



CLIENTS' PERCEPTIONS OF THE ONCOLOGY SOCIAL WORK SERVICE AT CANCERCARE

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the award of the degree of

MASTERS IN CLINICAL SOCIALWORK

By

Tasneem Variawa

(VRWTAS001)

Supervisor: Fatima Williams

Department of Social Development

Faculty of Humanities

University of Cape Town

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ABSTRACT

This study explored clients' perceptions of the oncology social work services offered at three Cancercare practices in Cape Town. It considered their motivation for using the service as well as their overall experience of the service. Positive aspects as well as the challenges encountered with the service were examined concerning the frequency and nature of intervention, and their professional relationship with the social workers. The research was conducted using a qualitative research design, more specifically phenomenology. Sixteen participants were selected using purposive sampling by the researcher. They were interviewed face-to-face using a semi-structured interview schedule. The data obtained were analysed using qualitative methods.

The findings of this study highlighted the value of a psychosocial service accessible to cancer patients. Psychosocial responses to diagnosis and treatment included the need for information, psychological support for the patient and family, and an assorted range of practical needs. Findings also highlighted the complexities surrounding public perceptions of social workers and psychologists, and the blurred boundaries between the professions in terms of services offered.

Participants identified six aspects of the service that were helpful. The challenges encountered with the service were presented in terms of the lack of clarity on the role of the social worker and the need for specific information about the service and external resources. Recommendations were made around the distribution of information within the practice and participants requested regular post-treatment support. Further recommendations were made in terms of professional contact within a public setting, early intervention and future research.

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CHAPTER ONE

Problem Formulation

1.1. Introduction

This research sought to explore clients' perceptions of the oncology social work services offered at three Cancercare practices in Cape Town. This chapter introduces the field of study which focuses on the field of oncology social work. The topic of this study is stated followed by the main research questions, objectives of the study, and clarification of key concepts. An overview of the ethical considerations pertaining to this study and reflexivity will be discussed. An outline of the structure of the dissertation will follow and conclusive remarks.

1.2. Background to the problem

Cancer begins in cells and refers to a group of many related diseases (Scientific American Inc, 1997; Bower & Waxman, 2016). Cancer cells grow rapidly and results in tumours. Tumours are considered to be either benign or malignant. Malignant tumours are referred to as being cancerous. Cancer can spread to other parts of the body and when this occurs; the disease is referred to as metastatic cancer (Scientific American Inc, 1997; Bower & Waxman, 2016). Current knowledge suggests that all cancers are both environmental and genetic proposing that the multiple causes of cancer involve environmental exposure outside the body as well as hereditary and genetic changes inside the body (Clapp, Howe & Jacobs, 2006).

Much of the research in the field of oncology has been dedicated to identifying the risk factors for cancer to occur. From this, it is clear that in its complexity cancer is caused by a mixture of lifestyle, hereditary and environmental factors (Scientific American Inc, 1997; Clapp et al, 2006). Those diagnosed with cancer may be concerned with their future and information geared at helping them understand their diagnosis and its implications can give them a better sense of direction and ease their fears. Global statistics published in 2008 estimated 12.7 million new cancer cases and 7.6 million cancer deaths (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011). In terms of the most recent statistics, the global burden of cancer continues to increase with an estimate of 14.1 million new cancer cases and 8.2 million deaths occurring in 2012 (Torre, Bray, Siegel, Ferlay, Lortet-Tieulent & Jemal, 2015).

Cancer is becoming an urgent public health issue in Africa and by 2050 the lifetime risk of the disease is expected to increase by fifty to sixty percent (Selman, Higginson, Agupio, Dinat, Downing, Gwyther, Mashao, Mmoledi, Moll, Sebuyira, Ikin & Harding, 2011). In April 2011, the South African Department of Health published the regulation on the compulsory registration of all persons with cancer in South Africa regardless of age (Lourens, 2013). The last cancer statistics report to be made available to the South African public was in 2013 and the Department of Health acknowledged that the lack of an updated cancer registry is a problem in terms of drafting national policy guidelines for cancer prevention and control. According to the National Cancer Registry a total of 72 530 new cancer cases were reported in South Africa in 2013. More than 100 000 South Africans are diagnosed with cancer every year with a reported 60% survival rate (www.cansa.org.za).

There is very sparse statistical data available in Africa resulting in an inaccurate representation of cancer incidence and mortality rates (Jemal et al., 2011). The researcher has noted the difficulty in obtaining recent South African cancer statistics pointing to the need for more local research and access to information. The head of research at the Cancer Association of South Africa argued that cancer is not a priority in South Africa as there are no national bodies that can coordinate the different components of an effective strategy. The figures released in 2008 by the International Agency for Research in Cancer (IARC) indicate that approximately 681000 new cases of cancer were reported in Africa as well as 512400 cancer deaths. Based on this, the numbers are projected to nearly double by the year 2030 due to ageing and growth in the population. This suggests that it is essential for South Africa to increase expenditure on cancer prevention, treatment and awareness; and to build better infrastructure in recording statistics. (www.cansa.org.za)

The diagnosis of cancer is often experienced as a crisis by many patients and their families and it can disrupt the patients work, family and social relationships, and sense of self (Cwikel & Behar, 1999). The inclusion of an oncology social worker in medical management is essential in focusing on the emotional aspects of adjustment to cancer, helping with decision making around treatment, long term care planning, addressing financial and employment issues as well as acting as a liaison between the patient and the treating team (Cwikel & Behar, 1999). A multi-disciplinary team approach fosters effective and appropriate cancer care (Gouws, Eedes, Marais, Valodia & De Villiers, 2012).

There is much debate about the effectiveness of social work practice and opinions tend to centre on the needs of those receiving the service and what the focus of the service should be. In light of this a number of authors call for evaluative research in the field of social work taking into account the perspectives of all involved (Cheetham, 1992; Lauria, Clarke, Hermann & Stearns, 2012). Social workers have an ethical and practical obligation to constantly evaluate methods of intervention accounting for the changing needs in society (Cheetham, 1992). The findings of such research should then be useful to practitioners, clients and the organisation funding the service. The significance of medical social work needs to be defended against other rising health care costs, and this requires accountability from social workers in terms of describing and evaluating their service (Cwikel & Behar, 1999). It is only through research that the benefit of oncology social work can be demonstrated. A study focused on service user's perceptions of social workers is important as it explores public confidence in the profession, provides incentive for people to join the profession and motivates for funding of the service (Staniforth, Fouche & Beddoe, 2014).

1.3. Rationale and significance of the study

The researcher has noticed that existing research conducted in the field of oncology social work and the profession's relevance to cancer care has mostly originated from international sources. In South Africa this research is lacking as there are no local ethical policies that guide effective social work practice within an oncology setting. Practice is guided by research conducted internationally. Recently published South African mortality statistics "creates the impression that South Africa enjoys the unique privilege of having been spared the increase in malignant disease seen in the rest of the world" (Stefan, 2015:103). However, upon further examination the statistics indicate that 8% percent of all deaths in South Africa are caused by cancer and that malignant tumours were the second most frequent causes of death in South Africa (Stefan, 2015). From this it is clear that cancer care should be a priority in South Africa and the need for more local research should be acknowledged.

With the establishment of oncology societies and forums, for example The South African Oncology Social Worker's Forum (SAOSWF), there has been an increased focus on palliative care and the psychosocial needs of cancer patients and their families. However it is argued that provisions of these services is patchy and faces significant challenges (Selman et al, 2011). South Africa faces a multiple burden of disease and cancer care is not the main focus due to increasing costs in a country that is already resource constrained (Gouws et al,

2012). While countries like South Africa and Uganda have made great strides in the provision of palliative care services, a major barrier to further development is the lack of data to inform service provision that meets the medical and psychological needs of patients (Selman et al, 2011). Stefan (2015) calls for more local research aimed at reducing the cancer burden and adequate attention to cancer care that includes a holistic approach to patient management.

There are several private oncology practices in Cape Town and the researcher has been employed by the Cancercare group as an oncology social worker for more than two years. The Cancercare group was founded in 1990 and has expanded to include nine private treatment practices in the Western Cape. Although each practice serves a different geographical area, they are managed by the same head office structure that ensures conformity in practice. Cancercare takes pride in the multidisciplinary approach to patient-centred cancer care and the team in each unit consists of oncologists, medical officers, speciality trained nursing, radiation therapists, oncology social workers and medically trained administrative. Cancercare recognises that a cancer diagnosis may have a domino effect on all aspects of the lives of patients and the oncology social workers are employed at each practice to support the psychosocial needs of cancer patients. Different support groups are run, and Cancercare supports local Non-Government Organisations that assist patients with the challenges faced along their cancer journey. (www.cancercare.co.za)

Patients are referred to the oncology social worker by the treating oncologist at their first consultation. It is often up to the patient and family to decide if they would like to engage with the service. As part of routine practice, all patients are required to complete a Distress Thermometer at their first consult, indicating what areas of functioning they are struggling with. Psychosocial service needs of patients must be assessed using the appropriate tools and the distress thermometer allows patients to identify the challenges they face with symptom control, emotional and spiritual disturbances as well as practical functioning (Carlson & Bultz, 2003). The purpose is to identify vulnerable patients as early on as possible enabling the treating team to proactively assist them with their current needs in the hope of avoiding psychosocial problems at a later stage. Distress screening is an ethical initiative in terms of identifying the psychosocial needs of cancer patients and the service response thereof (Carlson & Bultz, 2003).

The prevalence of psychosocial distress and psychiatric disorders in cancer patients is approximately 50% and most of these disturbances are related to the diagnosis of cancer and the experience of treatment (Breitbart & Alici, 2009). This suggests a need for the provision of appropriate and effective psychosocial support in all cancer care settings. The aim of this research is therefore to provide insight into the experiences, needs and perceptions of patients diagnosed with cancer in the urban context of South Africa. This study will create an awareness of the psychosocial needs of cancer patients and will hopefully contribute towards the limited academic knowledge of the oncology social work profession in South Africa.

Griffiths (2009) suggests that any research undertaken as collaboration between local health care professionals and service users is the most ideal approach as the user perspective strengthens the research findings. According to Cheetham (1992:5) “the language of effectiveness and evaluation is part of service delivery and research will continue to have an important contribution to the delivery of a care service”. Oncology social work includes a range of interventions from counselling to social care and its planning. The effectiveness of such a service cannot simply be observed and requires empirical evidences as a product of data collection processes and assumptions (Cheetham, 1992). The goal is to obtain data and information that leads to the improvement of an already existing service. Such evaluation is often subjective, taking into account the perspectives and assumptions of service providers and/or service users. In saying this, much of the progress identified in the development of social work lies in the precise matching of client’s problems to the responses developed by practitioners (Cheetham, 1992). For this reason, it has been suggested that social work research often takes on a qualitative exploratory approach.

The findings of this research will provide useful insights to cancer care providers, and more specifically, will be shared with the Cancercare practices in the Western Cape. It is hoped that this research will lead to not only an appreciation of the oncology social worker’s role in the multi-disciplinary team, but also an enhancement of the social work service provided at Cancercare practices. A positive perception of social work is very likely to lead to a better utilisation of the service as well as support and funding for suggested programmes (Olin, 2013).

1.4. Topic

Clients’ Perceptions of the Oncology Social Work Service at Cancercare

1.5. Main Research Questions

- 1.5.1. What were the clients' reasons for using the oncology social work service?
- 1.5.2. What were the clients' expectations of the oncology social work service?
- 1.5.3. What were the positive aspects of the oncology social work service?
- 1.5.4. What were the challenges in engaging with the oncology social work service?
- 1.5.5. What recommendations would the clients make to improve the oncology social work service?

1.6. Main Research Objectives

- 1.6.1. To explore the clients' reasons for using the oncology social work service.
- 1.6.2. To determine the clients' expectations of oncology social work service.
- 1.6.3. To determine the positive aspects of the oncology social work service.
- 1.6.4. To investigate the challenges clients experienced when engaging with the oncology social work service.
- 1.6.5. To examine the clients' recommendations pertaining to the improvement of the oncology social work service.

1.7. Clarification of Key Concepts

The following definitions provide clarity for terms used in this study:

Cancer – Cancer is malignant tissue that spreads to distant locations within the body invading and destroying healthy tissue (American Brain Tumour Association, 2010). There are many kinds of cancers. The Oncologists at Cancercare only manage solid tumours. Solid tumours are cancer of the organs and are an abnormal mass of tissue that usually does not contain cysts or liquid areas (National Cancer Institute, 2015).

Oncology – This field of medicine is devoted to the study of cancer and deals specifically with prevention, diagnosis and treatment (Raven 1990; American Brain Tumour Association, 2010). There are a number of different specialities within the field of oncology that are specific to the different types of cancers. There are three primary disciplines within the field of clinical oncology. Medical oncology refers to the treatment of cancer with medication like chemotherapy; surgical oncology refers to biopsy and staging procedures as well as the surgical removal of cancerous tumours; and radiation oncology involves the treatment of cancer with therapeutic radiation (Wagener, 2009).

Oncology Social Work - The Association of Oncology Social Workers define Oncology Social Work as “a profession designed to promote the patient’s best utilisation of the health care system, the optimal development of coping strategies and the mobilisation of community resources to support maximum functioning” (Fobair, Stearns, Christ, Dozier-Hall, Newman, Zabora, Hill Schnipper, Kennedy, Loscalzo, Stensland & Hedlund, 2009:115). For the purpose of this study, the oncology social worker will be referred to as the social worker.

Perceptions – This can be defined as “the way in which something is regarded, understood or interpreted” showing intuitive understanding and insight (Aarts, Chalker & Weiner, 2014:107). Perceptions do not necessarily reflect reality, but rather how humans come to understand reality; for this reason it drives the decisions and behaviour made by service users (Wantz & Firmin, 2011).

Palliative Care – Palliative care is a unique approach associated with the management of life threatening illness. The aim is to improve the quality of life of patients and their families by means of early identification and assessment. It entails the prevention and relief of human suffering as well as the treatment of problems that are physical, psychosocial and spiritual (World Health Organisation, 2002).

Curative Treatment – Is an approach to medicine that specifically focuses on the goal of a cure in order to improve and eventually eliminate symptoms (Fox, 1997).

Adjuvant Treatment – This treatment is provided in addition to a primary treatment. This form of treatment for cancer involves pre or post-operative chemotherapy or radiotherapy for localised clinical malignancies in order to help decrease the risk of the cancer recurring (Malik & Savage in Hanna, Crosby & Macbeth, 2015).

1.8. Ethical Considerations

In social work research there is increasing recognition that ethical responsibility is imperative in working towards successful practice (Strydom in De Vos, Strydom, Fouche & Delpont, 2011). The following ethical considerations were applied to this study:

1.8.1. Voluntary Participation and Informed Consent

Informed consent is related to providing accurate information about the research process to the subjects enabling them to fully comprehend the study and subsequently make a knowledgeable and voluntary decision with regards to participation (Strydom in De Vos et al, 2011). Subjects selected from the sample were initially contacted telephonically by the researcher and invited to participate in the study. All questions were answered and once they agreed to participate, informed and voluntary consent was obtained in writing (Appendix A).

1.8.2. Avoidance of harm

The researcher is ethically obliged to refrain from causing both physical and emotional harm to the participants of the study. Strydom in De Vos et al (2011) warns that traumatic memories maybe recalled during the investigation and could lead to feelings of embarrassment or harassment. For that reason the researcher did not probe into personal matters that were not relevant to the research. The general guideline in conducting research is that the risks should not exceed the potential benefits of the study (Brink, 2009). Therefore issues around physical discomfort, loss of privacy, emotional distress and financial implications were accounted for. Cancer narratives are deeply personal often leaving patient's feeling vulnerable and distressed. These patients are likely to have been exposed to anxiety, loss of control, fear and feelings of hopelessness (Fawzy, 1999; Manicom, 2010). In order to minimise risk to the participants they were informed of the possible effects of the study. In addition, they were assured that should the need arise they can contact a social worker for debriefing after the interview.

1.8.3. Anonymity, Privacy and Confidentiality

The researcher reassured the participants that whatever was disclosed will remain confidential and safeguarded, especially with regards to sensitive information (Strydom in De Vos et al, 2011). Brink (2009) reminds the researcher that when a research study is published and shared, the subjects must be informed and their anonymity guaranteed. This pertains to the data collected during interviews and transcriptions thereof. The participants may have been particularly concerned that their disclosure may jeopardise their relationship with their social worker or treatment team and for this reason that they were assured of the measures that were taken to ensure confidentiality and anonymity. These measures included referring to the participants anonymously in the findings as well as identifying them by aliases as opposed to their full names in the interview transcriptions.

The researcher was concerned about the tension that may arise should the more experienced members of the team feel that their current practice is being challenged. In order to minimise this, the researcher chose to focus on three different oncology practices, ensuring the anonymity of the social workers and the participants that were selected from the complete sample. In doing so, the responses of the participants cannot be linked to a specific staff member. The research schedule also refrained from mentioning the unit that the participant was being treated at thus all responses are a reflection of the service offered by the social workers at all three CancerCare units.

1.8.4. Deception of Subjects

Deception is deliberately misleading and withholding information pertaining to any aspect of the study that may affect the participants (Strydom in De Vos et al, 2011). There was no need to withhold any information from the subjects and they were fully informed about the purpose and nature of the study as well as the possible effects of the research process.

1.8.5. Publication of Findings

All findings have been released in the form of a written report that is clear and includes all the necessary information pertaining to the research study; as suggested by Strydom in De Vos et al (2011). The final report of this study has been submitted to the University of Cape Town and a report has been submitted to the CancerCare research board.

1.8.6. Actions and Competence of the researcher

The competency and skill of the researcher must be adequate in order to undertake a research study (Strydom in De Vos et al, 2011). The researcher had a suitable qualification to carry out the research, adequate supervision and refrained from making any personal judgements that could contaminate the data being obtained. The policies of the practices were respected and this process was closely monitored by the both the researcher's university and practice supervisor. Furthermore, the researcher acknowledged her dual role at the practice, as both a staff member and researcher; and this was dealt with openly and honestly so as to avoid compromising the findings.

1.8.7. Debriefing of the Respondents

Strydom in De Vos et al (2011) suggests that participants could need debriefing after sharing their experiences and encourages debriefing sessions. In keeping with the ethical

consideration of the avoidance of harm, this was offered to participants and they were encouraged to use it as an opportunity to process their experience. The researcher also arranged that a social worker was available at another practice upon request. None of the participants chose to participate in a debriefing session.

1.9. Reflexivity

Reflexivity is thought to be a defining feature of qualitative research as researchers have a role in the co-construction of knowledge (Finlay, 2002). This suggests that the researcher has an impact on data collection and analysis therefore giving rise to questions around the transparency of the research. Reflexivity can be understood in terms of the subjective self-awareness of the researcher in light of the fact that “research is co-constituted, a joint product of the participants, researcher and their relationship” (Finlay, 2002:212). In considering the choice of research for this study, the researcher was aware of being influenced as a social worker at Cancercare, and curiosity about the impact of the service. The researcher has personal feelings about being underutilised at the practice due to the belief oncology social work is of great benefit in the management of individuals diagnosed with cancer. It was the researcher’s assumption that not many oncology private practices in Cape Town offer this multidisciplinary approach therefore it was useful to explore clients’ perceptions of the service.

It was important for the researcher to be conscious of the interactions with participants so that they did not feel pressured to give positive feedback or were unable to critique the service. The researcher avoided making suggestions and leading the participants in the direction of her own biases. Here, Finlay (2002) refers to psychodynamic persuasion in terms of how the unconscious processes influence the relationship between the participant and the researcher. Supervision from both the practice and university supervisor assisted the researcher in identifying this and remaining focused. The researcher’s social work skills and experience assisted in managing the content of the interviews. Another factor that has been considered is the very nature of this research study and the choice of sample selection. The researcher’s employment at Cancercare undoubtedly contributes toward the support and cooperation of the management and staff in undertaking this research; but as mentioned, may have resulted in the anxiety of the other social workers when their practice came under scrutiny.

1.10. Structure of the Research Report

This report comprises of five chapters. Chapter one presents the problem formulation. Previous literature is presented in chapter two. The methodology is discussed in chapter three. Chapter four will report on the research findings and the final chapter will include recommendations based on the research findings as well as the researcher's concluding remarks.

1.11. Conclusion

This chapter outlined the background to the problem and identified the significance of this study. The researcher's intentions were explained through a clarification of the research objectives and the definition of key concepts. In addition, the researcher's reflexivity was discussed, and ethical matters were considered. Chapter two presents the literature review.

CHAPTER TWO

Literature Review

2.1. Introduction

This chapter presents the theoretical frameworks that underpin this research, the psychosocial needs of cancer patients and the National policies and legislation informing oncology practice are outlined. This is followed by a discussion of literature pertaining to themes of the study.

2.2. Theoretical Frameworks

2.2.1. Psychosocial Oncology

As a subspecialty of oncology, psycho-oncology emerged around the mid-1970s due to a growing emphasis on informing patients about their diagnosis and the implications thereof. In preceding centuries a cancer diagnosis was experienced as a death sentence and it would be cruel and inhumane to inform patients of their condition (Holland, 2003). Clinicians argued that such information would affect patients' mental wellbeing and ability to deal with the illness. Ruth Abrahams, a social worker at the Massachusetts General Hospital provided the first psychosocial services to patients with cancer (Holland, 2003). In the 1960's Elizabeth Kubler-Ross challenged the taboo of talking to patients about their diagnosis and argued that cancer patients have a need for dialogue around death (Holland, 2003). Her contributions were crucial in fostering and humanising palliative care.

The improvement of medical interventions, the increase in survival rate in cancer patients and the research demonstrating the emotional response to a cancer diagnosis led to the realisation of the field of psycho-oncology. It extended beyond the psychiatric profession to include pastoral counsellors, social workers and nurses (Holland, 2002). Oncology social work blossomed into a fully developed profession that uses multiple psychosocial interventions for cancer patients and their families (Fobair et al, 2009). This field has placed a growing emphasis on the importance of public cancer education, palliative care, pain management, quality of life and patients' right to support (Breitbart & Alici, 2009). Oncology social work emphasises the framework of addressing the whole person and this includes social support system within the community; this includes the physical, emotional, social, cultural, spiritual, intellectual an environmental aspects of each individual (Krise & Lundy, 2005).

Professor Tim McElwain, an oncologist based at Royal Marsden Hospital facilitated the introduction of psychosocial oncology care and this led to the development of the British Psychosocial Oncology Society in 1982 (Watson, Dunn & Holland, 2014). In the 1990s, there was an emerging interest worldwide in psychosocial care for cancer patients and the term 'distress' was chosen to describe the psychological impact of the diagnosis in an attempt to reduce the stigma associated with psychological issues (Watson et al. 2014). This theoretical framework is especially relevant to the approach used by social workers in managing the psychological, social and behavioural dimensions of cancer. It highlights the role of the social worker in a multidisciplinary team setting and allows for the inclusion of patients and families in the process of diagnosis and treatment. This theoretical framework informs the services provided by social workers at the Cancercare practices and is therefore useful in exploring how clients perceive the service.

2.2.2. System's Theory

The National Association of Social Work (NASW) defines System's Theory as an attempt to consider the holistic behaviour of people and societies through recognizing the interacting components of each system and identifying the controls that keep these subsystems stable; it is therefore concerned with the flow of information between people and the boundaries, roles and relationships in their lives (NASW, 2003 in Turner, 2011). The concepts that underpin this approach emphasise the reciprocal relationships between the different elements that constitute a whole (Stein 1974; Turner, 2011). System's Theory therefore considers the different structures around clients and includes the process of integrating individuals in the community (Turner, 2011). These structures refer to family, groups, organisations and institutions. The contextual nature of social work differentiates it from other professions, as human life and wellbeing can only be maintained if societal problems are understood within the context in which they occur (Turner, 2011). Social work is a profession that places itself between systems; knowledge and ways of explaining the world are constructed in the environments in which we live (Green & McDermott, 2010:2416). The professional stance of person-in-environment recognises that phenomena occurring at micro, meso and macro levels accounts for the complexity within social and human life (Stein, 1974; Green & McDermott, 2010).

In promoting optimal functioning social workers have a variety of interventions to choose from, but it is the understanding of the holistic nature of human functioning that is unique to

the social work profession. Social workers possess the unique knowledge that all parts of a system are interconnected, interdependent and interrelated, and that the influence between systems has a direct impact on client functioning (Turner, 2011). Systems are dynamic and the interfaces between them are constantly in the process of change (Stein 1974; Turner, 2011). Clients are observed in their total life situation in attempting to understand problems in social functioning. This understanding is applied to all levels of social and physical systems where a strong emphasis is placed on the meaning clients assign to the interactions between these systems (Turner, 2011).

In providing a social work service, consideration of these everyday structures is especially significant from the perspective of the individual and communication is key feature of what is going on between persons (Kihlstrom, 2011). The network of communication between systems is considered in light of the information given, how it is provided and the reaction it provokes; this is within the context of open system theory (Stein 1974; Kihlstrom, 2011). One example of this is the discussion of oncology treatment options and side-effects, the manner in which it is communicated and the reactions thereof. Put simply, the client has to come to a conclusion about the information provided before acting in line with that. The social worker is a “mutual communicating subject” that uses universal principals around human equality, human rights as well ethical and moral standards in working with the conditions of a presenting client (Kihlstrom, 2011:292). It is essentially a profession based on communication. In oncology social work, interventions are centred on helping clients find solutions that address physical, intra-psychic, interpersonal and environmental problems; the interactions between these systems and subsystems influence the client’s ability to manage diagnosis and treatment (Fobair et al, 2009). In view of this, systems theory is relevant to this study as it is the approach used to assess all patients in determining their psychosocial needs and providing a service thereof.

2.2.3. Erikson’s Psychosocial Stages of Development

Erik Erikson played a crucial role in addressing psychosocial development across the life span as well as the sociocultural influences on development (Cronin & Mandich, 2015). This study focuses on the psychosocial impact of cancer diagnosis and treatment on adults and the oncology social work service that is provided thereof. Adult development has been categorised in three stages; that is, young adults aged 20 to 39 years, middle-aged adults’ aged 40 to 64 years and older adults aged 65 years and older (Christ, Messner & Behar,

2015). Erikson's theory views development in light of conflicts or crisis that must be resolved in order to determine future functioning in all other developmental stages. The participants chosen in this study were either in the Intimacy versus Isolation (young adults) or Generativity versus Stagnation (middle-aged adults) stages of psychosocial development. This crisis faced by these adults in their respective developmental stages will determine the issues brought to counselling and the service provided by the social worker.

Erikson's theory around young adulthood suggests that the identity established in previous stages is used to form relationships both intimate and within the community. The need to develop the capacity for intimacy tests the firmness of the identity established "for deep involvement with another demands the strength to put one's own identity at risk" (Stevens, 1983:51). The unsuccessful resolution of this stage could lead to an inability to form meaningful relationships and in essence a strong sense of isolation. According to Bolte in Christ et al (2015) young adults are eight times more likely to be diagnosed with cancer and have lower survivorship rates. In light of this they face a number of significant developmental challenges; more specifically in relation to the biopsychosocial long-term effects of diagnosis and treatment. It is suggested that young adults diagnosed with cancer are at risk for higher levels of psychological distress, including anxiety and depression, impaired sexual health and functioning, and an interruption to the normative development significant of this stage (Schapmire in Christ et al, 2015). In view of this, a cancer diagnosis is likely to affect the young adult's identity and capacity to form meaningful relationships and speaks to the importance of love and support while navigating through this developmental stage.

Erikson's theory of psychosocial development characterises middle adulthood around active involvement with family, community and job satisfaction (Davis & Rust in Christ et al, 2015). Generativity is reflected in marriage, religious symbols and caring for others (Stevens, 1983). The diagnosis of cancer can therefore influence the adult's relationship with religious entities and inadequate symptom management could lead to physiological challenges that hinder the ability to care for someone other than oneself. This could lead to a strong sense of stagnation or extreme self-absorption (Cronin & Mandich, 2015). The diagnosis of cancer causes a disruption to these activities and can have a devastating impact of the successful resolution of this stage. These disruptions are both emotionally and practically challenging as they represent primary areas of identity, achievement, life satisfaction and economic capacity (Schapmire in Christ et al, 2015:505). Patients in this age group are left to grapple with the

re-negotiation of their roles both within their families and in the work place. Being unable to navigate through the crises that present during this developmental stage can leave these adults believing that life is meaningless and questioning the significance of leaving a lasting mark on society (Cronin & Mandich, 2015).

This theory provides a lens into the developmental needs of each participant and the impact their diagnosis has on their stage of development and subsequent psychosocial needs.

2.3. Policies and Legislation informing Oncology practice in South Africa

Social work in South Africa is considered to be a reflection of the broader political landscape (Gray & Lombard, 2008). The policies that emerged from the Truth and Reconciliation Commission led to a fundamental change in the values and principles of social work post-apartheid (Gray & Mazibuko, 2002). In the new era of democracy, the profession underwent a huge transformation contributing to the development of the White Paper for Social Welfare which informs current welfare practice (Gray & Lombard, 2008). Post 1994, the legislation and developments in the profession have been more specifically targeted at combatting social problems (Gray & Mazibuko, 2002). A huge challenge for South African social workers is that current practice is heavily reliant on the international standards and interpretations of the profession (Drower, 2002).

The standard operating procedures outlining ethical oncology social work practice at CancerCare is informed by the Constitution of the Republic of South Africa 1996 with particular reference to the Bill of Rights, and the National Health Act, 2004 (Act 61 of 2003). Practice standards are devised by the social work board and all ethical guidelines and policies informing practice fall under the umbrella of the South African Council of Social Service Professions (SACSSP).

It seems that oncology social work in South Africa is mostly guided by local generic social work policy as well as the international scope and standards of practice. Practice is also guided by standards set out by the Association of Oncology Social Work (AOSW) stating that social workers must be knowledgeable in oncologic disease and treatment, the psychosocial implications for patients and families, appropriate interventions and available community and government resources; and must have prior social work experience in a health care setting (www.aosw.org). Guidelines in the use of the distress screening tool and

palliative care are derived from the National Comprehensive Cancer Network (www.nccn.org).

In considering the policy and ethical issues associated with oncology social work practice, the general consensus is to empower patients to make important medical decisions and control their care (Stein in Christ et al, 2015). The basic ethical principles that support client care are; the right to patient autonomy and self-determination, advancing patients' best interests through beneficence and non-maleficence, and societal expectations of fairness (Guttman, 2006; Code of Ethics of the National Association of Social Work, 2008; Stein in Christ et al, 2015). Social workers are able to achieve this by applying psychosocial expertise in the multidisciplinary team, acting as a mediator between the team and the patient/family, enabling the inclusion of other services in the treatment plan and advocating on behalf of the patient/family interests. The ethical issues that are encountered in oncology social work practice include assisting in decision making with respect to treatment and care planning whilst respecting diverse and cultural family values, conducting psychosocial assessments that aid in determining capacity, support during disclosure of medical information and difficult news, clarifying advance directives and protecting vulnerable individuals from potential harm (Stein & Kerwin in Christ et al, 2015; Krise & Lundy, 2005).

2.4. The Psychosocial Needs of Cancer patients

Cancer patients have both medical and psychosocial needs, which cannot be separated from one another as the impact of the disease on their body and environment affects their overall psychological wellbeing and quality of life (Schroepfer, 2001). Quality of life refers to “an individuals' perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation, 2002). Due to advances in treatment, there is huge potential for psychological interventions that aim to improve mental wellbeing and functional status of those living with the disease (Davis, Feyer, Ortner & Zimmerman, 2011). This need for a psychosocial approach to cancer care places the profession of oncology social work at centre stage and points to the need for an evaluation of effectiveness and benefit of the service.

2.4.1 Medical Needs

The medical needs of cancer patients centre on diagnosis and treatment. The process of diagnosis involves a number of medical and sometimes surgical procedures that require

recovery prior to treatment (Scientific American Inc, 1997; American Cancer Society, 2014). Although many patients are diagnosed by referring specialists; the primary discussion of diagnosis and treatment takes place with the oncologist. Often this discussion focuses on the general health of the patient, the type of cancer, the staging, the treatment options available as well as the treatment intent and prognosis (Schroepfer, 2011). Both the medical team and the patient need to be clear about the aims of treatment and have realistic expectations about potential outcomes; furthermore the patient requires detailed information around the treatment regimens, the risks and the potential benefits (Malik & Savage in Hanna et al, 2015).

Treatment intent refers to the aim of treatment being curative, adjuvant or palliative. In the case of palliative treatment the benefit of treatment needs to be weighed against the quality of life of the patient as well the safety of what dosage of treatment the patient can tolerate (Malik & Savage in Hanna et al, 2005; Davis et al, 2011). The potential of side-effects needs to be discussed with the patient, and managed throughout a patient's illness trajectory. Side effects can include hair loss, vomiting and pain (Malik & Savage in Hanna et al, 2005). The problems experienced are relative to the type of treatment received; surgery patients may have grief reactions to the physical changes in their body, radiotherapy patients may suffer from psychotic like delusions and hallucinations, and chemotherapy patients may experience body image changes in addition to other adverse side-effects (Fawzy, 1999). In light of this, symptom management can include inpatient admissions, outpatient follow up appointments, referrals to other health care professionals and referrals to hospice for home-based support (Fawzy, 1999).

There has been a growing emphasis on the improvement of palliative care and pain management and the recognition of the importance of quality of life despite the diagnosis of terminal cancer (Breitbart & Alici, 2009). This includes symptom management of side-effects related to disease progression (Davis et al, 2011). Some patients are diagnosed too late to consider medical treatment options whilst others have to make the unfortunate transition from curative treatment to palliative care. The unmet psychosocial needs of terminal cancer patients have devastating consequences on their quality of life (Schroepfer, 2011). In addition, the focus needs to be on symptom management and supportive care to keep patients comfortable (Gardiner, Ingleton, Gott & Ryan, 2011). Patient's needs vary because of the disease as well as the resolving or exacerbation of treatment side-effects (Cwikel & Behar,

1999; Davis et al, 2011). This has a number of implications with respect to the psychological management of cancer patients and their instrumental needs.

2.4.2. Practical Needs

Cancer patients have a number of instrumental needs that include issues around finance, medical aid and insurance cover (Cwikel & Behar, 1999; Manicom, 2010). The issue of insurance and the provision of financial assistance is an essential need that should be addressed by all health care professionals. Donley and Danis (2011) suggest that in order for clinical discussions to promote fairness and respect for patient autonomy, health care professionals must outline the costs from the outset of chronic and terminal illness and incorporate financial considerations in care planning. The financial burden of illness is a pressing problem and can lead to significant distress for patients and their family members. Often they face trade-offs where they are left to decide if further treatment would significantly impact the progression of the cancer or if the finances should be reserved for home care or the family's needs after the patient has passed on (Donley & Danis, 2011). The ethics of such a discussion allows the patient and family to make informed decisions regarding the utilisation of the resources available to them and prepares them for end-of-life where treatment intent is of a palliative nature.

Often when faced with a cancer diagnosis, patients and family members think in terms of their practical needs before they are able to focus on emotional concerns (Fourie, 2010). There is also a tangible need for information about diagnosis and side-effects, community and care services, diet, self-care and practical coping mechanisms (Cwikel & Behar, 1999; Allen & Spitzer, 2016). Patients therefore require access to a service that distributes information, provides referrals to relevant resources and facilitates discussions around practical concerns. Furthermore, patients that receive palliative treatment or supportive care in the absence of treatment may require a space to discuss end-of-life planning, living wills, advance directives, hospice care and referral, and home nursing (Tanchel, 2003; Allen & Spitzer, 2016).

It is imperative to consider that patients may struggle to process and recall important information during the initial period of diagnosis due to the intensity of overwhelming emotion and anxiety (McCaughan & McKenna, 2007). For this reason, health care

professionals play a crucial role in offering help at the appropriate time (McCaughan & McKenna, 2007).

2.4.3. Psychological Needs

There is also growing emphasis on the recognition of improved quality of life, patients' rights and the need for supportive and psychologically orientated cancer care (Breitbart & Alici, 2009). There seems to be a high prevalence of psychiatric disorders in cancer patients (Ross, Boesen, Dalton & Johansen, 2002; Breitbart & Alici, 2009; Manicom, 2010; Allen & Spitzer, 2016). A cancer diagnosis affects patients' wellbeing and their sense of personal control; this often leads to depression, anxiety and loneliness (Boudioni, Mossman, Boulton, Ramirez, Moynhan & Leydon, 2000). This highlights the need for the provision of psychosocial interventions that aim at alleviating some of the distress caused by a cancer diagnosis.

The perceptions of the implications of a cancer diagnosis are enough to cause marked distress in patients and their family members. Much of the mental distress peaks from the moment diagnosis is suspected and long before treatment options are even discussed (Smith, 1990; Manicom, 2010). Patients are faced with uncertainty and a loss of control, and are forced to confront their own mortality while awaiting the possibility of a serious diagnosis (Manicom, 2010). Cancer patients tend to report suffering from both depression and anxiety as a result of not only diagnosis and treatment, but psychosocial concerns around their instrumental needs; and problems communicating with and supporting family members (Cwikel & Behar, 1999; Niemela, Vaisanen, Marshall, Hakko & Rasanen, 2010). The crisis of cancer often distracts patients from their emotional needs. Ohlen, Holm, Karlsson and Ahlberg (2005) suggest that a distressed person in crisis is less likely to seek help without assistance and encourages the professional to initiate contact and offer support.

Research shows that patients have an initial response of shock and denial, and try to keep their emotional distress in perspective while making crucial treatment decisions (Breitbart & Alici, 2009). However, the second phase of response can be characterised by a period of emotional turmoil. Patients face the fear of death and have major concerns around potential dependency, disfigurement, pain, relationship changes, their role within their systems and finances (Breitbart & Alici, 2009). They face a huge loss of the life they know and their planned future. Their responses are influenced by their own perceptions of the diagnosis as well as society's attitude toward cancer. The factors that modulate their adaption to the

diagnosis are interpersonal, intrapersonal and socio-economic in character (Breitbart & Alici, 2009). These need to be resolved with the additional support of family and friends before they can return to previously used coping strategies.

Treatment raises a number of psychosocial concerns that arise as a result of practical challenges as well as adverse side-effects. A well-documented side-effect is that of alopecia (hair loss). Not only has alopecia resulted in lower self-esteem in patients undergoing chemotherapy, it also affects their sense of self and has been reported to be one of the most traumatic side-effects (Rosman, 2004). Hair is considered to be a symbol of life and identity, and without it patients are left re-negotiating their roles in the social aspects of their lives, often experiencing the stigma of a cancer diagnosis and facing the reminder of their conditions every day (Rosman, 2004). Cancer treatment and its related side-effects have been documented to lead to a number of psychological sequelae (Fawzy, 1999:1562). These psychological consequences of both diagnosis and treatment can have a profound impact on the lives of cancer patients.

2.4.4. Supportive Needs

The incidence of cancer among young adults has risen faster than that of cancer diagnosed in the elderly (Zebrack, Bleyer, Albritton, Medearis and Tang, 2006). Young adults are often focused on building their careers, forming intimate relationships with significant others and starting their own families. The developmental challenges faced by this group may influence their adjustment to the diagnosis and adherence to treatment as their increased vulnerability affects both employment and relationships (Zebrack et al, 2006). There also appears to be a high demand for information and assistance around diet, exercise, infertility, sexuality, health insurance and psychosocial counselling (Zebrack, 2009).

Although the needs of terminal cancer patients may appear to be more instrumental in nature, psychosocial counselling need also focus on discussing their fears around death, managing their grief, and facilitating discussions whereby they can express their last wishes and say goodbye to their loved ones. Even when a referral to palliative care services is actively sought, the need for such a service is experienced as a major crisis to both patient and family.

The journey through life threatening illness is marked by losses at every level; these include the loss of income, physical health, independence and normal family life (Tanchel, 2003;

Manicom, 2010). Children of cancer patients display a range of emotional, behavioural and social reactions to diagnosis; this speaks to the importance of identifying the needs of children and providing appropriate support to the entire family (Speice, Harkness, Laneri, Frankel, Roter, Kornblith, Ahles, Winer, Fleishman, Luber, Zevon, McQuellon, Trief, Finkel, Spira, Greenberg, Rowland & Hollans, 2000; Niemela et al, 2010; Ernst, Beierlein, Romer, Moller, Koch & Bergelt, 2013). Psychosocial interventions and support has been found to ease this process for both patients and family members, enabling them to tackle their practical needs as well as express their fear and feelings of loss and grief (Schroepfer, 2001).

There is a chronic phase of psychological adaptation after treatment as the thoughts and fears of some patients may remain for a long time after treatment (Ohlen et al, 2005; Pranjic, Bajraktarevic & Ramic, 2016). This stage can be characterised by anxiety around less medical surveillance and withdrawal from social interaction (Manicom, 2010). Research has shown that symptoms similar to the criteria of post-traumatic stress disorder within the first 3 months after treatment is predictive of ongoing stress related problems six years later (Philip, Merluzzi, Zhang & Heitzmann, 2013). It is encouraged that patients receive psychosocial intervention during this stage of the illness trajectory (Ohlen et al, 2005; Manicom, 2010; Philip et al, 2013; Pranjic et al, 2016).

2.5. Oncology Social Work

2.5.1. The Historical Development of Oncology Social Work

While oncology social work has only become an internationally recognised specialisation in the last few decades, the profession blossomed in the 1970's because of advances in the fields of psycho-oncology and psycho-social oncology (Cwikel & Behar, 1999). Physicians began to recognise the need for a member of the team that understood cancer and the psychosocial implications of the disease. In 1974, the National Cancer Institute established a number of cancer centres and each centre was committed to providing oncology social work training within the medical social work departments (Holland, 2002; Fobair et al, 2009). It became such that the inclusion of social workers should be a part of the general standards of practice within hospitals and having them on staff was a necessity when registering for accreditation (Holland 2002; Fobair et al, 2009).

The National Association of Oncology Social Workers, now known as the Association of Oncology Social Work (AOSW) was established in New York City in 1983-1984

(www.aosw.org). Social workers were an important resource in the medical field due to their unique knowledge of the patients' psychosocial needs. Public discussion centred on the advances in treatment and the right to informed consent and patient autonomy. Oncology social work was assigned the task of working with the physician in adapting treatment to fit the patient's social condition. In 1994 the AOSW established legal status as a professional non-profit organisation that is dedicated to the provision of psychosocial services to cancer patients and their families (Fobair et al, 2009). Over the last 100 years, the achievements of oncology social work include advances in research practices, legitimacy of the profession within medical practice and effecting a change in the models of illness and health (Fobair et al, 2009). The influence on the role of the social worker in oncology practice will now be discussed.

2.5.2. The Role of the Oncology Social Worker

2.5.2.1 Psychosocial Assessment

In helping manage the crisis of a cancer diagnosis, the social worker often develops a close relationship with patients and families. The conditions under which these relationships develop are such that the social worker may be perceived as an extended family member in the keenness to have a more active role in the patient's battle with the disease (Boyle, Robinson, Dunn & Heinrich, 2005; Simon, Pryce, Roff & Klemmeck, 2005). There is recognition that patients sometimes do not have the resources to manage the diagnosis on their own, and protects the underlying values that are important to their sense of hope and dignity, but it is estimated that only about fifteen to twenty-five percent of those diagnosed will eventually use the social work service (Cwikel & Behar, 1999).

A central role of the social worker is assessment and the provision of interventions that focus on solutions addressing the client's environment, ensuring emotional and physical wellbeing and acting as educators in providing a service to the community (Fobair et al, 2009). Due to the generic nature of oncology social work practice and the diverse range of services offered dependent on the need of each of patient as well as the expectations of the multi-disciplinary team, it is challenging to simply categorise the role of the social worker. It has been suggested that doctors and nurses involved in cancer care tend to avoid the emotional aspects of the illness (Maguire & Faulkner, 1988). The social worker is an important resource for medical teams that are primarily focused on the medical management of the patient and have little time and expertise to address to psychosocial needs (Schroepfer, 2011).

Ohlen et al (2005) suggest that patients' expectations of a support service centre on adjustment after diagnosis and the provision of a non-judgemental space where hope can be regained. Here, Howard (2010) refers to the 'frame' in setting the scene of the therapeutic space; as a neutral environment helps to create a safe and predictable physical and psychological space that the client can learn to trust. With this, Guttman (2006) identifies confidentiality as significant ethical practice in social work that fosters a trusting and safe professional relationship. Courage is gained within this environment as the supportive space allows patients to find the words to express their hopes and fears (Ohlen et al, 2005). The counselling offered by social workers aims at helping patients understand their feelings and behaviour as a psychological response to the diagnosis, and helps them manage the adjustments to their body image, lifestyle and possibly a shortened life expectancy (Fallowfield, 1988).

2.5.2.2 Treatment

Cancer can no longer be viewed only as a terminal illness, but rather a chronic illness that requires effective management in order to ensure a better quality of life (Cwikel & Behar, 1999; Manicom, 2010; Davis et al, 2011). Both the chronically and terminally ill have always been a concern in medical social work through helping patients and families deal with the emotional and physical aspects of the disease. Fourie (2010) suggests that cancer patients have information needs occurring at the different stages of the disease and for this reason it is vital for social workers to recognise that psycho-education is imperative in helping patients and families to cope. In addition, they need to continually expand their knowledge around the rapidly changing treatment developments in the oncology field (Lauria et al, 2012). Such intervention is thought to help patients to accept their diagnosis and enhance coping and adjustment (Fawzy, 1999; Ohlen et al, 2005). The side-effects of treatment impact on the physical and emotional wellbeing of patients. The look good feel better project aims to help women overcome the distressing appearance related side effects of their treatment (Van Sonsbeek, 1995). This program has shown to decrease the negative effects of diagnosis and treatment as it leads to improved self-esteem and encourages interaction between patients (Van Sonsbeek, 1995).

The diagnosis and treatment of cancer accompanies a challenging journey that may begin with a curative approach that eventually leads to the need for palliative care. Social workers play a key role in initiating and managing transitions in the patients' condition; and ensuring

the continuity of care (Gardiner et al, 2011). It is recommended that in preparing for all discussions, the environment and the circumstances of the consultation should be considered as well as the patient's and family's emotional reactions (Schofield, MacCallum, Melbourne, Love & Nehill & Wein, 2006). There is a psychosocial dimension to managing palliative care and patients need help acquiring information, expressing their fears, talking about death and coping with helplessness (Tanchel, 2003). Studies have shown that some patients prefer to put the diagnosis out of their minds and as a result do not take advantage of the oncology social work services (Cwikel & Behar, 1999). Many of these patients become too ill to engage with the service, and the social workers provide a psychosocial service to the family members instead.

2.6. Positive Aspects of Social Work Services

2.6.1. Psychosocial Assessment

Assessment focuses on the functioning of patients within their environment (Schroepfer, 2011). Hence in addressing the psychosocial needs of clients, intervention is directed at improving the interactions within their environment (Schroepfer, 2011). This has a direct impact on the client's dynamic involvement with persons in the environment as well as various support structures. These assessment skills are extremely beneficial to practice within an oncology setting as it enables patients to reflect on their space within the broader environment, and access the resources available to them helping to meet the demand of both prognosis and treatment (Schroepfer, 2011). The effect of this is that the client's environment is strengthened to cope with the changes brought about by diagnosis thereby affecting the client's ability to better adapt. This approach communicates to clients that they are more than just cancer patients, and that there is value in their life beyond cancer (Schroepfer, 2011). Furthermore, such an assessment aids the social worker in advocating on behalf of patients with regards to their preferences regarding care and treatment, as they may not have the opportunity or the strength to discuss this with their treating oncologists (Schroepfer, 2011). Practice is therefore reframed so that the social worker becomes a part of each client's context, taking responsibility for aspects of that context and working with an environment instead of despite it (Green & McDermott, 2010).

2.6.2. Psychosocial Intervention

The benefits of oncology social work services are thought to be both psychological as well as instrumental. Cwikel and Behar (1999:58) have outlined a range of social work services that

include dealing with the emotional aspects of adjusting to a diagnosis of cancer, developing coping mechanisms, making treatment decisions and long term care planning; as well as addressing the issues of finance, insurance, home help and employment issues. The benefits of such psychosocial interventions have been shown to reduce psychological morbidity, better symptom control and fewer maladaptive coping responses (Boulton, Boudioni, Mossman, Moynihan, Leydon & Ramirez, 2001). More specifically, research has shown that patients have been able to gain emotional relief by confronting their fear of death, accepting their diagnosis and recovering a measure of control in their lives (Boulton et al, 2001). In the power dynamic between patients and the medical team, social workers are also able to teach their clients communicate directly and assertively with medical professionals to ensure that their needs are met and therefore be an active participant in their treatment plan (Andersen, Farrar, Golden-Kreutz, Emery, Glaser, Crespín & Carson, 2007).

2.6.3. Family Services

Cancer is recognised as a family disease that disrupts the lives of all involved (Schmid-Buchi, Halfens, Dassen & Van Den Borne, 2008; McCarthy, 2011). This can lead to feelings of helplessness and barriers in communication between family members (Speice et al, 2000). In light of this, family members have supportive needs at the different stages of the illness trajectory, and this can be addressed through a collaborative approach to patient treatment (Donley & Danis, 2011). By allowing family members to access a support service as well, relationships are improved and families learn to communicate more directly (Ohlen et al, 2005). Focus group research with cancer patients has shown that psychosocial support services are especially important to both them and their families, and the counselling service has enabled them to better cope with and adjust to their situation (Boudioni et al, 2000).

2.6.4 Perceptions of the Profession

A few studies have focused on how the public perceive social workers and the impact it has on their decision to seek out the service; the general perception of the profession has been varied, complex and multifaceted (Staniforth, Deane & Beddoe, 2016). Despite the ambivalent views, many felt that social workers were helpful and perceived that the profession is stressful and does not receive sufficient credit for its contribution to society (Staniforth et al, 2016). Additionally, findings have indicated that the public perception and understanding of the profession improved when people had utilised social work services (Staniforth et al, 2016; Kagan, 2016).

Modern Social work encompasses a broader scope of practice and research has shown that the public have an improved awareness of the range of services offered (LeCroy & Stinson, 2004). The most common benefits associated with the services were that the social workers were helpful, caring, met specific personal needs and listened when providing counselling (Staniforth et al, 2016). Furthermore, research findings have suggested that positive attitudes towards the profession influenced service users trust in social workers and predicted their use of the service for guidance, treatment or any form of help (Kagan, 2016). The negative perceptions associated with social work therefore pose a major challenge to service delivery.

2.6.5 Post-traumatic Growth

Research has indicated that cancer patients were able to learn from a counselling experience; and through examining their own thoughts and feelings with the guidance of a skilled professional, they could handle difficult situations in a different way (Boulton et al, 2001; Ohlen et al, 2005). Posttraumatic growth is described in terms of the positive cognitive and affective changes that occur following a trauma (Shand, Cowlshaw, Brooker, Burney & Ricciardelli, 2015). The positive life lessons gained from the cancer journey is considered a domain of posttraumatic growth and includes emotional growth, an increased appreciation of life and a perceived closeness and appreciation of others (Shand et al, 2015). Findings from Boulton et al's (2001) study indicate that 95% of their respondents would follow up with a support service at a later stage and would recommend such a service to others diagnosed with cancer; based on the perceived benefit.

Despite these positive aspects, there are a number of challenges that hinder service delivery.

2.7. Challenges Encountered in Social Work Practice

2.7.1. Lack of occupational exclusivity

The relational character of social work practice within the diverse organisational contexts in which practice occurs makes it difficult to define a unique area of expertise shared across the profession (Healy & Meagher, 2004). This could have influence service user's perception of the service as it may be difficult to pinpoint the social worker's exact role within a particular setting. Social work is commonly associated with a diverse range of functions that include counselling as well as practical and administrative tasks. Healy and Meagher (2004) argue that the social work profession has not achieved occupational closure as the expertise of the profession is not exclusive to the profession alone; the generic form of practice has created

human service positions enabling other professions to step in and fulfil the role of a social worker.

Social workers are not always positively associated with the role of therapist or counsellor, with the majority of respondents in three studies indicating that they would prefer to see a psychologist or registered counsellor (LeCroy & Stinson, 2004; Wantz & Firmin, 2011; Olin, 2013). This is based on the perception that a psychology degree is thought to be more lucrative than a social work degree (Staniforth et al, 2016). Moreover, due to the fact that there is little to no charge for engaging with the service, the profession has a much lower status than that of psychologists, as clients feel that the more expensive the service, the higher its perceived value and effectiveness (Wantz & Firmin, 2011). This is thought to pose a major threat to the quality of social work practice.

2.7.2. Perceptions of the public

Research conducted with both service users and the general public has recognised a number of challenges in the perceptions of the social work profession. Many studies suggest that there is public confusion around the role of social workers within the different settings (Staniforth et al, 2014). Confusion about what social workers do and the different services that they provide was also reflected in research conducted with professionals who work alongside social workers (Staniforth et al, 2014). It seems that ‘outsiders’ see social workers as people who talk to clients and arrange access to services, and have described it as a task that anyone can do with very little training (Reid, 2002). In fact, many respondents in studies of this nature reported that they knew little about the training and qualifications required in becoming a social worker and some described it as a vocation rather than a profession (Olin 2013; Staniforth et al, 2016). The most common role associated with social workers was that of ‘child protector’ and the stigma associated with seeing a social worker led to many respondents reporting that they would not see a social worker for their personal problems (Staniforth et al, 2016). Social workers are more often associated with various personality traits and are described as “busy-bodies, interfering, inefficient and ineffectual” (Staniforth et al, 2016:15).

2.7.3. Perceptions of other Professionals

Perceptions of the profession has a number of implications for the confidence other professionals have in making referrals to the social worker (Staniforth et al, 2016). Social

workers are continuously redefining their role in response to the increasing demands imposed by changing treatment modalities and limited resources (Lauria et al, 2012). This leads to perceived re-definitions of social worker's roles by other staff members which can result in a limited understanding oncology social work practice. Social workers most often work in multi-disciplinary teams and the potential for cross-disciplinary disagreements with regards to the best action plan for the client is strongly impacted by the team members' inability to recognise the multiple roles of the social worker as well as the profession's unique contribution in addressing human problems (Howard & Jenson, 1999).

Educating team members on the diversity of the social worker's role can be challenging and can lead to an underutilisation of the service. The team members' perceptions of the role of the social worker can lead to inappropriate referrals as well a lack of appreciation for the worker's clinical assessment and therapeutic skills (Lauria et al, 2012). Some patients reported that they were under the impression that such a service was an extension of their contact with the oncologist, and that they would get more practical advice as opposed to counselling (Boulton et al, 2001).

2.7.4. Capacity for Intervention

Due to higher caseloads, social workers are expected to provide a condensed service to patients that address practical and administrative tasks as well as feelings (Lauria et al, 2012). A limited number of sessions may be a source of complaint as it can leave clients feeling as if they may not have benefited at all (Boulton et al, 2001). Research has shown that challenges identified by patients included the limited number of sessions offered, the waiting time for first appointments and challenges with travel (Boudioni et al, 2000). An improvement in cancer treatments means that people live for much longer periods with their illness. This has a number of financial implications and the financial burden of ongoing illness has been a major of cause of deteriorating quality of life (Lederberg & Holland, 2011). Furthermore, this financial burden extends to the costs of travel to the medical practice (Hanratty, Holland, Jacoby & Whitehead, 2007). This could have an impact on the face-to-face contact patients have with the social worker leading to more telephonic contact or perhaps difficulty accessing the service. According to Ohlen et al (2005), it is not uncommon for patients to feel insufficiently supported if they perceived that they would have more time with the supporting professional.

The challenge in South Africa is that more specialised services are not easily accessible to disadvantaged communities, and there is a need for more social service professionals in the poorer regions and communities (Patel, 2005). As a result, service provision remains a major challenge for social workers as high workloads have resulted in generalist services that do not necessarily meet the needs of specific communities (Patel, 2005). This has implications for access to specialised welfare services, like oncology social workers, in disadvantaged communities.

2.7.5. Intervention in a Medical Setting

Treatment choices can sometimes undermine the patient's autonomy as they are forced to consider the trade-off between intrusive treatment modalities and what they consider to be an acceptable quality of life or death (Lauria et al, 2012). This goes against the profession's core principle of ensuring patient autonomy, self-determination and quality of life (Guttman, 2006). Research with patients undergoing treatment has shown that adverse side-effects lead to psychic distress where chemotherapy is viewed as extremely harmful, attacking the body rather than healing it (Rosman, 2004). The ethical dilemma is supporting the recommendation of the treating team; even when the patient is struggling and the benefit of such recommendations are unclear (Lauria et al, 2012). In light of this, patients have reported the frustration in having their private thoughts dealt with medically which has led to feelings of being unsupported and uneasiness during sessions (Terry, Olsen, Wilss, Boulton-Lewis, 2006). In order to address these challenges, social workers are encouraged to explore public opinion in improving their service delivery.

From this discussion, it is clear that role of the social worker within a multidisciplinary team is imperative in addressing the psychosocial needs of clients. However, there needs to be tangible evidence of the effectiveness of the service as it cannot simply be observed.

2.8. Recommendations to improve Social Work Practice

2.8.1. Provide Holistic Services

Social workers should provide a holistic model for patient care (Lauria et al, 2012). Recommendations include facilitating a safe environment where discussions around diagnosis, treatment and prognosis are explicit; providing support and counselling in response to the emotional reactions of patients, introducing appropriate services dependent on the patient's condition and care needs whilst still respecting cultural and religious diversity,

ensuring continuity of care and addressing family concerns (Schofield et al, 2006). Studies have shown that consumer-confidence in a helping profession increases when clinicians are fully informed of the effectiveness of the service and are able to make appropriate referrals in helping clients to utilise the service (Wantz & Firmin, 2011).

2.8.2. Support Groups

McCaugan and McKenna (2007) recognise the value of the shared insights and experiences of other cancer patients, as lived experience is preferred to the information provided by health care professionals. Support groups provide a space to share about cancer related experiences enabling patients to support one another across the illness trajectory (Weis, 2003). The relationship that develops between cancer patients allows for honest dialogue, and is a powerful experience that creates a sense of belonging and acts as a tangible form of social support (McCaugan & McKenne, 2007; Evans, Mallet, Bazillier & Amiel, 2015).

2.8.3. Family services

Family relationships are often of primary importance to cancer patients as it helps them maintain a sense of purpose; this form of support contributes towards the adaption of a cancer diagnosis (Speice et al, 2000; McCaugan & Mc Kenna, 2007). Furthermore, the support provided by family complements the skills of the healthcare professionals (Speice et al, 2000; McCaugan & Mc Kenna, 2007).

2.8.4. A Collaborative Approach to Practice

Due to increased survival rates for many cancer patients, treatment options continue to expand and economic factors are influencing funding, staffing and health care delivery (Lauria et al, 2012). This has a major impact on oncology social work practice, as roles need to be continuously re-defined to meet the needs of all involved. Social workers therefore need to develop effective ways of increasing their value to the team by keeping up to date with these changes, seeking clinical knowledge and additional training, and speaking to patients about their accounts of the cancer-experience (Lauria et al, 2012). Team work is crucial in this process as it ensures continuity of care and allows patients to receive a holistic service. Inter-disciplinary collaboration has been suggested to be a “perception-changing and image-enhancing possibility” (Olin, 2013:99).

2.8.5. Ongoing Evaluation in Social Work Practice

Healy and Meagher (2004) suggest improving the quality of social work service by implementing evidence based practice formed from research focusing primarily on service delivery and practice processes. In the field of oncology much of the research is based on studies conducted by medical professionals within a medical setting; it is argued that without a multi-disciplinary perspective, there are gaps in the results of these studies that do not address social and relationship factors as well as financial and workplace concerns (Lauria et al, 2012). A consideration of the social impact of the entirety of the disease would provide a broader understanding of the overall impact of a cancer diagnosis. The specialised knowledge and clinical experience of social workers is considered to be a great strength in undertaking research as many researchers lack first-hand knowledge and have not worked in a clinical setting (Lauria et al, 2012).

Research efforts within the field need to be increased so that the knowledge base of oncology social work can be expanded and applied in service delivery. An attempt at this would be a study on the perceptions clients have about the oncology social work service as Staniforth et al (2016) suggest that their perceptions of the profession influence their confidence in engaging with the service. In current society, social worker's exist in an arena where psychosocial care is being devalued and the need for the profession in health care settings is being questioned (Lauria et al, 2012). This calls for an ongoing evaluation of social work practice in order to promote the necessity and effectiveness of the service. Research initiatives are likely to ensure continuation of the service.

2.8.6. Effective Advertising

The public's perceptions of a social work service are largely influenced by the depictions social workers in the media and reports that are sensational, rather than routine work practica (Kagan, 2016). Throughout the literature, much of the recommendations in improving the perceptions of the profession seem to centre on social workers increasing knowledge of the profession in the media. Olin (2013) suggest that social workers are best suited to influencing the public's perception of their service and encourages more initiative in enhancing the public's knowledge and understanding of the profession through effective engagement with media outlets. Suggestions from respondents include advertising campaigns to create awareness; these include a regular use of all media platforms (Olin, 2013). Detailed and more visible information would provide the public with a more accurate representation of the

social work profession and actively demonstrates effectiveness (LeCroy and Stinson, 2004; Staniforth et al, 2014).

2.9. Conclusion

Based on the review of the relevant literature, it is clear that cancer patients have a number of psychosocial needs that affect their adjustment to diagnosis and treatment. If not appropriately addressed, these needs can affect their overall quality of life. The inclusion of a social worker in multi-disciplinary teams is imperative in the holistic management of cancer patients. Although social workers employed within the private sector in South Africa appear to be valued members of the treating team, the profession of social work within medical settings seems to be undervalued. For this reason, evaluative research is important in establishing the effectiveness of social work services in health care settings and promoting the development of the profession. This chapter has outlined literature pertaining to the study. Chapter three presents the methodology used in this research.

CHAPTER THREE

Methodology

3.1. Introduction

This chapter presents the methodology of this research. It discusses the research design, sampling, data collection and analysis, as well as data verification. The chapter closes with a critical analysis of the limitations of the study.

3.2. Research Design

This research took on an exploratory, qualitative approach. Qualitative research aims to understand and capture the meaning, perceptions and experiences people attach to certain social phenomena (Fouche & Schurink in De Vos et al, 2011). This meaning is discovered through the use of language. In making sense of the social world qualitative researchers are committed to the naturalistic perspective that there is no single truth, but rather a socially and personally constructed reality that can only be determined by the active involvement of the subjects in the research; It is an approach that generates non-numerical data and has added a new dimension to research in evaluating human behaviour (Fouche & Schurink in De Vos et al, 2011). The qualitative design used in this study is phenomenology as the researcher is seeking to obtain the true essence of the participants' experiences, as suggested by Cresswell (2014). As part of uncovering meaning, the researcher is encouraged attempt to understand participants' perceptions and first hand experience, and articulate the findings by relating them to existing theory and research (Cresswell, 2014; Delport & Fouche in De Vos et al, 2011). Furthermore, Brink (2009) suggests that research should be evaluative in nature as it allows for the assessment of an intervention practice, the accomplishment of its purpose and how useful it is to the patient's engaging with the service. This helps to determine the effectiveness of the service, if the service has neglected certain areas of need and if there is room for improvement.

This study explores clients perception of the oncology social worker service at the Cancercare private practices. The researcher in this paradigm attempted to evaluate this service from the participant's point of view and therefore the insider perspective is the dominant perspective. Due to the sensitive nature of the oncology social work profession, a qualitative approach was considered the most suitable approach in describing the

participant's lived experience of the service and attributed meaning. This speaks to the importance of the research conducted in a non-intrusive manner. The best research design is one that is "most appropriate to the research problem and purpose" (Brink, 2009:119). In light of this, a qualitative approach is thought to be justified because exploration of the service was needed and could not be measured by what Creswell (2014) refers to as silent voices. Furthermore, this form of research provides a detailed understanding of the service by empowering individuals to share their stories and allowing for a collaboration between the researcher and participant (Creswell, 2014). This was considered in an attempt to minimise the power dynamic between both parties.

3.3. Sampling Method

A non-probability sample was used in the selection of the research sample. This means that because the qualitative researcher did not know the size or members of the population, the odds of selecting a particular individual was not known (Strydom & Delpont in De Vos et al, 2011:391). An advantage of such an approach is that it involves low cost and is less time consuming in terms of selecting the sample (Strydom & Delpont in De Vos et al, 2011). More specifically, a purposive sample was selected in order to make best use of the specific information obtained from and about the particular context. A purposive sample contains the most characteristic attributes of the chosen population, and participants are specifically chosen based on specific criteria that are of interest to the particular study (Strydom & Delpont in De Vos et al, 2011). The sample was therefore chosen according to pre-selected criteria and was highly subjective in order to provide rich meaning to the data obtained during the interviews.

A sample of 16 participants was selected. In light of the small scale of this study, the variables needed to be limited as too many participants would obscure the issues and complicate the analysis process (Brink, 2009). The following criteria were used to select research participants from patients who have engaged with the oncology social work service:

- Male and female patients that have a diagnosis of cancer; more specifically cancer of the organs as Cancercare practices do not manage other forms of cancer diagnosis.
- Patients that are over the age of 30 years and under the age of 65 years.

- Patients that had a face-to-face interaction with the social worker for at least two sessions and at least one telephonic follow-up contact. This allowed for a realistic reflection of the generic oncology social work service offered at the Cancercare practices, as the researcher has noted that the service offered has a limited face-to-face contact given the patient's condition during and after treatment. A generic service is challenging to categorise therefore the researcher focused on the number of contacts as opposed to the participant's condition at the time of consult.
- Patients that met with the social worker in the last nine months. The reason for this being that Reamer (1998) discusses the issue of memory recall and the researcher is concerned that participants may struggle to recall experiences and feelings from too long ago.

The researcher initially set out to interview a sample of twenty participants; however a significant number of patients that were contacted declined the invitation to participate due to negative treatment side effects, recovery after surgery and some participants were deceased. Calman, Brunton and Molassiotis (2013) identify cancer patients as a vulnerable population in conducting qualitative research speaking specifically to their high symptom burden and poor prognosis; however these authors caution that such participants should be given the option of participation as they may value being able to contribute their views (Calman et al, 2013).

The interest of this study is clients' experience of the generic oncology social work service offered at the Cancercare practices. These include the practice based the Vergelegen unit in Somerset West, the Cape Gate unit and the Panorama unit. The reason that the three practices have been included is that the researcher did not want to single out the practice of one specific social worker as this study would then be a reflection of that social worker's service. The researcher identified patients in each social worker's diary that met the specified research criteria. Participants were chosen from each unit by the process of random selection and invited to participate in the study. This allowed for a sample of sixteen purposely selected participants.

3.4. Data Collection

3.4.1. Data Collection Approach

Face-to-face interviews are a method of data collection that is often used in exploratory, qualitative research studies (Brink, 2009). In depth face-to-face interviewing was used to gather the data to be analysed in this study. Face-to-face interaction takes place in a natural setting whereby information is gathered by talking directly to participants and observing them behave within their context (Creswell, 2014). This form of interviewing fits perfectly with the qualitative design of this study in that it gives the researcher insight into the participant's perceptions and experience of the oncology social work service. Objectivism is a key feature in the qualitative paradigm enabling the researcher to study things as they really are by restraining personal judgement and emotions (Fouche & Schurink in De Vos et al, 2011).

In depth face-to-face interviewing uses observation and communication as a form of collecting data. Collecting data in this manner allows for great insight into the participant's thoughts and feelings about the research issue, including what influences them and why (Griffiths, 2009). It can also highlight the fact that the participants' perceptions may be different to that of researcher. Participants are empowered as they have an active role in the research by voicing their beliefs. Due to the use of purposive sampling, this research sought typical and divergent data in purposefully informing an understanding the research problem, as suggested by Strydom and Delport in De Vos et al (2011). These interviews were conducted by the researcher either at the respective Cancercare units or at the participant's homes. Some participants were concerned that meeting at the practice would jeopardise their anonymity and for this reason opted to have the interview at home. Each interview lasted approximately 60 minutes.

3.4.2. Data Collection Instrument

A semi-structured interview schedule was utilised in this study and it was based on the study's research objectives (Appendix B). This was a useful approach as it allowed the researcher to obtain a detailed picture of the participant's experience of the service. Although the interview was guided by a set of questions in the schedule, the open-ended nature helped to illicit the views and opinions of the participants and allowed them to steer the researcher in a direction that may not have been initially thought of (Greeff in De Vos et al, 2011; Creswell, 2014).

3.4.3. Data Collection Apparatus

The data collection apparatus used in this study was a Dictaphone. This was done with the permission of the participant and the data obtained was transcribed at a later stage. A Dictaphone provides a fuller record of the data as compared to the distraction of note taking and allows for observation of non-verbal cues. In doing so, Greeff in De Vos et al (2011) suggests that the researcher is able to fully concentrate on the interview and its content.

3.4.4. Pilot Study

It is important to conduct a pilot study as it allows the researcher to review the literature in relation to the study, identify themes for further investigation and assess the feasibility of the study (Strydom & Delpont in De Vos et al, 2011). Furthermore, the researcher is able to test the effectiveness of the data collection instrument and make the necessary modifications to the interview schedule prior to the main investigation (Strydom & Delpont in De Vos et al, 2011). A pilot study was conducted with two patients selected by the social worker based at the Cancercare unit at the Rondebosch Medical centre. No changes were made to the interview schedule after the pilot study was conducted.

3.5. Data Analysis

Data was analysed using the analytic procedures outline by Marshall and Rossman (2016:217). The steps are as follows:

1. The data was organised by reading through all the transcriptions carefully and logging the profile of the respondents (Table 4.1). This gave the researcher a sense of the whole before jotting down ideas.
2. Immersion in the data was accounted for by rereading through the data in order to become familiar with the material; noting the themes and concepts that arose.
3. The coding of the data entailed identifying the relationship between the theory-generated codes derived from the literature review and the vivo codes that emerged from the data that was collected. This aided in generating categories and themes that were abbreviated into codes. Passages in the data were then marked thoroughly using the coding scheme. Codes were then constantly compared to seek patterns, commonalties and differences; allowing the researcher to reduce the number of categories.

4. The process of writing notes and reflective memos helped to identify linkages among the coded data; as well as gaps and questions in the data. Such analytic memos also considered the methodology implemented in the study and its limitations during data collection.
5. In order to bring meaning and coherence to the emerging themes and categories, codes were then constantly compared to seek patterns, commonalities and differences; allowing the researcher to reduce the number of categories and develop a story line that illuminates the questions being explored. Useful data segments were selected to support this.
6. The researcher searched for alternative understandings by scrutinising the data, being suspicious of own biases and generating interpretations based on the actual interactions, words and sentiments of the participants. The plausibility of such interpretations were compared with the emerging themes and explanations in the literature review, also noting new variations with credible explanation.
7. The researcher considered patterns amongst the population of participants and how often this occurred.
8. The findings of this study is presented in the form of a final report.

3.6. Data Verification

The consensus amongst theorists is that the construct of verification allows for investigating, checking, questioning and theorising; and is therefore an integral component of both qualitative and quantitative inquiry (Morse, Barrett, Mayan, Olson & Spiers, 2002). Lincoln and Guba (1985) proposed four criteria in the qualitative paradigm to ensure “trustworthiness”; these are credibility, transferability, dependability and confirmability (Morse et al, 2002).

Credibility essentially questions the truth-value of the findings and ensuring that the study measures what it actually intended. A number of methodological strategies such as the member checks when coding and formulating results, and peer debriefing, are suggested to ensure credibility (Guba & Lincoln, 1989). Peer debriefing took the form of discussing the various stages of the research with members of the multi-disciplinary team members at CancerCare, as well as keeping the social workers at the selected practices updated on the progress of the study. As proposed by Morse et al (2002), the sample selected for the study consisted of participants that had knowledge of the research subject.

Transferability questions whether the findings can be applied to another sample in a different context; and Lincoln and Guba (1985) use the term ‘thick descriptions’ to determine a study’s applicability and encourage the researcher to provide a detailed account the field experience. This was accounted for in the methodological description in chapter three, as well as a detailed account of the participant’s responses in chapter four.

Dependability refers to the consistency of the findings and whether the study could be replicated within the same context with the same participants and reach the same conclusions (Guba & Lincoln, 1989). An audit trail is suggested as a means of assuring consistency as dependability may be established if the reader is able to view the process that influenced the actions of the researcher (Carcary 2009:15). Due to the academic nature of this dissertation, both the University of Cape Town and the research committee at Cancercare have carefully supervised the process.

Conformability refers to the neutrality of the researcher and questions the extent to which the findings were affected by personal bias (Guba & Lincoln, 1989). An intellectual audit is presented in chapter one where the problem formulation and reflexivity have been discussed; as well as in the discussion and conclusion of the findings in chapters four and five. As advised by Carcary (2009), these chapters outline the evolution of the researcher’s thinking throughout all phases of the study. The data was also categorized and coded according to the procedures outlined by Marshall and Rossman (2016:217), and all unintended findings were accounted for and discussed.

3.7. Limitations

The limitations of this study pertain to:

3.7.1. Research Design

In focusing on the meaning of the participants’ responses, the researcher relied heavily on the subjectivity of the data (Fouche & Schurink, in De Vos et al, 2011). In addition, this form of inquiry does not allow findings to be generalised to populations outside of those under the study (Creswell, 2014). Despite all research designs having their limitations; the qualitative paradigm was the most appropriate approach for the purpose of this study as the researcher was not seeking to obtain numerical data, and rather valued the active involvement of the

participants. This approach better aided in understanding their perceptions and experiences of the oncology social work service.

3.7.2. Sampling

The small sample is not representative of the larger South African population and is relatively limited in its selection of participants. According to Strydom and Delport in De Vos et al (2011) non-probability purposive sampling is not generalised to the larger population and relies too prominently on the judgement of the individual researcher. In saying this, each patient engaging with the oncology social work service was not provided with an opportunity to be selected for the sample. The findings of this study can increase awareness of the psychosocial needs of cancer patients. Although the researcher was unable to meet the requirements of a larger sample, new participants were brought into the study until the data replicated. Morse et al (2002) refer to this as the process of saturation as it increases the scope and appropriateness of the data. Furthermore; the opinions voiced by this sample are in-depth and assist in evaluating the effectiveness of the existing social work service at the Cancercare practices, calling for further investigation.

3.7.3. Data Collection

The response to semi-structured interviews becomes problematic when the subjects are untruthful about their experiences and therefore relies heavily on the researcher's ability to probe (Greeff in De Vos et al, 2011). It is the researcher's assumption that the subjects may have felt pressured to provide positive feedback as it may affect their relationship with their treatment team. This could account for incomplete responses that do not effectively evaluate the service. In order to minimise this, the researcher clarified with each subject that their participation will not affect the service they receive at Cancercare and individual responses will be kept confidential. In addition, an informed consent form explained this in writing and was given to each participant at the beginning of the interview (Annexure A).

Face-to-face interviewing is a time consuming approach and requires the energy of both the researcher and the participants (Greeff in De Vos et al, 2011). In addition, participants undergoing treatment may have felt tired and unwell and this would have affected the overall quality of the interviewing process. The researcher was careful of not taking on the counsellor role during the interview, as this contributes towards researcher bias. The inclusion of a pilot study aided in preparing the researcher for the data collection process.

A Dictaphone has the advantage of easing the possibility of data overload and allows the researcher to focus solely on the interview. However, the limitation lies with the fact that the quality of the data may be jeopardised by the possibility that some participants could be affected by the presence of a recording device, despite giving their consent. The researcher adhered to Greef in De Vos's (2011) suggestion in overcoming this limitation, by placing the instrument unobtrusively so as to avoid distracting the participants.

3.7.4. Data Analysis

Schurink, Fouche and De Vos in De Vos et al (2011) points out that data analysis is heavily dependent on the researcher's ability to code and categorise the data obtained. In light of that, the researcher may overlook certain themes that arise in the analysis of the data. Furthermore, analysis should not be restricted to findings that have immediate bearing to the investigation, but should also allow for an exploration of economic conditions, social trends and cultural values (De Vos et al, 2011). The limitation lies with the fact that this study investigates the attitudes of the subjects and not their demographics; for this reason, the findings of this study could not be compared to findings from other studies where factors such as socio-economic status were included to assess experience of a service. However, the aim of the study was to examine the perceptions of patients at Cancercare practices in the Northern Suburbs about the oncology social work service and the findings therefore do not need to be generalised to the wider community.

3.7.5. The Researcher

The researcher is the central figure in the research study and both "influences and constructs the collection, selection and interpretation of data" (Finlay, 2002:212). Due to the researcher's employment as a social worker at a Cancercare group practice, the participants of the study may have felt pressured to provide positive feedback. In an attempt to minimise this, the sample excluded all patients seen by the researcher in a professional capacity. The researcher should also be conscious of over reporting on the strengths of a service in an attempt to minimise the weaknesses (Stake & Mabry, 1998). The researcher therefore had an obligation to report on findings as accurately as possible, fully disclosing both supportive findings and shortcomings. The researcher had to carefully consider the concept of reflexivity in undertaking this investigation. The use of supervision assisted in avoiding researcher bias during the data collection and interpretation process.

3.8. Conclusion

This chapter has described methodology of the study. The penultimate chapter presents the findings of this study.

CHAPTER FOUR

Findings

4.1. Introduction

In this chapter, the findings of the study are discussed with reference to the literature outlined in chapter two. The profile of the respondents will be indicated and findings will be presented within a framework of analysis. The findings will further be categorised under the research objectives. A conclusion will complete the chapter.

4.2. Profile of respondents

Table 4.1: Profile of Respondents

| Partic. | Age | Sex | Marital Status | Area of residence | Occupation | Employment status | Diagnosis | No. of Sessions |
|----------------|------------|------------|-----------------------|--------------------------|-------------------|--------------------------|------------------|------------------------|
| 1 | 55 | F | Divorced | Hermanus | Secretary | Employed | 2016 | 4 |
| 2 | 49 | F | Married | Paarl | Finance officer | Unemployed | 2012 | 2+ |
| 3 | 54 | F | Single | Strand | Nurse | Unemployed | 2014 | 2+ |
| 4 | 51 | F | Married | Somerset | Administrator | Boarded | 2013 | 2 |
| 5 | 38 | F | Single | Stellenbosch | Health Coach | Employed | 2016 | 2 |
| 6 | 48 | F | Married | Somerset | Teacher | Employed | 2010 | 3+ |
| 7 | 64 | F | Divorced | Somerset | Administrator | Employed | 2016 | 2 |
| 8 | 58 | F | Married | Vyeboom | Administrator | Employed | 2016 | 2+ |
| 9 | 34 | F | Married | Durbanville | Analyst | Employed | 2012 | 3+ |
| 10 | 32 | M | Married | Brackenfell | Manager | Employed | 2016 | 2+ |
| 11 | 35 | F | Married | Brackenfell | Skin therapist | Employed | 2016 | 2+ |
| 12 | 65 | F | Married | Kuils River | None | Unemployed | 2016 | 2 |
| 13 | 58 | F | Divorced | Durbanville | Tennis Coach | Pension | 2016 | 2+ |
| 14 | 57 | F | Married | Bellville | Marketing | Employed | 2016 | 2 |
| 15 | 47 | F | Married | Platteklouf | Consultant | Employed | 2016 | 2+ |
| 16 | 36 | F | Married | Strand | Student | Unemployed | 2016 | 2+ |

The respondents in this sample were aged between thirty-two and sixty-five years old; and were diagnosed with cancer between the year 2012 and 2016. There was only one male that was willing to participate in the study. Most participants were able to continue working after diagnosis, but one female respondent was medically boarded and another opted for early

retirement. Some participants struggled to recall the exact number of face-to-face sessions as the social workers connected with them in their offices and occasionally during their treatment sessions in the chemo-room. The researcher has noted that this form of contact was documented on the Cancercare system as a follow-up session.

4.3. Framework of analysis

Table 4.2: Framework of Analysis

| | Theme | Category | Sub-Category |
|--------------------------------------|--|--|--|
| 4.4.1 | The clients' reasons for seeing the oncology social worker | 1. Being informed by the team | |
| | | 2. Being approached by the social worker | |
| | | 3. Psychosocial needs | 1. Information on treatment and side-effects |
| | | | 2. Psychological needs i) Individual needs ii) Dealing with the response of children |
| 4.4.2 | The clients' expectations of the oncology social work service | 1. Perceptions of the social work profession | 1. Comparing social work and psychology |
| | | | 2. The role of the social worker i) General assumptions of the social work profession ii) Social work in oncology practice |
| | | 2. Supportive Care | 1. Individual Support |
| | | | 2. Family Support |
| 4.4.3 | The positive aspects of the oncology social work service | 1. Accessibility of the service | 1. Availability of the social worker 2. Chemotherapy room visits 3. Regular follow-up |
| | | 2. Professionalism of the social worker | 1. Maintaining confidentiality |
| | | | 2. Personal qualities of the social worker |
| | | 3. Provision of Psychosocial care | 1. Preparation for treatment |
| | | | 2. Psychological care i) Professional objectivity ii) Supportive counselling iii) Normalising feelings iv) Dealing with children |
| | | | 3. Assistance with practical needs i) Work related assistance ii) Referral to the Look Good Feel Better workshop |
| | | 4. Multidisciplinary team approach | |
| 5. Family services | | | |
| 6. Post-traumatic growth | | | |
| 4.4.4 | Challenges experienced when engaging with the oncology social work service | 1. Lack of clarity on the role of the oncology social worker | |
| | | 2. Contact with the social worker | 1. Follow-up |
| | | | 2. Contact in a public setting |
| | | 3. Information needs | 1. Information overload at the time of diagnosis |
| 2. The need for specific information | | | |
| | | 4. Post treatment contact | |

| | Theme | Category | Sub-Category |
|-------|---|--|---|
| 4.4.5 | Recommendations to improve the oncology social work service | 1. Reasons for recommending the service | |
| | | 2. The need for information about the social work service | 1. Clarifying the role of the social worker 2. Referrals to support groups |
| | | 3. Early Intervention | |
| | | 4. The need for post treatment support | |
| | | 5. The need for the social worker to be more available | |
| 4.4.6 | Data that emerged from the interviews | 1. Camaraderie amongst cancer patients 2. The role of the family as a support network | |

4.4. Findings

The findings are presented below under the heading of each objective.

4.4.1. Objective One: To explore the clients’ reasons for seeing the oncology social worker

The participants explained how they found out about the social work service and their reasons for seeing the social worker. Either a multidisciplinary team member or the social worker at the practice informed patients about the service.

4.4.1.1. Being informed by the team

A number of participants were first told about the service when consulting with their oncologists or when introduced to other members of the treating team. Other participants were directly contacted by the social worker and informed about the availability of the service at the practice.

“When I had my first appointment with the Doctor, the social worker had an appointment booked for me. It all happened once I got here. I went to the nurse, the social worker and the doctor” (Participant 1)

“She worked there. The oncologist just took us there” (Participant 14)

“Through the doctors and Cancercare. Before we started treatment, you first go in to see the doctor and then they discuss the treatment plan with you... so she told me about the social worker” (Participant 16)

This finding echoes Lauria et al’s (2012) suggestion that the team members’ perceptions of the role of the social worker are vital in terms of their appreciation for what the service can offer as it has direct implications for the utilisation of the service. The theory of psychosocial oncology strongly emphasises the need for multidisciplinary informed practice with cancer patients (Holland, 2002; Watson et al, 2014). It is estimated that only about fifteen to twenty percent of patients diagnosed with cancer will eventually use the social worker service (Cwikel & Behar, 1999). When considering these statistics, medical staff serve as a direct referral source in encouraging patients to engage with the service.

4.4.1.2. Being approached by the social worker

The social worker contacted some participants directly and informed them about the service. This was done via email, telephonically or in person.

“She came to me, and said to me if I have any problems, she is here for me ... in the waiting room, and then in the chemo room. She also phoned me after chemo to see how I feel. So I called if I had any difficulties or needed advice” (Participant 2)

“She knew my name, and then she called me one day and said, I see you here every week, but you don’t make an appointment... and then she offered, don’t you want to come and see me? And I am like okay, let’s give this a try” (Participant 9)

Boyle et al (2005) refer to the pragmatic skill of the social worker and this finding supports their keenness to have more of an active role in the battle of cancer. By volunteering assistance, the social worker was viewed more positively by participants. This contributed towards their confidence in using the service when needed.

4.4.1.3. Psychosocial needs

The researcher explored the participant’s reasons for seeing the oncology social worker and what led them to initiating the process. There were three main areas that emerged:

4.4.1.3.1. Information on the treatment and related side-effects

A number of respondents indicated that their information needs led them to make contact with the social worker. These needs centred on information about cancer, treatment and related side effects.

“My partner and I did eventually make an appointment with the social worker and she talked about the effects of the chemo on my body... I wanted him to hear it from someone else and not from me, so that he could understand. Because he started to think that I was just not into him anymore” (Participant 5)

“My mother phoned her just to speak to me, because the way I am feeling, is it normal or not? You don’t know, are you dying, are you supposed to be feeling this way? ... That was the most difficult part of it. The treatment more than being diagnosed” (Participant 10)

“I just thought any kind of support. Maybe she could shed some light, because it was before any kind of treatment or anything started. So we were a bit in the dark about cancer and all that” (Participant 11)

These findings echo those of Allen and Spitzer (2016) who identified a tangible need for information about diagnosis and treatment side effects. Fourie (2010) points out that this information needs occur at different stages of the disease and recognises the vital role of the social worker in providing psychoeducation in helping patients and their families to cope.

4.4.1.3.2. Psychological needs

Participants experienced psychological distress and some stage of their diagnosis and sought out the social worker for this reason. Their psychological needs have been categorised in terms of their personal individual needs and the needs of their children.

4.4.1.3.2 (i) Individual needs

Most participants in the study indicated that they saw the social worker to help ease their psychological distress. This was especially related to their personal struggles around living with cancer and coping with treatment.

“It was difficult to go on with life, ya, to see people around you suffer also. I think that people, family and friends, they come to you and chat to you and then they leave you. Definitely, it’s an isolating sickness... and cancer doesn’t stop, it’s an ongoing thing. It’s not like a cold” (Participant 2)

“I had a traumatic experience on the first day that I arrived at oncology. A guy was having a very bad reaction and he collapsed... the smell was horrific, that chemo smell and it scared the hell out of me. I turned around and I just ran... then the social worker, she gave me something to calm me down and she sat with me for a while and that sort of helped me to get back in there again” (Participant 12)

These findings concur with the vast literature on the subject of psychological distress, specifically in relation to significant human developmental challenges, the biopsychosocial effects of diagnosis and treatment, and the growing emphasis on psychologically oriented care (Ross et al, 2002; Schapmire in Christ et al, 2005; Breitbart & Alici, 2009; Manicom, 2010). It seems that patient’s responses can be influenced by society’s attitude towards cancer and subsequent feelings of isolation. In terms of Eriksonian theory, this is thought to be linked with the risk of one’s own identity in light of the crisis of a cancer diagnosis (Christ et al, 2005). The following section discusses the participants need for the social worker to help them deal with their children’s response to diagnosis.

4.4.1.3.2 (ii) Dealing with the response of children

A strong need of many the participants was help for their families, more specifically their children. Participants reported concerns around their children’s ability to cope with the news of diagnosis. It was noted that a majority of the support was needed for young children.

“I thought my daughter was in denial ... she was totally in denial about what was happening to her mum, and she handled me like that. I felt so sick and so bad that I couldn’t express it like she knows me to. She couldn’t understand... when the social worker contacted her she didn’t even reply” (Participants 1)

“We were also wanting to know, how do we tell my son what is going to be happening? ... Because the two of us don’t know what is going to happen” (Participant 11)

“I was worried it was going to be difficult for them and so I asked the social worker to see them. I wanted her to see them and tell me how they are doing, because sometimes they don’t tell you everything” (Participant 16)

These findings correspond with the research suggesting that children of cancer patients report emotional, behavioural and social reactions to the diagnosis including sadness, difficulties at school and conflict with family members (Niemela et al, 2010). Through identifying the needs of children, the social worker can provide appropriate family support and assist with communication between family members (Cwikel & Behar, 1999; Niemela et al, 2010; Ernst et al, 2013). This highlights the Eriksonian developmental challenges faced by adults around fulfilling and possibly renegotiating their role within the family (Christ et al, 2015). Furthermore, system’s theory encourages the social worker to act as a mediator between patients and their environment in order to improve interactions and communication and ease the patient’s ability to manage diagnosis (Fobair et al, 2009; Turner, 2011)

4.4.1.3.3. Practical Needs

Participants identified a number of practical needs and requested referral to external resources for help with side the effects of treatment that affected physical appearance and overall functioning.

“I have severe neuropathy of my hands and feet and I needed the oncologist to assess me with my insurance claim and she was just not forthcoming with it. And then the social worker spoke to her... and obviously the oncologist thought more of her opinion. I am not well enough to work. I have been put on disability benefit which was very stressful for me because of finances” (Participant 3)

“I asked her where do I find a wig... and also the girls that came to sell the bandanas... she actually could easily get you the info that you wanted” (Participant 13)

“I never knew where to start... It’s the practical stuff on finances, practical stuff what needs to be done, not just the emotional support” (Participant 15)

As the findings suggest, the instrumental needs of cancer patients include issues around finance and employment challenges as patients often think in terms of their practical needs

before being able to focus on their emotional needs (Fourie, 2010; Manicom, 2010). They therefore require access to a service that facilitates discussion around practical needs and provides referrals to relevant resources. The common focus for patients within the human developmental stages of young and middle adulthood is that of community and job satisfaction (Christ et al, 2015). In light of the disruption experienced due to a cancer diagnosis, there is a need for a focus on the different structures arounds patients in order to improve patient functioning (Turner, 2011).

The findings discussed under objective one reveal that the multidisciplinary team members were generally proactive in terms of referring participants to the social worker; and that the social worker reached out to a number of participants to inform them of the service. The participant's reasons for seeing the social worker included psychological distress and help with practical needs. After exploring the participant's reasons for seeing the social worker, their expectations are discussed below.

4.4.2. Objective Two: To determine the clients' expectations of the oncology social work service

Participant's perceptions of the role of the social worker and their expectations of the service will be discussed in this section.

4.4.2.1. Perceptions of the Social Work Profession

When asked about their expectations of the service, participants offered their perceptions of the social worker's role in an oncology setting and compared their perceptions of the role of a psychologist. This seemed to have influenced their expectations before meeting the social worker and influenced the needs they chose to express during the session. While this comparison has been indicated in the literature, it was not asked for in the interview schedule and presents as an unintended finding of the study.

4.4.2.1.1. Comparing Social Work and Psychology

Some participants voiced their surprise when they discovered that the social worker was not a psychologist by profession. This was especially in relation to their need for emotional support and the expectation that they would be seen by or referred to a psychologist.

“I thought she was a psychologist. I didn’t even know she was a social worker. I thought in oncology there should actually be a psychologist there. Because a psychologist will help you with your emotions” (Participant 4)

“It boils down to education from a patient point of view, knowing what services she was really supposed to help me with... because I didn’t know that social workers help with that, I thought that was for psychologists... I am not quite sure where to draw the line between social services and psychology services... where it stops being a social service and becomes an emotional service” (Participant 15)

Research has shown that in some instances, social workers are not positively associated with the role of counsellor or therapist as clients would prefer to see a psychologist for their emotional needs (LeCroy & Stinson, 2004; Wantz & Firmin, 2011; Olin, 2013). It seems that even after seeing the social worker, these participants were still not clear on the social worker’s role.

4.4.2.1.2. The Role of the Social Worker

Participants expressed their general assumptions around the profession of social work and their perceptions of the role of the social worker in an oncology setting. These perceptions influenced their expectations of the service, as they were surprised to learn of the social worker’s role in the first session or chose not to utilise the service any further as they were not aware of the needs that could have been addressed in those sessions. These findings are not reflective of the questions asked in the interview schedule; however vast literature indicates that incorrect perceptions of social work have been identified as a challenge of the profession.

4.4.2.1.2 (i) General assumptions of the Social Work Profession

The general perception of the role of a social worker seemed to centre on generic social work practice within the community. There was a common assumption that social workers provide a service to people from poorer socio economic communities and that these services entailed rescuing children and helping people who cannot care for themselves.

“For me a social worker is like somebody who helps with children. I had more an idea they work with kids, family who don’t look after they kids and stuff like that” (Participant 4)

“I think a social worker you know, arranges care for people who don’t have anyone to help them” (Participant 16)

“I didn’t know what the role specifically was of the social worker... in terms of my needs... because if I think of social work, we think old style social work... the people who actually go and take babies away from families who cannot look after them” (Participant 15)

The most common role associated with social workers is often that of ‘child protector’, and this is argued to influence clients’ decision to engage with a social work service in addressing their personal problems (Staniforth et al, 2016). This led to a discussion around the perceived role of the social worker in oncology practice.

4.4.2.1.2 (ii) Social work in Oncology Practice

With specific reference to the role on an oncology social worker, participants assumed that it was a service reserved for patients that didn’t have access to financial resources and required assistance for social problems or palliative care.

“I sat in the reception and saw the sign ‘oncology social worker’, and I thought, I am not going in there anytime. It’s for people busy dying, if you go in there that means you are dying. So I was scared of her door, what is behind that door. The stigma of seeing a social worker” (Participant 2)

“I am not quite sure how she really fits into a private oncology practice... well obviously if there is a financial problem, there will be definitely a role for them. That is why I don’t understand how she fits in here, because if you don’t have money or a medical insurance, you don’t come here” (Participant 3)

“I thought that the social worker there was just someone that is there that if you have got social problems, but not really to do with your condition” (Participant 14)

Findings indicate that participants were initially unable to recognise the social worker's role with regards to their diagnosis and that some participants were still confused about the social workers inclusion in the treating team in a privately run oncology practice. Several studies have revealed that there is public confusion around the role of the social worker within different settings (Staniforth et al, 2014). This is discussed further under objective four.

Despite the misunderstanding around the role of the social worker within oncology practice, there was an expectation that the social worker would offer supportive care.

4.4.2.2. Supportive Care

The participant's expectations around support fell into two categories:

4.4.2.2.1. Individual Support

Most participants expected the social worker to offer professional emotional support that could not be provided by family members or other team members.

“Support. Support during everything. I thought in the beginning it would just be for the person who has cancer” (Participant 1)

“How to deal with the news and how to share the news with family or friends... Coping with the disease. Trying to get your life back to normal and get into a routine” (Participant 6)

“I saw it just as somebody to talk to other than my immediate family, somebody that I can trust... somebody else that I can be completely honest with” (Participant 16)

These findings are similar to that of Ohlen et al (2005) where participant's expectations of a support service centred on managing this difficult life situation, becoming normal and seeing a professional that would express non-judgement and provide a space where hope could be regained. Research with cancer patients has shown that psychosocial support services are especially important to both patients and their families; where patients find relief in talking to someone who is not a family member and can be objective in their responses (Boudioni et al, 2000).

4.4.2.2.2. Family Support

Only three participants expected that the social worker would provide support to their family members as well. This expectation was not represented by the majority of the participants as many of them only learnt of this aspect of the service once engaging with the social worker. Participants expressed their concern for their young and adult children but did not necessarily expect the social worker to intervene.

**“More time with her yes, and even with my family also, we didn’t have much support”
(Participant 4)**

“I mean my husband and I could go in there behind a closed door and just cry our hearts out” (Participant 8)

“I can actually bring my husband here and he can talk about his frustrations... you almost become selfish, it’s all about me... I mean my husband was directly affected, my children” (Participant 9)

The finding that there is a need for family support is not surprising. Several authors recognise cancer as a family disease that is likely to disrupt the lives of all involved and place demands on the family in terms of the patient’s treatment and recovery process (Scmid-Buchi et al, 2008; Donley & Danis, 2011; McCarthy, 2011). According to Erikson’s theory of human development, young and middle aged adults are pre-occupied with meaningful relationships and active involvement with family (Christ et al, 2015). A systems theory approach that understands the patient within the context of community and family will assist in maintaining the wellbeing of all involved (Green & McDermott, 2010; Turner, 2011).

Participants’ expectations of the service were strongly influenced by their perceptions of the social work profession and they generally compared this to psychology as a profession. These perceptions were descriptive of generic social work practice leading them to question the role of the social worker in a medical setting. Most participants expected individual support, while the minority expected that the social worker would intervene at a family level as well. The positive aspects of the service are discussed below.

4.4.3. Objective Three: To determine the positive aspects of the oncology social work service

Participants identified six aspects of the service that were helpful. This included the following:

4.4.3.1. Accessibility of the Service

Participants were pleased about the accessibility of the service and described this in terms of the social worker's availability to see them as well as the regular chemotherapy room visits.

4.4.3.1.1. Availability of the Social Worker

Most participants expressed that the social worker was often available, and that they did not necessarily require a scheduled appointment. They also did not have a long wait when scheduling an appointment. Two of the participants referred to the fact that there is no charge for the service, making it more accessible in light of the other expenses encountered when managing a diagnosis of cancer.

“And also it was free. That was amazing because you didn't have to pay for that as well. Because if I did have to pay, I couldn't come because I couldn't afford it. It was included in the whole package; I see the people here as a package. Often I just pop in after the doctor has seen me to have a quick chat and that helped a lot hey” (Participant 1)

“On their part, it was like, make an appointment, and come see me. Just swing by, open the door, and ask if I'm available” (Participant 9)

The open-door policy of the social worker encouraged participants to make contact and provided reassurance of receiving help when it was sought. Schroepfer (2011) identifies the social worker as an important resource for medical teams as their role and expertise enables them to have more time to address psychosocial needs.

4.4.3.1.2. Chemotherapy room visits

Findings indicated that contact made between the participant and social worker took place primarily in the chemotherapy room.

“The social worker is there for all the loose ends. She is more available than the doctors. She didn’t sit behind closed doors and not be accessible to patients. I didn’t have to go to her, she came to me. She puts the stool in the chemo room and starts talking to each and every one. It’s more like a casual meeting which takes the pressure off” (Participant 2)

“Sometimes she would pop in there by the chemo room while we are having chemo and she would go around... she was available, readily available... so there was no long period of waiting. That I think was one of the good things of this service” (Participant 6)

These findings indicate a positive response to contact with the social worker during treatment sessions, as it created a non-threatening discussion in a neutral space that allowed them to start building a relationship. Howard (2010) suggests setting the scene for therapeutic work and refers to the ‘frame’ of the relationship in helping to create a safe and predictable physical and psychological space that the client can learn to trust. If the space is neutral, it will help clients to trust that they will not be over-stimulated or intruded upon (Howard, 2010).

4.4.3.1.3. Regular follow-up

Participants voiced their appreciation of the social worker’s follow-up efforts, especially in terms of emails and phone calls. In light of their treatment schedules and daily routines, they often did not have the time to schedule fixed appointments. They felt valued and appreciated the opportunity to share how they were feeling.

“And even emails, we would email each other and she would call me. Even far after I was done with the study and trial, she was still emailing me and checking how I am” (Participant 9)

“She checked in with me very often...It is always nice to hear from her and she always sends me emails and phones me. That feels like she remembers me” (Participant 11)

“Afterwards she invited me, emailed me and I saw her in the chemo room from time to time when she popped in there” (Participant 14)

Ohlen et al (2005:72) alludes to the need for the professional to initiate contact with the patient as a distressed person in crisis is less likely to seek help without assistance. While a patient should be empowered to ask for help themselves, the crisis of a cancer diagnosis may distract from their emotional needs. Regular follow up would then serve to provide an opportunity to patients to disclose and difficulty or distress.

4.4.3.2. Professionalism of the Social Worker

Participants appreciated the social workers' professionalism during their engagements and identified two aspects that that assisted in building trusting working relationship. These are:

4.4.3.2.1. Maintaining Confidentiality

The provision of a safe space to confide hidden fears and hopes were especially important to participants, as they valued the objectivity of the social worker.

“It was good to talk confidentially to someone that is not family; who don't know you because she will see the whole situation from outside because she is not involved in your personal life, very objective... impartial” (Participant 1)

“You sort of feel this is someone I can trust or I would tell this person something and you know it will be confidential” (Participant 9)

These findings are consistent with Guttman's (2006) identification of confidentiality as a significant ethical practice in social work and suggests that it enables a trusting relationship to build between the client and social worker.

4.4.3.2.2 Personal Qualities of the social worker

Participants referred specifically to the personal qualities of the social worker when describing the helpful nature of their working relationship.

“She has a softness in her that makes her like a cushion; she is not like the doctors and the others, where you can't say anything. I am not afraid of her... This work is her life. I feel confident knowing that this is her life every day.” (Participant 2)

“She is extremely sweet and caring...because she is just that type of person, very positive” (Participant 11)

“I got to know her as a person... she showed interest beyond her professional capability. I was more than just a patient; I was a person you know” (Participant 16)

Participants valued the skills of the social worker because the professional knowledge and exposure in the field of oncology reassured them of her ability to help them. The academic background and practical skill of social workers make them uniquely suited to work with cancer patients as a major focus of psychosocial oncology theory is addressing the whole person (Krise & Lundy, 2005; Schroepfer, 2011).

4.4.3.3. Provision of Psychosocial Care

Apart from the accessibility of the service, participants also voiced their appreciation of the care offered by the social worker. The psychosocial care fell into three categories:

4.4.3.1.1. Preparation for Treatment

Most participants were grateful for the social worker’s knowledge around cancer and treatment, with specific reference to the chemotherapy room and allowing them to familiarise themselves with the setting. This helped them to de-mystify chemotherapy therapy treatment and better prepared them for what to expect.

“I was surprised that she is very knowledgeable with regards to different types of treatments. Whatever information she gives you... she knows what she is talking about. She is very much on par with the doctors... she is very much informed about the treatment itself... she shared it with us in a very simple manner making sure we understand” (Participant 6)

“She explained to me everything. So the first time I walked into the chemo room I knew more or less what to expect... at least I knew what was on the other side... so all the questions I had I could discuss with her, and she answered me” (Participant 8)

“I had no knowledge of chemo, what the hell is going to happen now, and she actually said to me, let me go and show you the chemo room... it just took the fear of the unknown away” (Participant 13)

These findings suggest that cancer patients have information needs at different stages of the disease and Fourie (2010) points out that it is vital for social workers to provide psychoeducation as it is imperative in helping them to cope. Such intervention is thought to enhance coping and adjustment (Fawzy, 1999; Ohlen et al, 2005).

4.4.3.1.2. Psychological Care

While some of the participants struggled to identify the social worker’s role in managing emotional needs; a significant number were grateful for the psychological care provided by the social worker. This form of care has been categorised as follows:

4.4.3.1.2 (i) Professional objectivity

Participants expressed the challenge in sharing their struggles with their family members. They appreciated the social worker’s objective and non-judgemental approach. There was an acknowledgement and validation of their true feelings and the comfort of being themselves within that space.

“You can tell the social worker freely because friends and family... you will put on a brave face... just to put them at ease... so you can go in there just vent, be yourself and not worry about what the family is going to think about you... you will feel a weight off your shoulders” (Participant 9)

“The thing that I found most helpful was to say how I was feeling. To put it into words, without offending anybody or making anybody feel bad about how I was feeling” (Participant 16)

According to Boulton et al (2001), patients usually feel inhibited in opening up to family and appreciate the opportunity to express themselves freely without being concerned about the consequences of their disclosure. This led to a discussion around the benefit of supportive counselling where the field of psychosocial oncology highlights patients’ right to support (Breitbart & Alici, 2009).

4.4.3.1.2 (ii) Supportive Counselling

For the participants that identified the benefit of supportive counselling, findings suggest that the number of sessions did not matter. They received support that addressed their need within a particular session and felt comfortable utilising the service again if the need arose.

“I think just to unburden yourself a bit. I don’t think that there is always a change maybe in what you tell them, it is not going to change you. I am not going to suddenly feel I am looking fine, I don’t have to worry. But it is in that moment when everything gets too much, then you talk to someone, it gets better. It just brings a bit of relief” (Participant 7)

“Just having someone that would maybe focus more on how you are doing... even not related to cancer. Just how are things going now... it was nice to also focus on life semi-going on at home too, so we are trying to keep things as normal as possible” (Participant 11)

This supports the literature in that it was beneficial for participants to have a space to talk about more than just their diagnosis. Gaining emotional relief may be the most important outcome of supportive counselling and providing a space to talk about other problems impacts patient’s ability to deal with their diagnosis (Boulton, 2001; Ohlen et al, 2005). This approach helped to normalise what they were experiencing.

4.4.3.1.2 (iii) Normalising feelings

A significant number of the participants referred to instances where they struggled to identify if what they were experiencing emotionally and physically was normal. They appreciated the availability of the social worker in expressing their concerns and seeking reassurance.

“You realise also that you are not the only patient that she has... so, that also helped, that she would maybe mention that she had a patient that has also gone through something similar and they are doing well” (Participant 6)

“The way she explained to me the feelings, the scariness, it was normal. I felt normal” (Participant 8)

“I cannot even remember much, because I cried quite a bit. She just told me that it is normal to feel that way, that if I should feel down, I must come and talk to her” (Participant 12)

The range of emotional concerns interrupt the normative functioning of each patient’s human developmental stage (Fawzy, 1999; Boudioni et al, 2000; Christ et al, 2015). Boulton et al (2001) echo these findings as such reassurance provides emotional relief and not only normalises their experience, but also helps patients understand that their responses are normal given the circumstances.

4.4.3.1.2 (iv) Dealing with children

This finding arose under objective one and two. Here, participants appreciated the space and insights provided by the social worker because it gave them insight to the needs of their close family members. They made specific reference to their young children, and feeling relieved that the social worker, allowing them to pay attention to their own needs, could address their children’s needs. The discussions provided useful tools that guided their interactions with one another.

“I could talk about my family which I really appreciated because I needed the tools to help them. She said things that made me think about my family differently... That’s what made me look at my child and how he was being affected by this.” (Participant 2)

“Now the children see all this happening around me now... So I let her see them, she spoke to them, and actually I was relieved because she told me that they are well adjusted and they know exactly what is going on and I don’t have anything to worry about” (Participant 16)

These findings concur with Boulton et al’s (2001) suggestion that the supportive space provided to patients frees them to concentrate on their emotional needs while still better enabling them to focus on the needs of those closest to them. In considering systems theory, social work is a profession that places itself between systems; they often develop close relationships with patients and their families that lead to them to be perceived as an extended family member (Simon et al, 2005; Green & McDermott, 2010).

4.4.3.1.3. Assistance with Practical Needs

Along with psychological needs, participants expressed their practical needs. These are categorised according to work-related assistance and referral to the Look Good Feel Better Workshop.

4.4.3.1.3 (i) Work related assistance

Three of the participants identified the social workers assistance in terms of their employment needs and the communication needed between the practice and their employer.

“She said, you know I work with children and if my immune system is down, I will be able to pick up germs very easily; and then she was with the doctor, and she recommended that I be booked off from work for a longer period to build up my strength and I am very grateful to her” (Participant 6)

“She wrote a letter to my work and my boss; just to explain the symptoms and this can happen... the third week after chemo I could not come back to work. I was not strong enough. So it was in that time that she wrote a letter to explain why I cannot work” (Participant 10)

In accordance with these findings, the physical side-effects of treatment can be quite severe and often affect patients’ ability to cope and work related issues are not uncommon for cancer patients due to the severity of treatment side-effects and the deterioration in overall functioning (Fawzy, 1999; Cwikel & Behar, 1999; Manicom, 2010). This highlights the importance of working with the systems and subsystems within patients’ lives in order to optimise their functioning within their environment (Turner, 2011).

4.4.3.1.3 (ii) Referral to the Look Good Feel Better workshop

Most of the participants spoke of their attendance of Look Good Feel Better Workshop, hosted by all the Cancercare practices. The social worker was often the person that shared the information and encouraged their attendance. While this was noted in the literature, it was not asked for and therefore serves as an unintended finding of the study.

“The things they offer, like the ‘look good feel better; that helps a lot... you are concerned about not having hair and here they are bringing people to show you how to

actually put a scarf around your head, or makeup that will make you look beautiful again. Because during that time, believe me you don't feel beautiful at all" (Participant 9)

"She actually also referred me to go and join the group of people and they had like... a women's gathering , where you could go have a make-up session... but it was actually quite nice seeing other people without hair, with little caps and wigs. You didn't feel like you were isolated. You just don't feel very feminine. Just to feel that little bit prettier... makes a difference in your life" (Participant 12)

Woman diagnosed with cancer and undergoing treatment often struggle with feelings of dejection, isolation and an invasion of their self-esteem; and the Look Good Feel Better project has shown to decrease the negative effects of diagnosis and treatment as it leads to higher self-esteem (Van Sonsbeek, 1995).

In considering the emphasis on networking and accessibility of external resources, participants also valued the multidisciplinary team approach within the practice.

4.4.3.4. Multidisciplinary team approach

A significant number of participants identified the benefit of a team approach to treatment planning, and valued the different inputs of each profession in working towards the overall wellbeing of the patients.

"They obviously are a very good connection for, you know, between the doctors and the homecare and things like that" (Participant 3)

"It is not something separate from your treatment. They all play a role, and they are all involved. They are all aware of your particular situation, it is not just generalised" (Participant 6)

"I think once you start the treatment and you get sort of surrounded by, like I had obviously the oncologist, the surgeon, the social worker, all like in a team, surrounding me and supporting me" (Participant 9)

This finding reinforces the basis for the implementation of psychosocial oncology theory within practice; social workers are an important resource for cancer care teams as medical professionals are primarily focused on the medical management of the patient and have little time and expertise to address psychosocial needs of the patients (Holland, 2002; Schroepfer, 2011).

The penultimate area that arose under objective three was the value of a family service within the practice.

4.4.3.5. Family services

Support for family members was a common theme that arose across the research objectives. It was not only an expectation, and the reason participants sought out the service; but also a perceived benefit that the services were extended to family members as well.

“The service, it opened my mind to realise that it is not just me going through it, it’s my whole family and I can actually bring them also in and let them talk about how they deal with it... my husband and I, we could just cry our hearts out there. I felt a sense of you can unpack and it being in a safe space” (Participant 9)

“My husband and I went to see her and my daughter was four years old... and she wanted to see my daughter... and she explained that even at that age, they can pick up on things. She said that I must not worry about her, she will take care of it. That helped a lot” (Participant 6)

These findings are indicative of the importance of the availability of a family service in oncology practice and is therefore suggestive of a systems approach to cancer care. Speice et al (2000) point out that having a loved one diagnosed with cancer is incredibly distressing for family members and can lead to feelings of helplessness and barriers in communication. Ohlen et al (2005) found that by including family members in the support service, it improved relationships and allowed for communication that is more direct. This recognises the importance of a systems theory approach where communication is key in supporting the dynamic interactions within the patient’s environment (Kihlstrom, 2011).

4.4.3.6. Post-traumatic Growth

Thus far, the literature and findings refer to the trauma and difficult emotions associated with a cancer diagnosis. However, some participants identified their cancer journey as being a learning curve in their lives, and the added benefit of seeing the social worker and learning to prioritise themselves and their families above all else.

“How to look after my child’s wellbeing, that’s the biggest thing, and look after my marriage” (Participant 2)

“Just knowing that there was a support system made it easier for me to carry on. That is what I learnt from it” (Participant 12)

“Don’t sweat the small things now. That is what I learned about this whole thing... not to fuss about the rules, enjoy the children instead” (Participant 16)

Consistent with these findings, a significant theme that arose in Ohlen et al’s (2005:70) study was that of being able to learn from the counselling experience. Through this, clients are able to examine their own thoughts and feelings and value the skills of the professional in guiding them through the process (Boulton et al, 2001). These participants also referred to the positive life lessons that were gained from their journey. This is considered as a domain of post-traumatic growth and includes a perceived closeness and appreciation of others as well as an increased appreciation of life (Shand et al, 2015). In light of the crisis experienced, this could assist with the resolution of the Eriksonian developmental stage and would determine the future functioning in all other stages (Christ et al, 2015).

Participants were able to identify a number of positive aspects of the service and referred to the professionalism and personal qualities of the social worker as being an important predictor in their continued use of the service. There was significant value in sharing and seeking help from an objective outsider that could also assist with support for family members. A significant finding from the female sample was the perceived benefit of the Look Good Feel Better workshop and being offered a space that not only normalises their experience but also creates a feeling of camaraderie amongst the attendees. This is discussed under the additional data that emerged from the interviews.

4.4.4. Objective Four: To investigate the challenges clients experienced when engaging with the oncology social work service.

Participants identified a number of challenges they encountered when engaging with the oncology social work service. Their feedback fell into the following categories:

4.4.4.1. Lack of clarity on the Role of the Oncology Social Worker

A significant finding was that the majority of participants were uncertain about the role of the social worker within an oncology setting. This was reported by participants who had seen the social worker at least twice, as well some who had significantly more contact with the social worker.

“I always thought a social worker is someone who works with families or in the case where there is a patient who passed away or who is terminally ill... I don’t know what a social worker is trained in exactly or their qualifications” (Participant 5)

“What is a social worker supposed to do? What is her job description there? ... It could just have been the secretary at that stage... I don’t even know what her name is... I am not sure where the social worker fits in” (Participant 14)

Regarding these findings, it is not uncommon for social workers to be seen as people who talk to clients and arrange access to services, and there is uncertainty around the nature of training needed for their perceived tasks (Reid, 2002; Olin, 2013; Staniforth et al, 2016).

4.4.4.2. Contact with the Social Worker

While a number of participants appreciated regular follow-up and discussions with the social worker in the chemotherapy room, some felt that chemotherapy room contact invaded their privacy amongst fellow patients and were dissatisfied with the lack of follow up.

4.4.4.2.1. Follow-up

A few participants felt that they received minimal benefit from the service because the social worker failed to initiate more contact with them. This was also related to the fact that they were unclear on her role and were uncertain about reaching out for help themselves.

“I didn’t see her at the practice very often. I don’t know if her door is always closed, because it is the social worker’s door... but I cannot remember seeing her face that often... there could be more interaction in general” (Participant 5)

“She explained to me, you know, what her services were about or what I was going through was normal. That was basically it. There was no real follow up in terms of let’s get together, let’s talk about things, what is your needs etc. How are you doing today? It was always just at that level, it never went any deeper than that” (Participant 15)

These findings are suggestive of the evident debate in the literature regarding the perceived benefit and challenge in terms of regular follow up within the social work profession. However, Ohlen et al’s (2005) findings suggest that it is not uncommon for patients to feel dissatisfied with a service if they feel insufficiently supported; this finding was noted particularly in relation to not having enough time with the professional providing the support.

4.4.4.2.2. Contact in a public setting

It has been noted that some participants appreciated that the social worker reached out to them in the treatment room during their chemotherapy sessions. However, some participants were uncomfortable with this as they felt that the space was too public to discuss the intimate details of their cancer journey. It was felt that they needed to be offered a private space and the perception was that the social worker was too busy and could not offer this.

“Even though she comes in the chemo room, she would like move around talking to the patients... but I thought there would be more interaction... everything is time consuming. You could see she needed to see other people, so you didn’t have enough time to really talk past how you are... I don’t think she will even know me when I walk past her. There was no real relationship” (Participant 4)

“I was just thinking one-on-one, my honest opinion... maybe I would have asked her to tell me more if it was not like my neighbour was next to me listening... I did not want other people to hear my stuff in the chemo room” (Participant 8)

These findings speak to research that has indicated patients feel unsupported and uneasy during sessions when they perceive that their emotions and private thoughts are dealt with in

a medical manner (Terry et al, 2006). Due to high caseloads, oncology social workers are expected to provide a condensed service to patients that addresses all of their psychosocial needs (Laurie et al, 2012).

4.4.4.3. Information Needs

4.4.4.3.1. Information overload at the time of diagnosis

Most participants voiced their challenge in processing the information that was given to them in the initial stages of their diagnosis. Some expressed that while they found it helpful that the social worker was knowledgeable enough to meet their information needs, they were unable to process or recall the conversation.

“The first time when I went to her, she was explaining to me everything, but you listen and you don’t listen. You don’t hear because your mind is occupied, there is so much information. For me I cannot even remember what was taking place” (Participant 4)

“It was just information overload at that stage... I mean for you it is all just words” (Participant 9)

“I obviously in her defence also say, I am sure, and I can’t recall much of that day, because I was so upset, and it was so much information – that she would have told me what her role was” (Participant 15)

These findings reflect those of McCaughan and McKenna (2007) indicating that cancer patients struggle to recall important information during the initial period of diagnosis as their anxiety affects their ability to think clearly. The diagnosis of cancer is described as a time of crisis and for patients going through a roller coaster of emotions, there may be problems with the way in which the information they receive is processed (McCaughan & McKenna, 2007:2097).

4.4.4.3.2. The need for specific information

The social worker’s knowledge and distribution of information was identified as a positive and unexpected aspect of the service. However a significant finding amongst some participants indicated that they received too much information at the time of diagnosis,

needed more specific information with regards to the social work service and access to external resources.

“Because when you come here you don’t know what questions to ask. You end up having to go through stuff on the internet to see what it’s all about. You don’t know which questions to ask and they don’t tell you what you are in for. So the communication gap again leaves you feeling very unprepared” (Participant 1)

“You see lots of pamphlets in terms of wigs, prosthesis and whatever; it is all accessible but it is actually inaccessible in terms of really understanding what our needs are. I would have liked my social worker to have a one on one with me... it was all just a little bit of paperwork that was lying around everywhere in a pamphlet box, but nothing ever reached me as a patient” (Participant 15)

This finding speaks to the need for patients to have access to a service that distributes relevant information pertaining to their practical needs (Cwikel & Behar, 1999; Allen & Spitzer, 2016).

4.4.4.4. Post-treatment contact

Participants that were interviewed post treatment expressed their need for a service that continued to consider their psychosocial needs after treatment. It was felt that once their treatment was over, there was little to no follow up regarding their adjustment to life after diagnosis and treatment.

“Because I am done now, I haven’t heard from her after the trial, but I think mainly because it’s a different practice. So when they switched me back, they thought hands off” (Participant 9)

“It is a known fact that people who have gone through this suffer from post-traumatic stress. What do we do with it? I am in a position where my treatment finished off in March... I am in limbo... I could have probably walked out feeling a little bit better about myself and the experience if I had a little bit more of an emotional support” (Participant 15)

Consistent with these findings, Pranjic et al (2016) point out that cancer changes the life of the individual and refers to the chronic phase of psychological adaptation after treatment. Respondents' thoughts and fears remained for a long time after treatment, and a space is required to work through this (Ohlen et al, 2005). This speaks to the need to resolve a crisis that occurs within the Eriksonian developmental stage of the patient, and provide some continuity in terms of addressing the patient within a system that needs to be adapted to allow reintegration to occur (Kihlstrom, 2011; Christ et al, 2015).

The findings suggest that the lack of clarity on the role of the social worker had some impact on participants' utilisation of the service. Some participants reported minimal follow up from the social worker and also discussed the discomfort of being approached by the social worker in the chemotherapy room setting to discuss private matters. While the social worker's knowledge and access to information was noted, participants felt that the distribution of information needed to be paced and relevant to the individual patient. Some participants felt that their needs were forgotten once they had stopped treatment. In light of these challenges, the participants' recommendations are outlined under objective five.

4.4.5. Objective Five: To examine the clients' recommendations pertaining to the improvement of the oncology social work service.

The participants' recommendations were asked for in relation to two areas; these were their reasons for recommending the service and their suggestions for improving the service.

4.4.5.1. Reasons for recommending the service

The majority of participants agreed that they would recommend the social work service to other patients. It was noted that some participants who did not engage with the social worker for more than two sessions strongly recommended the service in light of their experience of having cancer and the insights gained.

“Because it actually helps you recover faster. It builds your self-esteem and has a great impact on how you live with the disease. You find peace from speaking about everything” (Participant 1)

“Especially for cancer patients yes and I think having somebody at the hospital also at that time, because they are more understanding and they are comforting and they can

give you reassurance and if you have questions or uncertainties they are available more than the others... But she has an overall knowledge of what is going on there and I could have gone to her any time” (Participant 13)

Accordingly, Boulton et al’s (2001) findings indicate that 95% of their respondents would follow up with a support service if they needed further help and would also recommend the service to others. This finding was based on the perceived benefits of the service after having engaged with it.

4.4.5.2. The need for information about the social work service

Participants offered that in order to improve the service, more information is needed about the social work service as well as the support groups available to patients.

4.4.5.2.1. Clarifying the role of the social worker

The need to clarify the role of the social worker in oncology practice and the nature of the service was quite prominent amongst participants who perceived benefit of the service and those who encountered challenges. It was suggested that information leaflets or posters outlining this would be useful.

“Maybe just a little bit more information of what she does and how she can assist if you need help. Maybe to explain it the first time she sees a person, or have information leaflets or something like that. So that we can have more information about how she fits in to the private practice in oncology” (Participant 3)

“The oncologists could also reiterate the importance of the role of the social worker, during the initial stages of seeing a patient. To say, we have these facilities and we want you to make use of it. Perhaps schedule a fixed appointment with the patient to go and see that social worker, so that they really understand what it is... When the patient is slightly more clearly thinking, not when you have a break down in the reception area and you are supposed to remember what she said six months down the line” (Participant 15)

Patients are usually traumatised by the diagnosis of cancer and react by blocking out information until they are ready for it and health professionals play a crucial role in offering

help at the appropriate time (McCaughan & McKenna, 2007). The role of the oncologist is also highlighted in recognising the role of the social worker and the profession's unique contribution to addressing human problems; without this there could be an underutilisation of the service (Howard & Jenson, 1999; Lauria et al, 2012).

4.4.5.2.2. Referrals to Support Groups

The need for support within a group of other cancer patients was strongly highlighted by several participants. This finding included participants who felt that their information needs were met by the social worker.

“Also I feel like there was no-one to share with, so they need support groups there to share information with each other and support each other. Like information on managing side-effects” (Participant 14)

“I am not sure, just like those notices of support groups ... was it just women? Maybe I didn't feel comfortable sitting with a guy talking about how I feel losing my breasts. I needed that kind of interaction from a social worker to say we are running xyz, how would you feel about joining” (Participant 15)

The findings indicate the need for shared support and McCaughan and McKenna (2007) point out that cancer patients value the insights and experience of other cancer patients as it helps them make sense of their own disease; this lived experience is valued over the information that can be provided by healthcare professionals about diagnosis and treatment. Furthermore, support groups provide a space to share experiences about cancer related issues and enables patients to emotionally support one another through their fears and unknown futures (Weis, 2003). In assisting with the provision of a sub-system that allows for meaningful interaction, patients are able to access a resource that supports physical, intra-psyche and interpersonal solutions (Kihlstrom, 2011).

4.4.5.3. Early Intervention

This finding was not a criticism of the service, but rather a suggestion in terms of the participants' emotional needs while awaiting diagnosis and prior to treatment. Participants that spoke of the period between tests and diagnosis indicated a strong need for emotional support.

“In that three week period, or however long the waiting game is until you get your results, if it is suggested that in that period of time, come and see the social worker... that to me was the worst part of the whole thing, the waiting” (Participant 5)

“I think before anything, after you see the doctor, maybe before, even better, that you can see the social worker; and that before the chemo, that you can see a social worker. They must actually do a program, that you are a part of the program. Not just if you want to contact them, because people think they are okay” (Participant 8)

Manicom (2010) refers to the preliminary and diagnosis stages of the cancer journey, where patients undergo investigations and tests that create an awareness of the possibility of serious diagnosis and leads to the confrontation of their own mortality. During this time patients have to cope with overwhelming emotions as well as uncertainty and a sense of not being control (Manicom, 2010:59).

4.4.5.4. The need for Post-treatment Support

The participants that were interviewed post treatment indicated their need for supportive follow-up in terms of adjusting to life without the disease.

“All of a sudden it is over and then you kind of go through a phase where you have changed in so many ways, it is almost like an identity crisis in a way I think if it can be suggested to a patient to maybe come and see the social worker once a month or three months after treatment, just to integrate all those changes” (Participant 5)

“I am in a position where my treatment finished off in March, and I feel that I am in complete limbo in life, I am different. I am no longer the same person I used to be, so I am trying to adjust to the changes within me.... So I think support groups are important during the process and afterwards, especially afterwards” (Participant 15)

While this is a finding that often represents the minority of cancer patients that have undergone treatment, research has shown that symptoms of intrusive thoughts and avoidance within the first three months post treatment is predicative of ongoing stress related problems six years later (Philip et al, 2013). The post treatment stage is characterised by anxiety around

having less medical surveillance, possible withdrawal from family and friends and the adjustment to a 'new normal' once treatment is over (Manicom, 2010).

4.4.5.5. The need for the Social Worker to be more available

There was a need for the social worker to be more available to patients during working hours. The perception was that the social worker has a high caseload and the suggestion was employing more than one social worker in each practice.

“More availability through the day, 8am to 5pm” (Participant 1)

“I think though that they are overloaded with work... I think that if it is affordable, they could have more than one person. It seems that they are quite swamped” (Participant 7)

“Maybe more than one social worker for the amount of patients that there is, so that they are more available” (Participant 16)

This finding is based on the perception that the participants would have had more sessions if there was more than one social worker available. This recommendation is not uncommon in light of the fact that dissatisfaction with a supportive service often centres on the limited number of sessions (Boudioni et al, 2000).

A number of themes arose during the interviews that were not accounted for under the research objectives. This is presented under the additional data that emerged from data analysis.

4.4.6. Data that emerged from the interviews

The additional data that emerged from the interviews was the sense of camaraderie amongst cancer patients undergoing treatment and the supportive role of family members.

4.4.6.1. Camaraderie amongst Cancer patients

A common finding amongst participants was that they felt a sense of belonging amongst other cancer patients and valued the interaction with them during their chemotherapy treatment sessions.

“I have contact with people I met here, and got to know. They actually became my friends. Because I think that people, family and friends, that you know, they come to you and chat to you, and then they leave you. Definitely, it’s an isolating sickness. So these patients understand what is happening to me, they don’t leave” (Participant 2)

“I like the way they setup the chemo room; it was like in a little circle. So you had fellow patients opposite you and next to you. I could relate to their stories and then somehow you tell yourself, okay, it does not look so bad, it does not seem so bad. So, at least you have someone else going through it also, so you can exchange numbers” (Participant 9)

The supportive space between patients and their family members or treatment medical team differs from the relationship between cancer patients, where they can rely on one another for honesty and dialogue around shared experiences (McCaughan and McKenna, 2007). This is a tangible form of social support as it is considered a positive and powerful experience that creates a sense of belonging allowing for networking and getting to know others in similar situations (Evans et al, 2015).

4.4.6.2. The role of family as a supportive network

The majority of participants expressed their gratitude for the support of family and friends, and a few participants did not require regular follow up with the social worker because they felt supported enough by their family.

“I had incredible support from my family” (Participant 5)

“I will rather speak to my parents, to my family and friends, those type of people... We have a very strong relationship and support structure in our family” (Participant 10)

“I had very supportive family and friends, so I didn’t need the social worker as much” (Participant 11)

Research indicates that family relationships are often of primary importance to cancer patients as it helps them maintain a sense of purpose (Speice et al, 2000; McCaughan & McKenna, 2007). Family and social support act as mediating factors that contribute towards the adaption of a cancer diagnosis as family members provide meaningful support that

complements the skills of healthcare professionals (Speice et al, 2000; McCaugan & McKenna, 2007)

4.5. Conclusion

The findings illustrate participants' perceptions of the social work service offered at Cancercare practices. It was clear that these perceptions were based on individual experiences; however all responses indicated the need for psychosocial support and the value in having access to a support service. Positive experiences centred on the overall psychosocial care received at the practice. Some dissatisfaction was expressed and participants made useful recommendations concerning improvement of the service. The final chapter of the research discusses the conclusions and recommendations of the study.

CHAPTER FIVE

Conclusions and Recommendations

5.1. Introduction

The final chapter presents the conclusions and recommendations drawn from the findings of the study. The conclusions are discussed under each research objective. Recommendations are made in relation to improved practice and further research.

5.2. Conclusions

The conclusions are presented below:

5.2.1. Objective One: To explore the clients' reasons for seeing the oncology social worker

The participants either were informed of the social work service by a member of the treating team, most often the oncologist; or were directly contacted by the social workers after their first appointment at the practice. It was clear that the social workers were proactive in making direct contact with new patients.

A primary reason for seeing a social worker was to seek help for various psychosocial needs. The psychosocial effect of diagnosis and treatment was traumatic for all the participants; and the need for information centred on treatment and the related side-effects. Common feelings were that of fear, sadness, loneliness and isolation. These primary concerns were the emotional lives of loved ones, especially young children and the need for guidance and support in sharing the news of their diagnosis. Practical needs ranged from guide with finances and medical cover to employment challenges and the need to access disability benefits.

5.2.2. Objective Two: To determine the clients' expectations of the oncology social work service

There appeared to be some misunderstanding around the role of the social worker in comparison to that of a psychologist. The perception was that a psychologist addressed emotional needs whilst a social worker addressed more practical needs. Some participants

perceived that social workers arrange palliative care for patients without family support, removed children from families and assisted patients from poor socio-economic backgrounds. This initially deterred them from accessing the service and added to their confusion around the role of the social worker within a private oncology setting.

There was a need for professional individual support. Participants referred to the need for a trusting and non-judgemental relationship that encouraged them to share their honest experiences. They required a space that supported them in adjusting to their new reality and allowed for discussion that was not centred on their diagnosis. They expected a supportive space for the family members as well.

5.2.3. Objective Three: To determine the positive aspects of the oncology social work service

The accessibility of the social workers were seen as a positive factor especially when unexpected contact to enquire about their wellbeing was made. There was also specific reference to visits from the social workers in the chemotherapy room, and telephonic or email contact. This helped in demystifying the role of the social worker within the practice and for some marked the beginning of a supportive professional relationship. Where the social workers' displayed a caring and supportive demeanour, the social work service was more likely to be used; the confidentiality of the service was also an important factor in predicting their use of the service.

Participants found the sessions to be informative and they appreciated the social workers' insights as this helped to normalise their experiences and provide better understanding of the disease. It was helpful that a similar service was offered to family members as well. Participants were comforted by the multidisciplinary team approach as it each professional played a role in ensuring their overall wellbeing.

Participants appreciated the referral to the 'Look Good Feel Better Workshop' as this resource encouraged them to meet new people and normalised their experience. They also referred to the benefit of the therapeutic space as it encouraged posttraumatic growth.

5.2.4. Objective Four: To investigate the challenges clients experienced when engage with the oncology social work service.

Some participants that engaged with the service were still unsure about the social workers' scope of practice and felt that they did not utilise the service fully. While some felt that the social workers initiated regular follow up, others felt that the invitation was not extended beyond the initial contact stage. The findings were indicative of personal preference as some appreciated the contact during the chemotherapy sessions; whilst others felt that contact in a public setting was an invasion of their privacy.

There was a difference of opinion between the participants concerning the information received in the initial stages of diagnosis. While all participants found the social workers' provision of knowledge to be valuable, many struggled to process and retain the information. Participants also expected more information regarding the social work service and access to external resources.

Some participants had recently completed their treatment cycle and expressed disappointment that the social workers had not followed up with them since. Reference was made to post traumatic stress and the challenge in resuming life when treatment is complete. It was felt that more support is needed during that transition of the illness trajectory.

5.2.5. Objective Five: To examine the clients' recommendations pertaining to the improvement of the oncology social work service.

Participants would recommend the service to other patients based on their experience of the service, and their insights around the need for professional support. It was suggested that in hindsight, they would have better utilised the service if they had more information on the role of the social worker and the scope of practice. They requested that information leaflets and posters are made available and visible in that regard. There was a strong need for a support group that fosters connections and learning between patients. It was suggested that more staff capacity is needed in the practices; and there was a perception that the social workers carried high caseloads and therefore provided a condensed service.

There was a request for earlier intervention from the social worker between the period of medical testing and diagnosis. Post-treatment follow-up and support was highlighted alongside the challenge of adjusting to life after treatment and reintegration into society.

5.3. Data that emerged during the interviews

Participants described a sense of camaraderie and belonging amongst the other patients during their treatment sessions. It was a positive experience that affirmed the challenges they encounter during their cancer journey. A mediating factor, which contributed to their overall adaption to their journey, was the support of family members.

5.4. Recommendations

Recommendations are made to Cancercare and for future research in this field.

5.3.1. Recommendations for Cancercare

Information sessions

It is recommended that the social workers consider the timing in terms of providing information related to diagnosis, treatment and side-effects, and the nature of the service; taking into account the information needs verbalised by patients, as well as their current mental state. A pamphlet explaining the role of the social worker within oncology practice and the nature of the service could be handed to new patients at the end of their first session or included in the information pack they receive at reception.

Professional contact in a public setting

Treatment rooms and other public spaces should remain neutral environments and should only be used for making introductions; not for counselling sessions. Sessions should only be held in the social workers' offices.

Advertising to address public perception

Incorrect perceptions of the social work profession could be addressed by placing visible posters in the waiting and treatment rooms; outlining the scope of the social worker's practice within an oncology setting. The pamphlet explaining the social workers' role would assist with this as well.

An integrated family treatment model

It is encouraged that support groups are offered to family members as they are considered an important resource to the treating team. These support groups could be facilitated by the social workers and physician extenders within the practice. Patients should also be encouraged to bring a family member along to information sessions as this may assist with

the holding of the information. The recommendations derived from Speice et al (2000) suggest that routine family meetings should be incorporated into the treatment model of all multidisciplinary team members.

Support groups for patients

The inclusion of a patient support group that fosters learning from shared experiences serves as a tangible form of social support. This could be offered fortnightly, or once a month by the social workers. It need not be sourced within the practice, and may be outsourced by external professionals or organisations; however outsourcing may incur additional costs. If the latter option is considered, patients could be charged a fee for joining the support group.

Post-treatment support

Patients follow up at the practice at various stages during the first year post-treatment and have access to all members of the multidisciplinary team. In light of the challenges faced by patients during this stage; the social workers are encouraged to actively seek out these patients and offer support sessions within the first six months. A support group would also be valuable for patients during this transitional period.

Early intervention

The researcher acknowledges that patients are only referred to the practice once a patient is diagnosed with cancer. For this reason, the social work department is encouraged to consider intervention strategies and psychoeducational outreach initiatives that address the trauma experienced between medical testing and diagnosis. Further research could be undertaken by the department in this regard.

5.3.2. Recommendations for future research

Not much research has been found regarding the psychosocial needs of cancer patients in South Africa, and the influence of a psychosocial service. Further research would be valuable in determining if these needs are being met within the practices that offer psychosocial services. Future research could expand on this study with a larger number of participants from a number of privately run oncology practices, to determine if this multidisciplinary model of practice has a beneficial influence on cancer patients and should be included in the treatment model.

Circumstances and experiences leading to post-traumatic stress disorder or post-traumatic growth in patients diagnosed with cancer, are underrepresented in South African research. This type of research initiative would assist mental health practitioners in formulating intervention strategies that encourage post-traumatic growth.

There is also need for South African research on the needs of cancer patients post treatment and in the survivorship stage of the illness trajectory. This will aid in formulating psychosocial interventions that target this population specifically.

A comparison between a services that offers family intervention strategies against a service that does not, could highlight the value of including the family the treatment model.

5.4. Conclusion

Through the lenses of Psychosocial Oncology, Human Development and Systems theories, this study has explored the experiences of sixteen cancer patients who received a psychosocial service at three Cancer care practices. Their responses have indicated the value derived from the service as well as the challenges they have encountered. This has also served to provide insight into their psychosocial needs during their cancer journey. The conclusions reached by most participants, despite the challenges they encountered, was that they had benefited from the service and would recommend the service to others. Recommendations were provided to address these challenges as well for further research.

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APPENDIX A

PARTICIPANT INFORMATION AND CONSENT FORM:

Title of Dissertation: Clients' perceptions of the oncology social work service at Cancercare

Researcher: Tasneem Variawa

Contact No.: 084 892 8072

You are invited to take part in a research project at Cancercare. Please take some time to read the following information about this study. You are welcome to ask questions at any point. Please note that participation in this research is completely voluntary. If you agree to participate, you are still entitled to withdraw from the study at any point.

This study has been approved by the ethics committee of the University of Cape Town, as well as the Cancercare Research Committee.

What is this research about?

The aim of this study is to explore the experience and perceptions of the oncology social work services offered by the Cancercare group practices. The researcher is interested in the way in which patients have benefited from this service and recommendations that can lead to further development of the oncology social work services in South Africa.

Why have you been invited to participate?

You have used the oncology social work service within the last six months and therefore are an expert of your own experience.

What will be required of you?

The researcher will interview you about your experience of the oncology social work service. This interview should take about one hour of your time. All interviews will be recorded via a Dictaphone for transcription purposes only. These recordings will not be available to the practice or the oncology social workers.

The time and place of the interview will be determined by your convenience. Due to the personal nature of the interview, you may find that the interview covers sensitive topics. Should you feel uncomfortable with a question, you are under no obligation to answer it. If

the interview brings up difficult memories or emotions, debriefing and counselling will be offered to you by the oncology social workers at the CancerCare practices at no cost.

How will participating benefit you?

Participation may not have any direct benefit to you at this stage, but sharing your experience may lead to the development of the profession within the practice and an improved service for other patients and family members. You will not be paid for your participation.

What will happen if you withdraw from the study?

Choosing not to participate in the study will in no way jeopardise your relationship with your oncology social worker or medical treating team.

Who will have access to this information?

Confidentiality will be carefully protected and your name will not be mentioned in this study. The Dictaphone recording will only be heard by the researcher and an independent transcriber, who is bound by confidentiality.

How public will this research be?

As per the Master’s level dissertation procedure at the University of Cape Town, all studies are published on OpenAccess and therefore available to the general public. The findings of this study will also be shared with the CancerCare group practices.

INFORMED CONSENT OF PARTICIPANT:

I _____
agree to take part in this research study titled “Clients’ perceptions of the oncology social work service at CancerCare”.

I agree that:

- I have read all the information provided.
- I understand the information given and is written in a language that I understand
- I have been offered an opportunity to ask questions about this research study and my questions have been answered adequately.

- I understand that my participation is voluntary and I have not been forced or pressurised to participate.
- I understand that I can choose to withdraw from this study, or not answer any questions that make me feel uncomfortable. There will be no consequences or prejudice from the researcher.

Signed at: _____ on the _____ 2017.

Signature of participant

Signature of Witness

APPENDIX B

SEMI-STRUCTURED INTERVIEW SCHEDULE

Re-introduction of the researcher and the study – this includes a clarification around the purpose of the study and confidentiality. The participant will be asked to sign the consent form once it is explained and understood.

1. Demographics:

- How old are you?
- Where do you live?
- What is your marital status?
- What is your occupation?
- Are you currently employed?
- Tell me a bit about when your diagnosis was made?

2. Reasons for seeing the oncology social worker:

- Before seeing the social worker, did you see someone else for support?
- What were your reasons for seeing the social worker?
- How did you find out about the social work service?
- How did you feel about seeing a social worker?
- What were your expectations of the service?
- How long did you have to wait for an appointment?

3. The oncology social work service:

- How many sessions did you have with the social worker?
- On average, how long was each session?
- How did you find the sessions? What were they like?
- If you think about your relationship with the social worker, how would you describe it?

4. Positive aspects of the oncology social work service:

- Do you feel that you benefitted from the service?
- What did you find helpful about the service?

- Do you feel that you learnt anything new, something that you didn't already know? If so, what did you learn?
- Were you able to implement this knowledge into your life? How so?

5. Challenging aspects of the oncology social work service:

- Was there any aspect of the service that you did not find helpful?
- (If yes) What were these aspects?
- How did you deal with this?
- If you raised your concerns, was the feedback heard by the social worker?
- If not, looking back now, would you have dealt with it differently?

6. Recommendations:

- Would you recommend the service to others?
- (If yes), what would be your reasons for recommending the service? (If no) what would be your reasons for not recommending the service?
- If you could change anything about this service, what would you change?
- Is there anything that you would like to add that I have not asked?

The participants were thanked for their participation in the study and offered the option of debriefing with the researcher or an oncology social worker of their choosing.