012c: Kindle location 16263). The theory of meaning-management is based on the central premise of meaning in human adaptation. In the context of meaning-management, meaning encompasses the human quest for meaning, purpose and understanding, as well as the human capacity to discover and create meaning out of the adversities of life. Meaning-management theory recognises that meaning-making encompasses several cognitive processes: adaptive processes associated with stress appraisal and attribution, the executive decision making processes inclusive of problem solving, goal-setting, making commitment, taking responsible action, and the creative process of symbolisation, imagination and myth making (Wong, 2010:89).

Wong distinguishes between three meaning-related activities: meaning seeking, meaning-making, and meaning reconstructions. Meaning seeking involves causal attribution and existential attribution. Existential attribution refers to one's ability to find the positive in adversity, to see the "silver lining". Meaning-making refers to one's investment and activities towards personal growth. Meaning reconstruction refers to the processes of meaning seeking and making following a traumatic event that requires one to redefine oneself and to restructure one's life (Tomer, 2012; Kindle location 6510).

Meaning management supports the dual-systems model, because it focuses on meaning-related processes in approach and avoidance tendencies, and explores the construction and reconstruction of one's general meaning systems, apart from specific goals or problems (Wong, 2012c:Kindle location 16268).

The MCCT model emphasised goal striving. Patients should be encouraged to explore their goals, prioritise their lives and evaluate if existing goals are realistic. Changes in their global meaning, demands of side effects or late-effects of treatment, and the prognosis may warrant setting new goals. This contributes to creating a new normal, which provides patients with a sense of purpose and meaning. Accepting the irreversible, incurable status of their

cancer, and understanding that treatment can still offer prolonging of life and creating quality of life assist patients to seek meaning in their circumstances.

## **5.5.7 Intervention strategies of MCCT**

### **5.5.7.1 PURE strategies of life expansion**

The working definition of meaning, according to meaning-management theory, is that meaning consists of four main components: purpose, understanding, responsible action, and evaluation. These four components represent the best strategies upon which to build a healthier and happier future, thus positive appraisal. Wong proposed the PURE model to achieve positive appraisal (Wong 2010:90). A meaning perspective enables one to become aware of the objectives of one's goals. This enhances a sense of purpose and significance that can increase the motivation for goal striving (Wong, 2012b: Kindle location 1036).

**Purpose:** This is the motivational component and includes goals, directives, incentive objects, values, aspirations, and objectives (Wong, 2010:90). The purpose component is the most important component in the meaning structure. Purpose includes goals, directions, incentive objects, values, aspirations, and objectives and is concerned with questions associated with validated oneself, for example, what should one do with one's life? What are one's strengths? What does one do best? What are one's dreams and interests? What does life demand from one? What does one value most? What really matters in life? What is worth living and dying for? A meaning mind-set increases the likelihood that one's life purpose is consistent with one's life calling and highest values (Wong, 2012b: Kindle location 1039).

**Understanding:** This is the cognitive component, encompassing a sense of coherence, making sense of situations, understanding one's own identity and other people, and effective communications. This process evokes in one questions associated with integrating the event, for example, what has

happened? Why me? Why does God allow this to happen [to me]? Why is it that all the prayers and hard work do not get me anywhere? What does it mean? What kind of person am I? (Wong 2010:90). The understanding component enhances clarity and coherence (Wong, 2012b: Kindle location 1055).

**Responsible action:** This behavioural component includes appropriate reactions and actions, doing what is right, finding the right solutions, making amends, and taking actions that are congruent with highest values. This process evokes in one question, for example, associated with choices: What is my responsibility in this situation? What is the right thing to do? Given the circumstances and my own limitations, what real options do I have? What choices should I make? Which options are most consistent with my beliefs and values? Have I made amends for my mistakes? Have I expressed my gratitude to my parents? Have I done anything to help my family? (Wong, 2010:90). Wong (2012b:Kindle location 1062) concludes that a meaning mind-set prompts one to do what is right and behave responsibly in the face of pressures and temptations.

**Evaluation:** The affective component is associated with assessing levels of satisfaction or dissatisfaction with the situation or life as a whole. The evaluation component is concerned with questions associated with valuing and prioritising one's life. Questions to ask are how is one's life unfolding? Has one achieved what one set out to do? Is one satisfied with how one lived one's life? If this is love, why is one still unhappy? Why is one so unhappy in your profession? What is the best thing one has done in one's life? (Wong, 2010: 90). Wong, 2012b: Kindle location 1066) concludes that a meaningful life is based on reflection and self-evaluation.

Each of the PURE components requires a set of interventions skills that manage negative and positive areas in an adaptive manner. Some commonly used skills include challenging cognitive distortions, clarifying values, goal-setting, prioritising, reality checks, fast-forwarding of consequences of

choices, the Socrates dialogue, and Wong's Personal Meaning Profile. With the successful appraisal of each component, one's level of positivity moves up. However, when one encounters a serious setback, the avoidance system is activated and then the ABCDE strategy becomes applicable (Wong, 2010:91).

#### **5.5.7.2 ABCDE strategy of life protection**

The ABCDE intervention strategy is the main tool of MCCT in dealing with negative life experiences. (Wong, 2012c: Kindle location 16297). The ABCDE intervention strategy in meaning therapy must be differentiated from the ABCDE strategies of rational-emotive therapy and acceptance and commitment therapy. Wong (2010:91, 92) include the following principles in the ABCDE strategy of life protection:

**A:** The reality principle: The power of **acceptance**. A tenet of meaning therapy is that recovery begins with accepting the fact that something is wrong and that change is needed. The objective is to empower one to confront reality and motivate one to strive for positive change. Confronting reality also means that one needs to learn how to transcend and transform what cannot be changed. One needs to be clear that acceptance neither means, giving up hope or change, nor does it mean passively accepting reality as fate. It means that one needs to honestly recognise the constraints and facticity of reality. It implies that one tries to make changes in areas where one has some control and surrender one's control to God or fate in areas beyond one's control (Wong, 2012c:Kindle location 16318).

The different levels of acceptance that meaning therapists strive for are:

- cognitive acceptance –rationally acknowledging that something has gone wrong or has happened,
- emotional acceptance – willingness to confront and re-experience the painful emotional reaction to the event
- full acceptance – recognising honestly the full impact of the event on one's life
- integrative acceptance –learning to integrate the negative life event with the rest of one's life
- existential acceptance – learning to endure and live with what cannot be changed
- transcendental acceptance – willing to rise above the acceptance, let go of the past and move forward
- transformative acceptance – learning to transform the negative event into something positive (Wong 2011).

Interventions that can facilitate acceptance include reviewing the traumatic events in details, normalising adversities, accept one's own limitations and weaknesses, practising gratitude and forgiveness, and mindful meditation, praying, and re-authoring (Wong, 2010:92).

**B:** The faith principle, the power of **belief** and affirmation. One needs to affirm the intrinsic value of being alive and maintain realistic hope. This process facilitates moving forward.

Interventions that can be utilised to install and maintain realistic hope include affirmation, appreciative inquiry, reflective journaling, visualising, and myth making.

Belief, whether it is religious faith or humanistic affirmation, provides one with hope. Belief provides the motivation for change. If one believes that one can

get better and that life is worth living, then one is more likely to be committed to taking the steps to change (Wong 2012c:Kindle location 16359).

**C:** The action principle, - the power of action and **commitments**. Real change requires specific action, in a specific direction. Action and experience is more important than feeling and thinking when one aims to make significant changes. Wong (2011) observes: "Promise without following through remains empty. Remorse is simply sentimentality without an actual change of direction."

Interventions in this area are closely connected to commitment. Recovery depends on commitment to pursuing certain values; it also depends on taking responsible action for making changes in various areas of life. One needs to develop persistence in order to succeed in making lasting changes and forming new patterns of thinking and behaviour. The meaning therapist uses modelling and reinforcement to encourage commitment. Wong (2011) recommends the following exercises:

- Contracting to perform specific behavioural tasks
- Develop and implement plans of action
- Set concrete, specific and realistic goals
- Take small steps toward one's goal
- Monitor one's progress on a daily basis
- Keep on making adjustments and improvements
- Practice meaning-seeking and meaning-making skills
- Do some kind deeds for someone each day.

**D:** The AHA principle - the power of **discovery**. Meaning therapists need to alert patients to the possibilities of discoveries; for instance, the forgotten aspects of a painful experience, and the hidden strengths of oneself.

Skills that can be used to assist patients to see themselves in a new way include mindful meditation, dream work, expressive therapy, magic

questioning, journaling, self-reflection, the Socrates dialogue, cognitive reframing, meaning construction, and re-storing. Wong (2011) suggests the following possibilities to be explored:

- Discover the forgotten positive aspects of one's life
- Discover the hidden strengths of oneself
- Discover the significance of mundane matters
- Discover joy in every step and every breath
- Discover newness in old routines
- Discover sacred moments in secular engagements
- Learn to hear, see and think deeply
- Practice looking towards the sky beyond the horizon
- Walk towards the sun and leave behind the shadow.

**E:** The self-regulating principle – **evaluating and enjoying** the outcome. To reiterate, evaluation represents the affective component of self-regulating behaviour. Wong (2011) cautions, that if one feels stuck and miserable, then it is time to make adjustments. Positive feelings and outcomes reinforce positive change.

### **5.5.7.3 Double vision strategy**

The double vision strategy is a two-pronged strategy designed to address both the immediate presenting problems and the underlying big picture issues, such as death anxiety, the quest for meaning, and the struggle against injustice. Meaning therapists can gain deeper insights of patient's predicaments by looking at the larger context. Meaning counseling seeks to awaken a patient's sense of responsibility. Restoring a patient's passion and purpose for living, will reinforce the patient's motivation to make the necessary changes (Wong, 2011)

The PURE strategy of life expansion is used to make people aware of the meanings in their lives. The researcher employs the PURE strategies, when

patients are coping well, and the objectives are to make them aware that they have meaning in their lives, despite the cancer. It creates awareness of strengths, self-efficacies and resources, help to create a sense of coherence namely, that they have cancer, and that they can live beyond the cancer. Understanding the demands of treatment and cancer also motivates patients to comply with treatment regiments, and to understand the value of maintenance or terminal care. The PURE strategy reiterates to patients what is good in their lives.

The ABCDE strategy of life protection is used when a negative response manifests that impact negatively on a patients functioning. The oncology social worker explores with patients their global meaning system, how it correlates with the situational meaning of having cancer, and where attitudinal changes are needed. It is necessary to assist these patients to become aware that they still have control. For example, lifestyle changes, compliance to treatment regimes, their own attitude that can prevent them from becoming as emotional drain on their social network. The ABCDE strategy helps patients to accept the reality of their circumstances, build realistic hope, and adjust to a new normal. The MCCT model emphasises that clients process events in their own unique time frame.

As stated the double vision strategy addressed deeper underlying issues which impacts on patients' ability to cope with cancer. Patients need to explore, recognizes and address these issues.

## **5.6 SUMMARY**

The impact of cancer on personhood, families, and societies, calls for social work intervention. In South Africa, there are currently not enough oncology social workers to address the psychosocial needs of the oncology population. The social work training and expertise qualify the social worker to fulfil a pivotal role in the oncology team. Oncology social workers make a significant contribution to health care as they provide therapeutic interventions and

resources that are an integral part of oncology care. The discussion on the oncology social work indicates that generalist social workers and health social workers will need specialised knowledge in order to practice as oncology social workers.

MCCT offers a flexible, integrative approach to oncology social work and may be more effective than strict adherence to a single theory of therapy. For patients in remission it offers an intervention that can assist them to avoid alienation, powerlessness, and dread associated with living with incurable cancer. The MCCT model offers interventions to assist patients with learning how to develop self-regulation skills that are essential for resolving problems and deriving meaning in life. MCCT empowers patients to accept the facticity of incurable cancer, accept their mortality, and mobilise them to make fundamental changes, including building realistic hope and future orientation. It enables patients to perceive themselves in a new and positive light, and to pursue their lives in a responsible, purposeful and hopeful manner, and it equips the patients with skills to build and maintain rewarding relationships. MCCT can assist patients to gain a deeper understanding of living with an incurable cancer, develop a deeper understanding of their own values and meaning systems, become aware of opportunities that life offer them, accept roles and responsibilities, and become aware of the meanings of each moment. This put them on a journey to derive meaning in their lives.

Meaning-construal was described, focussing on the human tendency to survive, seek please, find meaning, and validate themselves. Characteristics of the MCCT model that were identified are as follows. MCCT is an integrative and holistic approach that recognises the patients as a complete human being in a specific cultural context. MCCT offers an existential approach to deriving meaning during the cancer experience, focussing on personal growth, and purpose and goal satisfaction. A tenet of MCCT is that religious beliefs and spirituality are core themes in meaning fulfilment. Another tenet of MCCT is that relationships are central to healing. Thus, a patient in remission needs a

support network. MCCT is positively oriented; building on the Logotherapy and existential philosophies that life has meaning under all circumstances. Health literacy is an important role of oncology social work, and MCCT advocates a psycho-educational approach.

Techniques of MCCT that were described are: contextualisation of the problem, attributional probing, life review and playing back, fast-forwarding, magical thinking, constructing a personal meaning profile, targeting and contracting, acquiring affective coping strategies, and recognising and addressing the Achilles heel.

MCCT is built on two interrelated conceptual frameworks, the dual systems framework, and the meaning-management theory. The dual system conceptual framework is built on the mindful-awareness hypothesis, the duality hypothesis, the deep and wide hypothesis, the breaking-point hypothesis, and the meaning-mind-set hypothesis. The meaning-management theory highlights the human capacity to adaptation.

The PURE strategies of life expansion (purpose, understanding, responsible action, and evaluation) provide strategies to manage demands in an adaptive manner. The ABCDE strategy of life protection (acceptance, belief, commitment, discovery, and evaluating and enjoyment) provides strategies to manage avoidance behaviour. The double vision strategy addresses both immediate presenting problem and possible underlying problems.

The researcher postulates that within the South African context, the meaning concept is challenged by considerable intercultural differences. A tenet of MCCT is that it is inherently multicultural.

For social workers there are also benefits in working in the psychosocial field of oncology. Effective intervention provides satisfaction for social workers. Oncology social work provides opportunity for self-discovery and growth, and a meaning-centered orientation evokes in social workers their own quest for

meaning. As with the patients, MCCT challenges social workers to examine their philosophy of life, spirituality, personal and professional attitudes, value systems, and their purposes in life. A meaning-centered approach offers social workers opportunities to continuously experience growth and meaning.

The next chapter focuses on the research methodology.

## CHAPTER 6

### 6 RESEARCH METHODOLOGY

#### 6.1 INTRODUCTION

In this chapter, the research methodology followed in the research study is described. As indicated in chapter 1, the research study was intended to explore meaning-centeredness in adult cancer patients who are in remission. The increase in the number of patients, as well as the increase in the life expectancy of patients that are in remission, and the knowledge of the incurable status of their cancer, poses the question “How do cancer patients who are in remission, derive meaning in their lives?” Addressing this question from a meaning perspective, the research question was formulated as follows: **“Does meaning-centeredness play a role in adult cancer patients in coping with remission?”**

The goal of this research study was formulated as: **To explore meaning-centeredness in adult cancer patients who are in remission.**

In order to achieve this goal the following objectives were formulated:

- to contextualise cancer survivorship, specifically focussing on remission as a field of study
- to provide a broad theoretical overview of social work in oncology
- to explore meaning-centeredness in adult cancer patients in remission at the Radiation Oncology Unit, Sandton Oncology Centre
- to provide conclusions and recommendations to social workers for consideration during intervention with cancer patients who are in remission
- to provide conclusions and recommendations as well as to heighten the awareness of the oncology team regarding patients who are in remission
- to create awareness of the role of the oncology social worker.

## 6.2 RESEARCH APPROACH

The nature of this research calls for a qualitative enquiry into participants' perceptions of how they derive meaning in their lives, knowing that their cancer is incurable. Grinnell (1997:14) defines the qualitative social work research process as a structured inquiry that utilises acceptable methodology to solve human problems and create new knowledge that can contribute to and increase the body of generalizable knowledge about social work concerns. According to Creswell (2014:186,189) the focus of qualitative research is on the purposefully selected participants' perceptions and experiences, and the way they make sense of their lives. In the entire qualitative research study, the researcher keeps a focus on learning the meaning that the participants hold about the problem or issue, not the meaning that the researcher brings to the research or that writers express in the literature. In qualitative research, the researcher has face-to-face contact with participants, collecting the participants' reflections of their experiences. The researcher is the data collecting instrument, which offers opportunity for observation. Multiple sources of data are used and, in this study, it includes perusing the medical files and interviews with the radiation oncologist that treated each participant.

Ventegodt and Merrick (2012:Kindle location 14783) argue that qualitative research is applicable for meaning-focussed research. Roberts et al. (2003:19) infer that the qualitative approach offers a methodology to capture the experiences of patients and their families to analyse, and gain a better understanding of any poorly understood phenomenon in oncology. In this research study, the researcher acknowledged participants as self-knowing subjects, and used their subjective accounts to explore meaning-construal while living in remission. This falls within the paradigm of the qualitative approach, which is to construct a detailed description of participants' social reality. Qualitative research is concerned with identifying participants' beliefs and values that underlie the phenomena under investigation (Fouchè &

Delport, 2011:65). In this study, participants reported how they derive meaning, which is shaped by their worldviews, coping capacities and the way in which they integrated cancer in their lives. This research explores their personal experiences and, therefore, a qualitative approach was followed.

The passage of time is an integral part of qualitative research. It allows the researcher to detect process and causal relationships (Neuman, 2000:148). All the participants in this research study experienced a recurrence of cancer.. They all have received a combination of treatment at various times of the disease progression. Therefore, it is possible to observe how they have, over time, adjusted to living with cancer.

### **6.3 TYPE OF RESEARCH**

As stated in chapter 1, this study falls within the paradigm of applied research. Grinnell (1997:20) infers that most applied research has implications for knowledge development. From this statement, the researcher concludes that if the findings obtained from this research study contribute to the practice of social work, this study falls within the scope of applied research. This study is applied research because the researcher aims at using the information collected from this research to improve oncology social workers' understanding of the research topic. This may lead to the development of guidelines for improved oncology social work intervention, specifically for cancer survivors who are in remission. The researcher agrees with the sentiment of Roberts et al. (2003:1) that oncology social workers should be committed to the goal of evidence-based practice with cancer patients, survivors and their families. Social workers need empirical support to confirm their clinical perceptions and to establish which interventions will be the most effective with a given population.

The nature of this research is exploratory because the purpose is to gain a broader understanding of a situation, a phenomenon, community, or person (Bless et al., 2006:47). Exploratory research is applicable because there is

little known on the subject of cancer patients living in remission, and, more specifically, on how those patients derive meaning in their lives whilst in remission.

In the context of applied research, the researcher also incorporated an interpretive approach. Interpretive research aims to understand and describe meaningful social action (Neuman, 2006:105), and, in the context of this research, the participants described the demands of living with recurrent cancer. From their narratives, the researcher interpreted the meaning-construal efforts. The reality of patients in remission is that they have an incurable cancer and have to adjust to living with cancer. A human tendency is to create meaning and make sense of their worlds (Neuman, 2003:105), manifesting in this research study as a continuous process of prioritising and re-evaluation of their lives, and adjusting to living with an incurable cancer. The researcher, in her role as a social worker at an oncology centre, observed that patients go through a cognitive and emotional process in order to assimilate and integrate living in remission. This research study provided an opportunity to identify some of the processes that leads to meaning-construal that the participants reported.

#### **6.4 RESEARCH DESIGN**

Research design refers to the options available for the researcher to study phenomena according to certain methods fitting specific research goals (Fouché & Schurink, 2011:308).

The researcher implemented a case study design. In qualitative research, researchers are primarily interested in the meanings that participants subscribe to their life experiences, and therefore, qualitative researchers utilise case study design (Fouché and Schurink, 2011:320). Case study design is the study of a single individual, or a very small group, with the purpose of obtaining a detailed description of the experiences of an individual or small group (Gravetter & Forzano, 2009:373) within a specific time and

setting (Fouchè, 2005:273). Creswell (2013:97) defines case study research as “a qualitative approach in which the investigator explores a bounded system (case) or multiple bounded systems (cases) over time through detailed, in-depth data collecting involving multiple sources of information (for example, observations, interviews, audio-visual material, and documents and reports), and reports a case description and case themes.” Robert Stake has identified three different types of case studies, namely intrinsic case studies, instrumental case studies, and collective case studies (Silverman, 2014:342). The characteristics of the case can determine what type of case study it is. This study was a collective case study, because multiple cases were involved, and it contributed to the researcher knowledge base (Fouchè, 2005:272). Silverman (2013:143) states that in a collective case study, also known as multisite case study or multiple case studies, a number of cases is studied to investigate a phenomenon. The researcher observed in practice that the demands on patients, who live with recurrent cancer, are often not recognised. The data collected provided the researcher with rich, albeit subjective, information on how patients derive meaning in their lives, knowing that their cancers are incurable. The researcher is optimistic that the interpretation of this data will expand the knowledge base of oncology social workers, and create awareness for the need to develop intervention programmes for patients in remission.

## **6.5 RESEARCH METHODS**

### **6.5.1 Research population**

Gravetter and Forzano (2009:128) define the research population as the entire set of individuals of interest to the researcher. Although the entire research population usually do not participate in a study, the results from the study are generalised to the entire population. Population should specify four things: content, units, extent, and time. The content of the population refers to the particular characteristics that the members of the population have in common (Monette, Sullivan & de Jong, 2005:13). The rationale for using the

case study design is availability of a special case that merit investigation (Rubin & Babbie, 2013:250). In this research study, the population comprises cancer patients in remission, with active or inactive disease, who have received radiation treatment as primary, adjuvant or concomitant treatment at the Radiation Clinic of Sandton Oncology Centre. The unit indicates the unit of analyses that in this research study is a group of individuals who are in remission. Extent of population refers to geographic coverage (Monette et al., 2005:131). Sandton Oncology Centre is a private medical institution and provides services to patients from all over Africa. The majority of patients are from Gauteng. The patients are mainly adults. Being a private medical facility indicates that patients have suitable medical aid insurance or can afford the medical cost. The patients come mainly from upper to middle class socio-economic environments. Time refers to the period during which a unit must possess the appropriate characteristics (Monette et al., 2005:131). In this research study, no time limit was put on when patients were diagnosed. In this research study time refer to the period between recurrences. The research population is not representative of the broad South African cancer population. The majority of the population, patients receiving treatment at the Radiation Clinic at the Sandton Oncology Centre, are racially classified as White. This research will thus not reflect the cultural diversity of the South African population.

### **6.5.2 Sampling**

The sample is the actual elements of the population included in the research (Strydom, 2005b:194). Sampling is the process whereby a part of a population or universe is taken to represent that population or universe. Therefore, it is presumed that the sample is representative of the population or universe (Strydom, 2011b:193). In this study, participants who met the sampling criteria were adult cancer survivors who are in remission, and have experienced one or more recurrences of cancer.

Monette et al. (2005:130,145) explain that the major reason for sampling is feasibility. Sampling allows a researcher to study a workable number of cases, from a larger group, to obtain findings that are relevant for all members of the group. In addition, sampling allows researchers to collect specific cases, events, or actions that can clarify and deepen understanding and, therefore, the tendency is to use non-probability sampling. In qualitative research, the focus is on how the sample or small collection of cases, units or activities reveals social life. Qualitative researchers focus less on a sample's representativeness or on detailed techniques for drawing a probability sample. Their focus is on how the sample or small collection of cases, units or activities reveals social life. With non-probability sampling the researchers seldom determine the sample size in advance and have limited knowledge about the larger group or population from which the sample is taken (Neuman 2006:220).

When a sample comprises approximately the same characteristics as the research population, the sample is considered representative. The representativeness of a sample influences the generalisability of the research findings (Strydom, 2005b:196; Strydom & Delport 2011:391). In this research study, non-probability sampling was applied. Non-probability sampling is defined as sampling without randomisation (Strydom, 2005b:198), and the odds of selecting a particular person are not known because the researcher does not know the population size or the members of the population (Gravetter and Forenzo, 2009:144). The different types of non-probability sampling are purposive sampling, theoretical sampling, deviant case sampling, sequential sampling, and snowball sampling, key informant sampling, and volunteer sampling (Strydom & Delport, 2011:392-394). Focus groups rely on purposive sampling (Greeff, 2011:365) because participants illustrate some feature or process that is of interest for this particular study (Silverman, 2010:141). In purposive sampling participants are selected because participants' narratives and perceptions of their experiences can purposefully inform and expand an understanding of the research problem

(Strydom & Delpont, 2011:392). In this study, participants were purposively chosen because they are in remission from cancer, experienced either one or more recurrences. In this research study, with the exception of two participants, all the participants' cancers have metastasised. Yegidis and Weinbach (1996:122) concur that purposive sampling is based on the assumption that this method will provide a researcher access to some specialised insight, or a special perspective, experience, characteristic, or condition that is being researched.

Participants were purposively chosen from the group of patients that had received treatment for cancer more than once, and who were in remission. No distinction was made between cancer type and the duration of disease. Four focus group sessions were conducted (comprising 5 or 6 participants per group), giving a total of 21 participants. Each focus group session last approximately 90 minutes.

Cella, Jacobson, and Lesko (1990:741) maintain that the feasibility of the study must be considered in the context of collaboration with medical oncology personnel. In line with the recommendations of Strydom (2005a:207,208), several experts, oncologists as well as social workers, were consulted to explore the anticipated value of this study. Strydom and Delpont (2011:395) reiterate that in qualitative research, the purpose of interviewing other experts in the field is to identify themes for further investigation, or to do a valid literature research with the objective of verifying research findings. As indicated in chapter 1, the researcher interviewed oncologists and social workers.

The researcher adhered to the criteria for sampling when she contacted those patients who were at that time in remission. The aim of the research study was explained, as well as what was expected from them. They were invited to participate voluntarily in the research study. For this research, the sampling criteria were set as follows:

- Participants had to be proficient in English. A primary constraint in conducting focus groups is that the facilitator must understand the language (Greeff 2005:309). The researcher is proficient only in Afrikaans and English.
- Participants had to be adult patients who have been in remission for at least one year and who have had one or more recurrences of cancer. The Sandton Oncology Clinic mainly provides treatment to adults. Chart 1 reflects the age range of the sample.
- No distinction was made between cancer types. Different types of cancer have different rates of relapse (Coleman, 2006:65); and recurrences are influenced by the stage and aggressiveness of the cancer, and other co-morbidities that influenced treatment. Table 5 reflects the cancer types in the sample.
- No distinction was made regarding participant's gender or race.
- Participants who have experienced one or more relapses or recurrences were selected. Table 5 indicates the amount of recurrences that each participant experienced.

Over a period of one month, the researcher perused the medical files of patients who, post treatment, consulted the radiation oncologists. Patients who are in remission were invited by the radiation oncologist to participate in the study. If patients showed interest, the researcher contacted them and explained the goal and objectives of the study. Purposive sampling was used to frame a sample of patients whose recurrent cancer was at that time in remission. From this list, the researcher contacted patients until a sample of 30 participants was collected. However, at the times when the focus groups interviews were held, only 21 participants were available to participate in the study. The reasons for some patients not participating in the focus groups were: one participant was involved in a car accident on the way to the focus group; one participant's travel arrangements fell through; three participants received the news that their cancer recurred and had to start active treatment; and one participant excused himself due to fatigue experienced. The

researcher argued that, for those participants' whose cancer recurred, their focus shifts to entering treatment again, thus disqualifying them from participation in this study. Patients who were on maintenance medication were included, because the objectives of these treatments are to maintain remission. Some treatments, for example, hormone manipulation treatments, are prophylactic. The researcher did not encounter any patients who were unwilling to participate in the research when they were invited. The main reason why patients turned down the invitation to participate was that they were not available on the dates that the focus groups were conducted, for example out of the country for business or holidays, and alternative engagements made on proposed days. All these patients expressed their willingness to participate in other research. The fact that the patients met the researcher during the times that they received treatment, may have contributed to their willingness to participate in the research. The researcher postulates that the main reasons why the patients were so willing to participate in the research are an indication of unmet and unacknowledged needs of patients in remission. This is an indication of a lack of medical and psychosocial support that cancer survivors experience. The patients' willingness to participate in research may also be due to self-transcendence: wanting to give something back to other cancer patients.

### **6.5.3 Data collection methods**

Data was collected by means of focus groups. Focus subjective data reported into the meaning-construal process of patients in remission and offered a method to explore participants' subjective understanding of living in remission. According to Stewart et al. (2007:109) the most common purpose of focus groups in research is to provide an in-depth exploration of a topic about which little is known. In this case, focus groups provided the opportunity for participants, as self-knowing subjects, to speak authoritatively about their perceptions of living in remission. From participants' accounts, the researcher was able to identify common themes and trends. Nieuwenhuis (2007:56)

maintains that in qualitative research the knowledge should emerge out of the local context and should privilege the voice of the “insider” [patient], taking into account what people say, do and feel, and how they make meaning on the phenomenon under investigation [living in remission]. In line with the suggestions of Fouchè and Delport (2011:66), participants’ natural language was used to obtain a genuine understanding of their world. Data was obtained from participants’ verbal accounts of their experiences of living in remission, and provided opportunity to explore participants’ attitudes, behaviours, and experiences.

At the root of in-depth interviewing, which focus groups provide, is an interest in understanding the experience of other people and the meaning they make of that experience (Seidman, 1998:3). After reiterating the objectives of and the methodology of the research study, the researcher emphasised her role as researcher and not social worker, and asked participants to introduce themselves, and relate their cancer history to the group. This confirmed that all participants had experienced one or more recurrences, or that they have been diagnosed with another primary cancer. Participants talked easily about their experiences and showed a genuine interest in other participants’ accounts, asking questions and adding their own experiences. The ease with which participants reported their cancer history may be due to being in remission, and having had to tell the history to numerous medical professionals. Another contributing factor may be that they adapted to living with the incurable status of their cancer. Participants may also not have been given a previous opportunity to express emotions relating to remission. Various participants reported that the response of family members and friends to treatment after a recurrence was along the lines of “you have coped with cancer and the treatment before; therefore you will do it again.” Various participants reported that in spite of good support, they perceive that family, friends, and many members of the oncology team did not understand the emotional implications of living with incurable cancer. The attitude of some of the oncology team members was “You have been through this, therefore you know what to

expect.” Some participants reported feeling pressurised to present that they were living a normal life. This ‘normal’ is according to the carers’ perception and not necessary in line with the ‘new normal’ that participants’ had to create due to their living in remission.

Focus groups are group interviews where the researcher creates a tolerant environment that encourages participants to share perceptions, points of view, experiences, wishes and concerns, without pressurising participants to vote or reach consensus (Greeff, 2011:360). The purpose of focus group interviews is to promote self-disclosure among participants. The objective is to learn what participants really think and feel (Krueger & Casey 2000:7). The researcher observed that after focus group interviews, many participants lingered and, over refreshments, continued to share their experiences, which the researcher postulates were the result of feeling safe in the group. Stewart et al. (2007:39) emphasise that the key to successfully using focus groups in social science research is ensuring that their use are consistent with the objectives and purpose of the specific research study. In this research study, using focus groups as a data collecting method offered a way to gain insight into the challenges and issues faced by cancer patients who are in remission.

In line with the ethical principles, permission was obtained for the focus groups to be videotaped and transcribed. Videotaping the focus group interviews offered the researcher the opportunity to repeatedly, observe participants’ behaviour. The focus group interviews were conducted at the Sandton Oncology Center. The focus group interviews were conducted over weekends when no other patients were present. This provided group members with privacy. Conducting the interviews when no other patients or oncology team members were present safeguarded against the focus group sessions interrupted. The only other people present at the venue were, the researcher’s husband, who videotaped the proceedings, and the security staff. The researcher beforehand informed the security staff about the focus groups. The researcher, in her role as social worker, also conducts support

groups on some Saturdays. Therefore, the security staff had no need to investigate and interrupt the focus groups interviews.

From participants' descriptions, the researcher identified beliefs and values that relate to the research topic, and reflect participants' realities. This data was then used to generate themes and categories for analysis and interpretation.

Stewart et al. (2007:42,43), identify seven advantages that focus groups provide relative to other types of data collection. Of these, the researcher identified the following advantages to be applicable to this research study:

- Focus groups provided data from a group of people faster than would be the case if individuals were interviewed separately. Focus groups could be assembled on short notice.
- Focus groups allowed the researcher to interact directly with participants. This provided opportunities for the clarification of responses, for follow-up questions, and for the probing of responses. It was possible for the researcher to observe nonverbal responses such as gestures, smiles, frowns, and so forth, which carried information that supplemented and, on occasion, even contradicted the verbal responses.
- The open response format of a focus group provided opportunity to obtain large and rich amounts of data in participants' own words. The researcher could obtain deeper levels of meaning, make important connections, and identify subtle nuances, both in expression and meaning.
- Focus groups allowed participants to react to, and build on the responses of other group members. The synergistic effect of the group setting, probed participants to respond to, and report data and ideas, which may have remained uncovered in individual interviews. Differences in opinion among group members also helped the

researcher to identify how and why individuals embrace or reject particular ideas or views.

The focus group interview guide was designed with specific open-ended questions to direct participants towards the aim of the research study. Greeff (2011:370) suggests that the most distinctive feature of a focus group is the open-ended question technique. Seidman (1998:11) purports that open-ended questions applied in interviewing focus on the subjective experiences of participants. An open-ended question establishes the territory to be explored while allowing participants to take any direction he or she wants. Probing questions helps to clarify certain aspects of a subject's experience. Furthermore, it also encouraged participants to give their own assessment of how they cope with living with cancer. This provided free-flowing narratives during the focus groups. Participants were eager to share their experiences and hear about the experiences of other participants. The researcher experienced that once participants started talking, most questions were covered in participants' discussions. Participants were eager to share their experiences and hear about the experiences of other participants. It became clear that many participants had a need to reflect about their experiences and the benefits they derived from cancer and remission. Feedback from participants after the focus groups was that they found the group valuable. This is an indication that patients in remission need social work interventions and support groups.

Themes were used to explore participants' subjective experiences. Seidman (1998:11) affirms that people's behaviour becomes meaningful and understandable when placed in the context of their lives (in this research study, living in remission), and the lives of those around them (in this research study, the family and other social attachments). Without context (in this study the cancer history, support systems, and the integration and assimilation that the cancer is incurable), there is little possibility of the meaning of an experience.

#### **6.5.4 Method of data analysis**

Creswell (2005:190) depicts the process of data analysis and interpretation as follows: "...making sense out of text and image data. It involves preparing the data for analysis, conducting different analyses, moving deeper into understanding the data and making an interpretation of the larger meaning of the data". Nieuwenhuis (2007:99) posits that in qualitative data analysis, the researcher tries to establish how participants make meaning of a specific phenomenon by analysing their perceptions, attitudes, understanding, knowledge, values, feelings, and experiences. In focus group research, the depth and intensity of data analysis is determined by the purpose of the study. Greeff (2011:373) suggests looking for trends and patterns that reappear within a single focus group or among various focus groups. The complexity of group interaction and group dynamics is added to focus group analysis. In analysing focus group data, the researcher should consider the words, context, internal consistency, frequency of comments, extensiveness of comments, specificity of comments and what was said and what was not said, as well as finding the "big idea". The transcribed data from the focus groups were used to identify themes, and subthemes. Data analysis was done according to the six steps of data analysis that Creswell (2014:197 - 200) proposed:

- Organising and preparing data for analysis

Once the focus groups were recorded and notes taken, the focus group interviews were transcribed. The focus groups were conducted in English.

- Reading through data and recording general thoughts

Here, the objective was to obtain a general sense of the information and to reflect on its overall meaning. The researcher read the transcriptions several times in order to identify data that was significant to the research study.

- Analysis and coding process

An inductive reasoning process was followed to apply the knowledge gained from the research study. The inductive approach emphasises developing insights and generalisations out of the data collected (Neuman 2000:122). In qualitative research, the researchers rarely know the specifics of data analysis when they begin a research study. Thus, from the data collected, the researcher aims to organise the data into a coherent framework of interlocking concepts. Therefore qualitative researchers look for patterns or relationships. The data analysis begins early in the research and the results of this early analysis guide subsequent data collection. Coding involved sorting data into categories and labelling those categories. The categories identified for this research study are meaning-construal associated with attribution, meaning-construal associated with appraisal, and meaning-construal associated with re-appraisal.

- Description of the people as well as the categories and themes for analysis

Description involves information about participants' cancer history. The researcher used the coding to generate themes for the categories and identified theme connections.

- Representation of data

The researcher's findings are presented in chapter 7.

- Interpretation of data

The findings of the data are represented in chapter 7, an intervention strategy is proposed in chapter 5, and the recommendations are presented in chapter 8.

The focus group sessions were videotaped, transcribed, and then analysed. The researcher's husband acted as research assistant to manage the recordings. He was introduced to the participants prior to the start of each focus group, and he monitored the recording from an adjacent office in a non-invasive manner. He was also informed about the necessity to maintain confidentiality.

## **6.6 TRUSTWORTHINESS**

Since the researcher was working independently during the data-collecting process, the authenticity of data was important. Strandberg (2009:283) infers that in qualitative research, trustworthiness refers to credibility – which refers to enquiry of the study, applicability – which refers to the result of the study, and consistency – which refers to the dependability of the study. The researcher adopted Lincoln and Guba's (1985) model on trustworthiness, as discussed in de Vos (2005:346).

- **Credibility**

Qualitative researchers strive to present a true picture of the research topic. Qualitative researchers use the term credibility in preference to internal validity (Shenton, 2004:63,64) Merriam as quoted by Shenton (2004:64), purports that credibility deals with the question "How congruent are the findings with reality?" Participants participated voluntarily. From the participants' narratives, the researcher identified beliefs and values that related to the research topic. The researcher stated the goal and objectives of the research when participants were invited to the research study. These parameters were reiterated at the beginning of each focus group interview. De Vos (2005:346) infers that if a researcher adheres to the parameters of the setting, population and theoretical framework, the research will be valid.

Shenton (2004:69) adds that a detailed description of the research topic promotes credibility "...as it helps to convey the actual situations that have

been investigated and, to an extent, the contexts that surround them. Without this insight, it is difficult for the reader of the final account to determine the extent to which the overall findings ‘ring true.’” This study provided a description of the participants’ narratives of living with recurrent cancer.

The researcher is known to participants. She had previous contact with and will have continued contact with participants on those occasions when they have follow-up consultations with the radiation oncologists, or when they experience a need to consult with the social worker, or when the radiation oncologists refer a patient. This left the potential threat of researcher bias, as described in chapter 1. Researcher tried to minimize researcher bias by preparing herself for each focus group interview; by wearing the hat of a researcher and not of a social worker and by being as objective as possible during the focus group interview.

- Transferability

To allow transferability, qualitative researchers provide sufficient information for readers to decide whether the findings can be justifiably applied to another setting. Qualitative researchers use the terms transferability or applicability in preference to external validity/generalisability (Shenton, 2006:63,64).

Mouton (2005:118) infers that whenever a researcher draws a sample from a target population, and then when the results are available, generalises from the sample to refer back to the population, the researcher is employing inductive generalisation. Interviewing a number of participants enabled the researcher to connect participants’ experiences and check the comments of one participant against those of others. Creswell (2003:59) defines inductive reasoning as “a reasoning process where one uses the specific observations to propose generalizations that apply to the whole”. This research study endeavours to generalise the observed meaning-construal of participants back to the target population, namely patients in remission. This research ties into a body of research regarding cancer survivorship and meaning theory.

Qualitative researchers accept that different researchers, or a single researcher using different measures to measure the same constructs, will get distinctive results (Neuman, 2000:170). In qualitative research, the uniqueness of a research study within a specific context diminishes the possibility of replicating the study exactly in another context (Creswell, 1994:159). In the researcher's opinion, the results of this study can be transferred to patients living with similar life-threatening diseases.

- Dependability

Qualitative researchers use the terms dependability or consistency in preference to reliability (Shenton, 2006:64).

The researcher, participants, the measuring instrument, and the research context all influence the reliability of observations (Mouton & Marais, 1990:81). "Reliability means dependability or consistency" (Neuman, 2000:164), and in order to ensure reliability a pilot study was conducted prior to the focus group interviews with 3 participants. Royse (1995:172) adds that the purpose of a pilot study is to determine whether relevant data can be obtained from participants.

Qualitative researchers deal with the reliability issue by using purposive sampling based on knowledge of those being studied, review of the literature related to the participants and using teams of observers (Cherry, 2000:65). Two of the strategies that Creswell (2003:196) proposes are member checking and peer debriefing. The researcher offered a follow up group session after data interpretation. This offer was not taken up by any of the participants, although the participants showed continuous interest in the progress of the research study. As described in chapter I, the researcher consulted with other professionals prior to the focus group interviews. These consultations with social workers and oncologists confirmed the feasibility of the research study.

- Conformability

To achieve conformability, qualitative researchers strive to demonstrate that the findings emerged from the data and not the researchers' own predispositions. Qualitative researchers use the term conformability in preference to objectivity (Shenton, 2004:63,64).

Active listening and observation of nonverbal aspects gave the researcher a sense of participant's authenticity. Because the research is concerned with participants' understanding of the experience, in this context, deriving meaning while living in remission, the authenticity of what participants reported made it reasonable for the researcher to have confidence in its validity for participants (Seidman, 1998:16 - 19). The researcher believes that participants gave credible, fair, honest, albeit subjective, accounts of meaning-construal while living in remission.

To the researcher's knowledge, no other research has yet been conducted to investigate meaning-centeredness or meaning-construal with patients with recurrent cancer.

## **6.7 PILOT STUDY**

Bless et al. (2006:184) define a pilot study as follows: "A small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments, and analysis are adequate and appropriate". The purpose of a pilot study in qualitative research is to determine whether the relevant data can be obtained from the respondents (Royse, 1995:172). The pilot study provided the researcher with the opportunity to test the research procedures and interview schedule on a small scale, before embarking on the full research study.

During the pilot focus group interview, one of the three participants was, at different times, diagnosed with 2 different primary cancers. She had not

experienced any recurrences. Her experience differed significantly from those participants who had experienced recurrences, especially with regards to hope. Her hope for a cure was realistic. There was no evidence of disease of either of the cancers. Therefore, sampling was delineated to the patients who had experienced recurrences. The participants in the pilot study did not form part of the main study. This is in line with the suggestions Yin (2014:240) that the data of the pilot study not be included in the formal case study.

### **6.7.1 Literature study**

The pilot study commenced with a literature study. This is in accordance with the proposition of Delport, Fouchè and Schurink (2011:302) that a review of literature contributes towards a clearer understanding of the nature and meaning of the problem that has been identified. The literature review assists the researcher to substantiate the data by literature. Key findings of the literature study are described in chapter 8.

### **6.7.2 Pretesting**

In line with the advice of Stewart et al. (2007:66), an interview schedule was used. Pretesting of the interview guide provided an opportunity to determine whether the wording of questions was appropriate, to determine whether questions would elicit discussions, and to identify questions that were not easily understood. Another suggestion is to discuss the guide with experts in the field and with other members of the research team (Greeff, 2005:308). Prior to pilot testing, the proposed interview guide was discussed both with Mrs Wilna Burgers, social worker, and with Dr Sally Bairstow, radiation oncologist at Sandton Oncology Centre.

## **6.8 ETHICAL ISSUES**

Strydom (2011c:114) infers that ethical guidelines serve as standards and a basis upon which a researcher should evaluate his or her conduct. Gravetter

and Forzano (2009:98) caution that research ethics must not be confused with morality; research ethics concerns the proper conduct of researchers. They define research ethics as the responsibility of researchers to be honest and respectful to all individuals who are affected by their research studies or their reports of the studies' results. Researchers are usually governed by a set of ethical guidelines that assist them to make proper decisions and choose proper actions. Strydom (2005c:67 68) points out that no ethical code for research exists in South Africa and suggests that The Code of Ethics of the National Association of Social Workers in the United States can best serve as guideline for social work research. Ross and Deverell (2010:70) suggest that researchers in health oncology social work adhere to the guidelines for research involving human participants that the Medical Research Council (2001) provides. The Ethics Committee of the Faculty of Humanities of the University of Pretoria granted ethical approval for this research.

The researcher strived to uphold the following ethical issues that were considered relevant to this research study:

### **6.8.1 Informed consent**

Neuman (2006:135) states that informed consent involves getting a statement, usually written, from participants before the research study begins. This statement should explain the aspects of the study, and should ask for participants' voluntary agreement to participate in the research study. According to Mark (1996:4), the principle of informed consent is at the heart of efforts to ensure that all participation is voluntary. Individuals participated on a voluntary basis and informed consent, with specific emphasis on confidentiality, was obtained prior to their inclusion in the study. Written consent was secured from each participant. Participants were provided with sufficient information about the study to allow informed consent. The goal, objectives, and risks of this study were explained to patients when they were invited to participate. Participants were also informed of the use of data

recording instruments (De Vos, 2005:335). At the beginning of each focus group interview, the researcher reiterated that participation was voluntary; she also re-stated the goals and objectives of the study.

Participants were informed that they could withdraw from the study at any time without any consequence. Participants received no financial compensation from the researcher for participating in the research study. The researcher maintained an awareness of participants' health, and participants were not coerced to attend the focus group meetings if they did not feel well. This was illustrated in accepting a participant's withdrawal from the research because he experienced post treatment fatigue. This links with the intention of avoiding deception of participants as well as the aim of causing no harm to participants (Ross & Deverell, 2010:70; Strydom, 2011c:115).

### **6.8.2 Avoidance of harm**

Within the context of qualitative research, harm refers to physical and/or emotional harm, that can be inflicted on participants during the research or harm that might manifest after the research study is completed. It is the researcher's responsibility to ensure that before participants engage in a research study, participants are thoroughly briefed of the potential impact of the research study, and by implication of any potential harm that they may experience (Strydom 2011c:115). Participants should be exposed to minimal risks, and the researcher should protect the safety and dignity of participants (Ross & Deverell, 2010:70).

The researcher ensured that participants were competent to give informed consent by excluding vulnerable patients (for instance, patients whose cognitive functioning is impaired). Participation in this study did not involve any physical harmful situation. Emotional harm is more difficult to predict, so debriefing was offered to the all participants. There was no need to refer any participants to a counsellor.

### **6.8.3 Deception of participants**

Deception involves intentionally misrepresenting facts or intentionally withholding information, in order to coerce potential participants into participating in a research study (Strydom, 2011c:118,119). Neuman (2006:135) advises researchers to follow the principle of voluntary consent, namely, to never forcing anyone to participate in any research. The researcher informed participants of the goal and objectives of the study. Participants were also informed about the use of recording, and videotaping procedures, the analyses and the publication of the findings in a scientific journal.

### **6.8.4 Privacy, confidentiality and anonymity**

Researchers have the right to collect data through interviewing people but not at the expense of participants' right of privacy (Mouton, 2001:239). Privacy implies the element of personal privacy, confidentiality indicates the handling of information in a confidential way, whilst self-determination implies that individuals have the right and competence to evaluate available information and make their own decisions (Strydom, 2011c:119). The Medical Research Council (2001), as cited in Ross and Deverell (2010:70), advises that researchers should protect the confidentiality of participants by ensuring:

- privacy during participation
- confidentiality of participants' identities and responses
- securing archives for raw data or destroying raw data after a period of time designated by a research ethics committee
- removing of unique identifiers from shared data.

In line with the above suggestions and the suggestions of Strydom (2011c:119) and Mark (1996:48), the researcher adhered to the principles of privacy and confidentiality in the following ways:

- by allocating a number to each participant (known only to the researcher)
- by respecting participants' self-determination rights through the provision of adequate information in order for them to give informed consent to participate in the research
- by keeping confidential all information about participants
- by recording only information that was applicable for this research study
- by controlling access to all information. People who have access to the information are all bound by ethical codes to respect the confidentiality of participants
- by emphasising at the onset of each focus group that the members should also adhere to the principle of confidentiality
- by conducting the focus groups during week-ends, when no other staff members or patients were in attendance at the Sandton Oncology Center
- the final report will only report the interpretation of the research data,
- by archiving the data at the Department of Social Work and Criminology of the University of Pretoria.

Anonymity could not be guaranteed in this study. True anonymity was also not possible because focus groups necessitate face-to-face interaction. When they were recruited for the study, participants were informed of the possibility that they may have met other participants previously. As anticipated, some participants have met during their treatment, or during follow-up visits. Some participants befriended other group members and kept in contact.

During one focus group focus group session, a mother and daughter (both cancer survivors) attended.

### **6.8.5 Debriefing**

Counselling should be offered in case of potentially sensitive or invasive research that can evoke feeling of distress or cause emotional trauma (Ross & Deverell, 2010:70). Following the focus groups, the researcher debriefed all participants. The researcher offered a debriefing group session to all participants, but none of participants took up this offer. The majority of the participants verbalised that they found the focus group interviews beneficial. The researcher observed no need for debriefing, but still debriefed the participants at the end of the sessions. On the contrary, various participants thanked the researcher for the opportunity to participate in the focus groups and expressed that it had been a meaningful experience for them. The researcher thus comes from a known and trusted environment.

### **6.8.6 Action and competence of researcher**

Where sensitive investigation is involved, researchers must ensure that they are competent and adequately skilled to undertake the proposed research (Strydom, 2011c:123). In qualitative research, researchers interpret what they observe, hear, and understand. Therefore, the researchers' interpretations cannot be separated from their own background history, context, and prior understanding (Fouchè & Delpont, 2011:65). This researcher is an experienced social worker and has completed the theoretical study of research methodology required to conduct this study. She works exclusively with oncology patients. Her caseload includes a range of patients including those that receive treatment for the first time, those that receive treatment because of a recurrence or another primary tumour, and those who are cancer survivors. Researcher bias cannot be completely excluded because the participants and researcher have met professionally on previous occasions. Therefore, interpretations of data will be influenced by this information. The researcher will strive to uphold objectivity and refrain from making value judgements (Strydom, 2011c:124). The researcher focused on the participants' unique and personal perceptions with an awareness of and

respect for the cultural differences of each participant. The researcher anticipated having future contact with the participants when they have follow up visits with the oncologist, or when the oncologist refers them for counselling, or when a participant initiates counselling. There was no need to refer any participants to a counsellor.

#### **6.8.7 Release of findings**

Where sensitive investigation is involved, researchers must ensure that they are competent and adequately skilled to undertake the proposed research (Strydom, 2005c:63). The researcher will focus on the participants' unique and personal perceptions with an awareness of and respect for the cultural differences of each participant. The researcher anticipates having future contact with the participants when they have follow up visits with the oncologist, or when the oncologist refers them for counselling, or when a participant initiates counselling. The findings will be released in the form of a dissertation, available at the library of the University of Pretoria. The results will also be shared with the Sandton Oncology Clinic and other professional in the form of a workshop. The study has already been shared recently at an international oncology conference, the South African Society of Clinical and Radiation Oncology (SASCRO).

#### **6.9 SUMMARY**

This chapter discussed the methodology followed. A qualitative research design was chosen because it provided the researcher with the opportunity to gain a better understanding of the experiences and the challenges that remission imposes on participants. Focus groups were used as the data collection instrument. Data was analysed and categorised in themes and sub-themes. The ethical aspects were considered and discussed.

The empirical findings will be discussed in the next chapter.

## CHAPTER 7

### 7 EMPIRICAL RESEARCH FINDINGS

#### 7.1 INTRODUCTION

This chapter will present and discuss the research findings. The empirical investigation was guided by the following research question: “**Does meaning-centeredness play a role in adult cancer patients in coping with remission?**” The researcher’s rationale for conducting this study was based on the existentially-orientated proposition that life has meaning under all circumstances, including adverse events. The researcher acknowledges that all people are able to derive meaning in their lives, but in this research study, the focus is on an adverse event, namely remission.

The thematic analysis identifies the relevant experiences, attitudes, and insights that participants reported that enabled them to integrate the knowledge and demands of living with incurable cancer and to derive meaning in their lives, in spite of suffering, as well as an awareness of the transitoriness of life. Different themes and sub-themes were identified in this regard, verbatim quotes are used to support these themes, and literature is used to substantiate these findings.

This qualitative research study was conducted at the Radiation Clinic of the Sandton Oncology Center, in Morningside. Four focus group sessions were conducted to gather data (comprising 5 to 6 participants per group), with a total of 21 participants. The research sample was drawn from the patients who were at the time that the focus groups were conducted, in remission. An interview guide was used to guide the focus groups and a video recorder was used with the permission of participants. Each focus group interview lasted approximately 90 minutes.

Participants reported their unique experiences of living in remission and meaning-construal. These subjective data reported from participants as self-

knowing subjects, were used to generate themes and sub themes for analysis. In qualitative research, data are in the form of words, which are inexact, diffuse, and context-base. Words have different meanings to different people in different situations (Neuman, 2003:419), therefore, the researcher asked for clarification if a participant's remark was unclear.

Since the researcher was working independently during the data-collecting process, the authenticity of data was important. The researcher therefore adopted Lincoln and Guba's (1985) model on trustworthiness, as discussed in de Vos (2005:346).

The researcher, participants, the measuring instrument and the research context affect the reliability of observations (Mouton & Marais, 1990:81). Participants know the researcher. She had previous contact with, and will have continued contact with participants on those occasions when they have follow-up consultations with the radiation oncologists, or when they experience a need to consult with the social worker, or when the radiation oncologists refer a patient. "Reliability means dependability or consistency" (Neuman, 2000:164), and in order to ensure reliability a pilot study was conducted prior to the focus group interviews. Royse (1995:72) adds that the purpose of a pilot study is to determine whether relevant data can be obtained from participants. Qualitative researchers accept that different researchers, or a single researcher using different measures to measure the same constructs, will get distinctive results (Neuman, 2000:170). In qualitative research, the uniqueness of a research study within a specific context diminishes the possibility of replicating the study exactly in another context (Creswell, 1994:159).

Active listening and observation of nonverbal aspects gave the researcher a sense of participant's authenticity. Because the research is concerned with participants' understanding of the experience, in this context, deriving meaning while living in remission, the authenticity of what participants reported made it reasonable for the researcher to have confidence in its

validity for participants (Seidman, 1998:16 -19). The researcher believes that participants gave credible, fair, honest, albeit subjective, accounts of meaning-construal while living in remission.

The researcher relied on knowledge gained from literature study to generate themes according to which the data was coded. By doing so, the researcher stated the theoretical parameters of the research, and demonstrated how this research study ties into a body of research. Mouton (2005:118) infers that whenever a researcher draws a sample from a target population, and then when the results are available, generalises from the sample to refer back to the population, the researcher is employing inductive generalisation. Interviewing a number of respondents enabled the researcher to connect participants' experiences and check the comments of one participant against those of others. The research methods are described in detail in the previous chapter.

## **7.2 GOAL AND OBJECTIVES**

The goal of this research study was formulated as: **To explore meaning-centeredness in cancer patients who are in remission.**

In order to realise the goal the following objectives were formulated:

- to contextualise cancer survivorship, specifically focussing on remission as a field of study
- to provide a broad theoretical overview of social work in oncology
- to explore meaning-centeredness in adult cancer patients in remission at the Radiation Oncology Unit, Sandton Oncology Centre
- to provide conclusions and recommendations to social workers for consideration during intervention with cancer patients who are in remission
- to provide conclusions and recommendations as well as to heighten the awareness of the oncology team regarding patients who are in remission

- to create awareness of the role of the oncology social worker.

### **7.3 EMPIRICAL FINDINGS**

The findings of the study are presented according to the following outline:

Section 7.3.1: A biographic profile of participants, including a profile of their cancer history.

Section 7.3.2: A thematic analysis of the themes and sub-themes that emerged from the data analyses. Each theme and sub-theme will be discussed and responses of participants that verify the findings will be quoted. The findings will also be substantiated with the literature.

#### **7.3.1 Biographical profile of participants**

The following is a biographical profile of the sample of 21 participants. Participants are all patients at the Sandton Oncology Centre where they received radiotherapy. The focus groups were conducted at the Radiotherapy Clinic at the Sandton Oncology Centre. This biographical data was obtained from the sample, and due to the sampling method used, it cannot be extrapolated to the research population or the global cancer population.

##### **7.3.1.1 Diagnosis**

Participants with different diagnoses were included in the sample. Due to the sampling method utilised, not all cancers could be represented in the sample. The demands of remission may differ due to the type of cancer, treatments received, side effects and late-effects, other co-morbidities, and social circumstances. Deriving meaning from the cancer experience is not dependent on cancer type; it is a basic human need (Frankl, 1985:121; Weinstein, Ryan & Deci, 2012:Kindle location 2861). Referring to various authors, Park (2012:Kindle location 13505), reports that efforts to make meaning out of their cancer experience is a near universal experience for

cancer survivors. The sample is not intended to indicate whether certain cancers display a higher tendency to recur. The sample is also not an indication of the most common cancers diagnosed. The criteria for the sample were patients who had experienced one or more recurrences, or who were diagnosed with another primary cancer. After the pilot group was conducted, the criteria became having experienced a recurrence, regardless whether another primary cancer was diagnosed.

Table 8: Diagnosis of participants

**n=21**

<b>Diagnosis of first primary</b>	<b>Participants</b>	<b>Male</b>	<b>Female</b>
Brain	2	2	
Breast	7		7
Endometrium	1		1
Lymphoma	1		1
Melanoma	1	1	
Oesophagus	2	2	
Ovarian	5		5
Prostate	1	1	
BCC (skin)	1	1	
<b>Total</b>	<b>21</b>	<b>7</b>	<b>14</b>

*Table 8: Diagnosis of participants*

One participant was diagnosed with endometrium cancer and later with breast cancer as another primary cancer. Yet another participant was diagnosed with ovarian cancer and later on with breast cancer. Another participant had been diagnosed with three primary cancers, over the years, ovarian cancer, colon cancer, and lung cancer. This is unusual and raises questions regarding the onset of treatment related cancers. This issue was never raised in the focus group interviews and is beyond the scope of this research study, but is a possible recommendation for future research.

### 7.3.1.2 Remissions experienced

This table only indicate that cancer has the tendency to metastasise, and therefore highlights the uncertainty which cancer survivors live with. In this sample, participants' remission history at the time of the focus groups is presented in table 9 below:

Table 9: Dates of recurrences that participants experienced

**n=21**

Participant	Primary diagnosis	First diagnosis	Remission	Date of recurrences
1	Brain	2004	2	2005
2	Brain	2006	2	2009
3	Breast	1992	2	2009
4	Breast	2000	3	2008; 2010
5	Breast	2003	3	2005;2008
6	Breast	2006	2	2009
7	Breast	2006	3	2008; 2009
8	Breast	2006	3	2009; 2010
9	Breast	2006	2	2009
10	Endometrium / breast	1987	3	1995 ;2006
11	Lymphoma malt	2002	2	2004
12	Melanoma	2003	2	2004
13	Oesophagus	2009	2	2010
14	Oesophagus	2009	2	2010
15	Ovarian	1988	7	1995; 2001; 2003; 2004; 2007; 2009
16	Ovarian	2000	2	2005
17	Ovarian	2003	7	2003;2006;2007;2008;2009; 2010
18	Ovarian/breast	1993	4	1998; 2002; 2009
19	Ovarian/colon/lung	1991	4	2002; 2007; 2009
20	Prostate	2000	4	2006; 2008; 2009
21	Skin	2001	2	2008

*Table 9: Dates of recurrences that participants experienced*

This table confirms that the period between remissions is not related to a type of cancer. Factors that influence disease progressions include - the stage of cancer at the first diagnosis, treatments available and received at the time of each diagnosis, the patient's ability to tolerate treatments, other co-morbidities

present, and the age and fitness levels of patients. This table indicates the first primary cancer diagnosed. These primaries are not indicated, but participants were included because they experienced recurrences.

The period since the first diagnosis was not considered as a criteria for inclusion in the sample. The aim of this table is to indicate that participants lived with incurable cancer for a variety of time spans.

### **7.3.1.3 Treatment modalities**

Treatment modalities include radiotherapy, chemotherapy, and surgery. Table 10 below provides a summary of participants' treatments. With the exception of one participant, all participants have received radiation therapy. The participant, who did not receive radiation therapy, was referred for consultation. He was advised that radiotherapy was not needed at that stage. Because he was referred for consultation with the radiation oncologist during the time span of sampling, and met the researcher, the researcher included him in the research sample. Three participants have not received chemotherapy. This is not an indication that chemotherapy will not be prescribed in the future. Four participants have not undergone surgery. The sample indicates that even with the same diagnosis, patients do not all receive the same treatment. Treatment choices are impacted by the stage of cancer, the oncologists' (medical and radiation) opinions, the surgeon's opinion, and the patient's choice. This table does not indicate how many times a participant received any of the treatments.

Table 10: Summary of treatment that participants received

n=21

Participant	Primary diagnosis	First diagnosis	Treatment modalities		
			Radio	Chemo	Surgery
1	Brain	2004	X	X	X
2	Brain	2006	X		X
3	Breast	1992	X	X	
4	Breast	2000	X	X	X
5	Breast	2003	X	X	X
6	Breast	2006	X	X	X
7	Breast	2006	X	X	X
8	Breast	2006	X	X	X
9	Breast	2006	X		X
10	Endometrium/breast	1987	X	X	X
11	Lymphoma	2002	X	X	
12	Melanoma	2003		X	X
13	Oesophagus	2009	X	X	
14	Oesophagus	2009	X	X	
15	Ovarian	1988	X	X	X
16	Ovarian	2000	X	X	X
17	Ovarian	2003	X		X
18	Ovarian / breast	1993	X	X	X
19	Ovarian, colon lung	1991	X	X	X
20	Prostate	2000	X	X	X
21	Skin	2001	X	X	X

Table 10: Summary of treatment that participants received

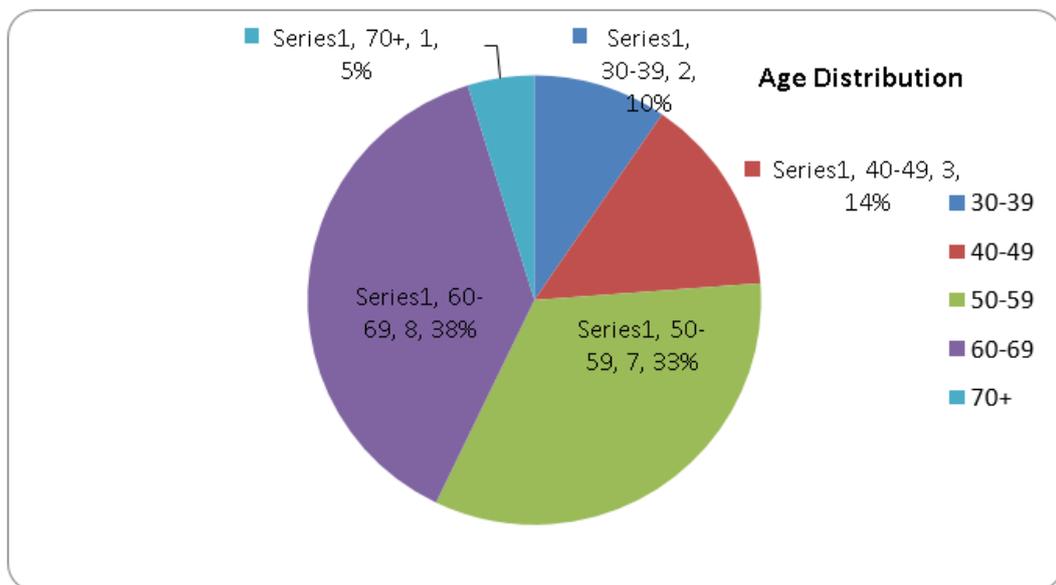
The cancer types represented in this study include cancers of the brain, endometrium, breast, lymphoma, melanoma, oesophagus, prostate, and skin. These cancers fall into the categories of carcinoma, germ cell tumours, gliomas, lymphomas, and melanomas. Not all cancer types or categories were included in the sample. This sample is not intended to indicate a cancer type's tendency to recur. This table does not indicate how many recurrences a participant experienced, only when the cancer was first diagnosed.

### 7.3.1.4 Age of participants

Sandton Oncology Centre offers mainly treatment to adults. Thus, only adults were included in the sample. This sample is not intended to show if people are more prone to cancer at certain ages or if age is an indication for recurrences. The ages of participants are portrayed below in chart 1. The mean age was 56 years and 6 months. The age range was between 38 years and 72 years, with the largest majority, 15 out of the 21 participants, falling in the range between 51 years to 67 years.

Chart 1: Age of participants

n = 21



The majority (71%) falls in the age group between 50 years and 69 years. This impact on research findings because the subjective report on meaning-construal comes from an age group referred to as older adults that include the developmental stages of middle adulthood and late adulthood. These developmental stages are characterised by heightening of introspection and reflection. Reker & Wong, (2012:Kindle locations 11472) posit that reflection is needed for meaning-construal.

### **7.3.1.5 Gender of participants**

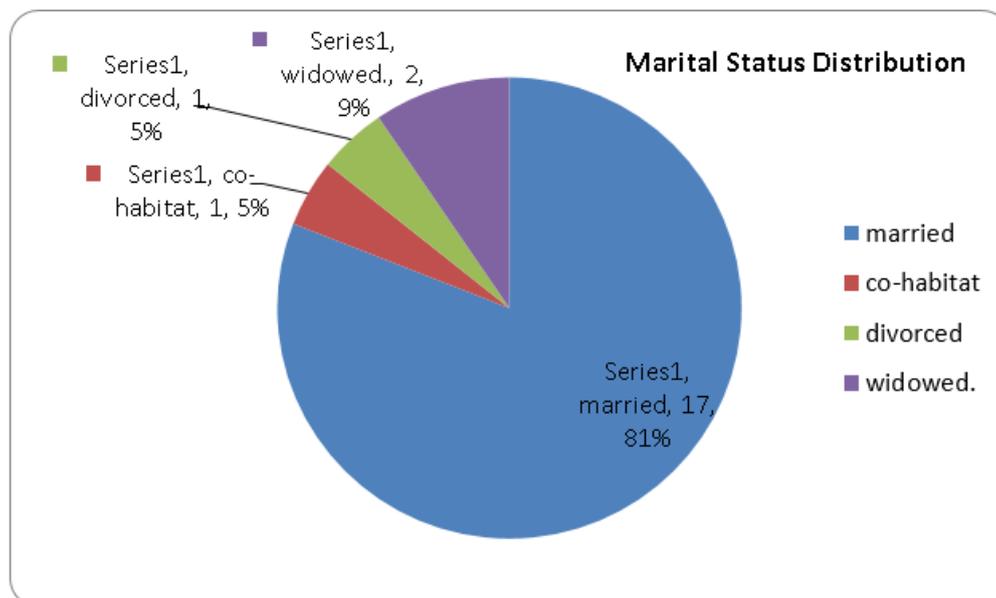
Seven males and fourteen females participated in this research study. The gender representation of the sample does not represent the global incidence statistics. This is due to the sampling method utilised. This information does not indicate that females are more prone to recurrences than males.

### **7.3.1.6 Marital status of participants**

Marital status was indicated, because relationships are important in meaning-construal. All participants reported happy, supportive relationships. In cases where participants were divorced and married again, they are only portrayed as married. Divorce indicated those participants who were divorced and not in a relationship at the time of the focus group. This sample does not aim to represent the marital status of the research population. The marital status of participants is portrayed in chart 2.

Chart 2: Marital status of participants

n = 21



Single persons account for only 14% of this sample. This impacts on findings, because healthy supportive relationships contribute to better coping with cancer. The participants, who are single, reported good support from family and friends.

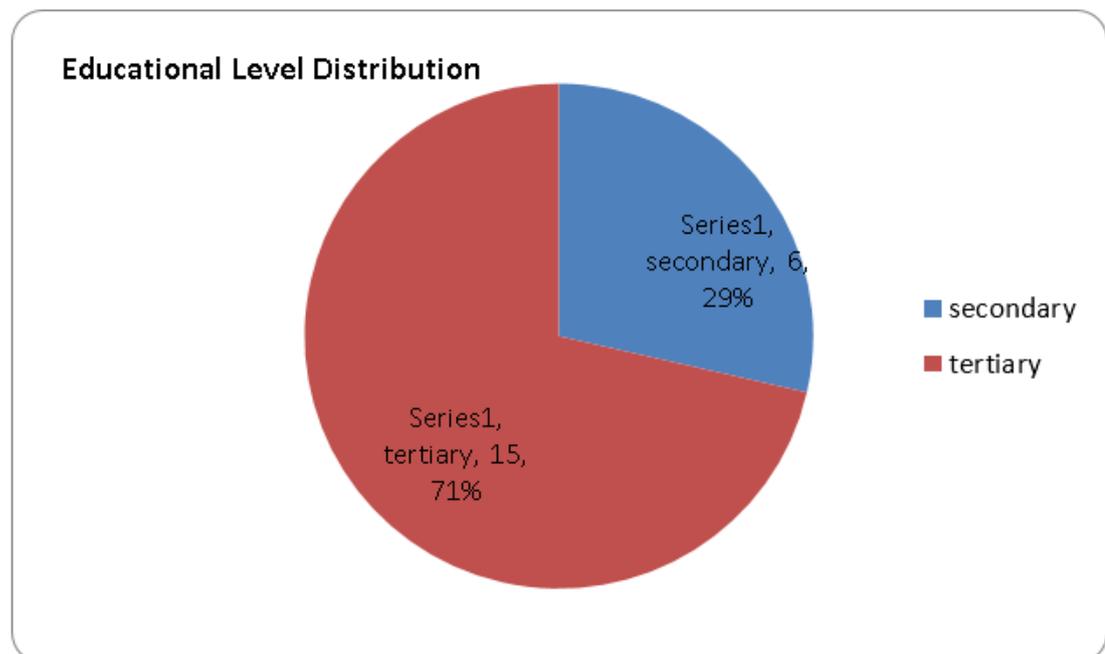
### 7.3.1.7 Academic qualification of participants

This sample is not representative of the population as a whole. Fifteen of the participants received tertiary education and six finished their high school education. Tertiary education referred to university degrees and technical and secretarial diplomas. It was also interesting to note that of participants' children who were independent, the majority received tertiary education. The participants' education may have contributed to their ability to generate a good income and thus they are able to afford private medical care.

Academic qualifications are portrayed in the chart below.

Chart 3: Educational qualifications of participants.

n=21



#### 7.3.1.8 Dependants

In line with the literature, this study confirms that family is a priority in cancer patients' lives. Family can be supportive and nurturing, or not comprehending the demand of living with incurable cancer, or be demanding on the emotional and financial resources of a patient, or provide patients with an awareness that they still have life tasks to fulfil. Eight participants reported that they have children who are dependent upon them for school or tertiary education. One participant has an elderly parent who is dependent on her. One participant reported a spouse, that is a cancer survivor, and who is not a dependant. One participant reported that her late husband died of cancer. Three participants do not have children, due to cancer treatment. Two of the participants are mother and daughter, who, at different times of recurrences, were dependent on each other.

All participants who have children dependent on them, place a high priority on providing their children with tertiary education. Providing children with tertiary

education is a goal for participants and, in turn, goal striving contributes to meaning-construal.

#### **7.3.1.9 Language and race of participants**

All participants were fluent in English. The focus groups were conducted in English. One participant was Afrikaans speaking, and one participant was Zulu speaking. The geographic location of the Sandton Oncology Centre is a possible reason why the majority of participants were English speaking.

Only one participant was Black all the other participants were White. As a private oncology centre, the Sandton Oncology Centre treats patients of all different racial groups. The above racial presentation of patients is not evidence of the racial presentation of patients treated at the Sandton Oncology Centre.

#### **7.3.2 Thematic analysis**

The meanings that one derives from an experience are the end-results, or the changes that occurred from the meaning-construal process (Park, 2010: 260). The researcher infers that patients who are in remission will also tend towards meaning-seeking and meaning-construal behaviour. The following are the common themes that were reflected in the data by participants on how they derived meaning whilst living in remission. These themes and sub-themes are represented in table 11.

Table 11: A summary of identified themes and sub-themes

<b>Themes</b>	<b>Sub-themes</b>
Theme 1: Meaning-construal associated with attribution	1.1 Hope 1.2 Spirituality 1.3 Death awareness and awareness of the transitoriness of life and a foreshortened future
Theme 2: Meaning-construal associated with appraisal	2.1 Benefit-finding 2.2 Growth 2.3 Relationships 2.4 Increased appreciation of life, and prioritising
Theme 3: Meaning-construal associated with reappraisals	3.1 Sense of self 3.2 Sense of coherence 3.3 Assumptive world 3.4 Adapting to the new normal 3.5 Transcendence

*Table 11: A summary of identified themes and sub-themes*

Each theme will be supported by two or more verbatim quotations from various participants and then integrated with the literature to verify the findings.

### **7.3.2.1 Theme 1: Meaning-construal associated with attribution**

Gehlert and Bollinger (2012:127) explain that the attribution theory holds that when one is confronted with events over which one has little control, one attempts to impose control by offering explanations or causes for what happened. Tomer (2012:Kindle location 6507) defines meaning seeking as “the efforts designed to see events, in particular events of our own life, as causally interconnected and therefore less arbitrary.” In the context of this study, causal attribution refers to the meaning-seeking process and includes efforts to integrate one or more recurrences, metastases, or another primary cancer. The most common explanation of recurrences or metastases is that it is the nature of cancer. Often cancer metastasises but in some cases, a secondary cancer may be treatment induced, or some patients experience other primary cancers that are unrelated to the first cancer. This unpredictable

nature of cancer leaves the option of existential attribution. This attribution allows patients in remission to see the “silver lining” (Tomer, 2012:Kindle location 6508), to make sense of remission by discovering positive aspects in living with incurable cancer. Such attribution can contribute to hope and success (Wong, 2011). Wong & Weiner, (1981) as cited in Wong and Wong (2012:Kindle location 15184, 15346), observe that how one interprets and reacts to events, determines how one copes. They purport that insight about life and death, as well as one’s place in the larger scheme of things is needed to discover the meaning of life.

Meaning-construal associated with attribution includes hope, spirituality and death awareness as well as an awareness of the transitoriness of life and a foreshortened future.

### **Sub-theme 1.1: Hope**

The following quotes reflect participants’ experience of hope.

#### Participant 8

“My friend had her cancer 20 years ago, and she is still here...So I...[*that*] it’s another 15 years for me, so Megan [*daughter*] will be in her 20’s. If I am like her [*friend*] - OK then Megan will be OK. You start thinking like that. She will be big enough...” She said earlier .... “She [*Megan*] has a very clear path ahead of her. She knows where she is going. She **is** going to St Anne’s and then she is going to UCT, and after that, she can do what she likes. **But** she has to...Those are her responsibilities to fulfil. She got to do her education. And I want to see that. And I want to see her grow up. And, I had to have those conversations. And I will make sure that...that everybody is very clear, and will, and give that - the commitment to keep her on that path...that is how Megan’s life will be...(Participant 5 interjected: ...*Regardless*) [*participant 8 nodded her head in agreement*] Participant 8 continues “Regardless if I am here. And once that was made, said, all of a sudden I am OK. I am fine. And I am so not afraid to die now. So if I get hit by a bus tomorrow. It is OK because I know Megan is going to be OK. I still want to see her grow up. I want to see her getting married. I want to see her having children...I want to have all that. I still want that.”

#### Participant 13

“I’m not one to preach, but my hope is in God. If He takes me, He takes me, if He heals me, that is His mind.”

#### Participant 19

“I had ovarian, lung cancer and colon cancer and I am...still have [*tumours*] on my head.” In spite of this widely metastasised cancer, this participant hoped that she might benefit from new treatments: “But the odds are getting better every day, because they found new ways.” Earlier in the focus group interview, she remarked, “I want to live. That is it. Basic answer. I wanted to see my children grow up. I wanted to see my grandchildren. And I have two [*grandchildren*].”

#### Participant 20

“My cancer was diagnosed in 2000, prostate cancer, and based on PSA elevation which is the marker, again in 2006, 2008, 2009, and well, we will see where I am now. Later in the focus group, he adds, “I think that we are living in modern times where cancer is treatable. In the old days it wasn’t.”

### **Discussion of findings in sub-theme 1.1**

The remarks by Participant 19 and Participant 20 indicate hope for cure changed to hope for quality of life (Cordoba et al., 1993:60), or that further treatment will prolong life. For Participant 13 hope is rooted in her faith. Hedlund and Clark (2001:309) infer that hope enhances quality of life. They distinguish between generalised hope and particularised hope. In the oncology context, generalised hope refers to conceptual issues, for example, hoping to live life to the full, in whatever time is remaining. Particularised hope is more specific. Particularised hope is expressed in Participant 8 with her hope to see her daughter grow up, and Participant 19 who hopes to see her grandchildren grow up, and that life still offers opportunities.

Meaning can be found in accepting the unavoidable (Havenga-Coetzer, 2003:57). They integrate the experience of remission in the context of a threat to their lives (Kenne-Sarenmalm et al., 2009:1119). They have to assimilate

the knowledge of the incurable status of their cancer. They live in uncertainty and a sense of a foreshortened future (Park 2012:Kindle location 13424). The remark of Participant 20 is in line with literature that indicates that patients have to build hope that is proportional to the prognosis of their cancer (Kneier et al., reviewed 2010). The hope for cure changed to the hope for manageability of the cancer. Life has potential meaning under all circumstances (Shantall et al., 2002:24). A meaning-centered life can thus assist patients to take their focus away from the demands of remission, and focus on what life still offers in each patient's unique circumstances. It implies that patients can choose their attitude towards their circumstances of living in remission, and can create a mind-set of 'living with cancer' instead of 'dying of cancer'. This conclusion is in line with the hypothesis of Wong (2011) that the extent to which individuals report having achieved a sense of acceptance or of having come to terms with life-events has also been considered meanings made.

Participant 8 accepts that of her role as mother exists and continues. This provides her with a sense of purpose. This is in line with Scioli and Biller (2010:63 - 66) observations that reasonable hope facilitates self-discovery, resulting in people prioritising, exploring their abilities and the options available to them. They use this information to forge a sense of purpose in life.

Contact with another long-term survivor, helped Participant 8 to reframe her cancer experience. Cordoba et al. (1993:62) purport that those patients who reframe the cancer experience into a more positive experience, report spiritual enrichment, increased appreciation of each day, and greater intimacy with loved ones. These authors infer that reframing cancer into a more positive light indicates good coping strategies.

## Sub theme 1.2: Spirituality

The following quotes reflect the spirituality issues reflected by the participants:

### Participant 5

“I don’t think we realise the sources that we have until we are in the situation.” She described her bargaining and the awareness of her responsibility that came from this process as follows: “When I first got it [2003], my philosophical bent said, ‘If my tasks in life is over, then it is great, I fulfilled these tasks, then we move on’ [*meaning after life*]. Then suddenly I had visions of my 8-year old daughter, who is not going through an easy time in general, and I suddenly started bargaining with God, saying ‘no, no, no’. Bargaining saying, ‘Actually, I am not ready to go now, so...’ In a certain sense, it was the younger kids that kept me going. If it was for the older children, well OK. Sometimes it feels what do you need that [*treatment, suffering with late-effects, uncertainty*] all for? Is there is something better than this? [*implying this life compared to afterlife*]. But, then you become aware of the people around you. Sometimes you are doing it for them...So in a sense it is that you have not fulfilled your tasks. There are responsibilities that you have not fulfilled. And you don’t want to leave it to somebody else.” Participant 4: Plus every day when I wake up I say: “Hello Lord I am alive”. I am. I’m alive. ...And that to me is one of the greatest things to be alive and you’ve got today to enjoy. Like the first day for the rest of your life.”

### Participant 6

“And you say to yourself, why is it happening to us again and again and again? And they say maybe there is a lesson that we have to learn. But what is the lesson? What lesson do you need to learn?”

### Participant 14

“Uhm...I think I also got a bit more spiritual, uhm... not hectic, not going overboard. And I am not criticizing it, I think different things suit different people. But definitely that helped me a lot.”

### Participant 16

“Hmm. We are human, we have these fears. When I become fearful, thinking ‘Oh my God...what have I, How long have I?’ I try not to stay too long in that place. And what helped me was quoting the scripture. God has given me a spirit of...[*Cannot hear, participant speaks to softly*]. Whatever I feel, I would look it up in the scripture. And that helped me. I try to change my focus from

fear. Especially at night with the thoughts. The fear is there. And I think that is normal. So I am going for walks.” Later in the focus group interview she added, “If you have tumours elsewhere...they...you see the lung is inoperable. If it was just here [*indicating*] they would have operated. But, the thing is that the chemo tablets reduced the size of all of them, the 4. And now they hoping to maintain it or shrink it more. If not, chemo might be an option. But like you, I found my faith really saw me through. But, I mean, it has been a long time. We come from a great Godly heritage. So we trust God in little things, so when big things come it is a little easier.”

### **Discussion of findings in sub-theme 1.2:**

Wong (2012c:Kindle location 15869) posits that meaning-construal and developing faith and spirituality is pivotal in coping with the complexities of adverse circumstances. Spirituality, faith and prayer play an important role in cancer patients' journeys. Most people have some fundamental spiritual beliefs (Kneier et al., reviewed 2010). They call upon these beliefs to help them cope with remission and the uncertain future (Park, 2012:Kindle location 13430) as expressed by Participant 16. Spiritual wellbeing is interrelated with psychological wellbeing (De Klerk et al., 2009:315). For Participant 6, her faith assists her to defocus from the “Why me?” question. This appraisal assists participants to maintain a sense of coherence (Wong, 2012b:Kindle location 1055). Spiritual beliefs provide people with a sense that there is something inside and around them that is more potent than any present or future danger (Scioli & Biller, 2010:66). A religious framework provides patients with an appreciation of each day, as expressed by Participant 4. As such, religious and spiritual beliefs and practices help participants to understand, appraise, and derive meaning from stressful life events, or help them to change their appraisals of illness to make it less threatening (Aspinwall, Leaf & Leachman, 2012:Kindle location 12001-12007). For Participant 5, this means, becoming aware of existing life tasks, whereby she validated herself. Faith helped her to recognise her strengths. Participant 14 distinguished between spirituality and faith. Spirituality, faith and religion help people to move forward (Wong, 2012c:Kindle location 1639). Hope, as expressed by Participant 6, is

bolstered by faith that there is a reason for what has happened, even if she does not understand what that reason is (Lauria, 2001:129).

### **Sub-theme 1.3: Death awareness and awareness of the transitoriness of life and a foreshortened future**

The following quotes reflect the participants' death awareness, awareness of the transitoriness of life, and their awareness of a foreshortened future.

Participant 1:

“And one never knows if it is going to come back. My feeling is, it...it will. You just have to carry on. And I think there is an acceptance of life. You know you not on this planet forever.” Later in the focus group interview, he added: “Yes, I think that is the appreciation [*of life*]. 100%. Except that, I don't want to jump out of aeroplanes. [*laughter from group*]. Fortunately I have some excuses, because I am not allowed to do [*it*].” He also highlighted the possibilities of the future: “But *ja*, the things that you like, gives life such a meaningful shade. I think you also have to have some passions that keep you ticking over day after day.” Later on he adds “And also you have to get to a point where you are comfortable where you are.”

This participant also remarked: “Ja, you're right. You live for yourself, for your family.”

Referring to causality of cancer, this participant remarked: “Life is not fair....”

Discussing the concept of living in the moment, living each day to the full, participants had different views as indicated by the following exchange: Participant 14: “I disagree with the living for the day. ‘The comment I want to live for today’. Ja, I hear what you all saying. But I also want to live for that future there. I want to go on a holiday that I have not been on for a year because of these circumstances, [*cancer related*] these things that I am going through [*demands of remission*] and there are other things that I want.” This is related to their sense of a foreshortened future as indicated by the others. Participant 1: “The time line is not finite. I know what you are saying. But I think you have to...live for today”. Researcher: “You want to live in today, but you must be able to plan for tomorrow?” Participant 15: “I think a very simple answer to your question, Why do you want to live, is because I don't want to die.” Participant 1: “Survival.” Participant 15: “That is the basic answer. That it is your instinct as a human being”. Participant 1: “Basic instinct, ja.” Participant 15: “Your instinct as human beings, we cling to life”. Participant 7: “And if you do live, you live for yourself, first, before you can live for

something else.” Participant 1: “Ja, you’re right. You live for yourself, for your family.”

#### Participant 4

“Somebody asked him [*husband*] “How did you feel of going through the last 10 years kind of thing?” And he said the first time it was a shock. The second time it was: Oh, please you’ve been through it, you’ll get through this one. The next time it is the same sort of thing. But it is important that you talk about it. To tell, to tell... my girls this is what is happening. We’ll all together. I am going to be here for you. Blah di blah di blah....So that they are aware of it, and that they understand as girls that they must go and have check-ups, they must go see somebody when they a bit older, just to make sure that they are fine. And I think it is that what keeps you going. Plus every day when I wake up I say “Hello Lord I am alive”. I am. I’m alive. .... And that to me is one of the greatest things to be alive and you’ve got today to enjoy. Like the first day for the rest of your life”.

#### Participant 5

Ja, ja, hopefully it does not escalate. I just lost a friend’s daughter this week, and there is the reminder. In our little tight-knit community, three have gone this year [*cancer related deaths*]. All cancers. So that it the reminder...it is real.”

#### Participant 8

“I think it is very different...when your [*cancer*] comes back. You know what you are in for - you know you are in for a shit time [*laughing*]. You know there is just no two ways about it. You know you are in for a really crap time. And the primary standing there at your door: knocking, saying ‘Hi I am back’....You going ‘Go away, leave me alone’ I think...[*pensive*] I found it...I found it quite traumatic the second time around...because the first time you found, well I found I was just going through the motions, cause everything is kind of like a blur. Almost, because it is such a shock to you. You go ‘Oh shucks I have cancer’... you go “Oh, oh” [*indicating not comprehending*]. And you don’t... Now I have to go and have an operation. Then I have to go and do this, and then I have to go and do that ...So you kind a just go through the motions. And I found I was only after everything was actually finished that I had a complete, you know, mental wobbly. Not during the first treatment. The second time around, it just freaked me out completely. I just thought I have done everything that they told me to do, and it still came back. And you just think...Well... what more am I supposed to do? And then it comes back again...and you think... [*pull up shoulders*]. And then is when it starts getting boring. You just think, ‘ag not again’...” Later in the focus group interview, she

added: "And that is when you become philosophical about it saying 'Oh well.'" Later in the session she described her bargaining process, adapting her role as mother, and the confrontation with the transitoriness of her life as follows: "The reason why I had my daughter is not...(because my daughter also went through difficulties)...I think they all go through difficult times....and stuff...And you do it for them. I would say, .also bargain 'Let me just see her through senior school and into varsity'. That...that is all. When she is 18, and she has gone through St Anne's, and she has done her bit there, and she is at UCT, then I will be happy to go. You know? Let me just, let me...She is too young to not have a mommy So you keep [*indicating bargaining*] let me first do this...Uhm...and for me it is 'what happens when I am gone? What is going to happen to her? What is going to be her path and who is going to drive it?'"

#### Participant 10

"That is the thing with groups. I stop going largely, because you see people 'disappear'. I get e-mail from them and it says, so and so unfortunately died or is going to die. And I have actually just taken myself away. I realise they are worse off than me, but you know, it is depressing, when you hear it all the time".

#### Participant 12

"One thing I know for a long time is that life is not fair, which you were saying earlier. I've got sensitive skin, which I inherited from my mother etc. And she also had funny things. Over the years, I had all of little things, but never anything serious. And then one happened in 2004 where it was a little blib on my face. And they took it out. And decided not to do anything, because it was not really necessary. So I had a bit of surgery..." Later in the interview, he added: "It was malignant. It was a melanoma. But if it is very small, then there is a good change that it has not spread any further in the body. But they had to sort of make that decision to. Once you taken it out, it is gone. Do you do anything else? Yhmm. I decided not to, but unfortunately, a year later I suddenly got swelling in one of these lymph glands. And it had in fact spread. So I had that out. And then we went sort of one step further and I went onto... What do you call it? It is not the same as chemotherapy; It is a sort of preventative thing. I had it for a year. And I had to self-injected it."

#### Participant 15:

"He [*husband*] just says: 'You're so strong, you always fight it. You are going to make it. You are going to make it through it again. Just get your mind right, and you will do it.' That is the sort of attitude. 'You are such a strong person, you will get through it.' And I think, the day that I am not going to get through it, it is going to be such a shock, for the 4 kids and the grandkids. Finally.

Because the day is going to come when, actually the tumours win. That will happen. It is a matter of when..."

"I have a small fear though. Because my cancer has been going so long, So...like my one son, we actually work together, I always say to him, this time when it was back again badly, I said to him 'This feel a bit different,' and he said: 'Ah, you have said that before, and you have always get through it.'" She repeated her fear as stated earlier in the focus group interview "And I always think, one day I am not going to get through it. And it is going to be such a shock to them. Because it has been going for so long, and they always think, you always get through it. And one time I am actually not going to."

She later describes her death-awareness: "I think my thoughts of dying comes and goes, it fluctuates. Like when I just had a scan and you see these tumours sitting there. If they're bad, you think huh O.K. maybe it is sooner than I think. And then, other times when there are just a lot of little small ones scattered around, and you think: 'Oh. That is nothing.' And you just sort of ignore it."

"Have any of you ever thought that your cancer was a punishment?" She relays her conflict: "Because I have. When I thought maybe something bad I have done in my life. I have done a few things when I was younger. Maybe this is the punishment that I have been given to deal with."

#### Participant 16

"I mean I go through stages that I think. Oh if I die...oh. Is my husband going to remarry? [*laughter from group*] I don't want her to be in my space. Take the affection that the grandchildren have for me and for him. But you know, you have to put that aside, because you are not here then. So obviously...It goes without saying..." [*Participant 4 interjected: "that goes for all of us."*]. Participant 16 continuous: "You have to deal with it" [*awareness of death*]."

Participant 4 and Participant 8 powerfully described how this time is meaningful for them. In line with this Participant 1 mentioned the awareness of limited time: "Time is precious, so I think that is the thing. There is no guarantee on the timeline. And that [*time*] is the bucket list."

### **Discussion of findings in sub-theme 1.3**

During and after a recurrence, helplessness and feelings of vulnerability can increase, because patients do not know how to prevent further recurrences (Cordoba et al., 1993:52). They therefore need to look for intrapersonal resources for meaning-construal. Hope, spirituality, and death awareness are

identified as factors that assist patients to cope with the vagueness around the causes of cancer. Participants described their awareness of death, that at certain times the awareness is more acute. Generally, they do not dwell on the thoughts of impending death. They focus on getting the most out of every day, and they plan for the future. The researcher proposes that this planning assists them to create a sense of normalcy. Participants put a high priority on creating a quality of life.

Participant 8 described the process of having to come to terms with recurrences and the demands of treatments. In order to cope with the demands of cancer, and specifically remission, participants had to integrate and assimilate the unpredictability and unfairness of their cancer. This is in line with the observation of Herman (1993:16). Park (2012:Kindle Location 13543) states that receiving a diagnosis of cancer can violate such important global beliefs as a belief in the fairness, benevolence, and controllability of the world as well as one's own sense of invulnerability and personal control. The researcher posits that recurrence and remission intensify these experiences. In addition, other cancer patients' deaths made participants aware of their own impending death. Summarily, Participant 10 described how attending of support groups made her aware of her impending death.

Only one participant indicates that in pensive and reflective times, she sometimes questions if cancer is a punishment. Lauria (2001:129) states that occasionally, some patients perceive cancer as punishments for current and past behaviours and misdemeanours. The other participants view cancer as events that happened. They are able to recognise the positive in their unique circumstances.

The responses reported indicate that participants move from fear of not being able to fulfil responsibilities, to an appreciation and motivation to fulfil roles. Participant 1 observed that in spite of uncertainty, he reached a point where he is comfortable with where he is [*living with incurable brain cancer*]. Participants described the roles of families, both in the sense of motivation to

fight for life, as well as concerns for the suffering of the family. They are aware that family members also live with uncertainty and ambiguity. Participant 4 indicates how her cancer, a cancer with the tendency to run in families, made her daughters aware of their own vulnerability towards cancer

Cancer, and in particular remission, forces patients to face a foreshortened future, but cancer offers the opportunity to create a more meaningful life (Park 2012:Kindle location 13424). An interesting observation is that as participants experienced more recurrences, the responses from family and friends changed (Participants 15 and 16), leaving participants with the fear that their loved ones may be unprepared when they eventually die (Participant 16). Recurrence brings for them another confrontation with impending death, but the family responses block them from expressing their fears and experiences.

The researcher observed that patients refer to treatment during a recurrence as “buying time.” This is another indication of their awareness of the incurable states of their cancer, and a foreshortened future.

#### **7.3.2.1.1 Key findings in theme 1:**

Living in remission implies the loss of hope for cure. Deriving meaning in their lives provides patients in remission with a perspective that in spite of an uncertain life-expectancy, life still offers opportunities. The reality of a foreshortened future, and the prioritising process that follows, motivate participants to find meaning in the remainder of their lives. Even if a person cannot understand why he or she has cancer, he or she can still derive meaning, because, as Wong (2012c:Kindle location 15934) infers, life has meaning not only in specific situations, but also in one’s existence as a whole. When one cannot understand the causal factors of an event, one can still assign meaning to the event. Park (2010:260) concurs with Taylor (1983 in Park, 2010: 260) that when no answer can be found to an event, meaning is reflected in the answer to the question, “What does my life mean now?” From the participants’ responses, it can be concluded that their cancer journey

caused them to re-evaluate their lives, validate themselves, and that they are able to build realistic hope.

In adverse circumstances, one's spirituality can grow and deepen. Wong (2012c:Kindle location 15888) views the spirit as one's healthy core: one's quest for meaning and yearning for spirituality. The human spirit may be blocked by biological or psychological sickness, but it remains intact; the spirit does not get sick, even when the psychobiological organism is sick. Patients often report a deepening in their spirituality or faith. They report an awareness of their inner strengths, of what their anchors in life are, and what guides them in life. It builds their awareness of their ability to cope with the demands of living in remission.

Participants reported that they seldom dwell in their death. They faced the actuality of their death and then focused on living. There are times, normally associated with a recurrence or the death of another cancer patient they knew, that cause them to revisit the actuality of their own death. The researcher interpreted this as participants experiencing heightened death awareness, and a need to face their own mortality.

From the participants' reflections, the researcher deducted that an adaptive attributional style, assists participants to reframe the cancer experience and remission into a more positive light. They shifted their attention away from trying to find causal factors for cancer and recurrences, and focused on getting on with the business of living. It was noticeable that participants, who cultivated a positive adaptive attribution style, displayed a higher degree of persistence to seek quality of live, build hope, create a new normal, and focus on what life offers now. The researcher concludes that adaptive attribution builds resilience, which prepares participants to cope with remission and recurrence.

### **7.3.2.2 Theme 2: Meaning-construal associated with appraisal**

Folkman and Greer (2000:12) state that appraisal has to do with one's evaluation of the personal significance of a given event and the adequacy of one's resources for coping. In the context of this analysis, the event is living in remission and the appraisal refers to the meaning-making processes. Meaning-making is based on an appraisal of one's life as coherent, significant, and directed (McDonald et al., 2012:Kindle locations 9899). Appraisal includes integration and reappraisal processes. Weisman and Worden (1976), as cited in (Rowland, 1990b:52), state that appraisal-focussed coping presents not as accepting an event, but redefining it. Participants redefined remission in terms of benefit-finding, posttraumatic growth, improved relationships, and an increased appreciation of life. For participants the appraisal processes were seemingly an indeliberate process. This is in line with Park's (2012:Kindle location 13570) findings that meaning-making processes often occur beneath the level of awareness or without conscious effort. She underscores that many of the meanings cancer survivors attribute to their cancer experience are related to psychological well-being.

Meaning-construal associated with appraisal includes the sub-themes of benefit-findings, growth, relationships, and an increased appreciation of life.

#### **Sub-theme 2.1: Benefit-finding**

The following quotes reflect the participants' experiences of benefit-finding.

Participant 2

"Ja, it is also about responsibilities. I have 2 daughters at varsity and then I have one that is going to go to school. So I just have to work.... and thank God I can, and while I am able to I carry on [*working*]."

Participant 3

“I took positives out of it as well, because it could have been worse, for not being diagnosed later. There was a lot more positives for me the second time than there were the first time.”

Participant 4

“My oldest daughter is 20 and my youngest one is 17. [*Researcher: You saw them growing up?*]. Yes seen them growing up, and I see them carry on with their lives”.

Participant 15

“From that point of view I am very lucky. I have tumours that I lived with for 15 years.” She does not perceive that remission prevents her from living a meaningful life. “I am not worse off. I am having a good life, I am skiing. It doesn’t really stop me doing anything [*Participant 1 “Ja, Ja” indicating that it is also his perception of his life*]. I do all the things that I want to do, maybe not immediately...But I have seen people coming through this Oncology Centre, friends, people that I know and 6 months later they are dead.” She accepted change. “And when we go on skiing holiday, we used to ski like maniacs down the mountain. I mean 6000 times a day-nonstop! And now, if I go and do an hour and stop and have tea, another half-hour and have lunch. OK now we’re tired, go sleep for the afternoon.”

Participant 11

“No I must admit, I have been very lucky for the as far as friend goes, and family. And our life is on standstill because we cannot do anything with my mother around. I have always been a fairly negative person. But I have not let it [*remission*] get me down; I have a wonderful job, and a loving husband. I love the people I work with, so it is my saving grace, really.” This participant finds benefit in comparing her cancer and circumstances to other patients’ circumstances. “And you don’t actually realise anything until you sit in here, in your chemo treatment, and you’re looking around at everybody, you know, and you realise: No, you can survive.”

**Discussion of findings in sub-theme 2.1**

There is an increasing body of literature that shows that patients have found benefits from a wide range of medical problems (Sears, Stanton, & Danoff-Burg, 2003) including cancers (Ho, Chan, & Ho, 2004; Schulz & Mohammed, 2004). The benefits most frequently reported include a greater appreciation of life (as expressed by Participants 5 and 11), improved relationships with

family and friends (all participants), changes in life priorities (all participants), increased spirituality, and personal growth (feeling stronger and more compassionate). Theoretical conceptualisations of benefit finding vary. Taylor (1983) suggests that the positive evaluation on one's circumstances through benefit finding minimises or mitigates the negative implications and is necessary to maintain self-worth. Benefit finding is a selective cognitive process involved in the evaluation of a situation, which minimises victimisation by appraising benefits to help individuals to adapt. Therefore, benefit finding is regarded as an appraisal (Taylor, Wood, & Lichtman, 1983). Benefit finding is also regarded as a cognitive reappraisal coping strategy, conceptualised as part of the meaning-making process within the extended transactional model of stress (Park & Folkman, 1977 in Rinaldis et al., 2010:260). Participant 3 expressed her relief that a recurrence was diagnosed in an early stage.

When participants compare their circumstances to other patients, it emphasised to them that remission has prolonged their lives, which enables them to enjoy life and to fulfil purposes. They cite jobs, families, and friends as giving meaning to their lives.

### **Sub-theme 2.2: Growth**

The following quotes reflect the participants' reflections on posttraumatic growth.

#### Participant 1

"We're not who we used to be. So for me, I feel terribly blessed. Did I want this? **NO**. Will I wish it on any of my family or friends? **NO**. I feel I am strong enough to get through it. I think it has been an experience, lessons in life and a realisation of how lucky you are. I could be a damn side worse."

#### Participant 5

"The first time I had chemo I had the red devil. And I was totally, totally debilitated. I did not work because we found a substitute in our own little teaching business that we run. But she pulled out before my second last

chemo so I was forced to go back. So you sometimes don't have a choice. If I was not going back, the place was going to collapse and we would not have an income. Sometimes you are forced back into life, even if you choose to just be in the side-lines, you don't actually have a choice. And I suppose it is a good thing, because it is very easy to withdraw from life."

Participant 18

"You see it is probably the cancer that you have that is giving you the strength now – to be able to cope with all."

### **Discussion of findings in sub-theme 2.2**

Many cancer survivors experienced posttraumatic growth that they link to an outcome of their cancer experience. The growth that patients reported include positive changes in relationships, increased self-confidence and coping skills, and higher levels of spirituality and appreciation for life (Park, 2012:Kindle location 13622; Thornton, 2001:154). Participant 1 expressed that change was for the better, Participant 5 listed improved self-awareness, Participant 15 experience living life to the full, and Participant 18 referred to discovering own strengths.

### **Sub-theme 2.3: Relationships**

The following quotes reflect the participants' reflections of relationship issues.

Participant 8:

"I drive along the road and I phone my Dad. 'Daddy I just want to cry' [*in tearful voice*]."

Participant 9

"People came into my life, with the cancer, that are absolutely amazing. Do...old friends are not always the best friends. You know. I also became more honest, like when I have a bad day my friends know - if the phone is off the hook, don't contact me. I am having a bad day. And on the good days, I do everything. Then I do all the things that I want to do, not what somebody else wants me to do."

#### Participant 15

“I have been really lucky. I go to bed the Saturday and Sunday and often my daughter comes and just climbs in the bed with me and just spends the whole day with me. Watch TV...talk rubbish, ja. She just does it. I never have to ask her.” She later adds: “I’ve been very lucky. They’ve been very understanding about it. My husband more than anybody else. I think he makes the kids understand. They all have grown up. My eldest son is 42 and my daughter is 27. So he will do things like, it was always a tradition that birthdays I always did the catering at home and we had 20 people for dinner . And now he will say ‘Come and have your dinner, but Mom is not cooking. You’re going to do it.’ So, he’ll like pass the buck saying ‘Fine we will do it at our house, but you need to come early and you need to cook the supper’. You know those kind of things.”

#### Participant 20

“The other side and I think somehow we are comfortable with what we know, and with nurturing relationships, with nurturing people, with things that make you feel cherished and special and loved and something that gives you a feeling of ‘I am O.K.’”

### **Discussion of findings in sub-theme 2.3**

All participants indicated that prioritising their lives highlighted the importance of family. This is in line with Thornton’s (2002:158) inference that, for cancer survivors, family becomes important, and that they are more aware of their importance to others and they put more emphasis on social relationships. Greenstein and Breitbart (2000:492,493) reiterates the importance of social support, stating that social support is one of the most important variables associated with good adjustment to cancer. The support of family and friends facilitates coping with cancer and the outcome of treatment. Patients endorse deepening relationships as the most frequent positive aspect of their illness. Participant 9 refers to the valued people that entered her life. They enriched her life and became her trusted support network. Participant 20 described the value of nurturing relationships.

Participant 15 indicated the family’s ability to adapt to the demands of remission, accommodating changed roles.

Participant 8, who, as a young adult was diagnosed with breast cancer, indicates the role of her parents. They supported her, and were a comfort in times when she had to process the reality of remission.

#### **Sub-theme 2.4: Increased enjoyment and appreciation of life and prioritising**

The following quotes reflect the participants' experiences of an increased enjoyment of life, increased appreciation of the small things and life, and the prioritising that took place.

##### Participant 1

"I think that what I realise is that money is not important...I was offered quite a substantial promotion. And I grappled with it. And that was to get out of the whole taxation scenario of First Rand. I am generally an A-type personality. So you almost want to say 'Yes'. I said let me think about it, and then discuss it at home, total introspection, evaluation and eventually I said no. And I have lot of self-recrimination afterwards. And now it has kind of gone away. You know you almost say well 'so what.' It is that much more money, that much more stress, So, ja, my job is stressful enough. Overload. In normal circumstances before, pre-cancer, I would have probably gone for it."

##### Participant 3 "

"You know you said you noticed the trees and this, that and the other. I also noticed that I became more tolerant. You know, I don't let little things niggle me. That is not important (agreement of group in the background). As they say – I don't sweat the small stuff."

##### Participant 13:

"There are so many lessons. So many things that I look at. I look at life differently. I am more appreciative of life. I say: 'Thank God, I am still here.'"

##### Participant 14

"I agree 100% with everybody that has mentioned that you see things as oppose to, to just looking. The Jacaranda trees. All this kind of thing. Nature. Just the birds singing in the morning, you know, that kind of awareness that I got. And it is all positive for me." Earlier in the focus group this participant said

“What are you living for? And I am quite comfortable in the answer. My answer is I am enjoying life, and I want to keep on enjoying life and then there is a lot of things that I want to do. That I am selfish and that I want to live.”

“But there have been many positives apart from family. There’s awareness...It is also now setting goals for what exactly do I want in life. A lot of the people here, from the sounds of it, have been through it. And I also got a pressurised job, I am a finance director. And I just sit back and I think ‘What exactly am I, why am I putting myself through all this stress?’ So obviously, I don’t want to stop work. But here’s...I might have to change my lifestyle to achieve my goal which is: I want to be with my family a lot longer.”

Participant 18:

“With me, I feel when I woke up in the morning and I saw the blue sky, and the birds were singing – that day I grabbed – if I felt well. For me, I looked at things differently. Little things that use to get me down, those pass you by now. You, You...I grabbed onto everything. Every day. And I still do. I live for the day. My life had to be programmed. That day that. That. That...everything...you know, lunch at 1 o’ clock you know, dee dah, dee dah, dee dah. Now it is no more. Now it is any day, anything. If somebody says: ‘We are going away for the week, will you join us?’ It is fine. It is not a case of planning. I will have my bags packed and next Monday we’re off. Now it is every day. I live for every day.”

#### **Discussion of findings in sub-theme 2.4**

Thornton (2002:154,157), referring to various authors, states that many cancer patients attribute an increased appreciation of life, an appreciation of the “small things”, and being less concerned about trivial matters, as a positive outcome of their struggle with cancer. For participants it resulted in them prioritising what is important and what is of secondary importance. Participants 1 and 14, both successful businessmen, acknowledged that cancer changed their work ethics. They still want to perform in their jobs, but not at the cost of their health. They adapted their attitude and ambitions to accommodate the new reality of living with incurable cancer.

Participants are able to adjust to the demands imposed on them by remission, and evaluated their lives as enjoyable. Positive appraisal took the emphasis off their suffering. Their worldviews broadened to an acceptance that life still

offers enjoyment and purpose. They, in essence, evaluated their lives as meaningful. This is in line with Wong's (2011) inference that existential coping strategies such as acceptance and seeing the positive potential of negative events are important in coping with situations beyond one's control. Participant 13 consciously look for enjoyment, and Participant 18 no longer feels obliged to do things that she perceived other people expected her to do. She exercised her right to make decisions, not sidestepping responsibility, but reacting with responsibility Havenga-Coetzer (2003:87) infers that responsibility in an inner discipline, when one responds not because one is forced to, but because it is one's decision.

#### **7.3.2.2.1 Key findings in theme 2**

Finding meaning in living in remission, may be achieved by realising that remission revealed previously unrecognised inner strength, or that remission heightened a renewed appreciation of life, or that remission improved relationships with significant others. Meaning-construal is thus associated with how patients appraise the cancer experience and living in remission.

Positive appraisal indicates that participants focus away from causal attribution to finding benefits in the cancer experience. Participants did not indicate that they found any benefit in remission, but rather that they found benefits in the cancer experience. All participants agreed that they were able to find some benefit in the cancer experience. Participants also reported awareness of posttraumatic growth, and a greater awareness and appreciation of the "small things in life". The most common outcome they reported was a deepening and strengthening of relationships. This concurs with the findings of Park (2012:Kindle location 13563) that cancer survivors attempt to reduce the discrepancy between their global meaning and their appraisal of the cancer. Survivors thus try to bring their understanding of cancer (appraisal) in line with their outlook (global meaning) of life. When there is a discrepancy that cannot be integrated into participants meaning process, participants reappraise the event.

### 7.3.2.3 Theme 3: Meaning-construal associated with reappraisal

The following quotes reflect participants' reflections on their sense of self.

Meaning-making processes include coping efforts such as reappraising the event, reconsidering global beliefs and goals, and searching for some understanding of their cancer and its implications for themselves and their lives. Researchers have posited that survivors assimilate the cancer experience into their pre-existing global meaning, or they change their global meaning to accommodate the cancer experience. Meaning-making efforts are essential to adjustment. Survivors' perceptions of positive changes appear to result from meaning-making coping processes based on reinterpreting the cancer experience in a more positive light (Park 2012:Kindle location 13569). Reappraisal includes the sub-themes of sense of self, sense of coherence, assumptive world, adapting to a new normal, and self-transcendence.

#### Sub-theme 3.1: Sense of self

Participant 1:

"I think the thing about this funny thing called cancer, is that you have to look into yourself. You have to be truthful, to yourself."

Participant 2

Participant 2 described the permanency of his cancer, and living with uncertainty as follows: "It is brain tumour. I had radiation; they cannot operate where it is. I have been going back for MRI's every 6 months. Now [it is] every year. On the last one, it [*the tumour*] now has got bigger again. Now I am back at every 6 months. So we will see now in January what they say. It started, I forget, it is part of the problem [short-term memory loss]. I developed temporal neuralgia. So I cannot feel the tumour, I feel the effects of the tumour, it is constantly with me. I think it was 2004 when I developed the neuralgia and that was when they diagnosed the tumour which was causing the neuralgia. So I had radiation, and I see doctor... [*radiation oncologist*] every 6 months." Later the participant added: "Like this neuralgia, it is there all the time, because of the tumour, and sometimes it is better and sometimes it is worse. Now lately it has been worse. And I am thinking, 'what is the size of this tumour now? Is it taking over my brain, type of thing?' Then I try to be

positive, and I say to myself, maybe it got smaller, because this is the pain I had when it was first diagnosed. Maybe it got smaller and it is now busy reacting and that is why I am feeling like this.” Later on, he describes the side-effect to another participant as follows: “Yes it feels if someone is sticking a knife through your eye.”

#### Participant 9

“I think a lot of the doctors don’t give you enough information. I am not an Internet [*expert*], I don’t want to hear about the whole world and what they doing. I want to know what I have to do. If I am having the treatment, how is my skin going to feel? What am I going to put on my skin? How am I going to sleep better? Should I do this? And ... [*radiation oncologist*] went straight down the line for me.”

#### Participant 10

“Even with the breast cancer they put me on Femara, which is an aromatase inhibitor, it messes with your hormones. It was the worse time of my life. It was a year of purgatory. It was a 5-year plan, and I came to [*radiation oncologist*] one day and said ‘I am just not coping’. Everything that could go wrong, went wrong...[*hormone replacement*], it causes depression, it causes insomnia, it causes weight gain.”

#### Participant 15:

“It never occurred to me that I am going to die. It was not in my thought process at all. Because I had a 7 year gap from the first diagnosis, from 88 to 95. And from 95 to now. In the last 15 years, I have had 13 chemo’s and 1 radiation in 15 years. But it still has not occurred to me that I am now going to die. And I have at the moment 5 liver tumours, 2 spleen tumours and something else, somewhere else. But still, you keep going. That’s it. Since I’ve had chemo I learned to scuba dive, learned to snow ski, travelled the world and I am going skiing in January. [*Researcher: Fantastic. Acknowledgment from group*]. You just keep going. I think you sort of realise that life, you know, might be a bit shorter than somebody else’s so you actually have to live every day, you can’t just...I started a new business, I mean, so...You can’t just throw your hands up and say ‘That’s it. I’m done’ No...Yes you do have the odd bout of depression, tears and ‘snot and trane’ and then you sort of get yourself right the next day and off you go”. She also describes how work keeps her motivated. “People often say to me, ‘Why do you push yourself and go to work every day?’ Even when I go on chemo, I don’t miss a day’s work. I plan it so that I can go back to work on the Monday. You’ve got to. So you spend the week-end in bed so that I can go back to work. And people say ‘Why do you do that?’ I work with my own company;

nobody is taking leave of me. And I say; 'You know what, that is what is keeping me going.' Actually you have to have something that you push yourself for, or else you might just as well lie in bed, curl up and die, straight away. You need a motivation to keep going."

#### Participant 15

"Yes, and what is your coping mechanisms? I think it is the story of David and Goliath. He ran towards the giant. And he was equipped with 5 stones. That was the 4 relatives and the stone. And the coping mechanism, you have to work out for yourself. What my coping mechanisms are. So you become proactive. Dealing with your situation where it is [needed]. When you don't have it [coping mechanisms], it is not an issue, because you can get it."

#### Participant 17

Participant 17 is able to relate her cancer narrative in a humorous way. "I was operated on. I had the full hysterectomy, because it had infiltrated the colon. The primary was ovarian, with infiltration to the colon, so I had a sakkie [colostomy]. They resected my colon. I did not know about it, and when I woke up I had the sakkie. I actually found it quite fascinating [*fascinated with the colostomy*]. You know they say children get fascinated by their own poo. Well I was highly fascinated by all this, what they can do. I got to hate it though because I wear fitting clothes, and this thing will balloon up. It was difficult. Anyway, we got through all of that and then they reversed the opp. I came to [indicate oncology centre]. Dr [*medical oncologist*] was away, and I came to see the doctor who was sitting in for him. I came in and said to her. 'We're near the end of the treatment. I am going to have the reversal, and then I am not going to have the sakkie anymore.' That was to me a bigger thing than the chemo. And she said to me but there is no guarantee that they are going to reverse it. I said to her, 'They are going to reverse this thing, even if they are going to use swimming pool pipe. I don't care what they use. Join them up. Just get rid of the sakkie'. And doctor...[*medical oncologist, when he was back*] arranged everything...And then I went for check-ups every 3 months. Every 6 months it was a scan." Due to the hysterectomy, this participant cannot have children, and due to the uncertainty of the disease progression, she cannot adopt children. In her case, the colostomy addressed a symptom of the cancer; it put her back in remission. Since the colostomy, she had more recurrences.

#### Participant 21

"That was not easy; we had to go and find the only surgery that could do that kind of treatment. There is not anything here in this country. The hospital is about 20 floors...And I had to go back there [*America*], but the second time I

did not go into the hospital. I stayed in an apartment, and went for treatment every day. (*Difficult to hear because of damage to his voice*)...My wife could not be there all the time. So, you don't have the support system. I did [*have support*] because people took turns to come and take care of me. I had a whole bunch of issues. I could not eat, medically. I had to get one of those stomach tubes. Bags of food, horrible stuff. So I had to go through all that stuff. I mean I really lost weight...Just kind of chug on. You have to. [*Points to his neck*] This here is from my stomach. They had to remove that [*skin*]. Because I had radiation before, high dose, they could not give me more. They first used my chest [*skin*] to try to radiate, but unfortunately, the skin died. Then they had to use skin from my stomach, because the veins were good. And that survived. That was a long time. An awful long time." [*Remembering the time away from his wife, their new-born baby, and family and friends*].

### **Discussion of findings in sub-theme 3.1**

A sense of self allows participants to keep their identity. Patients in remission have to build a positive self-image with a new sense of self, develop a sense of competence, mastery, and control, continue building and maintaining satisfying relationships, regain a sense of normalcy, and integrate changes in values, goals, and priorities. Participant 15 reported her awareness of having choices regarding how she can react to cancer and remission. Her choices made her aware of her strengths, her ability, and resources to deal with the demands of cancer and remission. This attitude helped her to perceive her cancer as manageable, and this build her self-efficacy. Survivor identity correlated with better psychological well-being and posttraumatic growth, and victim identity with poorer well-being; neither identifying as a patient nor as a person with cancer was related to well-being (Park, 2012:Kindle location13678).

Reber and Reber, (2001:658,659) consider self as one of the more dominant aspects of human experience and it is the compelling sense of one's existence. The sense of uniqueness and autonomy contribute to a patient's self-validation and the meaningfulness of their lives. Patients need to maintain their sense of self and not allow cancer to substitute their identity, for instance, "I have cancer" not "I am cancer". Cancer survivors integrate the cancer experience into their self-concept, developing a sense of living through

and beyond cancer (Sommer et al., 2012:Kindle location 13657). This is particularly true for patients who are in remission. They also have to integrate the suffering that they experience during their cancer journey. Participants' narratives on their suffering indicated that they remained authentic.

Patients respond to the sense of personal loss of good health in unique ways. They have to reassess their appraisal of their own life and change their perceptions of themselves as a healthy individual to incorporate a life altered by cancer (Stearns, et al., 1993:52), and patients in remission have to incorporate the incurable status of their cancer. Their narratives tell about their suffering and their ability to adapt to changed circumstances in order to live a meaningful life. They needed to create a "new normal". This was especially evident in Participant 17 and Participant 21's narratives.

When negative changes were reported, they were most often related to physical limitations. In line with the researcher's experience, Park 2012 (Kindle location 13460) observed that, during active treatment, patients tend to focus on treatment decisions and dealing with the demands of the immediate situation, and that during remission patients tend to become more reflective.

Patients need adequate information as expressed by Participant 9. Self-efficacy includes ways to get reliable information. The researcher postulates that, it builds a patient's sense of self, if, as patients, they perceive that they are treated with dignity and honesty by the medical profession. In this way, it lowers feelings of unfairness.

A strong sense of self assists patients in perceiving their cancer as manageable.

### **Sub-theme 3.2: Sense of coherence**

The following quotes reflect the participants' reflection on their sense of coherence

#### Participant 6

"About 5 years ago [*when she got married, and was diagnosed 3 months afterwards*]...But then also, I could not have children. But I mean I was 43 so? But that was it. That is your sentence. No children. But that was fine." She explained her ability to accept this infertility. "Yes, but I was not devastated, because I think I was not sure, because I was 43 and I thought I don't know if I want to start now. It is a bit late. So... The Lord took mine..." She and her husband provide hope to each other. "My husband is also a survivor. It has been 18 years ago...It started as a melanoma. It started in the toe. In those days that was the only treatment. It was... they thought it was an itchy bite. Lost his toe. Did not do treatment. Then it came back in the groin, removed it. Had radiation, no he had... yeah he had radiation. Then it came back in the lung. Which is lodged by the heart. But they removed most of it, except the one that is close to the heart. But he had radiation and then chemo. Then it came back in the spine, a small one, when I was having my first chemo, he was having radiation. But he is fine. They say it is a miracle."

#### Participant 16

"So, anyway, I've started doing things that I can manage. The art and bridge, and you know things like that. And that is my new kind of normal. Perhaps in 6 months' time I won't need the tablets."

#### Participant 18

This participant struggles with debilitating side effects and conflicting medical opinions. "I felt worse with the hot flushes, and when I didn't have to deal with them, I could deal with everything else. One gynaecologist said to me 'Why should you be different? My wife is such and such an age and you can have it until you are a hundred'. And I said, 'No. no (*waging finger*) I don't suffer like this until I am a hundred. We do something about it.' And then I went to see doctor [*gynaecologist*] and he said... 'It is your choice'...I just could not handle it, and as we were saying just now, we choose it ourselves, that is the way I got through it, I have the hormone replacement. All right I am off it now, and I still get the hot flushes, and I keep, saying next year, next year I am going (*to go back on HRT*). Just speak to Dr [*medical oncologist*], or I am going to the gynaecologist. Because I know my gynaecologist will help me. But now that I had the cancer so many times...yet, As you said you were on

that inhibitor, I was on the Tamoxofin, and Debbie [*daughter*] brought me a medical book, and I read the thousand side effects, And I said to Dr...[*medical oncologist*], I don't want that. He didn't initially know about the side effects. And he wanted to know why. And I said because then I have to cope with this, this and this. I think there were about a thousand side effects. And I said, you know, I rather take my changes with cancer. You will have to fix it, I will take the risk. Then we sorted the hot flushes. So, this time when it came back, I asked myself, have I really caused it, and my gynea said 'No'. Because mine was not the original cancer. Then again, how many people, - they say at the age of [question mark] it is beneficial for you, for the bones and women with heart attacks. I feel then...You must choose for yourself."

### **Discussion of findings in sub-theme 3.2**

Patients need to continue to lead their lives despite the diagnosis of incurable cancer and as Spira and Kenemore (2002) observe it can be accomplished by assigning some meaning to the illness in order to maintain a sense of coherence and familiarity. Participant 18 chose quality of life, even though this choice was against the advice of her oncologist. Manageability and comprehensibility contribute to the meaningfulness of a situation. As discussed earlier, the manageability of cancer depends on the cancer, the progression of the cancer, availability of treatment, other co-morbidities, resources available, and the coping capacity of a patient. Participant 16 create a new normalcy lens that allows her to create quality of life by taking medication, and allows hope, hoping that she would be able to stop taking medication. There is seldom a reason provided for the cause of cancer or for recurrences or metastases. Therefore, patients have to accept that cancer happened and adapt their lifestyles. Participants 6 and 17 could not have children; they attributed age and arthritis as contributory factors.

### **Sub-theme 3.3: Assumptive world**

The following quotes reflect the participants' reflections of the shattering and rebuilding of their assumptive worlds.

### Participant 1

“I just think that life is not fair for me.” Later in the focus group interview, he observed, “So you need to do your bit of balancing here.” He later added: “But I think you have to live and also spoil yourself each year...It will never be the same again. That is the reality.”

### Participant 18

An interesting facet that was reported in this study is the impact on Participant 18, when her daughter, Participant 17 was also diagnosed with ovarian cancer: “I threw all my toys out of the cot when... [*Participant 17*] got ill, I felt I am the mother, I can cope with it. But when... [*Participant 17*] got ill, that is when I got angry and started asking questions, and if you are a very faithful person you are not supposed to ask questions. But I was very cross, I was very, very angry. I could not understand it. And when it reared its head, and when it recurred and recurred. That I was not happy with...and the girly that gives us gym, I just go to a general ladies gym and she said to me, ‘... can I come and speak to you one day, because I can see you a very angry and things aren’t right, and that is not good for you.’ And she spoke to me a little bit. But when that little man sits on your shoulder, it is very easy to become negative. You have to push through and force yourself.”

### **Discussion of findings in sub-theme 3.3**

Cancer leads to a shift in one’s sense of oneself, and of one’s assumptive world (Brennan, 2001:2). The researcher argues that a patient’s appraisal of remission builds his or her assumptions about coping with remission. When assumptions are distorted or shattered, one tends to rebuild one’s assumptions through the processes of accommodation or assimilation (Slattery & Park, 2012:Kindle location 12958). Referring to various authors, Park (2012:Kindle location 13543) states that receiving a diagnosis of cancer can violate such important global beliefs as a belief in the fairness, benevolence, and controllability of the world as well as one’s own sense of invulnerability and personal control. Beliefs in a loving God may also be violated. Participant 18 reported her anger. Further, having cancer almost invariably violates individuals’ goals for their current lives and their plans for the future. It is likely that different types of cancer and the specifics of an individual’s illness (for example, prognosis) would greatly influence the

situational meaning given and the extent of the discrepancy with global meaning. The researcher proposes that the mentioned research evidence of Park (2012) is also applicable for patients who experienced a recurrence, or who experienced another primary cancer. For Participant 16, remission helped her discover other interests. For Participants 1, 7, 8, 14, and 21, cancer impacted on their ability to execute in their jobs. Park (2012:Kindle location 1354) refers to the research of Carver (2005) that indicates that cancer almost invariably violates patients' goals for their current lives and disrupts their plans for their future.

#### **Sub-theme 3.4: Adapting to the new normal**

The following quotes reflect on how participants created a new normal that integrate living in remission.

##### Participant 8

“Ja, initially it was life is precious, nurture every moment, but you know. As you said, if you have been living with it, it becomes part of your normal life. And it is a part of who you are. And...I am not going to not crap my daughter out for not doing her homework. I will have those arguments with her. Otherwise, I am not bringing her up. I am not guiding her, disciplining her and she is going to turn into a complete monster, because I don't want to sweat the small stuff anymore [*meaning she still has a role and responsibilities*]. The small stuff does actually matter. That is who we are. That is why it irritated us before. That is who we are.”

##### Participant 16

“I am actually living with cancer. Instead of running away, I actually am going to face these giants. And, that is exactly what I have done. I have resigned myself to the fact that it is just an on-going thing, and I am going to enjoy life. But confront the issues, be pro-active, and find my new kind of 'normal'. Because, you know, being very active always, I am playing golf and sport and so on. With my feet being like this [*referring to neutropenia*] – it was fine when in between I could play the odd game. But now I can't wear closed shoes.” Later in the focus group interview she added: “Yes it is not fair, as you said, but ah... you know, the sun falls on the good and bad alike. Cancer has no respect of person.”

## Participant 20

Referring to what he wants from life, this participant said: "I think the inherent factor is that you want to feel O.K. You want to feel fine....You want to be normal."

### **Discussion of findings in sub-theme 3.4**

Participant 16 described her journey to accept the reality of remission and create a new normal. Park (2012:Kindle location 1343) observes that many cancer survivors encounter challenges as they leave primary treatment and return to lives altered by cancer and cancer treatment, but that survivorship offers opportunities to create a more meaningful life.

Participant 8 created normalcy by accepting responsibility, living beyond the cancer, and accepting remission as the new normal. The future-orientated dimension of meaning, suggests that one has a sense of purpose when one perceives that one's current behaviours are linked to future, desired outcomes (Sommer et al., 2012:Kindle location 8333). Participant 8 hoped that she would be able to raise her daughter. Frankl (1985:120) describes it as "meaning to be fulfilled by the patient in his future". It implies that life challenges individuals with demands to which they have to respond if they endeavour to derive meaning in life (Fabry, 1998:295). Meaning provides one with the sense that one's life matters, that life makes sense, and that life is more than the sum of our seconds, days, and years (Steger, 2012:Kindle location 5031).

All the other participants indicated that they perceive cancer as unfair. With the exception of two participants, all participants focussed on living with their cancer. The two participants that differed from the rest still hoped that their cancer would be cured, they had not yet comprehended that they are in remission.

Patients who are in remission have to assimilate the knowledge of the incurable status of their cancer. They live in uncertainty and with a sense of a foreshortened future. Patients need to find a new normal – a homeostasis where they are able to live their lives whilst in remission. All participants indicated that they wanted to live, and that their assessment of the quality of their lives is personal. This is in line with the NCCN (*For cancer survivors normal might not be so normal*) observation that for cancer patients, normal changes and that they create a new normal in their lives.

### **Sub-theme 3.5: Self-transcendence**

The following quotes reflect participants' reports on self-transcendence.

#### Participant 6

This participant described her role in her community and how it provided her with a sense of self-transcendence: "I just feel there is so many people who need help. If anybody is diagnosed in our community, the rabbi phones me and say please D you handle it. I phone them some people come here. They drive themselves. Sometimes the doctors don't tell them properly. Or they think they're going to be fine. And they come without a bottle of water or a sweet. And they don't know they...ag, those little stupid things that we just take for granted. A lot of people just don't know. I help a lot of people, with the wigs and whatever it was. And we all phone each other, even just to help each other."

#### Participant 7

"What I find, me working with clients. Lot of people [*that*] never used to be personal at all, open about themselves O.K. and since I've been through my treatments and that, lots of clients started asking me questions. I was like totally surprised. And they opened up a lot of themselves, but in that opening from them, they actually tried to fizz out questions and what do you go through. Because they have family and friends, and they never knew how to handle it. A lot of them, they learned a lot from me. There is lots of questions that I could not answer. I did best as far as I could, and must say, I didn't make really a study of breast cancer. But I read about it, spoke to people, and that is how I learned of breast cancer."

### Participant 12

This participant became involved with support groups. “I was going to say I have actually been clear now for about 5 years. And I have been, I’ve mentioned it to you, I [have] gone through this thing, realising that one has a different feeling at an early stage when it first hits you, and then when through treatment, you have different feelings, and then you go on and then you get back to running your own life. But I stayed involved in cancer support work, which you’re aware of. So I continue to do that. I am still not sure if it is because I got a need for myself or whether it is something that I just decided that is what I want to do.”

### Participant 17

She remarked in a humorous manner: “My husband who is the sporter. He has gone that route. That is his outlet. I think he is afraid that if I going to die, he will be left alone. So, he is pushing the limit now. The fast bikes. No chicks! We don’t do the chicks. I warned him no chicks. I am actually the biker chick, but I am never well enough to go. But he has gone that way. That is him.” She later added “He started smoking. I said to him, I am desperately trying to live, and you are desperately trying to die. But I think he is afraid.”

### **Discussion of findings in sub-theme 3.5**

Havenga-Coetzer (1003:89) depicts self-transcendence as the human characteristic of elating and being directed to something other than oneself. It is the ability to look away from the self, from one’s pain, circumstances, suffering, or grief; it is the ability to reach out to someone else, or to realise an ideal, fulfil a task, and to reach out to a Higher Being. Participants reported that they also had to support their families and friends. It was also apparent in the focus group that participants spontaneously reached out to each other and offered advice, shared experiences, and showed empathy to each other.

Meaning-making processes include coping efforts such as reappraising the event, reconsidering global beliefs and goals, and searching for some understanding of cancer and its implications for themselves and their lives. Researchers have posited that meaning-making efforts are essential to adjustment by either helping survivors to assimilate the cancer experience into their pre-existing global meaning, or helping them to change their global

meaning to accommodate it. Survivors' perceptions of positive changes appear to result from meaning-making coping processes based on reinterpreting the cancer experience in a more positive light (Park 2012:Kindle location 13569).

Effective coping assists them in taking stock of their most cherished reasons for living, strengthens and sustains participants in their fight against cancer. It serves to clarify to them that their survival is not the only important objective: the quality of their lives and relationships, the values they live by and their spirituality are deserving of attention and effort (Wong 2012a:Kindle location 728). He underscores that the key to posttraumatic growth (PTG) is the ability to reconstruct the assumptive world about the self and one's life. This meaning-making ability allows one to create a new narrative that facilitates one's positive change and growth. The discovery of new ways of perceiving life and negative events can lead to better adjustment.

#### **7.3.2.3.1 Key findings of theme 3**

Cancer survivors construe meaning out of the experience through assimilation or accommodating processes. Patients assimilate the experience into a pre-existing global meaning system, or by changing their global meaning system to accommodate the cancer experience (Park, 2012:Kindle location 13569). Reappraisal of the cancer experience is needed to accommodate the knowledge that they have incurable, recurrent cancer. Reappraisal is facilitated by their sense of self, a sense of coherence, the assumptive world, adapting to a new normal, and transcendence. The ways that patients reappraise the cancer experience has to be congruent with their sense of self, and their sense of coherence.

Applying Reker and Wong's (2012) observations regarding reappraisal of meaning, the researcher observed that reappraisal is facilitated through a sense of coherence, where the participants became aware of the option of living beyond the cancer. It is generally achieved through transformative and

transcendence processes: participants rethink their values, they revise the assumption they held about the world and their place in this world, and they prioritise their lives. The cancer experience interrupted participants' life plans, and they had to reintegrate the experience into their meaning systems. There are two ways that reintegration was achieved: by changing the global meaning or by changing the meaning of the life event. Participants' thus construe meaning while living in remission.

#### **7.4 SUMMARY**

In this chapter, the research findings of the focus group interviews were presented and discussed. Where applicable the research findings were integrated with literature. Data was analysed according to themes that participants reported. The quest for meaning was apparent in participants' cancer journey. Thus, there is a need for intervention programs that can guide patients to find meaning. In the next chapter, the researcher discusses the meaning-centered counselling and therapy model. The themes identified were as follows: Meaning-construal associated with attribution with sub-themes of hope, spirituality, and death awareness. Meaning-construal associated with appraisal of remission, including the sub-themes of benefit finding, growth, relationships, and an increased appreciation of life. The last theme is meaning-construal associated with reappraisals, including the sub-themes sense of self, sense of coherence, the assumptive world, adapting to a new normal, and transcendence.

In the next chapter the researcher's conclusions and recommendation regarding his study will be discussed.

## CHAPTER 8

### 8 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

#### 8.1 INTRODUCTION

Cancer poses a threat to life. For patients who have experienced one or more recurrences, the confrontation with the transitoriness of life, and a foreshortened future, is more penetrating. Wong (2012c:Kindle location 16064) stated that the affirmation of meaning is a bedrock foundation for survival and well-being. The researcher proposed that if patients can derive meaning in their lives, they can cope with the demands of remission and experience quality of life. The researcher inferred that when patients experience well-being, they live meaning-centered lives.

Against this background the study was guided by the following research question: **“Does meaning-centeredness play a role in adult cancer patients’ coping with remission?”**

Conclusions and recommendations are based on the empirical information and outcomes of this study as described in chapter 7. In this final chapter the researcher indicates how the goals and objectives of the study were achieved, presents the key findings of the study, draws conclusions from the findings, and makes recommendations based on the findings.

#### 8.2 SUMMARY

The objectives, goal, and research question of this research study will subsequently be addressed, as well as to what extent they were realised.

##### 8.2.1 Objectives

The goal of this study was achieved through the realisation of the objectives of the study. The objectives of the research study were:

- to contextualise cancer survivorship, specifically focussing on remission as a field of study
- to provide a broad theoretical overview of social work in oncology
- to explore meaning-centeredness in adult cancer patients in remission at the Radiation Oncology Unit, Sandton Oncology Centre to provide conclusions and recommendation to social workers for consideration during intervention with cancer patients who are in remission
- to provide conclusions and recommendation to heighten the awareness of the oncology team regarding patients who are in remission, and
- to create awareness of the role of the oncology social worker.

Each objective will subsequently be addressed, and the researcher will indicate how the objectives and subsequently the goal were achieved.

**Objective 1:** To contextualise cancer survivorship, specifically focussing on remission as a field of the study.

In order to form a knowledgebase for this research, the researcher discussed cancer as phenomenon in chapter 2. Chapter 2 provided an in-depth discussion of oncology and the current main treatment modalities. The aim was to create awareness of the need to be knowledgeable about the disease process and the commonly used treatment modalities. Cancer, carcinoma, and oncology and were defined. Cancer was described in terms of pathophysiology, and type of cancer. The difference between a primary cancer and metastasis, and the growth path of cancer were discussed. The discussion on the diagnosis of cancer included staging and grading of cancer. The different treatment modalities discussed included surgery, chemotherapy, and radiation therapy. The different outcomes of treatment as well as the side effects of treatments were discussed.

The phenomenon of living in remission was discussed in chapter 3. Survivorship includes cure and remission. In the context of this study, the researcher frequently referred to remission as living with incurable cancer.

Remission was identified as one of the key stress periods in the cancer experience. In order to create awareness of the demands set by remission, the following areas of living in remission were discussed: coping with the diagnosis of incurable cancer and coping with incurable cancer. The following variables associated with living in remission were discussed: distress; the impact of remission on the assumptive world; the experience of crises and trauma (with reference to the difference between acute trauma and cancer as a traumatic event); coping, posttraumatic growth, resilience, and a sense of coherence.

**Objectives 2:** To provide a broad theoretical overview of social work in oncology.

The need for health literacy as related to oncology was addressed in chapter 2. Chapter 2 provided a short introduction to oncology and the current main treatment modalities. The aim was to create awareness of the need to be knowledgeable about the disease process and the commonly used treatment modalities. Such knowledge will enable social workers to assist patients to make informed decisions about treatment during each phase of the cancer process. The researcher observed in practice that patients expressed a need for more information regarding most aspects of their cancer and treatment. By equipping healthcare professionals with skills to provide health information, this need can be met. In order to render effective intervention programmes, social workers who deal with cancer patients should understand what cancer is, what the frequently used treatment modalities are and what the common side effects of treatments are. This will enable social workers to assist the patient to explore and clarify the links between facts and fears associated with the patient's cancer.

**Objective 3:** To explore meaning-centeredness in adult cancer patients in remission at the Radiation Oncology Unit, Sandton Oncology Centre.

This objective was achieved through the literature study in chapter 4. Based on the inference from meaning theory that there is need to understand the uniquely human capacity for meaning-making and meaning seeking, the researcher explored the constructs of meaning, meaning-centeredness, and meaning-construal. Meaning was defined from different perspectives. This research study is based on the existential oriented proposition that meaning is a basic human need, and can be experienced in all circumstances. Adversity, and by implication remission, can trigger a quest or meaning. The meaning system was described according to types, structure, and its function. From the literature study, the researcher infers that when one derives meaning in one's life, one lives a meaning-centered life.

In order to create awareness of the feasibility of a meaning-centered intervention program, meaning-construal was described. The following variables associated with meaning-construal were described: meaning-construal associated with attribution, appraisal, and reappraisal.

This objective was also achieved through a detailed discussion of the research methodology in chapter 6.

This objective was further achieved by means of the empirical research as presented in chapter 7. Participants were given the opportunity to share their experiences, feelings of and perceptions regarding living in remission. The data collected from the focus group interviews revealed that living with the uncertainties and demands of remission, triggered a quest for meaning. These results were presented in themes and sub-themes. Theme 1 is meaning-construal associated with attribution, with sub-themes of hope, spirituality, and death awareness and awareness of the transitoriness of life and a foreshortened future. Theme 2 is meaning-construal associated with appraisal, with sub-themes of benefit finding, growth, relationships, and increased appreciation of life, and prioritising. Theme 3 is meaning-construal associated with reappraisal, and the sub-themes are sense of self, sense of coherence, assumptive world, adapting to a new normal, and transcendence.

This research study was conducted at the Radiation Clinic, Sandton Oncology Centre, Gauteng, South Africa. The Sandton Oncology Centre is a private oncology centre.

**Objective 4:** To provide recommendations to social workers for consideration during intervention with cancer patients who are in remission.

In chapter 5, social work in health care and oncology social work are discussed. The researcher proposes the implementation of Wong's (2012) Meaning-Centered Counselling and Therapy (MCCT) model for intervention with patients who are in remission. The characteristics, therapeutic goals, techniques, conceptual framework, and intervention strategies of MCCT are discussed. The researcher concluded that MCCT offers a flexible and integrative approach to psycho-oncology and that the MCCT model may be more effective than strict adherence to a single theory of therapy.

**Objective 5:** To provide conclusions and recommendations to heighten the awareness of the oncology team regarding patients who are in remission.

In chapter 3, the complexity of remission was discussed. Data collected during the focus group interviews revealed the demands that remission posed to participants. This is in line with the literature study presented in chapter 3. Coping with incurable cancer demands: coping with the fear of recurrence, living with ambiguity, constant fatigue, stress responses due to the side effects and late effects of treatment, coping with less medical surveillance, reintegrating their lives post treatment and living with a sense of a foreshortened future and loss of future memories. To live with incurable cancer demands adjustments. Adjustments to remission requires that survivors find activities, maintain a participatory stance, build support networks, build, and maintain positive attitudes, maintain realistic hope, and build high self-perception and self-esteem. As mentioned earlier, the variables associated with living in remission were defined and discussed.

The researcher presented on the topic of demands of survivorship to the transdisciplinary team of the Morningside Head and Neck Forum. The researcher has recently presented the research findings at a conference of South African Society of Clinical and Radiation Oncology (SASCRO). The audience at this presentation consisted mainly of social workers and oncology nurses. The researcher also presented at Social Workers In Palliative Care and Oncology (SWIPCO), a meeting for social workers in the field of oncology and palliative care. Presenting at these events enabled the researcher to advocate for, and raise awareness for patients in remission.

**Objective 6:** To create awareness of the role of the oncology social worker.

This objective was not fully realised. To provide a detailed theoretical overview of social work in oncology would require an overview of social work during each phase of the cancer process for patients and for their social attachments. This research study only focused on remission; therefore, the role of the oncology social worker during each phase of the cancer continuum was not described. The role of the health social work and an overview of the scope and principles on oncology social work were provided in chapter 5. In South Africa, oncology social work is not recognised as a fully-developed profession, and still falls under the discipline of social work in health care. Therefore, to contextualise oncology social work, the researcher used the international guidelines, standards, and principles as set by the Association of Oncology Social Workers (AOSW). The researcher first described the scope of health social work, and followed with a description of the different roles that an oncology social worker can fulfil. This distinction was necessary in order to emphasise the wide scope of oncology social work. It also highlights the need for specialised training.

## **8.2.2 Goal of the research study**

The conclusion of the study must be in line with the goals and objectives set in chapter 1. The goal of the study was to explore meaning-centeredness in adult cancer patients who are in remission.

### **8.2.2.1 Research Outcome**

The research study is built on the meaning hypothesis, which claims that people have the capacity for meaning-seeking and meaning-making. This includes a quest for both existential and cognitive meaning. Global meaning and situational meaning were described in the literature study. The empirical study focused on patients who are in remission and their quests for meaning.

The findings of the research study indicated that participants value their lives and that, at the root of these validations, is a sense that their lives are meaningful. Their efforts to prolong their subjectively valued quality of life, evidence that they live meaning-centered lives. Meaning-centeredness is thus subjective. It is the confrontational character of suffering: adjusting to the side effects and late-effects of treatment, the awareness of their mortality, and a foreshortened future that guided participants into living in a dimension where their lives are meaningful. The ways in which they appraised and reappraised the cancer journey, contributed to meaning-construal.

This research achieved this goal since the study brought into light the experiences, attitudes, and insights that participants reported that enables them to integrate the knowledge that their cancer is incurable, cope with the demands of living in remission, whilst deriving meaning in their lives. The constructs of meaning and meaning-construal are difficult to comprehend; therefore, the researcher deduced from the participants narratives of living in remission, how they derive meaning in their lives. Participants were not aware that they were involved in meaning-construal; they interpreted their efforts as a

quest for a good life. Their awareness of a foreshortened future triggered a prioritising process that resulted in living a meaning-centered life.

### **8.2.3 Research question**

The research question for this study was: “**Does meaning-centeredness play a role in adult cancer patients in coping with remission?**” This question is answered through this study and the conclusions below show clear evidence that **meaning-centeredness does play a role in adult cancer patients in coping with remission.**

## **8.3 KEY FINDINGS AND CONCLUSIONS**

The following conclusions were drawn from the key findings of the study.

### **8.3.1 Key findings and conclusions regarding research methodology**

#### **8.3.1.1 Key findings regarding research methodology**

The data collected from the focus group interviews, once transcribed, revealed the themes and sub-themes relating to the research question. These descriptive experiences of participants as self-knowing subjects were presented in the previous chapter on the research findings. From the findings, the following themes and sub-themes were identified. Theme 1: Meaning-construal associated with attribution with the sub-themes of hope, spirituality, and death awareness and a foreshortened future. Theme 2: Meaning-construal associated with appraisal, with the sub-themes of benefit-finding, growth, relationships, and an increased appreciation of life, and prioritising. Theme 3: Meaning-construal associated with reappraisals, with sub-themes of sense of self, sense of coherence, the assumptive world, adapting to new normal, and transcendence.

During the pilot focus group interview, one of the participants was, at different times, diagnosed with 2 primary cancers. She had not experienced any recurrences. Her experience differed significantly from those participants who had experienced recurrences, especially with regards to hope. Her hope for a cure was realistic. There was no evidence of disease of either of the cancers. Therefore, sampling was delineated to the patients who had experienced recurrences. Some participants were diagnosed with other primary cancers, but were included in the sample because they had experienced recurrence.

Using focus group interviews as data collecting instruments was effective in this qualitative study. The participants had the opportunity to verbalise their perspectives and experiences and listen to the perspectives and experiences of other members in the focus group. The focus group interviews enabled the researcher to obtain first-hand information. The participants had the opportunity to explore their meanings, and the value of this research was evident in the positive feedback from participants. Because of the value of the discussion held in the focus groups was immediately felt, it is reasonable to expect that meaning-centered interventions will have far-reaching positive implications for many more patients who find themselves on the cancer journey.

The collective case study design allowed the researcher to expand her knowledge on remission and on how patients in remission construe meaning in their lives. The researcher was able to collect, in the focus group interviews information from different participants (case studies). These findings presented from the collective cases included a profile of the participants (case studies) and the themes and sub-themes generated from this study.

#### **8.3.1.2 Conclusions regarding research methodology**

Purposive sampling was applied. Thus, these findings cannot be generalised, but they represent the experiences of this sample of participants. No statistics are available at the Sandton Radiation Clinic, nor of cancer patients in

remission in South Africa. Therefore, this study only reflects the experiences on being in remission of this group of participants. The researcher believes that the sample provided data that can help us better understand people who are in remission.

#### Conclusions regarding sampling:

- Size of sample: owing to the small size of the sample included in the study, the researcher recommends that future research should include a larger sample.
- The study included only adults. Although the sample was in line with indications from global statistics that the incidence of cancer is the highest in the age group of 65 and older, future research should include a wider age range. Future studies could focus on specific age ranges, because the demands made on patients, and life tasks across developmental age groups, differ.
- Gender: the gender distribution was unequal due to the sampling method used. This is not representative of the cancer population. Statistics indicate that the male to female ratio in cancer prevalence is almost equal.
- Racial distribution: Due to the sampling method used, the racial distribution of the research sample is not representative of the South African population. Meaning is derived from cultural and social environments, and therefore future research should represent the cultural diversity of the South African population. The bias is probably due to the geographic location of the Sandton Oncology Centre, and due to the Sandton Oncology Centre being a private oncology centre.
- This sample was biased in terms of financial status, and educational qualifications. Future studies should strive for demographic equality.
- The sample was biased in terms of cancer type, recurrences and disease progression. It appears that meaning-construal manifests independent of medical variables.

The researcher postulates that the academic qualification of participants can be an indication of participants' goals and expectations pertaining their roles, responsibilities and dreams. All participants are well educated. This may be an indication that participants are cognitively capable of comprehending their diagnosis and prognosis. Education may also influence a person's ability to generate income, which in turn may affect the ability to afford private medical care. The ability to comprehend the diagnosis and prognosis does not exclude participants from emotional responses such as denial, anger and fear.

Meaning-construal is a basic human need, and especially for patients in remission, as was found in this study. The MCCT model was discussed as being appropriate for intervention with patients in remission and who face a life-threatening illness.

The researcher accepts that implementation of the proposed Meaning-Centered Counselling and Therapy model, could have evidenced better the reason for proposing the model. Evaluating the model was not a goal or objective. The proposed model is a result of the empirical study that evidenced that patients in remission can derive meaning in their lives, and that a meaning-centered life contributes to well-being. This research study therefore provides a platform for future evaluation of and training in the proposed Meaning-Centered Counselling and Therapy intervention model.

A scarcity of measuring scales that measure meaning-construal or the experiences of meaning-centeredness in patients who are in remission was observed. Available scales measure the presence of meaning, and the search for meaning in people who experienced adversity. Some research on meaning has been conducted with cancer patients, but to the researcher's knowledge none that focus specifically on remission. To the researcher's knowledge, no scales specifically measure meaning-centeredness in patients who are in remission. The researcher acknowledges that scales that measure meaning-seeking efforts could have been adapted for this study. The

researcher wanted subjective descriptions of participants' experiences of living in remission, and therefore opted for a qualitative approach and not a combined approach. Thus measuring scales was not a prerequisite for this research study. Due to the lack of knowledge regarding remission, specifically after recurrence or metastases, the researcher implemented a case study design. This provided the researcher with detailed descriptions of the experiences of participants, and the information broadened the existing knowledge base.

### **8.3.2 Key findings and conclusions regarding literature study**

#### **8.3.2.1 Key findings regarding literature study on oncology, remission, meaning, meaning-centeredness and meaning-construal**

The literature study is presented in chapters 2, 3, and 4. The rationale for including three subjects in the literature study is to create an understanding of what cancer is and the main treatment modalities, delineating that in the study the focus is on survivors with recurrent, incurable cancer as well as the demands of remission after recurrence. Lastly, the construct of meaning was described, because meaning is the main construct on which this research study pivots.

In order to understand meaning-centeredness, one needs to understand meaning-construal. In consulting the literature, the researcher found that there are identified processes of meaning-construal, also referred to as meaning-seeking, meaning-making, or meanings made. For professionals who work in the field of psycho-oncology, a key responsibility is to support patients who are in remission, and to address the medical and psychosocial issues associated with living with incurable cancer. Remission encompasses threats to: life; bodily integrity; body image; self-concept; future plans; emotional equilibrium; social roles and activities. In addition, it presents the challenge of coping with side effects or late-effects of treatment. When patients derive

meaning in their lives, they can experience well-being. Oncology social workers can thus assist patients with meaning-construal.

The research findings confirmed the literature findings regarding meaning-construal associated with life perspectives, interpersonal relationships, as well as the self. Participants showed the ability to assimilate the knowledge that their cancer is recurrent and move to a place of getting on with their own lives. Meaning manifested in the way participants responded to life tasks; how they made sense out of the perplexities and calamities of remission; how they actualised their potential while living in remission; how they took accountability for their actions and decisions, and how they appraised life in remission.

Participants reported a sense of spiritual well-being. Religious and spiritual beliefs and practices helped participants to understand, appraise, and derive meaning from living with incurable cancer, or help them to change their appraisals of living in remission to make it less threatening. Spirituality provided participants with a connection to something larger than their self, and motivated them to pursue what is really important and sacred for them.

This research study confirmed that meaning-construal left participants with the acceptance that, in spite of the unfairness of cancer, their lives are meant to be, and they have life tasks to fulfil.

In line with the literature, the research findings confirm that meaning-construal efforts assist in the following ways: Participants have to be aware that their lives have purpose, and although they have a sense of a foreshortened future, they are able to plan for the future and form new goals due to the prioritising process. Participants validate themselves, find their strengths, and learn to live for every day. Participants develop a sense of self and regain control: by adjusting to the demands of remission and by implementing lifestyle changes. The understanding that their lives matter provides meaning which in turn develops coping capacities.

### **8.3.2.2 Conclusion regarding literature study on oncology, remission, meaning, meaning-centeredness, and meaning-construal**

The researcher concluded that the challenge of living in remission presents as a psychosocial process, which includes positive experiences, for example, meaning-construal, and/or negative experiences, for example, trauma. Participants have to integrate the knowledge that their cancer is life limiting, and this knowledge can initiate a quest for meaning. Most patients have the ability to comprehend the diagnosis and prognosis, but they need time to process the information. The way that participants respond to the loss of good health and in the context of this study, the loss of hope for cure, is unique.

The research findings provide general support for a theoretical model positing that meaning–construal contributes to coping with adverse events, which in the context of this study, is living with incurable cancer. The study suggests a meaning-centered intervention programme based on the MCCT model. This study emphasised the need for social workers to have knowledge regarding oncology and the needs of patients during the different phases of cancer. In the past, literature regarding meaning was mainly hailed from literature in the existential and humanistic domain. The renewed interest and recognition in meaning therapy, and organisation such as the International Network for Personal Meaning (INPM) promotes research. This research study underscores the need for guidelines for interventions with oncology patients. In order for intervention programs to be developed, it is important that the field of meaning-construal be explored further through qualitative studies conducted with cancer patients.

### **8.3.3 Key findings and conclusions regarding empirical study**

Themes and sub-themes deduced from the qualitative focus group interviews with patients in remission are presented in Table 11. Key findings and conclusions drawn will be presented according to these themes and sub-themes.

Table 11: Themes and sub-themes

Themes	Sub-themes
Theme 1: Meaning-construal associated with attribution	1.1 Hope 1.2 Spirituality 1.3 Death awareness and awareness of the transitoriness of life and a foreshortened future
Theme 2: Meaning-construal associated with appraisal	2.1 Benefit-finding 2.2 Growth 2.3 Relationships 2.4 Increased appreciation of life, and prioritising
Theme 3: Meaning-construal associated with reappraisals	3.1 Sense of self 3.2 Sense of coherence 3.3 Assumptive world 3.4 Adapting to the new normal 3.5 Transcendence

*Table 11: Themes and sub-themes*

## **Theme 1: Meaning-construal associated with attribution**

### **Key findings associated with attribution**

Based on the findings of this study as discussed and presented in chapter 7, the researcher identified the following key findings associated with attribution.

- This study evidenced that it is essential to maintain realistic hope for patients who live with incurable cancer. Realistic hope implies that patients have to maintain a degree of hope that is proportional to the positive survival chances that apply to their individual cancer and situation, including other co-morbidities present. They hope that their cancer will remain manageable, and that there will be treatment available for future recurrences. It is reasonable hope that assists patients in remission to create meaning in their lives and helps them to

comprehend that whilst their life expectancy may be unsure; they can still influence the quality of life they enjoy.

- Participants reported that setting goals enabled them to build and maintain hope. This research confirms that a sense of meaning is related to realistic hope, a sense of purpose, and future-orientated goal striving. Reasonable hope facilitates self-discovery, resulting in people prioritising, exploring their abilities and the options available to them. They use this information to forge a sense of purpose in life. Participants perceive their actions as having positive value, and this is expressed in participants' awareness of the roles they still fulfil.
- Most people have some fundamental spiritual belief, which they call upon in times of adversity, which can be, as evidenced by participants, in times of remission. Participants reported that they became more spiritual, and cancer often caused them to change or alter their worldviews. Furthermore, many participants reported that spirituality helps them to attain an internal acceptance of the inevitable, and experience peace, even if the incurable cancer remains incomprehensible. Some participants reported that faith or spirituality provided them with a sense of being protected.
- This study confirmed research that incurable cancer creates an awareness of the transitoriness of life, and a heightened sense of their vulnerability. Participants reported that they strive to live each day to the fullest. They recognised the limitation of time, are aware that past and possible future treatment "bought them time". The uncertainty associated with living in remission may set the stage for meaning-construal.
- A contradiction the researcher observed was that various participants reported that although they experienced support, their need to talk about their death-awareness, which was either ignored, downplayed, or quick and unrealistic assurances were provided. This resulted in them feeling isolated because they perceived that others did not really understand

their fears and the demands made on them. It blocked discussion, stopping them from “getting their house in order”, and placed obstacles in the way of focusing on living each day to the full.

- Another interesting variable that was reported is participants’ negative experiences of support groups. When a group member died, they were confronted with their own prognosis and death. This resulted in them avoiding attending subsequent support group meetings. During the time of the focus group interviews, only one participant reported being actively involved in a support group. In contraction, some participants reported that, it was beneficial for them to talk to other survivors. Talking to newly diagnosed patients provided the patients with a sense of self-transcendence.

### **Conclusions regarding key findings associated with attribution**

For the majority of patients who are in remission, what might initially have been a hope for cure, changes during remission and recurrence to hope for more short-term goals, implying that patients’ focus shifts to quality of life instead of quantity of life. Participants put a high priority on quality of life. The two participants who still hoped for cure focused on treatment outcomes, and did not put much emphasis on quality of life. This research study confirms that meaning can be found in accepting the unavoidable, in this context, living with incurable cancer. Participants created realistic hope; they are aware that they still have life tasks to fulfil, which provided them with a sense of purpose. Thus, meaning-centeredness offers participants a sense of purpose and realistic hope. Meaning can be found in accepting the unavoidable. It is realistic hope for a future, the awareness that they still have roles to fulfil, that give meaning to their lives.

Participants experienced a degree of hope that is proportional to each one’s individual survival chances, but they also experienced a degree of worry that is proportional to the mortality rate in similar cases. The literature refers to this

phenomenon as keeping balance and proportion. In this regard, contact with other cancer survivors was beneficial.

Spirituality, faith, and prayer play an important role in cancer patients' journeys. Spiritual beliefs provided participants with a sense that there is something inside and around them, which is more potent than any present or future danger. It provides them with a larger worldview that imparts meaning to their lives whilst living in remission. Several theorists have proposed that having an understanding of the cause of an event (an attribution for its occurrence) is an important type of made meaning. An understanding of the occurrence of cancer and cancer progression may help with addressing the "Why me?" question. Understanding occurrence can cause guilt, but can also serve as a motivation to change one's lifestyle, and to adjust to changed circumstances. An acceptance of the changed circumstances assists patients in taking control of their lives. This study confirms that participants were able to accept the inevitability and irreversibility of cancer and remission, even if the illness remains incomprehensible. For patients who struggle with the 'Why me?' question, spirituality can assist them to accept the unavoidable.

## **Theme 2: Meaning-construal associated with appraisal**

### **Key findings associated with appraisal**

Based on the findings of this study as discussed and presented in chapter 7, the researcher identified the following key findings associated with appraisal:

- This research indicates that participants' lives became meaningful when they experience something positive in remission. The most common benefit reported was improved relationships. All participants indicated that prioritising their lives highlighted the importance of family.
- The motivational aspect of meaning-construal was also evident in participants' reports that family motivates them to carry on, and that support from family helped them to cope with the demands of remission.

- Participants were able to do a mind shift from causal attribution to positive appraisal, focusing on the benefits they experienced during their cancer journeys. Reports of growth were often related to better psychological adjustments as posttraumatic growth moved patients to coping levels beyond the level of adaptation that they experienced pre-diagnosis. The growth that patients reported include positive changes in relationships, increased self-confidence and coping skills, and higher levels of spirituality and appreciation for life.
- It was beneficial for some participants to compare their cancer experiences with those of other cancer patients. It helped them to become aware of the positive aspect in their circumstances, that there are patients whose conditions are worse than theirs are. Contradictory to this, deaths of cancer buddies and support group members provoked fear, because it emphasised the incurable status of their cancer.
- Participants perceived their ability to continue to fulfil roles as a benefit. Participants, who had to give up, or change their jobs, reported it as a sense of loss.
- Participants reported the value of friendships.
- A continuous process of prioritising and re-evaluation of their lives, while adjusting to living with incurable cancer, was evident. Participants reported an increased appreciation of life, an appreciation of the “small things”, and being less concerned about trivial matters as positive outcomes of their struggle with cancer. This resulted in a process whereby participants prioritise what is of primary importance and what is of secondary importance.
- Participants reported adjusting to the changes following treatment included adjusting to side effects or late effects of treatment, for example, menopause, bone pain caused by medication, changed body image, for example, colostomy, and mastectomy, inability to perform work duties, and post treatment fatigue. Not all participants accept these unavoidable adjustments. Some participants questioned the unfairness

of having to suffer the rigours of treatment, and then have to cope with late-effects, and permanent body changes. Acceptance of unavoidable adjustments is a process that happens over time. The duration of this process is dependent on several factors, some of which are: the patients' character and coping capacities, available resources, side effects and late-effects of treatment, and the diagnosis and prognosis.

- Being in a position to choose their oncologists, and being able to afford oncology treatment, were also reported as benefits. This also provided them with a sense of control, they could change oncologist if they were not happy with service delivery, or doubt the oncologist's diagnosis or the prescribed treatment regime. This research was conducted at a private oncology centre, where patients have access to medical aids, or where they have the financial means to pay for the prescribed treatments.
- Participants reported posttraumatic growth that they link to an outcome of their cancer experience. The growth that patients reported include positive changes in relationships, increased self-confidence and coping skills, and higher levels of spirituality and appreciation for life.

### **Conclusion regarding key findings associated with appraisal.**

This research also confirms other studies with cancer patients where participants consistently and independently reported certain positive appraisals. These appraisals include changed life priorities, increased sense of self-efficacy, enhanced sensitivity to others, improved personal relationships, and increased spirituality. These appraisals are all interrelated, and the researcher could on many occasions, only make a distinction against the context in which remarks were made.

Participants accepted that cancer also influenced their family's lives. Participants strive to minimise disruption in family life. Therefore, they also learned to accept help from friends. Participants accepted emotional support

from friends when they did not want to put any more emotional strain on the family. Friendships also assisted in creating a sense of normalcy and minimised isolation, which in turn minimised alienation.

Participants described relationships as a motivational force. The vulnerability that they experience opens them to give and receive love. They prioritise their lives in a way that provides time for family and friends. They embrace supportive relationships, and address, eliminate, or avoid toxic relationships.

Awareness of life tasks to be fulfilled in the future is beneficial because participants experience that they are still needed. Family becomes a high priority and, in addition, participants are more aware of their importance to others and they put more emphasis on social relationships. This strengthening of family relationships was appraised as one of the most important benefits of the cancer journey.

Being able to prioritise, discovering what really is important to them, assisted in creating quality of life. For some participants, prioritising confirmed their worldviews and the ways they conduct their lives. For other participants, cancer and remission made them aware of changes needed. Prioritising also assisted participants to implement and adapt to required changes. They reported that they became more reflective in the post-treatment phases.

The meaning-making processes that participants experience, involves attempts to reduce the discrepancy between global meaning (assumptive world), and patients' appraisal of the cancer. Participants adjusted their view to include the positives and they focused on what they are still able to do, and they became aware of how much they enjoy their lives.

The way in which participants appraised cancer and remission, resulted in participants either adaptively 'assimilate' their experiences and/or 'accommodate' the changes required by their cancer journey.

### **Theme 3: Meaning-construal associated with reappraisal**

#### **Key findings based on reappraisal**

Based on the findings of this study, as discussed and presented in chapter 6, the researcher identified the following key findings associated with reappraisal:

- Participants described cancer as being a part of their lives. They want to be treated as authentic persons, and not only as cancer victims or cancer survivors. They formed a perception of “I have cancer,” and avoid a perception of “I am cancer”. This indicates a positive sense of self.
- Participants integrated remission into self by living beyond cancer, embracing life, and demonstrating responsibility. With exception of 2 participants, the other participants accepted the incurable status of their cancer.
- Participants also integrated the suffering that they experienced in their cancer journey.
- Participants developed their self-efficacy, which empowered them to live in the present, and have the capacity to influence the quality of the day, accepting that they are in control of their attitude. These participants accept new problems and attempt to solve problems through introspection, and understanding and sharing. They set reasonable and achievable goals, and they consciously try to downplay negative emotions and to focus rather on feelings of love and hope. They surrounded themselves with supportive friends and family members.
- Assigning some meaning to remission assisted participants to maintain a sense of coherence.
- Participants’ assumptions that the world is fair were disrupted and they had to adapt to the unfairness of cancer, initiating a process of restoration or rebuilding of their assumptive world.

- This study indicated that most participants assimilate the knowledge of the incurable status of their cancer. They live in uncertainty and have a sense of a foreshortened future. Participants found new normal, a homeostasis, where they are able to live their lives whilst in remission. All participants indicated that they wanted to live, and that their assessment of the quality of their lives is personal.
- Participants want to create normalcy by continuing with their lives and through role fulfilment.
- Remission offered the opportunity to reach out to other patients. Transcendence also manifested in the ability to accommodate family members' needs. The most prevalent changes participants reported included investing more time and energy in relationships, as well as increased sympathy, compassion and sensitivity to others.

### **Conclusion regarding key findings associated with reappraisal.**

Meaning-construal was evident in participants' ability to make a transition from attempts to look for causal factors to attempts that are concerned with developing a sense of the significance of remission and their lives. There is seldom a clear explanation of why a person develops cancer. The researcher observed in practice that patients look for causality, hoping that in future they can avoid such causes. They have to accept responsibility for lifestyle changes. Patients have to accept that they cannot change the past, but they have control over the attitude they choose, and they have control over how they respond to others. Some participants described that being assertive helped them to maintain a sense of control. Some participants described how their self-transcendence developed. They were able to find benefit, experienced growth, changed their life priorities, and became more compassionate towards others.

A sense of self allows participants to keep their identity. Participants maintained their sense of self and did not allow cancer to substitute their

identity. By engaging their self-efficacy skills, they claimed back their autonomy. They adopted a participatory stance and strove to make informed decisions about treatment, often resulting in exploring new possibilities of treatment or engaging in supportive treatment regimes.

The trauma of realising that their cancer is incurable, accentuated by recurrence and metastases, highlighted a foreshortened future and the loss of future memories; it shattered participants' assumptions that the world is fair and benevolent. They had to reappraise their lives, integrate their suffering into their sense of self, and rise above the suffering. Living with cancer involves embracing life, prioritising beliefs, values, and goals. This helped them to create a new normal. Each patient's new normal is unique.

Participants' appraisal of remission builds their awareness of self-efficacy, allowing them to focus on creating a quality of life. Awareness of self-efficacy and growth resulted in re-appraisal of themselves. They learn to trust their abilities, giving them confidence in their strengths and coping capacities.

The researcher concluded that the challenge of living in remission presents as a psychosocial process, which includes positive experiences, for example, meaning-construal, and/or negative experiences, for example, trauma. For patients in remission, life as they knew it has changed, and they have to make a cognitive shift from "I am dying of cancer" to "I am living with cancer". The process of integrating this knowledge can initiate a quest for meaning.

### **8.3.4 Key findings and conclusions regarding meaning theory**

#### **8.3.4.1 Key findings regarding meaning theory**

Based on the findings of this study as discussed and presented in chapter 7, the researcher identified the following key findings associated with meaning theory. Meaning theory is rooted in existentialism and the humanistic positive psychology. Applying the wide and deep hypothesis of meaning theory, this study confirms that:

- to live with incurable cancer, deepened participants' inner resources, for example, meaning-construal, faith, and courage
- to live with incurable cancer broadened participants' resources, for example, creativity, innovation, and social support
- participants attribute positive meaning to living with incurable cancer, and
- participants reported personal growth as a result of their cancer journey.

This research indicated that participants created a meaning mind-set, which consists of a worldview that:

- Life has intrinsic meaning and value.
- One has the capacity for meaning seeking and meaning-making.
- Meaning can be discovered anywhere, including living with incurable cancer.
- One can live at a deeper level by detecting the meaning and significance of any situation.
- One can live on a higher plane by serving a higher purpose and being attuned to the transcendental realm and sacredness in daily living.
- One can live life fully by integrating one's potentialities with one's vulnerabilities.

#### **8.3.4.2 Conclusions regarding meaning theory**

The research findings confirmed literature findings that meaning manifests in the way that participants' respond to life tasks, how they make sense out of the cancer experience, how they actualise their potential while living in remission, how they take accountability for their actions and decisions, and how they appraise life in remission. Meaning-construal left participants with the acceptance that in spite of the unfairness of cancer, their lives are meant to be. Those participants who struggled at times with the "Why me?" question, accepted that if the answer is not readily available, it will be in the future, perhaps even after death.

The research study confirmed that, for patients who live with an incurable cancer, deriving meaning in their lives holds the promise and opportunity to embrace life, to gain new insights and perspectives, and to prioritise their values. One of their life tasks is to integrate the experience of living in remission into their lives. Remission challenges patients to face their vulnerabilities. Meaning offers them a sense of purpose and experiencing well-being.

#### **8.4 RECOMMENDATIONS**

The recommendations below are made as outcomes of this study:

The high prevalence of cancer, prolonged survival, the increasing number of patients in remission, the impact of cancer on patients, survivors, families, communities and societies, and the need to develop social work intervention strategies, call for research in the field of psychosocial oncology. Professionals and volunteers should understand both the psychological impact of experiences and the complex ambiguities involved with recovering from cancer treatment and living in remission. Knowledge regarding the ambiguities inherent in remission can assist social workers to develop appropriate intervention programs to support patients and their social

attachments. Early detection and sophisticated treatment modalities prolong many patients' lives.

Social workers who practice in the oncology field need training regarding oncology and oncology social work. This training should include the psychosocial aspects in all the phases of the cancer continuum and should include patients and their social networks. Participants hope that more or new treatments will be available in the future, that these treatments would prolong their lives, and/or improve the quality of their lives. It is therefore necessary that social workers empower patients to explore their options and guide patients to ask relevant questions from their oncology team. Membership to the Association of Oncology Social Workers (AOSW) provides oncology social workers with information regarding new developments in oncology social work. The AOSW also provides literature, training and standards that can be utilised by oncology social workers worldwide.

Oncology social workers need knowledge and intervention programmes to accommodate patients in remission. The researcher proposed the MCCT model. Evaluation of this programme within the multicultural South African context is recommended. The MCCT model can be applied during any phase in the cancer continuum.

It appeared that there are support groups available for cancer survivors. However, there are no specific support groups available for patients who have experienced one or more recurrences. Such support groups should be started and when patients join these support groups, they should be prepared for the eventuality when a group member dies.

Currently, meaning therapy is receiving interest from researchers, with more literature becoming available. Future studies should include the emerging research on meaning literature to provide a more comprehensive literature overview. To the researcher's knowledge, few studies tested meaning-construal specifically as it manifests in patients in remission and the results

may be limited in their generalisability. Longitudinal studies that explore the development of meaning-construal at different stages of the cancer continuum are recommended. Further research within the psycho-oncology field should explore MCCT as an intervention model. This research argues in favour of a meaning-centered approach towards psycho-oncology, and suggests the consideration of MCCT as an intervention model. This research confirms that MCCT is a feasible intervention model for patients who are in remission. MCCT assists patients in developing coping capacities and gaining new perspectives. Effective coping facilitates adjustments, altered lifestyles, and changed perceptions that are required from patients, in order for each of them to live with incurable cancer, and to reframe remission into a more positive experience. This is true for intervention in any phase of the cancer continuum.

Training in meaning-centered therapy is recommended. To the researcher's knowledge, there is currently no training available in South Africa. There is training available on Logotherapy. Membership to International Network on Personal Meaning (INPM) provides information relating development of meaning-centered therapy. The INPM also offers international conferences.

A scarcity of measuring scales that focus on patients in remission was observed. Development of measuring scales, which focus on meaning-construal as well as the experiences of remission, should receive attention.

On a cautionary note, although meaning-construal seems to be a common experience following cancer, it is not a universal experience. Further research is required to understand how meaning-construal can contribute to coping with cancer during the different stages of the cancer continuum, and how meaning-construal affects adjustment. More data is required to establish relationships between the subjective experience of meaning and other variables.

Future studies should be on a larger scale and be more representative of the research population, and the multi-cultural South African population. The public oncology clinics should also be included in the research samples.

This study focussed only on patients in remission, another area worthy of research is meaning-construal processes in the lives of the social attachments of a patient living with incurable cancer.

## **8.5 CONCLUDING REMARKS**

This study contributes to the body of knowledge related to meaning-construal whilst living with incurable cancer or being in remission. It also provides suggestions for future research. Future research with larger and more diverse samples is needed to confirm and extend the findings of this study, in order to refine theoretical conceptualisation of meaning-construal during remission.

Oncology social workers need to be recognised and be employed in all oncology hospitals and practices. Social workers can assist patients to develop effective coping strategies that will facilitate the adjustment, altered lifestyles, and changed perceptions that are required from patients who are in remission. Intervention is needed and models such as MCCT is positively oriented, and thus MCCT offers to patients in remission an intervention that can assist them to address feelings of alienation and powerlessness, as well as avoiding the dread associated with living with recurrent, incurable cancer.

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**10 APPENDICES**

## 10.1 ETHICAL APPROVAL LETTER



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Ethics Committee

30 August 2010

Dear Prof Lombard

<b>Project:</b>	<b>Meaning-centeredness in adult cancer patients in remission</b>
<b>Researcher:</b>	<b>E Hamilton</b>
<b>Supervisor:</b>	<b>Dr C Carbonatto</b>
<b>Department:</b>	<b>Social Work and Criminology</b>
<b>Reference no:</b>	<b>28372728</b>

Thank you for your response to the Committee's letter of 12 August 2010.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study on 27 August 2010. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it would be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

A handwritten signature in black ink, appearing to read 'J. Sharp'.

**Prof. John Sharp**  
**Chair: Research Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: john.sharp@up.ac.za**

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof E Krüger; Prof A Mlambo; Dr S Ouzman; Dr C Panebianco-Warrens; Prof G Prinsloo; Prof J Sharp (Chair); Prof E Tallard ; Dr J van Dyk ; Dr FG Wolmarans

## 10.2 REQUEST TO CONDUCT RESEARCH AT THE SANDTON ONCOLOGY CENTRE



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Department of Social Work & Criminology

19/08/2010

Our Ref: Dr CL Carbonatto  
Tel: (012) 420-2410  
E-mail: Charlene.carbonatto@up.ac.za

2010-08-19

Dr Robbie de Muelenaere  
Sandton Oncology Centre  
159 Rivonia Road  
Morningside.

Dr Robbie de Muelenaere,

**Request: Permission to conduct research for MSW (Research) degree at the Radiation Unit: Sandton Oncology Centre by Ms E Hamilton (28372728)**

Permission is hereby requested for Ms Elma Hamilton, a postgraduate student and employee at your centre, to conduct a qualitative research study with the title: **Meaning-centeredness in adult cancer patients in remission** at your centre, supervised by Dr CL Carbonatto.

The goal of this research is to explore meaning-centeredness in adult cancer patients who are in remission. The objectives of the research study are to:

- Provide a broad theoretical overview of cancer survivorship, specifically focusing on remission as a field of study.
- Explore meaning-centeredness in cancer patients in remission.
- Develop guidelines for social work intervention with patients who are in remission.

The research design will be collective case studies, using focus groups to collect data. Focus groups offer a way to gain insight into how cancer patients derive meaning in their lives while in remission. Potential participants will be approached by the oncologist and informed of the intended study. The contact details of the researcher will then be given to those who wish to participate voluntarily. The sample will be chosen from these persons by means of purposive sampling according to specific criteria. A letter of informed consent will be given to these potential

Department of Social Work & Criminology    Tel: Number    00 27 12 420 2325/2030    www.up.ac.za  
University of Pretoria    Fax: Number    00 27 12 420 2093  
PRETORIA 0002  
Republic of South Africa

participants with all the details of the research procedure, for them to read and make an informed voluntary decision if they would like to participate in the study.

We understand that your permission is conditional to:

- Informed written consent to be obtained from participants prior to inclusion in this study.
- Participants will participate on a voluntary basis.
- Confidentiality of the information shared by participants to be adhered to and no identifying particulars of any participants will be used in the research report.
- Permission to be granted to Ms Hamilton to peruse the clinical files of potential participants.
- After completion of the research study, the data and documents relating to this research study will be stored for 15 years at this department at the university.

Attached please find a copy of the:

- Research proposal
- Letter of informed consent
- Data storage form
- Interview schedule for focus groups
- Conditional letter of approval of the Research Ethics Committee of the faculty, pending this letter of approval.

If you need more information please contact the researcher on: 082 451 1173 or at the Sandton Oncology Centre, 011 883 0900, or on e-mail: [elma@hamilton.co.za](mailto:elma@hamilton.co.za).

Yours sincerely,

Elma Hamilton

Researcher and Social worker (10-03421)



Dr Charlene L. Carbonatto (DPhil)

Senior Lecturer

## 10.3 PERMISSION TO CONDUCT RESEARCH AT THE SANDTON ONCOLOGY CENTRE

		<b>Dr. Robbie de Muelenaere</b> M.B.Ch.B., M.Med. (Rad. Onc.), L.K.Rad./Onk./SA <b>Dr. Ingo de Muelenaere</b> M.B.Ch.B., M.Med. (Rad. Onc.), L.K.Rad./Onk./SA <b>Dr. Sally Bairstow</b> M.B.Ch.B., F.C. Rad./Onk./SA		<b>Prof. Bernard Donde</b> M.B.Ch. (Wk), M.Med. Rad. (T), M.Med. <b>Dr. Linda van Zyl</b> M.B.Ch.B., F.C. Rad./Onk./SA <b>Dr. Kobie Pio</b> M.B.Ch.B., M.Med. (Rad. Onc.)	
17132 Groenkloof 0627		Stralingsoncologie / Radiation Oncologists Drs. G & R de Muelenaere Onc./Inc.   Reg. 97.0205321		EMERGENCY NUM. PRETORIA: +27 12 332 2146 SANDTON: +27 11 882 1692	
P/No: 020512 Medunet Hospital / Hospitaal Pekaapweg 577 Pretorius D. Arcadia, Pretoria ☎ +27 (12) 445 8889 / 341 4306 F: +27 (12) 445 8907	P/No: 028820 LDW Stralingsoncologie / Radiation Oncology Life Company of May Hickinbotham Hospital George Serravallostraat, Groenkloof, Pretoria ☎ +27 (12) 460 4749 F: +27 (12) 460 4438	P/No: 450055 Sandton Oncology Centre Rivoniaweg 155 Rivonia Road, Morningside, Sandton ☎ +27 (11) 883 0500/4 F: +27 (11) 882 1692	P/No: 400122 West Rand Oncology Centre Fook Clinic, Fook CH, Woodmead ☎ +27 (11) 475 0330/33 F: +27 (11) 475 0278		

2010-03-02

Dr Robbie de Muelenaere  
 Sandton Oncology Centre  
 159 Rivonia Road  
 Morningside.

Dr de R Muelenaere,

**Request to do research at the Sandton Oncology Centre.**

The research panel of the Department of Social Work and Criminology of the University of Pretoria has approved my research proposal to do a MSW (Social Work Research). The proposed topic of the research study is: Meaning-centeredness in adult cancer patients in remission. In order to continue I am now applying to the Ethics Committee of the University of Pretoria for ethical approval and clearance. The Ethics Committee requires that I obtain written permission to conduct this research at the Sandton Oncology Centre.

I propose to do a qualitative research study during which I will interview participants to obtain their perceptions of how they derive meaning in their lives while in remission. The goal of this research study is to explore meaning-centeredness in adult cancer patients who are in remission. The objectives of the research study are to:

- Provide a broad theoretical overview of cancer survivorship, specifically focusing on remission as a field of study.
- Explore meaning-centeredness in cancer patients in remission.
- Develop guidelines for social work intervention with patients who are in remission.

I therefore request permission to do above-mentioned research. I understand that permission is conditional to:

- Written consent to be obtained from participants prior to inclusion in this study. Participants will participate on a voluntary basis. Informed consent, with specific emphasis on confidentiality of information will be obtained from each participant.
- Permission to be granted to me to peruse the clinical files of potential participants. After completion of the research study, the data and documents relating to this research study will be stored at the Department of Social Work and Criminology of the University of Pretoria.

Attached a copy of the proposal for your information.

Thank you



.....  
Elma Hamilton  
Social worker  
10-03421  
Student no 28372728

I, Dr RAG de Mûelenaere, give permission that Elma Hamilton may, if she conforms to the above-mentioned conditions, do the research at the Sandton Oncology Centre.



.....  
Dr. RAG de Mûelenaere  
M.B.Ch.B., M.Med(Rad T), L.K.Rad.(Onk)SA

*15-04-2010*  
.....  
Date

## 10.4 LETTER OF INFORMED CONSENT



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Department of Social Work & Criminology

### LETTER OF INFORMED CONSENT

#### SECTION A: RESEARCH INFORMATION

##### 1. Title of the study

Meaning-centeredness in adult cancer patients in remission.

##### 2. Researcher

The researcher, Elma Hamilton, is a Masters student in Social Work at the Department of Social Work and Criminology, University of Pretoria. As the social worker at the Radiation Unit of Sandton Oncology Centre, researcher became aware to the lack of support services available for cancer survivors. Although the medical community continues to make progress in the treatment of cancer, recurrence of cancer is still frequent.

##### 3. Purpose of the study

This study will explore how adult cancer patients who are in remission, derive meaning in their lives. The motivation for this research derives from practice. Contact with patients who are in remission have led to the question "How do patients, knowing that they are in remission and not cured, derive meaning in their lives?"

##### 4. Procedures

I have been invited to voluntary participate in this research project. This letter serves to inform me what the research involves, and to help me decide if I want to participate in the research project. If I have any questions regarding this research study, I can ask for clarification. Participation is voluntary and I can withdraw from the research project any time, after which the data that I shared will be destroyed.

This study will be conducted with participants who will voluntarily partake in one of two focus group interview sessions to be held. I have been asked to be a participant in one focus group session. The focus

This study will be conducted with participants who will voluntarily partake in one of four focus group interview sessions to be held. I have been asked to be a participant in one focus group session. The focus group interview session will last approximately 90 minutes and there will be no more than six participants in each group. This focus group discussion will be with other patients who are in remission and for us to share our experiences of living with cancer. The researcher as facilitator of the focus groups will use an interview guide for this session. A tape recorder will be used with my permission, during the focus group session, to assist the researcher with the recording of the data. Following this session the researcher will transcribe this recorded session verbatim and use this to analyze the data. Thereafter a research report in the form of a dissertation will be written. The research material and the signed letters of informed consent will be stored in the Department of Social Work and Criminology, University of Pretoria for a period of 15 years, after which it will be destroyed.

I will receive a copy of this letter of informed consent.

#### **5. Risks and Discomforts**

No risks of discomforts are foreseen for me as participant. There is however the risk that the discussion may bring some unresolved issues to the fore. The researcher will conduct a debriefing group session directly after the focus group session and where further counseling is needed, the participants will be referred to Mrs. Wilna Burgers, a social worker specializing in oncology.

#### **6. Benefit of research**

I will not benefit directly from this research, but may benefit indirectly, because the information gained from this research will contribute to a better understanding of how patients who are in remission, derive meaning in their lives. This knowledge may in future benefit other cancer patients that are in remission. It may also guide social workers in developing intervention programmes for cancer patients who are in remission, or other patients who live with a life threatening disease.

#### **7. Participants rights**

Participation in this research project is voluntary and participants can refuse to participate or withdraw at any time without stating a reason and without suffering any consequences. Treatment at the Sandton

Oncology Clinic or any of the other practices of G&R de Mûelenaere (Inc) will not be affected in any way through participants' willingness or refusal to participate in this study.

**8. Confidentiality and anonymity**

All information obtained during the focus group session will be treated confidentially and shared confidentiality will be encouraged. Each participant will be assigned a pseudonym or false name after the session for the purposes of when researcher transcribes the focus group interview session. Thus no link will ever be made to you as participant and the information you shared during the session, maintaining anonymity. Only the researcher will know which participant is linked to which pseudonym. The people who will have access to anonymous data during the data analysis process are the supervisor of the researcher, Dr. C.L Carbonatto and Mrs. Wilna Burgers, social worker at Mary Potter Oncology Unit in Pretoria and a typist who will assist in the transcribing of the focus group interview sessions. Confidentiality will thus be maintained as no link will be made between you, the data and the pseudonyms used. A copy of the final research report (dissertation) will be given to the Radiation Unit of the Sandton Oncology Centre, where it will be accessible to the oncologists, radiotherapists, oncology nurses, social workers, and students of G& R de Mûelenaere (Inc.) Reg. 97/02/253/21. The participants will also have access to this report. All the signed letters of informed consent will be kept in a confidential file and will be stored on completion of the study in the Department of Social Work and Criminology, University of Pretoria for a period of 15 years, after which it will be destroyed.

**9. Contact details of researcher**

The researcher, Elma Hamilton can be contacted by me on 082 451 1173 if I have any concerns.

**Please sign the subsequent informed consent section.**

Yours sincerely,



**Elma Hamilton: Researcher**

**Dr CL Carbonatto: Supervisor**

**SECTION B: INFORMED CONSENT OF PARTICIPANT**

I, \_\_\_\_\_ (name and surname) the undersigned participant, understand my rights as a research participant. The goal and procedures of the study have been explained to me. I am aware of the confidential nature of this study. I have had the opportunity to ask any questions I had. I will be partaking voluntarily in this study and may withdraw at any time if I so wish without any consequences.

**Participant:**

Name and Surname: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Researcher:**

Name and Surname: Elma Hamilton

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## 10.5 FOCUS GROUP INTERVIEW SCHEDULE

### Group Interview Schedule

Welcome

- Welcome participants. Thank them for willingness to participate.
- Point out that interview will be videotaped.
- Refer to the consent forms, and confirm all the consent forms have been signed and collected. Emphasise voluntary participation, no consequences if any one decide to withdraw from study and explain confidentiality (explain again how researcher will uphold confidentiality and ask participants to also respect confidentiality).
- State purpose of study.

This study will explore how adult cancer patients who are in remission, derive meaning in their lives. The motivation for this research derives from practice. Contact with patients who are in remission have led to the question “How do patients, knowing that they are in remission and not cured, derive meaning in their lives?”

- Emphasise that there is no right or wrong answers and encourage discussion.
- Validate to participants the authenticity of their experiences.
- Ask each participant to complete Section B on sosiographic information and oncology history. Collect it when completed.

Section A: Proposed interview questions

1. What was the difference between hearing the initial diagnosis of cancer and the diagnosis of recurrence and/or metastasis?

Probing questions, if needed:

- Feelings of helplessness
  - Feelings of hopelessness
  - Denial/disbelief
  - Making informed decisions
  - Prioritising
  - Self-efficacy and previous experience of treatment
  - Support
2. Did you understand the concept of remission?
  3. When this cancer recurred/metastasised, why did you choose to have treatment again?
  4. Did you experience change and growth because you are living with cancer?

Probing questions, if needed:

- Better appreciation of time, life and relationships
  - Prioritising (including addressing toxic relationships)
  - Changes in self-concept
  - Accepting love, care and dependability on others
  - More tolerant and accepting of others
5. What are the things that are meaningful in your life?
  6. What help you now to create meaning in your life?

Probing questions, if needed:

- Support
- Issues addressed
- Relationships
- Tasks – coping with realisation of own mortality, accepting the reality of disease, treatment, and side effects. Reframing from “dying of cancer to living with cancer”
- Creating realistic positive attitude

- Realistic hope
- Building self-perception and self esteem
- Becoming aware of the anchors in your life
- Detoxifying death and dying

7. How do you create meaning in the times that you are in remission?

(Reframing the cancer experience into a more positive experience than a solely negative one)

## 10.6 DECLARATION OF EDITING AND PROOFREADING

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20<sup>th</sup> December 2013

*To Whom It May Concern*

**The thesis entitled Meaning-centeredness in adult cancer patients in remission -  
by Elma Hamilton**

I am pleased to confirm that, over the past few months, I have worked extensively with Elma Hamilton, editing the language and structure of the thesis entitled Meaning-centeredness in adult cancer patients in remission, leading up to its final compilation and presentation.

Yours sincerely,

A handwritten signature in black ink that reads "Philip Hall". The signature is written in a cursive style with a large initial 'P'.

JP (Phil) Hall