

The social functioning of women with breast cancer:
a social work perspective

Mini-dissertation

Submitted for the partial fulfilment of the requirements for the degree

Master of Social Work in Health Care

MSW (Health Care)

by

Jonita van Wyk

in the

Department of Social Work and Criminology

Faculty of Humanities

University of Pretoria

Supervisor: Dr. C.L. Carbonatto

November 2013



DECLARATION OF ORIGINALITY

Full names of student: Jonita van Wyk

Student Number: 10598783

Topic of dissertation:

The social functioning of women with breast cancer: a social work perspective

Declaration:

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this **dissertation** is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

Signature

Date

Department of Social Work & Criminology
University of Pretoria
PRETORIA 0002
Republic of South Africa

Tel: Number 00 27 12 420 2325/2030
Fax: Number 00 27 12 420 2093

www.up.ac.za

ACKNOWLEDGEMENTS

First and foremost I want to express gratitude to God for His guidance and love that supports me throughout.

Thank you to my family for their support, especially my mother who is a breast cancer survivor and a continual source of inspiration.

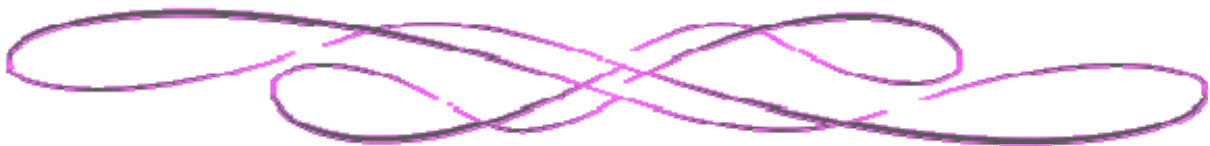
I want to express my appreciation for all my friends who have always motivated and supported me.

Dr. Susan Humpel, thank you for your guidance, support and especially for keeping me motivated and focused.

To all the participants of this study: it was a blessing to be a witness to your lives and I am inspired by your strength and grace.

Thank you to CANSA Potchefstroom, especially Sister Minne, for the opportunity to conduct this research study and the support throughout.

Lastly I want to express my gratitude to my supervisor, Dr C.L. Carbonatto, for the guidance and patience throughout this process.



ABSTRACT

Title: The social functioning of women with breast cancer: a social work perspective

Candidate name: Jonita van Wyk

Department: Social Work and Criminology

Degree: MSW (Health Care)

Supervisor: Dr. C.L. Carbonatto

Breast cancer is the most common form of cancer in women worldwide with one in 29 women diagnosed with breast cancer each year in South Africa (CANSAs, 2010). Breast cancer diagnosis and treatment can impact important areas of a woman's life: her relationship with herself as an individual and woman; her relationship with family members as a mother, wife, daughter and caregiver; her relationship with the environment as community member and career woman and her relationship with her religion and spiritual deity. In the reality of a woman with breast cancer, there are certain roles that arise from her relationship with herself and the world around her. This is related to with social functioning which is the fulfilment of an individual's roles, that are created by the individual's interactions with his/her own self, family, society and environment.

The diagnosis of breast cancer is marked by mixed emotions from the patient, including shock, denial and anxiety. Cancer treatment includes surgical intervention such as biopsy, lumpectomy and mastectomy; chemotherapy; radiation therapy and hormone therapy. The various cancer treatments have different side effects that the patient needs to cope with and adjust to. Breast cancer has an adverse effect on women and can influence social functioning in different ways during the phases of diagnosis, treatment and recovery.

This study focuses on breast cancer's influence on the social functioning of women. The goal of this study was: to explore the social functioning of women with breast cancer. The research question that guided this study is: how does breast cancer affect the social functioning of women?

A qualitative research approach was followed with a collective case study research design. The population for this study was women who have been diagnosed with breast cancer and are clients of CANSA Potchefstroom. In this study non-probability, purposive sampling was used to generate a sample.

Eight participants who were diagnosed with breast cancer were selected for this study. Semi-structured individual interviews were conducted with participants. Interviews were voice recorded with the permission of the participants and were transcribed by a contracted professional transcriber. The data were analysed by the researcher and themes and sub-themes were identified. The research findings are presented by providing a profile of the research participants and presenting the thematic analysis of the themes and sub-themes. In support of the findings a literature review and verbatim quotes from the transcriptions are given. The themes include the following: Theme One – Understanding cancer; Theme Two – Social functioning of women with breast cancer within the context of their life world; Theme Three - Social functioning of women with breast cancer within the context of their family and Theme Four - Social functioning of women with breast cancer within the context of their community.

The conclusions of this study indicate that breast cancer affects the social functioning of women in different areas of their lives. These women experienced changes in their personalities, spiritual aspects, physical abilities and roles. The family and community are supportive towards patients with breast cancer and this assists the woman diagnosed with breast cancer to cope.

The recommendations offered by this study can be used by professionals working with women who are diagnosed with breast cancer, to understand the influence of breast cancer on the social functioning of women and to assist social workers in their intervention with these women.

OPSOMMING

Titel: Die maatskaplike funksionering van vroue met borskanker: 'n maatskaplike werk perspektief

Naam van kandidaat: Jonita van Wyk

Departement: Departement Maatskaplike Werk en Krimonologie

Graad: MMW (Gesondheidsorg)

Studieleier: Dr. C.L. Carbonatto

Borskanker is die algemeenste kanker onder vroue wêreldwyd, een uit elke 29 vroue word elke jaar daarmee gediagnoseer in Suid Afrika (CANSA, 2010). Die diagnose en behandeling van borskanker kan 'n uitwerking hê op vele belangrike dele van 'n vrou se lewe: die vrou se verhouding met haarself as vrou en individu; haar verhouding met familieledede, as moeder, eggenote, dogter en versorger; haar verhouding met die omgewing as lid van die gemeenskap en as werknemer asook haar verhouding met God en geloof. In die leefwêreld van 'n vrou met borskanker kom daar sekere rolle na vore uit die verhouding wat sy met haarself en haar wêreld het. Die rolle hou verband met maatskaplike funksionering wat die vervulling van individuele rolle behels en ontstaan as gevolg van die individu se interaksie met hom/haarself, familie, die samelewing en die omgewing.

Die diagnose van borskanker word gekenmerk deur 'n pasiënt se gemengde gevoelens wat skok, ontkenning en angs insluit. Die behandeling van kanker sluit chirurgiese ingryping in soos biopsie, lumpektomie en mastektomie; asook chemoterapie; bestraling en hormoonterapie. Die verskillende behandelings het verskeie nuwe-effekte waarmee die pasiënt moet saamleef en by aanpas. Borskanker het 'n negatiewe uitwerking op vroue en kan maatskaplike funksionering op verskillende maniere beïnvloed gedurende al die fases, van diagnose na behandeling tot en met herstel.

Hierdie studie fokus op die invloed van borskanker op die maatskaplike funksionering van vroue. Die doel van hierdie studie is om die maatskaplike funksionering van vroue met borskanker, te ondersoek. Die navorsingsvraag wat die

studie gelei het is: hoe beïnvloed borskanker die maatskaplike funksionering van vroue?

‘n Kwalitatiewe benadering en kollektiewe gevallestudie navorsingsontwerp is gevolg. Die populasie vir die studie was vroue wat met borskanker gediagnoseer is en wat kliënte van KANSA Potchefstroom is. ‘n Nie-waarskynlikheids, doelgerigte steekproefmetode is gebruik om die steekproef vir die studie te genereer.

Agt deelnemers wat met borskanker gediagnoseer is, is gekies om deel te neem aan die studie. Semi-gestruktureerde individuele onderhoude is met die deelnemers gevoer. Die onderhoude is op band opgeneem en getranskribeer deur ‘n gekontrakteerde professionele transkribeerder. Die data is deur die navorser geanaliseer en temas en subtemas is geïdentifiseer. Die navorsingsbevindinge word voorgelê in ‘n profiel van die deelnemers met ‘n tematiese analise van die temas en subtemas. Ter ondersteuning van die bevindinge word ‘n literatuur oorsig en woord-vir-woord aanhalings van die transkripsies aangebied. Die temas sluit die volgende in: Tema Een – Verstaan Kanker; Tema Twee – Maatskaplike funksionering van vroue met borskanker in die konteks van hulle lewêreld; Tema Drie – Maatskaplike funksionering van vroue met borskanker in die konteks van hulle familie; Tema Vier – Maatskaplike funksionering van vroue met borskanker in die konteks van hulle gemeenskap.

Die gevolgtrekkings van die studie dui daarop dat borskanker die maatskaplike funksionering van vroue in verskeie areas van hulle lewens beïnvloed. Die vroue het veranderinge in hulle persoonlikhede, spirituele aspekte, fisiese vermoëns en rolle ervaar. Die familie en gemeenskap ondersteun pasiënte met borskanker en dit help die vroue wat met borskanker gediagnoseer is om dit te hanteer.

Die aanbevelings wat die studie bied kan deur professionele mense, wat met vroue werk wat met borskanker gediagnoseer is, gebruik word. Sodoende kan die invloed van borskanker op die maatskaplike funksionering van hierdie vroue beter te verstaan word. Die aanbevelings kan ook van nut wees vir maatskaplike werkers in hulle ingryping met hierdie vroue.

LIST OF KEY TERMS

CANCER

BREAST CANCER

WOMEN

SOCIAL FUNCTIONING

ROLE

ROLE THEORY

PSYCHO-ONCOLOGY

SOCIAL WORK IN HEALTH CARE

LYS VAN SLEUTELWOORDE

KANKER

BORSKANKER

VROUE

MAATSKAPLIKE FUNKSIONERING

ROL

ROL TEORIE

PSIGO-ONKOLOGIE

MAATSKAPLIKE WERK IN GESONDHEIDSORG

TABLE OF CONTENTS

DECLARATION OF ORIGINALITY	ii
ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
OPSOMMING	vi
LIST OF KEY TERMS	viii
LYS VAN SLEUTELWOORDE.....	viii
TABLE OF CONTENTS	ix
LIST OF TABLES	xiii
LIST OF DIAGRAMS.....	xiii
LIST OF APPENDICES.....	xiv

Chapter 1: Introduction1

1. Introduction	1
2. Literature review	2
3. Theoretical framework	3
4. Rational and problem statement.....	4
5. Goal and objectives of the study.....	5
6. Research question.....	5
7. Research Methodology	6
8. Ethical Issues	6
9. Definition of key concepts.....	7
10. Limitations of the study.....	9
11. Contents of research report.....	11

Chapter 2: Literature review.....12

1. Introduction	12
2. Medical terms	12
3. Definition of key concepts.....	15
4. Theoretical foundation – Role theory.....	16
5. Cancer	20
5.1 Breast Cancer	23

6. Cancer Treatment.....	28
6.1 Surgical	29
6.2 Radiation therapy	31
6.3 Chemotherapy	32
6.4 Hormone therapy	34
6.5 HER2 over-expression	35
7. Reaction to Cancer	35
7.1 Diagnosis	35
7.2 Treatment.....	36
7.3 Survivorship	38
7.4 Recurrence	39
7.5 End of life	39
8. Gender role.....	41
9. Social functioning.....	42
10. Social work in oncology	48
11. Summary	49

Chapter 3: Empirical Findings51

1. Introduction	51
2. Research methodology	52
2.1 Research approach	52
2.2 Type of research	52
3. Research methods.....	53
3.1 Research design	53
3.2 Population, sample and sampling method	53
3.2.1 <i>Population</i>	53
3.2.2 <i>Sampling method and technique</i>	53
3.2.3 <i>Sample</i>	54
3.3 Data collection method.....	54
3.4 Methods of data analysis	55
3.4.1 Steps in data analysis.....	56
3.4.2 Trustworthiness	57
4. Ethical issues.....	58

5. Research findings	60
5.1 Profile of participants.....	60
5.2 Themes and sub-themes	61
5.2.1 Theme 1: Cancer	62
5.2.2 Theme 2: Social functioning in the context of life world	69
5.2.3 Theme 3: Social functioning in the context of family	73
5.2.4 Theme 4: Social functioning in the context of community	81
5.3 Issues raised by participants that were not covered in themes	85
6. Summary	88

Chapter 4: Summary, Conclusions and Recommendations90

1. Introduction	90
2. Summary	90
2.1 The objectives of the study	90
2.1.1 Objective 1: To conceptualise the phenomenon of breast cancer, including diagnosis, treatment and recovery and aspects of the social functioning of women from the theoretical framework of role theory	90
2.1.2 Objective 2: To explore how breast cancer affects the functioning of a woman as an individual, mother and wife	91
2.1.3 Objective 3: To explore how breast cancer affects the functioning of a woman as a member of the community	91
2.1.4 Objective 4: To provide guidelines for social work practice with female breast cancer patients for health care social workers	92
2.2 The goal of the study.....	92
2.3 The research question	93
3. Conclusions	95
3.1 Theme 1: Cancer	95
3.2 Theme 2: Social functioning in the context of life world.....	97
3.3 Theme 3: Social functioning in the context of family	99
3.4 Theme 4: Social functioning in the context of community	101
4. Recommendations.....	102
4.1 Recommendations for practice	102
4.2 Recommendations for research	104
4.3 Recommendations according to themes.....	104

Closing statement.....	105
Reference List	106
Appendix 1: Ethical approval letter	120
Appendix 2: Permission letter from CANSA	121
Appendix 3: Interview schedule.....	122
Appendix 4: Letter of informed consent.....	124
Appendix 5: Declaration of language editing	127

LIST OF TABLES

Table 1: Breast cancer staging.....	28
Table 2: Demographic of participants.....	60
Table 3: Diagnosis and treatment options.....	61
Table 4: Themes and sub-themes of research.....	62; 94

LIST OF DIAGRAMS

Diagram 1: Tumour staging of breast cancer.....	25
Diagram 2: TNM staging.....	26
Diagram 3: Hormone drug side effects.....	35
Diagram 4: Five stages of dying.....	40
Diagram 5: Social functioning measuring tool developed by Tulman and Fawcett (2007:208).....	43
Diagram 6: Unhealthy stress symptoms experienced by breast cancer patients.....	46

LIST OF APPENDICES

Appendix 1: Ethical approval letter

Appendix 2: Permission letter from CANSA

Appendix 3: Interview schedule

Appendix 4: Letter of informed consent

Appendix 5: Declaration of language editing

Chapter 1

Introduction

1. Introduction

Social work practice is focused on the improvement or restoration of social functioning of individuals, families, groups and communities (Barker, 2003:408). Social functioning is a term used in social work practice and should not be confused with a term used by other professions. Social functioning from a social work perspective means the fulfilment of an individual's roles which originate as a result of the individual's interactions with his/her own self, family, society and environment (Barker, 2003:403; *New Social Work Dictionary*, 1995:58). Health care social work practice focuses on the social functioning of individuals, families, groups and communities afflicted by illness or disability.

Ross and Deverell (2004:36) explain that disabling illnesses cause strong emotional reactions in the patient as well as the family. DuBois and Miley (2005:316) cite Bracht in his explanation that illness disrupts an individual's equilibrium and capacity to cope. Disequilibrium is the lack of emotional stability in an organism (James, 2008:41) that can cause ineffective social functioning in individual and family life. Many illnesses, whether acute or chronic, can cause disequilibrium, but chronic illnesses can affect the individual in different ways throughout the duration of his/her lifetime. Chronic illnesses may include hypertension, diabetes mellitus, HIV and cancer. For the purpose of this study, the focus is on cancer, particularly breast cancer and how it affects women's social functioning.

The life world of women who have been diagnosed with breast cancer underlines the need for research in social functioning. Social functioning refers to the personal and societal expectations made of an individual and the individual's role performance at all levels and in interaction with others (Barker, 2003:403; *New Dictionary of Social Work*, 1995:58). Thus the focus in this study is on how breast cancer affects the social functioning of women.

During discussions with Dr Blaauw (2012), Oncologist at Wilmed Park Oncology, Klerksdorp, Ms Minne (2011), professional nurse at CANSA, Potchefstroom and Dr

Malan (2012) a practicing health care social worker, it was confirmed that breast cancer affects women's social functioning. What was unclear is the detail of how breast cancer affects women's roles, behaviour and the expectations that accompany those roles. It is, however, clear that these women need specific interventions and that most social workers lack knowledge and experience in this regard. Thus research on this topic will fill the gap that exists in this field.

2. Literature review

Cancer is a term for a group of diseases that arises when body cells divide abnormally and without control, killing normal cells. These cells invade surrounding tissue causing abnormal growth called a tumour, which and can spread to adjacent or distant organs causing secondary tumours (*Oxford Concise Medical Dictionary*, 2010:109; *Cambridge Advanced Learner's Dictionary*, 2010; Ross & Deverell, 2004:116). Breast cancer is the most common form of cancer found in women, it develops from the cells of one or both breasts and can spread to adjacent lymph nodes and other organs (Ehrlich & Schroeder, 2009:178; *Oxford Concise Medical Dictionary*, 2010:109).

According to the World Health Organization (2013a), breast cancer is the leading cancer amongst women worldwide, with 460 000 in 2008. In 2004, 20% of all cancer diagnoses in women in South Africa were breast cancer (National Cancer Registry, 2004). One in 29 women is diagnosed with breast cancer each year in South Africa (CANSAs, 2010). The risk for developing breast cancer can be further demarcated according race as African women have a one in 81 risk, white women have a one in 13 risk and Indian women have a one in 21 risk (Vorobiof, Sitas & Vorobiof, 2001:125). From these statistics, it is evident that the risk for breast cancer is high among South African women and this makes the rendering of services to this population essential.

Much research that focuses on different aspects of women and breast cancer from various perspectives has been done, but little research done from a social work point of view. Kralik, Brown and Kock (2001:594-602) focus on the experience of women who are diagnosed with a long-term illness, while Hirschman and Bourjolly (2005:17-32) discuss how support influences the experience of breast cancer. Research in the field of oncology nursing focuses on the changes in the mothers' roles (Fitch,

Bunston & Elliot, 1999:58-63) while psychiatric research focuses on breast cancer in young families (Forrest, Plumb, Ziebland & Stein, 2009:96-103). Most research is done from nursing, psychological or psychiatric perspectives and in the context of non-African countries. There is a gap in the research that has been done, specifically to the South African context and from a social work perspective, which this study strives to address this gap. Breast cancer is discussed in detail in chapter two.

3. Theoretical framework

The concept of “role” is central to the definition of social functioning because it is key to the approach of defining the person and social environments (Ashford & LeCroy, 2010:29). The term “role” comes from Shakespeare’s statement that all people are playing roles and that people’s behaviour is determined the parts they play in life (Diekman, 2007:762; Franks, 2007:3945). Role theory entails that there is a set of social expectations associated with certain roles and people internalize and assume these role expectations (Kimberley & Osmond, 2011:415). Role theory examines how roles affect the behaviour, attitudes, cognition and social interactions of a person occupying one or more roles (Diekman, 2007:763). Kimberley and Osmond (2001:418) believe that physical health problems should be considered because they could influence changes in role functioning and social responsibilities that are associated with these. Role theory can be used to assess the way in which breast cancer affects the social functioning of women.

Luoma and Hakamies-Blomqvist (2004:732) explain that women’s ability to perform routine activities is affected and it often happens that the woman’s role changes from that of a caregiver to a dependant. Furthermore, they explain that women with breast cancer are unable to continue employment, as they are on sick leave for long periods or they may even need to retire from the workforce completely (Luoma & Hakamies-Blomqvist, 2004:733). These changes influence women’s relationships and the ability to fulfil their roles. The medical treatments of cancer can have negative side effects that add stress to the lives of women and their family and friends (Brannon & Feist, 2010:270).

To be able to address the issue of social functioning and equip individuals and families to cope with breast cancer, there needs to be a thorough understanding of

the influence of breast cancer on social functioning through role theory. The role theory is discussed in detail in chapter two.

4. Rational and problem statement

Breast cancer, as a long term illness, profoundly influences women's lives and causes strain on the family roles and relationships (Ross & Deverell, 2004:15). Kreitler (2003:326) states that patients associate cancer with physical and psychological distress that affect important areas of a person's life and last for long periods of time. Consequently, the focus of this study will be on the social functioning of women with breast cancer, so that future interventions by social work professionals can be specifically developed to address their needs.

Social functioning encompasses the fulfilment of roles. Within the reality of a woman with breast cancer, there are certain roles that arise from her relationship with herself and the world around her. These include her relationship with herself as an individual and woman; her relationship with family members as mother, wife, daughter and caregiver; her relationship with the environment as community member and career woman and her relationship with her religion and spiritual deity. All of these connections form part of a woman's social functioning and could be affected by breast cancer. A study done by Luoma and Hakamies-Blomqvist (2004:733) shows that women receiving treatment for breast cancer feel that they cannot fulfil their roles as they used to. It is, however, unclear how breast cancer affects the women's "role performance in its entirety at all levels of existence in interaction with other individuals, families, groups, communities and situations" (*New Dictionary of Social Work*, 1995:58).

Breast cancer has an adverse effect on women and can influence social functioning in different ways during the phases of diagnosis, treatment and recovery. The effects of breast cancer include coping with side-effects; dealing with changes in self-concept; stress and adjustment reactions; managing others' unhelpful beliefs, expectation; emotions and issues with survival and growth (Beatty, Oxland, Koczwara & Wade, 2008:335). Breast cancer affects a woman as a person in her entirety. Consequently it affects women's social functioning which in turn affects her family, the environment and society as a whole.

These aspects have not been researched in their entirety, from a social work perspective. As a result, the effect on the women's social functioning and role changes as a result of breast cancer and breast cancer treatment are unclear. This study contributes to the understanding of the social functioning of women with breast cancer, in order to render effective intervention services to these women and their families.

5. Goal and objectives of the study

The goal of the study is:

To explore the social functioning of women with breast cancer.

To attain the goal of the research study, the following objectives are pursued:

- ❖ To conceptualise the phenomenon of breast cancer, including diagnosis, treatment and recovery and aspects of social functioning of women from the theoretical framework of role theory.
- ❖ To explore how breast cancer affects the functioning of a woman as an individual, mother and wife.
- ❖ To explore how breast cancer affects the functioning of a woman as a member of the community.
- ❖ To provide guidelines for health care social workers regarding social work practice with female breast cancer patients.

6. Research question

Todres (2005:108) describes the research question as a “life-world-evoking question” where the experience of a life world is described as richly as possible. In the context of this study, the following research question is asked:

How does breast cancer affect the social functioning of women?

This question can be demarcated into three specific areas:

- ❖ the social functioning of a woman with breast cancer, within the context of her life world;

- ❖ the social functioning of a woman with breast cancer, within the context of her family; and
- ❖ the social functioning of a woman with breast cancer, within the context of her community and environment.

7. Research Methodology

A qualitative research approach was followed to investigate the social functioning of women with breast cancer. A case study research design was followed in order to discover the meaning that people assign to a social phenomenon. More specifically, the collective case study research design was used so that the different cases could be compared with each other to identify similarities and differences between them.

The population focused on women who were diagnosed with breast cancer, receiving treatment and are clients of CANSA Potchefstroom. Non-probability, purposive sampling was chosen to sample women from the CANSA Potchefstroom database. Ten participants were selected for the pilot testing and main research.

Face-to-face, semi structured interviews were used to collect data from participants. This gives the opportunity for the interview to move into new directions. The interview schedule had themes that focused on different aspects of social functioning. The interviews were transcribed and data analysed. Similarities and differences were found and are discussed fully in chapter three. The research methodology is discussed in detail in chapter three as well.

8. Ethical Issues

Certain ethical issues were considered during the research project. Informed consent was obtained through signed informed consent forms that described the research and served to prepare the participants. Participants were informed that the research is voluntary and that they are free to terminate the interview at any point during the research process. Confidentiality was maintained through keeping participants names private and assigning numbers to each participant during the research study. Debriefing was done with all participants that were part of the research to ensure that no harm was done. Avoidance of harm was very important throughout the research

process and the researcher was attentive to the emotions of the participants. Methods of dealing with possible emotional harm was planned beforehand and followed through after research was completed. These ethical considerations are discussed in-depth in chapter three.

9. Definition of key concepts

Breast Cancer

“A malignant tumour of the breast, usually a carcinoma” (*Oxford Concise Medical Dictionary*, 2010:97).

“[Breast cancer] is a carcinoma that develops from the cells of the breast and can spread to adjacent lymph nodes and other body sites” (Ehrlich & Schroeder, 2009:178)

From these definitions it is clear that breast cancer is a tumour that develops from cells in the breast and can spread to the rest of the body.

Cancer

“Any of a number of diseases that include malignant tumours with the capability of growing and invading surrounding tissue” (*Medical Dictionary for Allied Health*, 2008:56).

“It arises from the abnormal, purposeless and uncontrolled division of cells that then invade and destroy surrounding tissues” (*Oxford Concise Medical Dictionary*, 2010:109).

Cancer can be seen as a life-threatening disease that is caused by uncontrolled growth of cells that invade and destroy other body tissues.

Medical Social Work/ Social Work in Health Care

Medical social work is defined as the social work practice within the health care setting that aids ill patients and their families to resolve social and psychological problems associated with their illness (Barker, 2003:266-267).

Social work in health care is social work interventions focus specifically on patients and families affected by illness.

Psycho-oncology

Psycho-oncology addresses the psychological, social and spiritual needs of individuals and families affected by cancer (Werner-Lin & Biank, 2006:507).

Psycho-oncology is a discipline that focuses on the effects of oncology on patients and their families.

Role

A role is a culturally determined pattern of social behaviour and conduct expected of a person in a specified and designated interpersonal social relationship (Zastrow & Kirst-Ashman, 2004:5; Zastrow & Kirst-Ashman, 2013:23).

A role is the expected behaviour of an individual.

Role theory

Role theory stipulates that in everyday life, people occupy particular social positions that lead to expectations for them to behave in a certain way or fulfil a certain role (DeLamater & Myers, 2011:7; Hindin, 2007:3951).

Role theory believes that people portray certain roles in their life which is expected of them by society.

Social Functioning

“Individuals role performance in its entirety at all levels of existence in interaction with other individuals, families, groups, communities and situations” (*New Dictionary of Social Work*, 1995:58).

“Living up to the expectations that are made of an individual by the person’s own self, by the immediate social environment and by society at large” (Barker, 2003:403).

Social functioning for the purpose of this study is the fulfilment of an individual's roles that are created by the individuals interactions with his/her own self, family, society and environment.

Woman

“An adult female person” (*Merriam Webster Dictionary*, 2013).

“Distinctively feminine nature” (*Merriam Webster Dictionary*, 2013).

For the purpose of this study, the term woman refers a female person with unique roles to fulfil within herself, her family and her community.

10. Limitations of the study

The study experienced limitations due to the nature of the research. Firstly, the sampling of participants did not occur as planned. CANSA Potchefstroom experienced a decrease in the number of breast cancer patients during the time that sampling for the research project took place. Only 13 women were diagnosed and were receiving services at CANSA Potchefstroom. Of these 13 women, one was not interested and two of the contact numbers provided were incorrect. The remaining 10 women volunteered to participate in the research. Two participants were then used for the pilot study and a sample of eight participants for the main study. The original sampling criteria were as follows:

- ❖ Between the ages of 30-50 years
- ❖ Married or in a relationship
- ❖ Must have dependent children
- ❖ Diagnosed with breast cancer
- ❖ Currently undergoing chemotherapy for the disease
- ❖ Residing in the Potchefstroom magisterial district, which includes Potchefstroom, Fochville and Ventersdorp
- ❖ Currently part of the client system of CANSA Potchefstroom

This criteria was then changed to the following so as to get sufficient participants for the study:

- ❖ Between the ages of 30-70
- ❖ Diagnosed with breast cancer
- ❖ Currently or recently undergone either surgical, radiation or chemotherapy for breast cancer
- ❖ Residing in Potchefstroom

Due to the change in criteria, some of the sub-themes could not be explored as originally planned. This includes the sub-theme of the role as mother because most of the children were adults living on their own. The role as wife could not be fully explored either because only five women were married, one was in a relationship, one was single and one divorced. The sub-theme of the role as daughter could not be explored fully because most of the women's' mothers were either deceased or ill. The employment sub-theme was not fully explored because only half of the women were employed.

Due to the limited number of clients at CANSA Potchefstroom, the pilot study consisted of two participants and the main study consisted of only eight participants, two less than was planned for during the research proposal phase. All the participants were white and that provided the study with a homogeneous group that lacked cultural diversity.

All participants did not receive the same treatment for breast cancer and not all participants had the same stage of breast cancer. The different treatment options cause different side effects and different levels of intensity experienced in terms of the side effects. Some participants' had stage I breast cancer while others had metastasised breast cancer which means that their prognosis is worse. This resulted in the views of the sample to differ as it was based on their different prognoses. Due to the qualitative nature of the research and small sample, the results of this study cannot be generalised or transferred. The results from this study are the personal views of this sample and their descriptive experiences.

11. Contents of research report

Chapter 1: General background

This section will introduce the research methodology that will be utilised during the course of the research project. It includes the problem formulation, the goals and objectives, research approach, the type of research, research design, sampling, data collection and analysis and the ethical considerations.

Chapter 2: Literature review

An in-depth literature review that discusses the phenomenon of breast cancer, the theoretical framework of role theory and the social functioning of women.

Chapter 3: Empirical findings

The empirical chapter commences with an overview of the research methods applied. The research findings will include: the results from the interviews as well as an analysis of the themes identified. This section will be divided into three sections:

- ❖ Social functioning of women in the context of the individual
- ❖ Social functioning of women in the context of the family
- ❖ Social functioning of women in the context of the community

Narratives from the interviews and literature are used to substantiate the findings.

Chapter 4: Conclusions and recommendations

A summary is made, which includes how the goal and objectives were met. Conclusions are drawn and recommendations made for the benefit of social work in oncology.

The following chapter will focus on the literature review.

Chapter 2

Literature review

1. Introduction

This section conceptualises the phenomenon of breast cancer, including diagnosis, treatment and recovery and aspects of the social functioning of women from the theoretical framework of role theory. This will include definitions of medical terms and key concepts in order to assist in the understanding of terminology used throughout this section.

Cancer is conceptualised and the discussion includes the development of cancer, the diagnostic process, prognosis and the development of a treatment plan. Specifically the focus will be given to breast cancer including the genetic foundation of breast cancer and staging process. Treatment of breast cancer includes surgical intervention, radiation therapy, chemotherapy and hormone therapy. Even though cancer in itself can cause serious and life altering symptoms, the treatment of cancer also has side effects that can be unpleasant and affect the quality of life of a person. When considering the implications of cancer and cancer treatment on a patient and family, there are different reactions to diagnosis, treatment, recurrence and end of life issues which will be discussed.

The theoretical foundation from where cancer and treatment are assessed include the gender role of women in South Africa, the meaning of social functioning from a social work perspective, social work within the oncology field and most importantly, role theory as a theoretical foundation.

2. Medical terms

Axillary lymph nodes

“Lymph nodes located in the armpit” (*Medical Dictionary for Allied Health*, 2008:35).

CT scan

“A form of x-ray examination in which the x-ray source and detector rotate around the object to be scanned and the information obtained can be used to produce cross-

sectional images by a computer. A higher radiation dose is received by the patient than with some conventional x-ray techniques, but the diagnostic information obtained is far greater and should outweigh the increased risk” (*Oxford Concise Medical Dictionary*, 2010:161).

DNA

“...abbreviation for deoxyribonucleic acid.” (*Medical Dictionary for Allied Health*, 2008:100).

“The genetic material of nearly all living organism, which controls heredity and is located in the cell nucleus” (*Oxford Concise Medical Dictionary*, 2010:218).

Histology

“The study of the microscopic structure and function of bodily tissues, work often done by pathologists” (*Medical Dictionary for Allied Health*, 2008:162).

Lymph

“The fluid present within the vessels of the lymphatic system. It consists of the fluid that bathes the tissues, which is derived from the blood and is drained by the lymphatic vessels. Lymph passes through a series of filters and is ultimately returned to the bloodstream via the thoracic duct. It is similar in composition to plasma but contains less protein and some cells mainly lymphocytes” (*Oxford Concise Medical Dictionary*, 2010:429).

Lymph node

“One of the small, roundish bodies of lymphatic tissue that lie along the lymphatic vessels and are the primary producers of lymphocytes” (*Medical Dictionary for Allied Health*, 2008:207).

Lymphoedema

“Swelling resulting from the accumulation of lymph in the tissues”. (*Medical Dictionary for Allied Health*, 2008:207).

MRI scan

“A non-invasive diagnostic technique used to generate computerised images of internal body tissues and organs while the patient lies inside a large magnetic tube; images are obtained through the use of a scanner that relies on magnetism and the application of radio waves to create an image” (*Medical Dictionary for Allied Health*, 2008:210).

Sentinel node

“The first lymph node to show evidence of metastasis of a malignant tumour via the lymphatic system. Absence of cancer cells in the sentinel node indicates that more distal lymph nodes will also be free of metastasis. In breast cancer, the change in practice to perform axillary lymph node dissection only if the sentinel node contains metastatic tumour has reduced the risk of arm lymphoedema” (*Oxford Concise Medical Dictionary*, 2010:665).

Sonography (ultrasound)

“The use of ultrasound to produce images of structures in the human body. The ultrasound probe sends out a short pulse of high-frequency sound and detects the reflected waves occurring at interfaces within the organs. The direction of the pulse can then be moved across the area of interest with each pulse to build up a complete image” (*Oxford Concise Medical Dictionary*, 2010:758).

X-Ray

“High-energy electromagnetic radiation that can penetrate most substances; the rays can be used in low doses to create radiographic images of the internal organs and structures of the body for diagnosing diseases and checking the integrity of the skeletal system; the rays can also be used in higher doses to destroy diseased tissues as a treatment of cancer” (*Medical Dictionary for Allied Health*, 2008:392).

3. Definition of key concepts

Cancer

Any of a number of diseases that include malignant tumours with the capability of growing and invading surrounding tissue (*Medical Dictionary for Allied Health*, 2008:56).

Breast cancer

“A malignant tumour of the breast, usually a carcinoma” (*Oxford Concise Medical Dictionary*, 2010:97).

Treatment

“Process of providing medical, surgical, alternative or psychological care for a disease or disorder or the care itself” (*Medical Dictionary for Allied Health*, 2008:363).

Roles

A role is a culturally determined pattern of social behaviour and conduct expected of a person in a specified and designated interpersonal social relationship (Zastrow & Kirst-Ashman, 2004:5; Zastrow & Kirst-Ashman, 2013:23).

Psychosocial

“Pertaining to both psychological and social aspects of behaviour” (*Medical Dictionary for Allied Health*, 2008:298).

Social functioning

Social functioning from a social work perspective means the fulfilment of an individual's roles that result from the individual's interactions with his/her own self, family, society and environment in order to perform tasks essential for daily living (Ashford & LeCroy, 2010:29; Barker, 2003:403; *New Social Work Dictionary*, 1995:58).

4. Theoretical foundation – Role theory

Role theory was developed in the 1930's by social scientists that compared social life to theatre. There were three independent contributors to role theory, each with their own agenda (Biddle, 1992:1681). Ralph Linton used role theory as a way to analyse social systems and status. George Herbert Mead saw roles as coping mechanisms. Jacob Moreno believed roles were harmful tactics adopted to imitate behaviour in order to learn new roles (Biddle, 1992:1681-1682).

Lang (1992:1676) explains that role theory was developed as a way to explain an individual's subjective experience of objective role forces.

Role theory stipulates that in everyday life, people occupy particular social positions that require them to behave in a certain way or fulfil a certain role (DeLamater & Myers, 2011:7; Hindin, 2007:3951). Role theory attempts to describe the way people assume roles and states that roles specify normative behaviours and attitudes (Jackson, 1998:50). People occupy various roles simultaneously and roles can influence people's behaviour, attitudes, and values and affect personal growth and development (DeLamater & Myers, 2011:7-8; Parrish 2010:124). Lang (1992:1676) states the following:

Role theory provides the underlying metaphor - that social life is structured and individuals occupy social positions such as employee, spouse and parents in much the same way as actors occupy roles in a play. To explain social individual and social activity, role theory focuses primarily on the influence of objective social structures and external forces.

Examples of social structures and external forces are job descriptions, cultural expectations and religious norms.

Biddle (1986:70-71), differentiates between different types of role theory, namely, functional role theory, symbolic interactionist role theory and cognitive role theory. Functional role theory focuses on behaviour and social positions and states that behaviours are thought norms. People are expected to conform to these norms and they expect others to conform to their norms (Biddle, 1986:70). Symbolic interactionist role theory focuses more on the development of social roles and roles

that evolve through norms, attitudes, contextual demands, negotiation and different situations (Biddle, 1986:71). Cognitive role theory focuses on the perception of expectations and the effects of a person's perceptions of behaviour (Biddle, 1986:74-75). Functional role theory is strict behaviour patterns guided by norms and it requires conformity. Symbolic interactionist role theory gives fluidity to roles and posits that different aspects influence people's roles and fulfilment of these roles. Cognitive role theory is a person's subjective beliefs with regard to role and role demands.

DeLamater and Myers (2011:8) describe the propositions held by role theory that is integral to the implementation of social functioning:

- ❖ people participate as members of groups and organisations;
- ❖ people occupy positions within these groups and organisations;
- ❖ each position holds a set of roles;
- ❖ roles are a set of expectations of functions that must be fulfilled by a person for the group;
- ❖ groups have rules stating how a person should behave. If a person performs well, he/she is rewarded and non-performance is punished;
- ❖ people conform to expectations held by others;
- ❖ members of the group check up on each other so that norms are conformed to.

Within role theory there are specific concepts that attempt to explain how people interact and experience life and their roles. **Role sets** are a group of roles that are inter-related or supporting roles (Franks, 2007:3945; Parrish, 2010:123). **Role complementarity** occurs when a congruent whole is formed between the roles, the expectations and behaviour of a person are in balance with the environment and people (Parrish, 2010:123). **Role overload** occurs when a person cannot perform all their expected roles (Hindin, 2007:3953). **Role distance** entails that people can perform roles with varied degrees of detachment or commitment (Bruce & Yearley, 2006:264). **Role strain** occurs "when a role important [a person's] identity demands contradictory identities" (Franks, 2007:3945). **Role ambiguity** is when the person is uncertain about the expectation attached to the role (Parrish, 2010:123). **Consensus** entails that the social system shares norms of conduct for specific social positions

and people can be counted on to fulfil these roles (Biddle, 1986:76). **Conformity** is compliance to the pattern of behaviour expected of a social position (Biddle, 1986:78).

Role conflict occurs when a person occupies numerous roles with different expectations and demands that are difficult to reconcile (Bruce & Yearley, 2006:264; Franks, 2007:3945). Role conflict can also mean that the expectations are mismatched due to poor communication and a lack of clarity regarding the role (Hindin, 2007:3953). Parrish (2010:123) gives a simple definition of role conflict: “when one role is incompatible with another.” It is possible for one role to have a requirement that is in conflict with the person’s beliefs or preferences, this is referred to as person-role conflict (Lang, 1992:1676). Biddle (1986:82) explains that when role conflict is experienced the person “will suffer stress, will have to ‘resolve’ the problem by adopting some form of coping behaviour and that the person and system will both be disrupted.”

An integral part of role theory and social functioning is the concept of “role”. A role is a culturally determined pattern of social behaviour and conduct expected of a person in a specified and designated interpersonal social relationship (Zastrow & Kirst-Ashman, 2004:5; Zastrow & Kirst-Ashman, 2013:23). Ashford and LeCroy (2010:29-30) describe the importance of social roles:

The person is formed by the particular combination of social roles incorporated within her or his self-definition and behaviour patterns. Through the playing of roles, the other levels of the biopsychosocial system are impacted, as the person’s self-definition – the organisation of the biophysical and psychological functions cannot be understood without reference to the roles a person plays.

Every person fulfils numerous roles in different contexts and with different people and different roles can produce different behaviours from the same person (Diekman, 2007:763; Franks, 2007:3945). Behaviour cannot be understood as separate from people’s expectations about their own behaviour and how they expect people to behave towards them (Banton, 2004:893). Roles are determined either by circumstances (such as being female or diagnosed with breast cancer) or by doing something (such as being a parent or wife) (Parrish, 2010:123).

Jackson (1998:51-53) describes some criticisms of role theory and its application to practical situations:

- ❖ Ideologies are concrete and universal

Roles are too strictly packaged and don't allow for fluidity. For example, the role of mother with regard to single mothers, homeless mothers, lesbian mothers, adoptive mothers and so forth.

- ❖ Emphasis on social conformity

Role theory supports behaviour that conform to what is 'socially acceptable' and outsiders are labelled as deviant.

- ❖ Not a comprehensive socialisation process

Role theory posits that families, schools and churches socialize individuals but do not account for power struggles and the creativity of individuals to deal with contradictions.

- ❖ Human agencies are not addressed

Role theory does not give account for how people address social, economic and familial forces in their personal life creatively.

- ❖ Promotes segmented occupations

Role theory explains people's roles as separate entities such as employee, friend and husband, this depicts them as isolated segments that must be dealt with independently.

Even though role theory is at times rigid and does not provide enough opportunity for creativity in the human experience, it can still be use as a framework to assess role fulfilment as an aspect of social functioning in women with breast cancer. Possible role conflict, role overload and how role fulfilment influences a person's identity can also be investigated using role theory.

5. Cancer

Cancer is not a single illness, it is a term used to refer to a group of diseases and there are more than 100 types of cancer (Meric-Benstam & Pollock, 2010; Rees, 2004:4; Ross & Deverell, 2004:116; Ross & Deverell, 2010:134). Statistics estimated that cancer accounted for 7.6 million deaths in 2008 (WHO, 2013a). It is estimated that the number of deaths due to cancer will increase with 45% from 2007 to 2030 (from 7.9 million to 11.5 million), this is largely due to an aging population (WHO, 2008). Cancer develops when a cell changes in quality and it is characterised by the uncontrolled division of these abnormal cells (Rees, 2004:5; *Oxford Concise Medical Dictionary*, 2010:109). Cancer cells need blood in order to grow therefore they release a chemical stimulant that stimulates new blood vessels to nourish the cancer so that uncontrolled growth can continue to take place (Alberts, 2012:6). These cancer cells invade surrounding tissue and spread through either the blood stream or lymphatic system to other body sites which is called metastasis (*Oxford Concise Medical Dictionary*, 2010:109; Pervan, Cohen & Jaftha, 1995:772). A tumour is defined by Pervan et al. (1995:783) as “an abnormal or morbid swelling or enlargement in any part of the body.”

A normal cell in the body receives a stimulus to divide and as soon as a sufficient number of cells have been created, the cell changes back to its specialised function and cell division ceases (Alberts, 2012:5). This is called cell growth and proliferation and this process is under strict control in the body (Meric-Benstam & Pollock, 2010). There are cells in the body that are replaced regularly such as skin cells; these cells maintain a balance in the dividing process where approximately only 10% of these cells are dividing and the others are in a rest phase (Alberts, 2012:5). Cancer cells do not follow the normal pattern and does not maintain a balance in cell division (Alberts, 2012:6).

For cells physiology to change to cause malignant growth, there are six alterations needed (Meric-Benstam & Pollock, 2010; Serfontein, 2010:64):

- ❖ self-sufficiency of growth signals which leads to uncontrolled growth of cancer cells;
- ❖ insensitivity to growth-inhibitory signals which would have caused cancer cells to stop dividing;

- ❖ the evasion of apoptosis which is the genetically regulated program that disposes of cells;
- ❖ the potential for limitless replication of cancer cells;
- ❖ the establishment of new blood vessels to stimulate growth thus depriving other cells of nutrients, this is referred to as angiogenesis;
- ❖ the invasion of surrounding tissue and metastasis.

The behaviour of all cells is controlled by genes which are DNA information in each cell of the body (Rees, 2004:5). Cancer initiation occurs when genes known as oncogenes gain function or genes known as tumour-suppressor genes lose function which can cause a single cell to have a distinct growth advantage (Meric-Benstam & Pollock, 2010). The body consists of proto-oncogenes that control normal growth in cells and oncogenes are a mutation from the normal proto-oncogenes (Alberts, 2012:11; *Oxford Concise Medical Dictionary*, 2010:516). The mutation of proto-oncogenes occurs when DNA damage takes place and this causes abnormal activity (Rees, 2004:9). When an oncogene is formed, it gives a cell a continuous stimulus to grow, which leads to cancer (Alberts, 2012:11).

Tumour-suppressor genes are a recent discovery and it is found in the DNA of each cell and their function is to restrain the cell from dividing (Alberts, 2012:11; Rees, 2004:9). Many cancers are caused by reduced activity of the tumour-suppressor gene as a result of mutation or damage in the DNA where the tumour-suppressor gene is (Alberts, 2012:11; Rees, 2004:9). Genes play a role in the behaviour of cancer and can cause: cells to invade adjacent tissues; cells that produce self-stimulating growth factors; and cells that eliminate anti-cancer drugs (Rees, 2004:9). Genetic damage can cause cells not to die and this has important implications for treatment (Rees, 2004:9).

Cancer cells have the ability to invade normal tissue. Tumours that do not invade the basement membranes are referred to as in situ cancer. This is the early stages of cancer spread and in situ cancers do not pose a threat to life but can become cancerous (Meric-Benstam & Pollock, 2010; *Oxford Concise Medical Dictionary*, 2010:114; Rees, 2004:12). Tumours that breach the basement membrane, are referred to as invasive cancer (Meric-Benstam & Pollock, 2010). When cancer cells spread from the primary site (where the cancer or tumour is first found) and forms

new tumours in distant sites, this is referred to as metastasis (Meric-Benstam & Pollock, 2010). The process of metastasis consists of specific steps as described by Meric-Benstam and Pollock (2010):

- ❖ the cancer cells develop access to circulation, either the blood stream or lymphatic system;
- ❖ the cancer cells circulate;
- ❖ the circulated cells lodge in new organs;
- ❖ the cancer cells initiate growth.

It is noteworthy to mention that not all circulated cancer cells are able to initiate metastasis (Meric-Benstam & Pollock, 2010).

Cancer is discovered due to the symptoms they cause that the person notices, such as a lump (Rees, 2004:13). Cancer can also be diagnosed through screening for cancer and regular screening is important to diagnose cancer at an early stage (Rees, 2004:14). An example of a screening method is a mammography for women aged 50 and older in order to detect breast cancer (Rees, 2004:15). One of the diagnostic methods is a biopsy, which is the removal of a small piece of tissue to be examined under a microscope (*Oxford Concise Medical Dictionary*, 2010:83). Cancer diagnosis of a tumour is made by a biopsy of the tumour and the results of the biopsy determine histology, the grade and it assists in therapeutic planning (Meric-Benstam & Pollock, 2010). X-rays can be used as a diagnostic method because a tumour can produce an abnormal appearance on an x-ray (Rees, 2004:25). MRI and CT scans can be used to show cross sectional images of the body more clearly than an x-ray (Rees, 2004:26-28).

To determine prognosis and treatment options, the cancer must be staged. Staging is a process of determining the extent of the cancer and where it is located (American Joint Committee on Cancer, 2010). Through physical exams, x-rays, CT scans, MRI, laboratory tests, pathological reports and surgical reports enough information is gathered to stage cancer (American Joint Committee on Cancer, 2010). Every cancer type has its own classification system and after a classification is made the cancer is staged. Stage I being the least advanced with a better

prognosis, while the higher stages are more advanced (American Joint Committee on Cancer, 2010).

There are 4 stages of cancer (Pervan et al., 1995:783):

- ❖ Stage I: The tumour mass is limited to the organ of origin.
- ❖ Stage II: The tumour shows evidence of spreading into surrounding tissue and lymph nodes.
- ❖ Stage III: The tumour shows extensive spreading and lymph nodes test positive for malignancy.
- ❖ Stage IV: Evidence of distant metastases.

A term that is used by oncologists to refer to the stage of cancer is TNM. The meaning of TNM is:

‘T’ refers to the primary tumour size, ‘N’ is for the extent of lymph node involvement and ‘M’ is for presence of metastasis (*Oxford Concise Medical Dictionary*, 2010:692,735; Rees, 2004:30). A number is allocated to each letter and Rees (2004:26) gives the following example: “a woman with a breast cancer three centimetres in diameter which has affected some of the lymph nodes in her armpit, but who does not have any evidence of more distant spread, could be said to have a ‘T2N1M0’ tumour.”

5.1 Breast Cancer

The breast is a fibrofatty organ which responds to recurring hormone production and contains structures for milk production (Kimmick & Muss, 2009). Cancer of the breast is defined as “a malignant tumour of the breast, usually a carcinoma” (*Oxford Concise Medical Dictionary*, 2010:97). The earliest stages of breast cancer is a ductal carcinoma in situ where the cancer is confined to the milk ducts of the breast and lobular carcinoma in situ is where the cancer is in the lobules of the breast (*Oxford Concise Medical Dictionary*, 2010:224, 424). Paget’s disease is a malignant nipple condition that resembles eczema and accounts for 1% of breast cancers (Giuliano & Hurvits, 2013; *Oxford Concise Medical Dictionary*, 2010:535; Mayeaux, 2009). The first record of breast cancer dates from 2000 BC and it has been noted in numerous periods throughout recorded history (Bryant, 1995:403; Mandal, [sa]).

In both developing and developed countries, breast cancer is one of the most prominent cancers in women and accounts for 16% of all female cancers (WHO, 2013b). Breast cancer is one of the five leading causes of deaths due to cancer worldwide and accounted for 458 000 deaths in 2008 (WHO, 2013a). Breast cancer is the second most common cancer in the world and one of the most common cancers in the African region (Longo, 2012; WHO, 2012). There are 8000 new cases of breast cancer diagnosed in South Africa per year and there were 3156 deaths in 2000 as a result of breast cancer (Apffelstaedt, 2008; South African Medical Research Council, 2010).

There are certain risk factors associated with breast cancer incidence (Guiliano & Hurvits, 2013; Kimmick & Muss, 2009; Meric-Benstam & Pollock, 2010; Patel, Buzdar & Hunt, 2011; WHO, 2013b):

- ❖ The risk of cancer increases greatly with age.
- ❖ Increased alcohol use is linked to an increased cancer risk.
- ❖ Obesity and lack of exercise.
- ❖ Family history of breast cancer increases the risk to develop breast cancer which is also linked to genetic mutations such as BRCA1 and BRCA 2 genes.
- ❖ Hormonal factors are linked to breast cancer such as the use of oral contraceptives, hormone replacement therapy, early menarche, late pregnancy and late menopause.
- ❖ Race can play a role in the risk for breast cancer as breast cancer is more frequently diagnosed in white women.
- ❖ The adoption of a western life-style in low and middle income countries increases the incidence of breast cancer.

A genetic risk for breast cancer is found in the BRCA family of tumour suppressor genes which are associated with 5-10% of breast cancers (Guiliano & Hurvits, 2013; Meric-Benstam & Pollock, 2010). BRCA1 mutation in chromosome 17 gives a 90% lifetime chance of developing breast cancer (Guiliano & Hurvits, 2013; Hunt, Newman, Copeland & Bland, 2010). The risk of developing breast cancer in carriers of the BRCA2 mutation is 85% in their lifetime (Hunt et al., 2010). It is estimated that 50% of children will inherit the BRCA 1 and BRCA 2 trait (Hunt et al., 2010). Clinical features of BRCA 1 and BRCA 2 cancer includes early onset and prevalence of

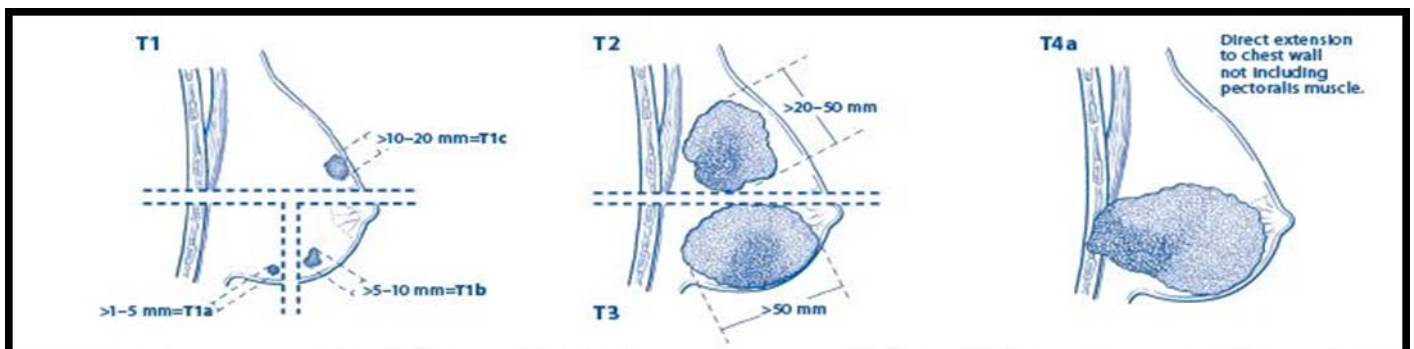
bilateral breast cancer (Hunt et al., 2010). The presence of the product of a dominant oncogene, HER2, plays a role in 25% of breast cancer cases (Lippman, 2012).

Increased exposure to oestrogen is associated with an increased risk for breast cancer which is why prevention of breast cancer is focused on lowering the exposure of breast tissue to oestrogen (Hunt et al., 2010; Kimmick & Muss, 2009). Normal breast tissue is oestrogen dependant and breast cancer tumours need to be tested to ascertain if they are oestrogen and progesterone dependant (Lippman, 2012).

Breast cancer screening is done by a mammography whereby the breast is compressed between two flat plates to take an x-ray picture to show abnormalities of the breast (Rees, 2004:15;26). Ultrasound can also be used in the investigation into breast cancer. An ultrasound is a probe that uses high frequency sound waves to produce an image on a screen (Rees, 2004:28). All breast cancers are diagnosed through biopsy of a nodule detected by palpation or a mammogram (Lippman, 2012).

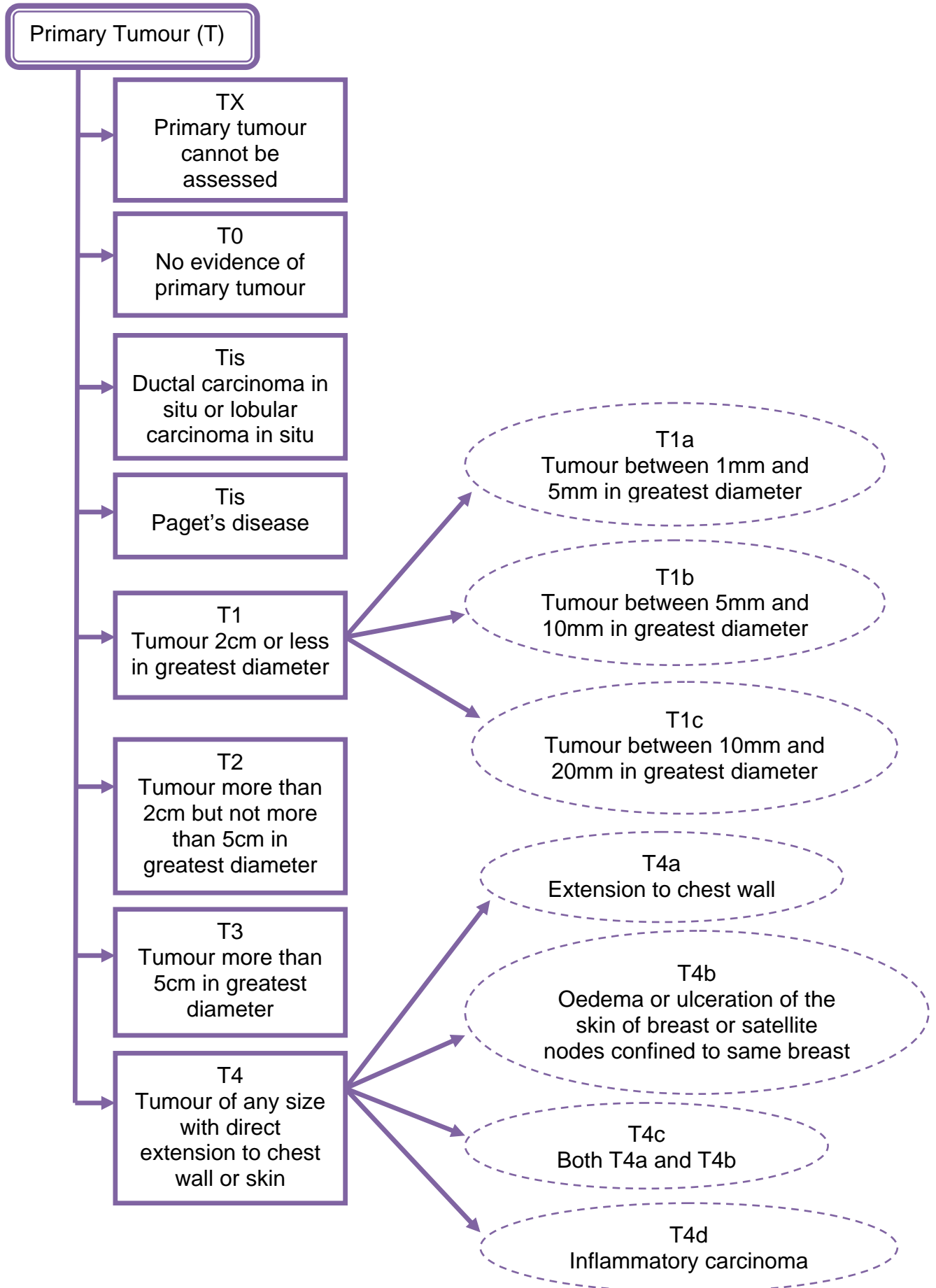
The primary tumour staging in the TNM staging for breast cancer according to the American Joint Committee on Cancer (2009) is depicted in the following diagram:

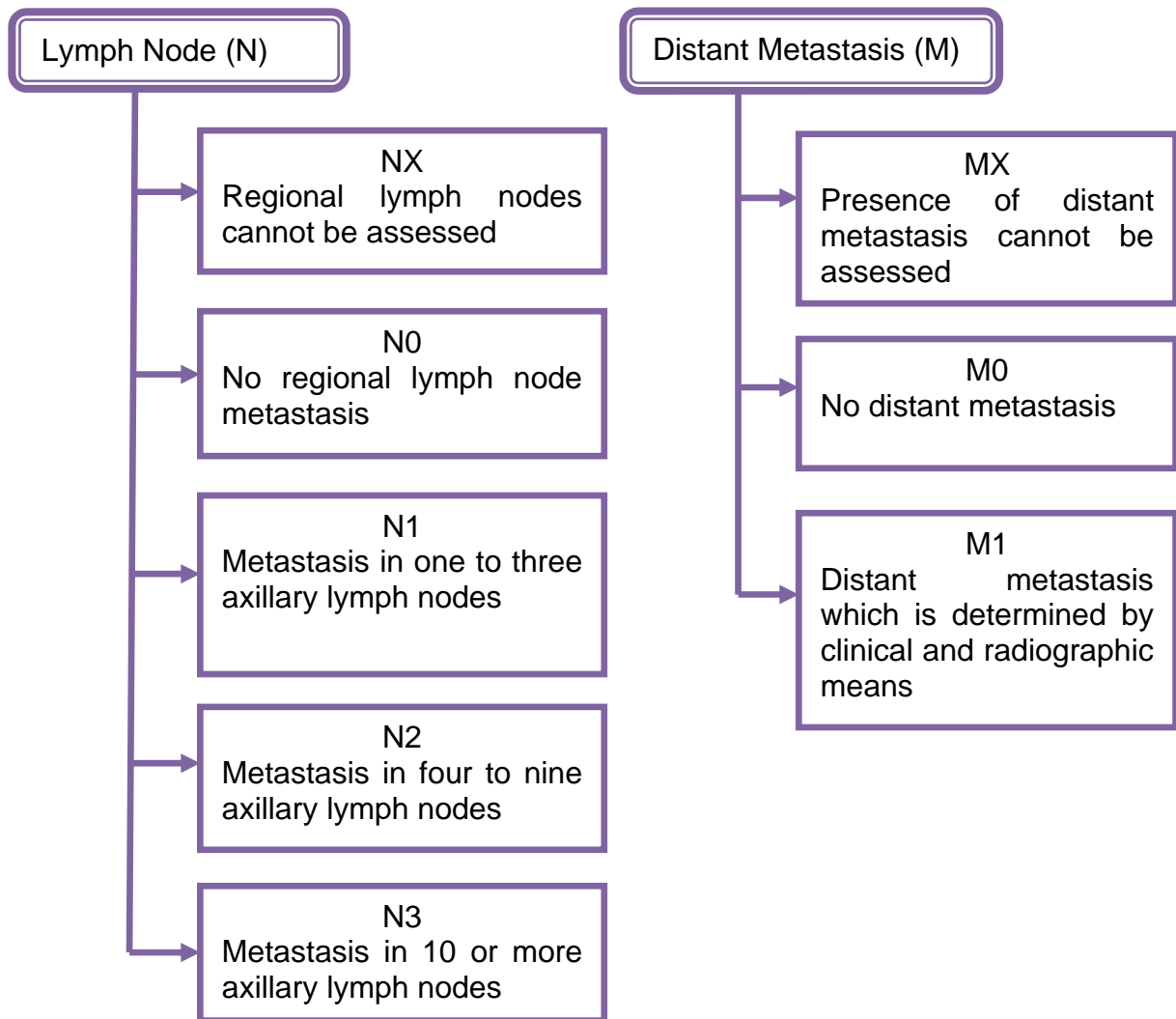
Diagram 1: Tumour staging of breast cancer



The TNM staging is represented in the following diagram (American Joint Committee on Cancer, 2009; Bryant, 1995:405-406; Lippman, 2012):

Diagram 2: TNM Staging





Breast cancer frequent metastasises to the bone, lungs, liver, brain, bone marrow, skin and eyes (Bryant, 1995:406, 421).

Final staging for breast cancer (American Joint Committee on Cancer, 2009; Lippman, 2012):

Table 1: Breast cancer staging

Stage	Primary Tumour (T)	Regional Lymph Nodes (N)	Distant Metastases (M)
Stage 0	Tis	N0	M0
Stage IA	T1	N0	M0
Stage IB	T0	N1	M0
	T1	N1	M0
Stage IIA	T0	N1	M0
	T1	N1	M0
	T2	N0	M0
Stage IIB	T2	N1	M0
	T3	N0	M0
Stage IIIA	T0	N2	M0
	T1	N2	M0
	T2	N2	M0
	T3	N1	M0
	T3	N2	M0
Stage IIIB	T4	N0	M0
	T4	N1	M0
	T4	N2	M0
Stage IIIC	Any T	N3	M0
Stage IV	Any T	Any N	M1

From the discussion, it is evident that cancer is a prevalent illness that can affect any person both in developed and developing countries. The diagnostic phase of cancer involves invasive procedures and can be a time consuming and anxiety provoking time. The diagnostic process is necessary to establish prognosis and treatment options. Breast cancer can be discovered in an early or progressed phase of illness, which will determine treatment options.

6. Cancer Treatment

The purpose of cancer treatment is primarily to eradicate cancer but if that cannot be accomplished, the purpose shifts to preserving quality of life and extending life (Sausville & Longo, 2012). The goal of adjuvant therapy is to kill cancer cells that have escaped the breast and lymph nodes and to prevent macro metastases and it greatly improves chances of survival (Giuliano & Hurvits, 2013; Lippman, 2012). The type of cancer treatment is determined by the stage of the disease (Hunt et al., 2010). Sausville and Longo (2012) categorised cancer treatment into the following three groups:

- ❖ Surgical
- ❖ Radiation therapy
- ❖ Chemotherapy (including hormone therapy)

6.1 Surgical

Surgery is used for prevention, diagnosis, staging, treatment, palliative care and rehabilitation in cancer care (Sausville & Longo, 2012). Surgery is the most common cancer treatment and can be divided into five categories (Jaftha & Brainers, 1995:173; Meric-Benstam & Pollock, 2010):

- ❖ Definitive surgery – to define the diagnosis.
- ❖ Staging surgery – to stage the disease so that prognosis and treatment can be decided on.
- ❖ Curative surgery – to remove tumours and lymph nodes in an attempt to place the patient in remission.
- ❖ Palliative surgery – removal of a tumour in order to make the patient comfortable and improve quality of life.
- ❖ Combination surgery – two or more of the above.

A biopsy is used as a diagnostic tool, where as much tissue is removed, as safely possible, to be examined (Rees, 2004:20; Sausville & Longo, 2012). The findings from a biopsy assist in histology, grading of a tumour and treatment planning (Meric-Benstam & Pollock, 2010).

Lymph nodes are an important component to cancer treatment because breast cancer has the ability to spread via the lymph nodes, therefore surgical interventions include draining or removing lymph nodes (Meric-Benstam & Pollock, 2010). A lymphadenectomy is used to reduce the risk of recurrence; for staging and has been proven to increase overall survival rate (Meric-Benstam & Pollock, 2010).

A new development in surgical intervention to lymph nodes is sentinel node biopsy, which identify lymph nodes most likely to contain metastases (Giuliano & Hurvits, 2013). The first lymph node to be drained is the sentinel node and is the most likely lymph node to contain metastases (Meric-Benstam & Pollock, 2010). If the sentinel node biopsy shows no axillary metastases, the likelihood of lymph node involvement is small and a lymphadenectomy is not necessary (Giuliano & Hurvits, 2013). If the

sentinel lymph nodes are positive for metastases, there is a 50% chance of axillary lymph node involvement (Kimmick & Muss, 2009).

According to the *Oxford Concise Medical Dictionary* (2010:427) a lumpectomy is:

An operation for breast cancer in which the tumour and surrounding breast tissue are removed: muscles, skin, and lymph nodes are intact. The procedure, usually followed by radiation, is indicated for patients with tumour less than 2cm in diameter and who have no metastases to local lymph nodes or to distant organs.

This is a breast conserving treatment and the 10 year survival results are as good as more invasive procedures such as mastectomy and radical mastectomy (Kimmick & Muss, 2009; Lippman, 2012). Breast conservation with radiation therapy is the preferred treatment options for patients with early stage breast cancer (Giuliano & Hurvits, 2013). The greatest consideration for breast conservation is the tumour size which will influence the possible deformity or cosmetic look of the breast post-surgery (Hunt et al., 2010; Giuliano & Hurvits, 2013).

According to the *Oxford Concise Medical Dictionary* (2010:440-441), a mastectomy is:

The surgical removal of a breast. Simple mastectomy, performed for extensive but not necessarily invasive tumours, involves simple removal of the breast; the skin and if possible the nipple may be retained and a prosthesis may be inserted under the skin to give the appearance of normality. When breast cancer has spread to involve the lymph nodes, radical mastectomy may be performed. This classically involves removal of the breast with the skin and underlying pectoral muscles together with all the lymphatic tissue of the armpit. This treatment may be followed up by radiotherapy and/or chemotherapy. In modern surgical practice a modified radical mastectomy, preserving the pectoral muscles, is more usual than the classic technique.

The benefit of radical mastectomy is that it can be curative which makes radiation therapy not necessary but the disadvantages of mastectomy is the cosmetic and

psychological impact (Giuliano & Hurvits, 2013). Breast reconstruction can be considered for all patients in order to restore body image (Kimmick & Muss, 2009).

Even though surgery is an effective treatment for cancer, the risk of death due to metastatic disease causes the treatment for cancer to be a multimodality approach including other therapies (Meric-Benstam & Pollock, 2010).

6.2 Radiation therapy

Radiation therapy entails the use of high dose radiation to a localised target and keeping the dose to normal tissue minimal (Engel-Hills, 1995:185). Radiation causes damage to cell DNA and causes damage to the cells reproductive ability (Meric-Benstam & Pollock, 2010; Sausville & Longo, 2012). Radiation therapy is an adjuvant treatment and can be used in the following instances (Engel-Hills, 1995:184-185; Meric-Benstam & Pollock, 2010):

- ❖ Pre-operative radiation therapy – decreases the size of the tumour that is then removed surgically and makes the treatment field smaller. The disadvantage of pre-operative radiation is that post-operative wound healing is prolonged.
- ❖ Post-operative radiation therapy – radiation therapy is given after surgery if there is a residual tumour. The disadvantage is that a larger volume of normal tissue is exposed to radiation.
- ❖ Radiation therapy and chemotherapy – radiation before chemotherapy is given to treat the primary tumour site. If chemotherapy is given in conjunction with radiation therapy, the cells may be desensitised to radiation.
- ❖ Surgery, radiation therapy and chemotherapy – the patient is treated with a combination of all three treatment options

The goal of radiation therapy with breast cancer patients is to reduce the risk of recurrence (Engel-Hills, 1995:191). Radiation is delivered in three ways (Sausville & Longo, 2012):

- ❖ Teletherapy, where a beam of radiation is aimed at the tumour from a distance. This is used in breast cancer patients as a curative therapy.
- ❖ Brachytherapy is where a source of radiation is implanted directly into or next to the tumour tissue.
- ❖ Systematic therapy where radionuclides are targeted to a tumour site.

Side effects associated with radiation therapy depend on the site, dose and volume of treatment as well as the individuals' response to treatment and can be acute or may occur weeks or even years after treatment (Brennan, 2004:229; Meric-Benstam & Pollock, 2010; Rees, 2004:51). Side effects include inflammation, fatigue, nausea, diarrhoea, skin soreness, weight loss, temporary change in skin colour and temporary or permanent hair loss (Brennan, 2004:229; Rees, 2004:51; Ross & Deverell, 2010:137; Sauseville & Longo, 2012).

Bone, heart, skeletal muscle and nerves are more radio resistant organs while male testis, female ovary and bone marrow are sensitive to radiotherapy (Sauseville & Longo, 2012). When breast cancer has metastasised, it can be treated with radiation therapy as a palliative care option to control ulceration, pain and other manifestations (Giuliano & Hurvits, 2013).

6.3 Chemotherapy

Chemotherapy interferes with the cell division of normal cells and cancer cells but especially cells that divide rapidly (Rees, 2004:59). Different chemotherapeutic agents interfere with different phases in the cell cycle and when they are combined they have the advantages of maximum cell kill, broader range of coverage and delayed drug-resistance (Meric-Benstam & Pollock, 2010).

Chemotherapy is the use of chemical agents in the treatment of cancer as the initial treatment or in conjunction with surgery and/or radiation therapy or in the instances where surgery and radiation therapy is not possible (Leon, De Jager & Toop, 1995:197). Adjuvant chemotherapy is given to eradicate metastatic disease and breast cancer responds well to multiple chemotherapeutic drugs (Giuliano & Hurvits, 2013; Meric-Benstam & Pollock, 2010). Giuliano and Hurvits (2013) confirmed that 90% of patients with locally advanced breast cancer respond well to multi drug chemotherapy.

Chemotherapy can be given before surgery and has the following advantages (Meric-Benstam & Pollock, 2010):

- ❖ regression of a tumour that was previously inoperable;
- ❖ treatment of metastatic disease without waiting for postoperative recovery;
- ❖ assessment of cancer's response to chemotherapy treatment.

Chemotherapy side effects are generally well controlled with the advancements made in medicine (Giulliano & Hurvits, 2013). The following side effects can be present in the use of chemotherapy (Leon et al., 1995:199; *Medical Dictionary for Allied Health*, 2008:21, 23, 158, 171, 185, 211, 312, 356-357, 369; *Oxford Concise Medical Dictionary*, 2010:513, 699, 730; Ross & Deverell, 2010:136):

- ❖ anorexia which presents as an aversion to food and persistent loss of appetite;
- ❖ nausea and vomiting;
- ❖ hair loss;
- ❖ stomatitis, which is inflammation of the mucus membrane in the mouth;
- ❖ thrombophlebitis, which is inflammation of the wall of a vein;
- ❖ oesophagitis, which is inflammation of the oesophagus;
- ❖ thrombocytopenia, which is the abnormal decrease in blood platelets which can cause hemorrhagic conditions;
- ❖ fatigue and/or tiredness;
- ❖ constipation;
- ❖ fluid retention;
- ❖ loss of appetite;
- ❖ altered sense of taste;
- ❖ weak, tired or sore muscles;
- ❖ local irritations caused by the inflammatory reaction of tissue to toxins;
- ❖ mouth ulceration occurs when there is a small open wound or sore in the mucous membrane caused by inflection, inflammation or pressure;
- ❖ infertility, which is the inability to conceive;
- ❖ suppression of ovarian or testicular function;
- ❖ abdominal pain;
- ❖ haemorrhage, which is excessive bleeding;
- ❖ diarrhoea;
- ❖ intestinal ulceration and perforation;
- ❖ acute renal failure, which is the inability of the kidneys to expel waste from the body;
- ❖ delayed wound healing;
- ❖ allergic reactions including skin rashes;

- ❖ fever;
- ❖ malaise and weakness indicated by feeling fatigue and in ill health;
- ❖ hypotension, which indicates low blood pressure meaning that there is not enough pressure to provide oxygen to the tissues in the body;
- ❖ headache;
- ❖ anaemia, which constitutes numerous condition marked by deficient red blood cells;
- ❖ development of secondary carcinomas; and
- ❖ bone marrow depression.

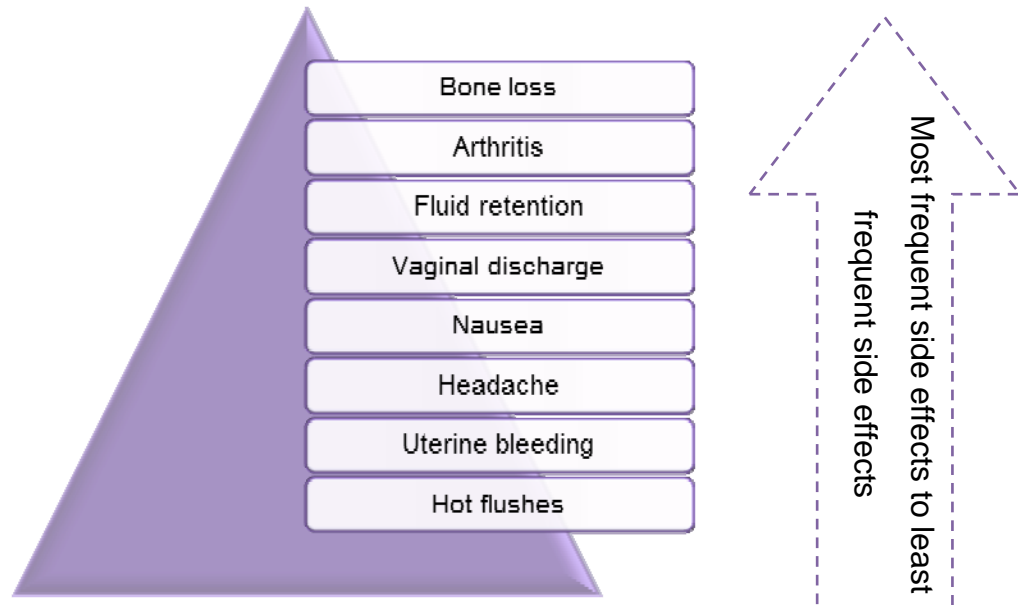
When a patient has stage IV breast cancer, the focus is on enhancing quality of life and then hormonal therapy is preferred over chemotherapy (Hunt et al., 2010).

6.4 Hormone therapy

Some cancers are dependent on hormones for growth and hormone treatment can aid in preventing cancer cells from getting the hormones needed for their growth (Rees, 2004:67). Hormone or hormone-like agents can be given to hamper tumour growth by blocking hormones like oestrogen for breast cancer (Meric-Benstam & Pollock, 2010). Tamoxifen is the most common drug used in breast cancer, it blocks the production of oestrogen that stimulates cancer cell growth (Lippman, 2012; Rees, 2004:67). Tamoxifen has good results and fewer side effects than chemotherapy and does not require the patient to undergo oophorectomy, the removal of an ovary (Giuliano & Hurvits, 2013; *Oxford Concise Medical Dictionary*, 2010:518). Oophorectomy is an effective treatment for eliminating oestrogen, progestin and androgens but not a desirable option for premenopausal women (Giuliano & Hurvits, 2013).

Giuliano and Hurvits (2013) give the following side effects of hormone drugs used for hormone management for metastatic breast cancer:

Diagram3: Hormone drug side effects



6.5 HER2 over-expression

Approximately 20% of breast cancers have HER2 overexpression but the poor prognosis associated with it has been improved with HER2-targeted therapy (Giulliano & Hurvits, 2013). Trastuzumab (Herceptin) that binds with HER2 has been proven effective with chemotherapy in both early and metastatic breast cancer (Giulliano & Hurvits, 2013).

Cancer treatment and its side effects have the ability to influence a person's functioning and overall wellbeing.

7. Reaction to Cancer

Cancer is a frightening disease for most people and treatment of cancer is seen as being cut, burned and poisoned (Brennan, 2004:1-2). For that reason, cancer diagnosis and treatment can have an intense effect on the patient and family. There are also issues pertaining to survivorship, recurrence and end of life.

7.1 Diagnosis

The range of emotional reactions to a cancer diagnosis includes shock, disbelief, anger, fear, numbness, depression and devastation (Fitch et al., 1999). Biopsy and medical investigation can be the "most anxiety-provoking stage for many patients and families" and fear is present in all patients facing surgery for cancer (Jaftha &

Brainers, 1995:174-175). Undergoing biopsy causes emotional turmoil in patients (Montgomery & McCrone, 2010:2388). Patients that continue with the process of searching for a diagnosis live with uncertainty and disruption of self-identity on a daily basis (Kralik et al., 2001:595). The diagnosis of cancer is a stressful event for the patient and family because it is marked with shock and uncertainty (Edwards & Clarke, 2004:562). Research by Kayser and Sormanti (2002:399) shows that in the initial stage of diagnosis and treatment, women have a low sense of power and efficacy with regard to their health. People find it difficult to come to terms with the cancer diagnosis and often experience a period of dissociation or dreamlike numbness that can last for hours to days (Brennan, 2004:19).

The word cancer causes fear for many people because they perceive it as a “death sentence” (Bryant, 1995:409). This is confirmed by research done by Venter (2008:23) where a respondent stated that “if you have cancer you die”. Some believe that the diagnosis of cancer is more destructive losing a breast (Bryant, 1995:414). Anxiousness and depression is linked to the prognosis, where metastatic disease with a poor prognosis is likely to cause more anxiety and depression (Siddiqi, Given, Given & Sikorskii, 2009:84). A study by Friedman, Kalidas, Elledge, Chang, Romero, Husain, Dulay and Liscum (2006:601) shows that there is no measurable improvement in quality of life in time from the diagnosis onwards. Women feel vulnerable and lost trying to understand the impact of the diagnosis on their present and future and experience their emotional reactions as more disabling than the diagnosis until they go through the adjustment process (Kralik et al., 2001:600).

7.2 Treatment

Before the patient and family have had time to absorb the diagnosis, the cancer treatment starts and at times a surgical treatment is given even before a definitive diagnosis is made (Brennan, 2004:60). When a person is hospitalised, it can be a daunting experience and the following concerns are associated with hospitalisation: the patient is worried about the seriousness of the illness; she is unfamiliar with the hospital environment; she is worried about home life; she experiences loss of control and lack of support (Brennan, 2004:215). When a parent is hospitalised it can mean separation from children and it requires an emotional readiness to have children visit the patient in hospital (Semple & McCance, 2010:1285).

Surgical intervention can mean that body image changes and a feeling of loss and intense feelings are experienced (Jaftha & Brainers, 1995:173). The negative aspects of a mastectomy are the cosmetic and psychological impacts of losing a breast (Giuliano & Hurvits, 2013). Patients who received surgical intervention for breast cancer had high levels of depression compared to patients who did not have surgery (Edwards & Clarke, 2004:572). Some women consider their breasts as their femininity, maternity and sexuality. A re-evaluation of life and functioning after a mastectomy occurs because disfigurement is a personal and social experience (Brennan, 2004:33; Skrzypulec, Tobor, Droszol & Nowosielski, 2008:614).

Cancer has an influence on body image, sexual functioning and intimacy and this causes feelings of shame and embarrassment (Kayser & Sormanti, 2002:404; Venter, 2008:26). Treatment can have physical, social, sexual and psychological challenges for the patient and family (Semple & McCance, 2010:1285). The treatment calendar (medical appointments and length of treatment) can have a greater psychosocial impact on the patient's life than the treatment or illness (Brennan, 2004:63). At times, patients must cope with not just one side-effect but numerous side-effects that are all connected (Semple & McCance, 2010:1285). During cancer treatment, the patient must learn to adjust to treatment and symptoms and later take on the task of long term adjustment (Kulik & Kronfeld, 2005:38). The chemotherapy toxicity directly influences the severity of symptoms and the physical functioning of patients' (Siddiqi, et al., 2009:93).

Brennan (2004:23) states the following in a chapter entitled "the catastrophe of cancer":

While people with cancer are doing their best to cope with the day-to-day challenges of their treatment, the uncertainty of the future, the reactions of their loved ones, and the reorganisation of their normal domestic and work routines, they are also engaged in the stressful process of integrating these new experiences into their mental maps of the world.

Although cancer can have negative aspects, there are also positive outcomes from having cancer such as an increased appreciation for life and re-evaluating priorities (Semple & McCance, 2010:1286). Positive emotions experienced by cancer patients are empathy for others and family, gratefulness to be alive, having hope and

acceptance of the illness and side effects (Venter, 2008:25-26). Positive outcomes after cancer are personal growth, development of new perspectives, lifestyle changes and increased spirituality (Venter, 2008:40).

7.3 Survivorship

The number of cancer cases is increasing worldwide and it is estimated that there will be a 45% increase in deaths due to cancer from 2007 to 2030 as a result of an aging population (WHO, 2008). The five year survival rate was 35% in 1954, but it has increased to 69% in 2005 (Schultz, Stava, Habra & Vassilopoulou-Sellin, 2011). Originally, a person was called a survivor when the cancer had been in remission for five years but now a person is referred to as a survivor once the cancer diagnosis is made (Schultz et al., 2011). Cancer has shifted from being classified as terminal to chronic, requiring a transition so as to attend to long-term cancer issues with a special focus on quality of life and the prevention of recurrence (Werner-Lin & Biank, 2006:508).

After treatment is completed, when patients return to work, they experience demotion, unwanted changes in tasks at work, problems with employers and co-workers, a decline in job mobility, changes in attitude towards work and feeling like less desirable workers (Kulik & Kronfeld, 2005:51; Longo, 2012). Patients return to work either wanting normalcy or due to their financial situation, but the return does assist in psychological wellbeing (Semple & McCance, 2010:1286). Cancer treatment has caused people to lose confidence and self-esteem which can make it difficult to return to their “normal life” after treatment is completed (Brennan, 2004:69). In social work practice with oncology patients, emphasis is placed on helping people to adjust to their new life and resuming their roles and activities (Werner-Lin & Biank, 2006:514).

Problems associated with survivorship include physical functioning, premature aging, fatigue, sexual problems, grief over infertility, employment problems and insurance discrimination, fear of recurrence, anxiety regarding medical follow-ups and vulnerability to colds and other illnesses (Kayser & Sormanti, 2002:392-393; Longo, 2012). Women who experience lymphoedema express that the physical symptoms such as pain cause them to avoid certain activities and cause them to constantly

worry, all of this alters their quality of life (Heppner, Tierney, Wang, Armer, Whitlow & Reynolds, 2009:334).

Women constantly worry about recurrence and have anxiety when they go for check-ups even after years of remission (Davis, 2004:330). Although patients fear recurrence, they also feel vulnerable after treatment is completed and the physical and psychological consequences of breast cancer may remain long after treatment is completed (Vivar, Canga, Canga & Arantzamendi, 2009:729).

7.4 Recurrence

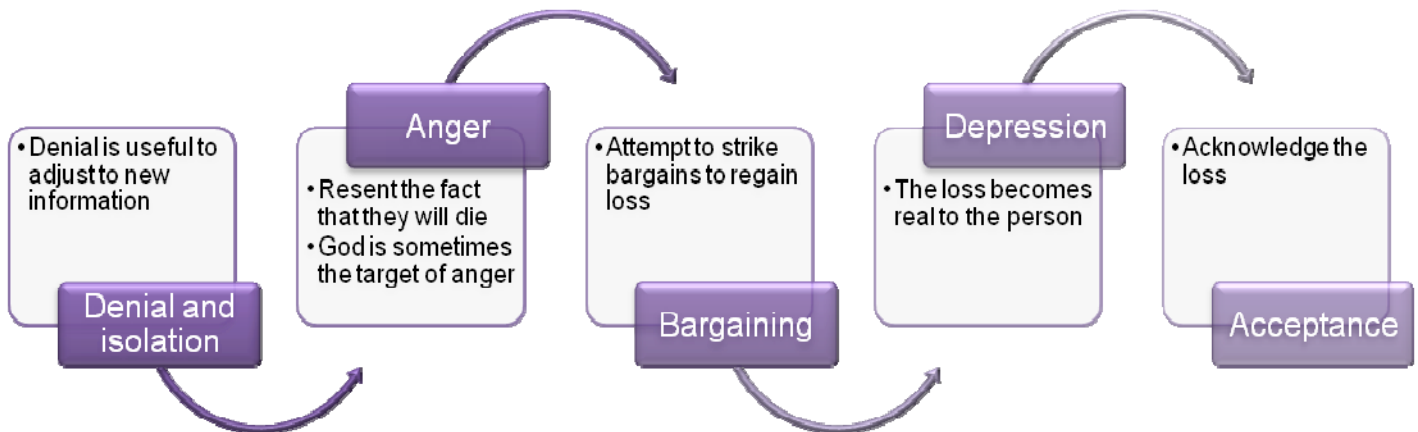
The recurrence of cancer happens when resistant cancer cells remain and they are too small to be detected with ordinary tests, because cells must divide 30 times before they can be detected (Alberts, 2012:240). When recurrence occurs, patients feel devastated, shocked, they fear the future, become uncertain and are confronted with their own mortality (Vivar et al., 2009:730-731). This is worsened when the patient has negative memories and emotions associated with treatment, this causes a more intense emotional experience than the first diagnosis (Vivar et al., 2009:731-732). Recurrence of cancer is worse than the initial diagnosis of cancer and makes patients and families to feel pessimistic (Brennan, 2004:51, 226).

7.5 End of life

Although patients and families hope for a cure, when cancer becomes terminal, patients shift their need to wanting to die with dignity and without pain (Werner-Lin & Biank, 2006:515). As described earlier, higher stages of cancer are more advanced with poorer prognoses (American Joint Committee on Cancer, 2010). Women express fear of death more in terms of fear of pain and losing control (Luoma & Hakamies-Blomqvist, 2004:735). This fear is legitimate seeing that physical symptoms associated with end stage illnesses include pain, nausea, fatigue, weakness, anorexia, bowel obstructions, bed sores, insomnia, anxiety, depression and confusion (Alberts, 2012:265-266; Bernacki & Meier, 2012). Another concern regarding death is children, especially women with younger children and the realisation that they will not be raising their children (Luoma & Hakamies-Blomqvist, 2004:735). That is why it is important for the dying patient to give up their role as a parent to a partner (Brennan, 2004:117).

The process of dying has emotional aspects associated with it. The most notable emotions are those explicated by Elizabeth Kübler-Ross (in 1969) as she describes the five stages of dying (Adams, 2010:613):

Diagram 4: Five stages of dying



The diagram illustrates the different stages and emotions a person and family can go through when it comes to the end of the person's life. The process includes being in denial about the prognosis to acknowledging the loss through acceptance. The patient and family will need to be assisted through these emotions. Adams (2010:616) goes on to describe the basic needs of an older person who is near death:

- ❖ the dying person needs pain and medical management of symptoms during the dying process, an example is shortness of breath;
- ❖ the dying person needs gentle physical care to assist with comfort and personal dignity;
- ❖ the dying person and their family members require straightforward information and assistance in making important decisions;
- ❖ the person needs support for emotional distress and handling fears, that can cause anxiety which can result in suffering for the dying person and their family;
- ❖ the dying person and their family require spiritual support and the opportunity to engage in rituals for comfort appropriate to their culture and religion.

8. Gender role

A distinction must be made between “sex” and “gender”. A person’s sex refers to biology while gender refers to characteristics that culture and society expect of a person based on their sex (Commission on Gender Equality, 2000:45). People are socialised into gender from an early age (Kilroe, 2009:17). Gender roles are not natural roles but are defined by a society and refer to economic, social and cultural roles, behaviour, characteristics and opportunities that a society associates with being either male or female (Commission on Gender Equality, 2000:45; Kornegay, 2000:18). Gender roles are present in all spheres of society and establish roles for men and women, which are perceived as normal (Pretorius, 1998).

Gender roles differ from culture to culture and they also change over time (Brennan, 2004:121). This means that people’s culture teaches them the social role behaviours expected of a certain position (Blakely & Dziadosz, [sa]). South Africa has strong cultural beliefs regarding gender roles, which in turn has strengthened the roles that men and women fulfil (Byrnes, 1996). Patriarchy continues to be the accepted social norm across all races and class lines and gender roles are delineated based on patriarchy (Kilroe, 2009:40; Palitza, 2008). Gender roles for women in South Africa include household chores like cooking, cleaning, mending and shopping and also caring roles like childbearing, caring for children and being a care giver for other family members (Education and Training Unit, 2007; Pretorius, 1998).

Furthermore, women play an integral role in the community, specifically within their church (Education and Training Unit, 2007). Christian countries are more egalitarian in terms of gender ideologies, meaning that it views men and women as equally important and posit that men should not dominate women (Kilroe, 2009:36). The Afrikaner religious beliefs have a theoretically biblical basis for women’s roles in society (Byrnes, 1996). Kilroe (2009:33) describes the importance of religion in gender roles as follows:

Ultimately religion appears to be another important factor in creating the social knowledge and discourse which constructs the individual’s view of gender and the role and place of gender in society, and that like all other constructs religion and its relationships to gender roles is

very much dependant on the input of the society in which it occurs and vice versa.

Gender roles define the division of labour in the family and usually domestic chores are allocated to women (Pretorious, 1998). Every member of a family fulfils a variety of roles that are integrated into the family structure and have certain expectations, norms and rules. These roles can be adapted according to developmental changes or changes in the family or individual circumstance (Parrish, 2010:228). The impact of cancer on the family depends on the stage of cancer and the different needs of the members of the family (Brennan, 2004:100).

Research has indicated that women with cancer have difficulty with responsibilities around the house due to their treatment and that 67% reported difficulties with their roles (Hirschman & Bourjolly, 2005:27). Bourjolly, Kerson and Nuamah (1999:2) cite Green's research that women tend to maintain more responsibilities than they release to their family and friends and that in the first year of diagnosis women return to the same level of household performance than they did before diagnosis.

Although there are gender roles, one cannot assume that everyone conforms to these roles and when facing illness, people are forced into roles that they are not prepared or equipped for (Brennan, 2004:121). Perceived gender roles and family roles have the ability to impact a person's social functioning when confronted with cancer diagnosis and treatment.

9. Social functioning

The framework of social functioning was first developed by Werner Boehm in 1958 when he observes that "the physician focuses on enhancing a client's physical functioning and the social worker should focus on enhancing the client's social functioning" (Ashford & LeCroy, 2010:29). Social functioning from a social work perspective means the fulfilment of an individual's roles that exist as a result of the individual's interactions with his/her own self, family, society and environment in order to perform tasks essential for daily living (Ashford & LeCroy, 2010:29; Barker, 2003:403; *New Social Work Dictionary*, 1995:58).

Social functioning is related to functional status, which is a person's performance of activities associated with their roles and for women with breast cancer these activities include household, family, social, community, self-care and occupation activities (Bourjolly et al., 1999:2). Tulman and Fawcett (2007:205) developed a measurement tool for a comprehensive inventory of functioning for cancer patients. This tool measures the following aspects (Tulman & Fawcett, 2007:208):

Diagram 5: Social functioning measuring tool developed by Tulman and Fawcett (2007:208)



The measuring tool of Tulman and Fawcett (2007:208) is derived from three role categories: the primary role which is based on gender, age and developmental state; the secondary role based on tasks to be fulfilled for developmental state; and the tertiary role which is an extension of the secondary role, for example your role as an employee (Tulman & Fawcett, 2007:206). As seen from the areas measured in Tulman and Fawcett's measurement tool, social functioning encompasses many spheres of a person's daily life and roles. Social functioning can be linked to the concept of quality of life. Quality of life has seven core components (Brennan, 2004:38-39):

- ❖ physical concerns such as pain and symptoms;
- ❖ functional ability such as mobility, self-care and activity level;

- ❖ family wellbeing;
- ❖ emotional wellbeing;
- ❖ treatment satisfaction;
- ❖ sexuality including body image; and
- ❖ social functioning (interaction with social networks).

When contemplating the implications of cancer on social functioning, the following need to be considered:

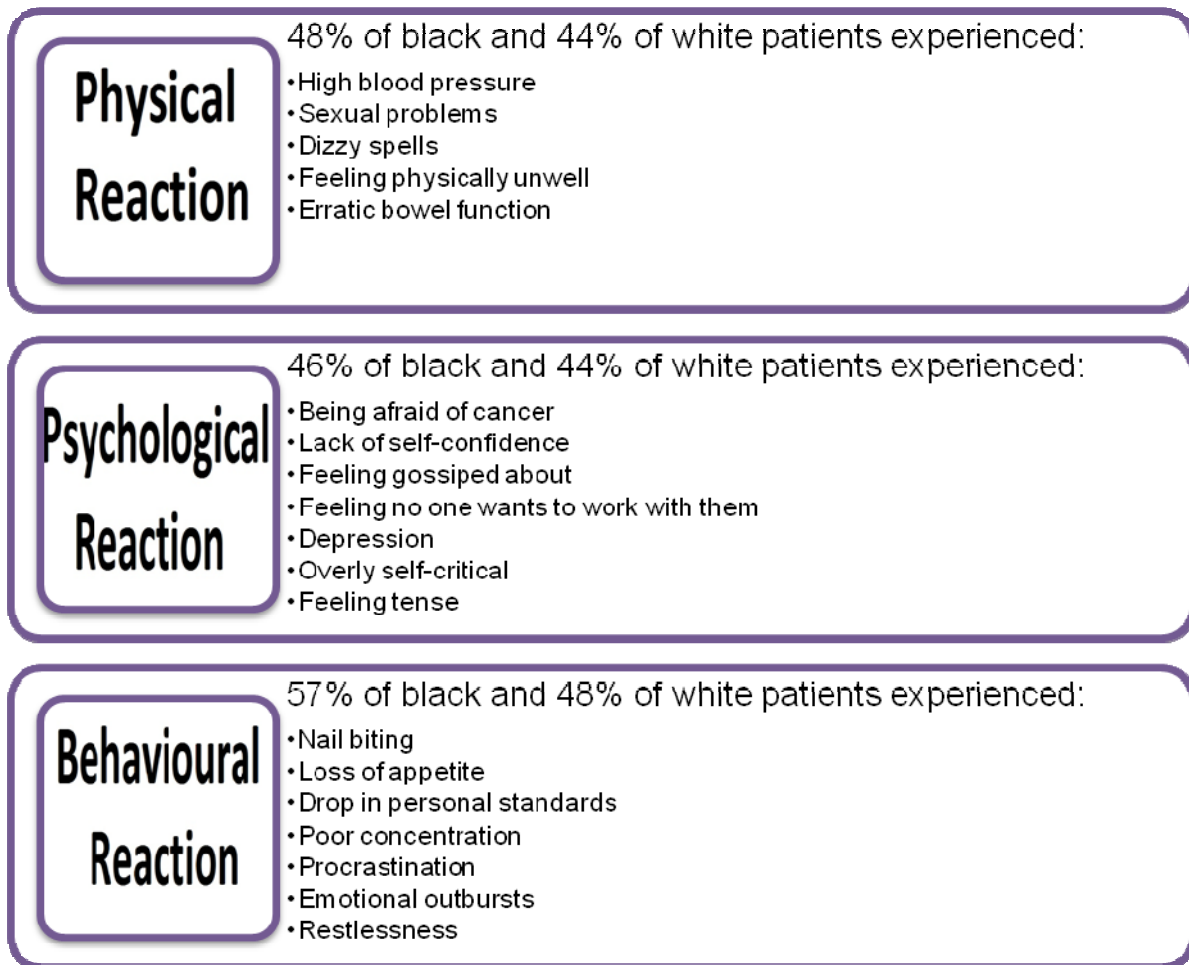
Cancer and cancer treatment may cause physical impairments that affect the functioning of a patient and also vocational, psychological, economic, social problems (Cheville, Troxel, Basford & Kornblith, 2008:2621, 2628). Chemotherapy and radiation therapy can compromise a persons' social functioning (Bourjolly et al., 1999:3). The psychological distress that women go through during the diagnosis of breast cancer can interfere with her ability to perform everyday tasks living (Montgomery & McCrone, 2010:2388). Due to the side effects of cancer treatment, which include nausea, pain and fatigue, people are unable to plan for the future and this causes them to disengage from previously appealing activities (Brennan, 2004:72). Cancer treatment causes limitations in performing daily activities such as driving, walking, housework, family activities, leisure activities and self-care as well as experiencing changed roles and feelings of helplessness (Luoma & Hakamies-Blomqvist, 2004:732).

Role changes are prominent with adaption to cancer diagnosis and treatment. Role functioning is limited with regard to employment and domestic work and women tend find it difficult to ask for assistance because they want to continue to feel autonomous (Luoma & Hakamies-Blomqvist, 2004:733). Women perceive the impact of cancer and treatment as changes in their roles and relationships (Fitch et al., 1999). Diagnosis and treatment can rob people of family and social roles, which cause emotional distress for all involved (Werner-Lin & Biank, 2006:513). A person's ability to fulfil certain roles is linked with self-worth, thus a woman's self-worth is adversely influenced when she is unable to fulfil her roles in the family and society (Brennan, 2004:69). It is possible that role fulfilment can be linked with the concept of validation, where validation reminds people that they are valued and loved and will not be abandoned (Brennan, 2004:94).

Patients experience loss of previous abilities and lifestyle and often compare their physical functioning to a time before diagnosis and treatment (Luoma & Hakamies-Blomqvist, 2004:732; Venter, 2008:32). People have complex lives and cancer is not the only source of stress and needs to be accommodated in already busy lives (Brennan, 2004:63). A person with cancer needs to find a balance between being needed and allowing oneself to be sick, and a balance between his/her own demands and wanting to be strong (Billhult & Segesten, 2003:124). Women's social functioning is worse when they use escape-avoidance coping; feel that cancer keeps them from doing what they want to do and that cancer threatens their self-esteem (Bourjolly et al., 1999:16).

Emotional functioning which influences the ability to enjoy life, is affected and this causes emotions such as being bad-tempered, depression, lack of tolerance, bitterness and fear of pain and death (Luoma & Hakamies-Blomqvist, 2004:732). A follow-up study shows poorer emotional functioning at 18 months compared to baseline assessment of breast cancer patients (Montazeri, Vahdaninia, Harirchi, Ebrahimi, Khaleghi, & Jarvandi, 2008). South African research by Lo Castro and Schlebusch (2006:768-775) indicates that breast cancer patients experienced unhealthy stress symptoms such as:

Diagram 6: Unhealthy stress symptoms experienced by breast cancer patients



Cancer also affects the family system (Edwards & Clarke, 2004:570) which in turn affects the woman's social functioning. Children need to assume responsibilities of household chores and caring for younger siblings as well as dealing with their own emotional reactions to their mothers' breast cancer and treatment (Stiffler, Barada, Hosei & Haase, 2008:936). Family roles and responsibilities are shifted which can cause resentment, blame and guilt (Brennan, 2004:101). A study by Kissane, McKenzie, McKenzie, Forbes, O'Neill and Bloch (2003:536) shows that of the 257 families screened, a quarter (64 families) was classified as dysfunctional.

The consequences for relationships are seen through problems with body image, sexual functioning and decreased sexual enjoyment (Montazeri et al., 2008). People who are diagnosed with cancer and undergo treatment must renegotiate relationships which can lead to relationship problems and permanent disability can change the way people relate to each other and structure their lives (Brennan,

2004:74-75). Research by Fitch et al. (1999), shows that relationships became either closer or more distant with one respondent stating that her husband “sort of stays away from me, I don’t know why.” Another research respondent stated that she thinks her husband feels that she’s ugly and not lovable anymore (Mak Wai Ming, 2002:47). When a partner has cancer, people respond in the following ways (Brennan, 2004:114):

- ❖ supportive and caring;
- ❖ trying to fix the problem;
- ❖ minimizing the seriousness of the situation;
- ❖ silent and withdrawn;
- ❖ critical and undermining.

There are positive aspects that arise in relationships where the couple re-examines their lives and communicate with each other (Brennan, 2004:117).

Support is an important aspect of social functioning because when women are supported it enables them to fulfil their roles such as self-care and housekeeping (Hirschman & Bourjolly, 2005:18). Social support assists people in managing cancer and social networks help sustain people in good and bad times (Brennan, 2004:92). Even in social contexts, women miss mutual social relationships and being accepted as an equal because they feel isolated and like an outsider (Luoma & Hakamies-Blomqvist, 2004:732, 734). Patients with fewer social resources are more distressed which shows that family and social relationships provide meaning to life, life satisfaction and purpose (Jim & Andersen, 2007:376).

It’s the task of a social worker to assess how physical impairments influence a person’s ability to fulfil life tasks (Ashford & LeCroy, 2010:77). Social workers can intervene to help women cope with role changes and to resume roles in the family and community (Bourjolly et al., 1999:17). Werner-Lin and Biank (2006:525) describe the role of the social worker in oncology as:

The direct practice work with patients and their families is frequently both physically and emotionally taxing and, despite our best efforts, the work does not make cancer go away. As families require on-going intervention and consultation, social workers build long-term

relationships with clients, many of whom will die. Much of the work involves travelling with clients and families down treacherous roads, aiding them in sorting through existential and ethical dilemmas about the quantity versus quality of life.

10. Social work in oncology

Medical social work is defined as the social work practice within the health care setting in order to aid ill patients and their families to resolve social and psychological problems associated with their illness (Barker, 2003:266-267). The field of oncology social work is a specialised field within social work that addresses the needs of people affected by cancer and is based on the foundation of psycho-oncology (Werner-Lin & Biank, 2006:507). Psycho-oncology addresses the psychological, social and spiritual needs of individuals and families affected by cancer (Werner-Lin & Biank, 2006:507). The Association of Oncology Social Work (2013) describes the scope of practice as follows:

- ❖ “Services to cancer survivors, families, and caregivers through clinical practice providing comprehensive psychosocial services and programs through all phases of the cancer experience.
- ❖ Services to institutions and agencies to increase their knowledge of the psychosocial, social, cultural and spiritual factors that impact coping with cancer and its effects and to ensure provision of quality psychosocial programs and care.
- ❖ Services to the community through education, consultation, research and volunteering to utilize, promote or strengthen the community services, programs, and resources available to meet the needs of cancer survivors.
- ❖ Services to the profession to support the appropriate orientation, supervision and evaluation of clinical social work in oncology; participate in and promote student training and professional education in oncology social work; and advance knowledge through clinical and other research.”

Social work in the oncology field focuses on many different aspects of cancer care including individual counselling, family counselling, education, community outreach and research. Social work professionals are well trained in individual counselling,

group and family counselling and dealing with emotional and environmental problems (Van Schalkwyk, 1995:651). Van Schalkwyk (1995:651) goes so far as to describe the social worker as a “vital member of the treatment team.” In Yvonne Ortega’s (2010:111) book about her journey through breast cancer, she gives the following account of her experience with a medical social worker:

How grateful I was that the hospital realized the value of a medical social worker. The fears, the disappointments, and all the other concerns that come with cancer didn’t seem overwhelming when I shared them with a person who could understand and encourage me.

11. Summary

From the discussion it is clear that cancer, from diagnosis to treatment can affect patients’ and their family’s lives. Cancer is an uncontrollable growth of cells that can be attributed to genetic factors, lifestyle issues or an unknown cause and affects all people from different countries in the world. Breast cancer is one of the most prevalent cancers found in women worldwide and the number of breast cancer cases being detected is on the rise.

Breast cancer treatment includes surgical intervention such as biopsy in the diagnosis and staging processes as well as lumpectomy and mastectomy. Radiation therapy is used to treat breast cancer, which involves daily doses of radiation and has side effects including skin problems and fatigue. Chemotherapy is administered to treat breast cancer and has severe side effects including hair loss, nausea, fatigue, infertility and infections which patients need to deal with. Lastly, breast cancer treatment also involves hormone therapy to treat cancer that is sensitive to the hormone oestrogen and causes premature menopause. The breast cancer patient and her family need to deal with the diagnosis of cancer, the treatment and side effects and their worries and fears associated with cancer. Due to the early detection and improved treatment plans, the amount of cancer survivors has increased as well. This confirms the need to deal with survivorship issues such as the fear of recurrence.

Cancer treatment can interfere with the roles people fulfil in their personal life, family life and work life. Role theory explains that roles are a fundamental element of life

and that society expects certain people to fulfil certain roles in set ways and when these roles cannot be completed it causes conflict in the person and social environment. Social functioning posits that people's functioning is linked to the roles that they fulfil in their daily lives. Role theory together with social functioning can help assess the experience of women with breast cancer.

The following chapter focuses on the research methodology and findings.

Chapter 3

Empirical Findings

1. Introduction

This chapter has a twofold goal. The chapter discusses the research methodology that was followed during the research process and a representation of the data collected according to themes is also given. Data is conveyed by quotes from the participants accompanied by the English translation in italics. The themes and sub-themes are interpreted and discussed.

The goal of the study was:

to explore the social functioning of women with breast cancer.

To attain the goal of the research study, the following objectives were pursued:

- ❖ To conceptualise the phenomenon of breast cancer, including diagnosis, treatment and recovery and aspects of the social functioning of women from the theoretical framework of role theory.
- ❖ To explore how breast cancer affects the functioning of a woman as an individual, mother and wife.
- ❖ To explore how breast cancer affects the functioning of a woman as a member of the community.
- ❖ To provide guidelines for social work practice with female breast cancer patients for health care social workers.

The research question is the core of the research study and all the research processes strive to answer the research question. Todres (2005:108) describes it as a “life-world-evoking question” where the experience of a life world is described as richly as possible. In the context of this study, the following research question was asked:

How does breast cancer affect the social functioning of women?

This question was demarcated into three specific areas which are the main themes of the study:

- ❖ The social functioning of women with breast cancer, within the context of their life world.
- ❖ The social functioning of women with breast cancer, within the context of their family.
- ❖ The social functioning of women with breast cancer, within the context of their community and environment.

2. Research methodology

2.1 Research approach

Because of the nature of the research topic, it was decided that a qualitative research approach will be used, as it enables the researcher to study the personal experiences of women living with breast cancer and how it affects their social functioning. With this approach the researcher used unstructured methods that allowed the study to evolve into unfamiliar directions and enabled the researcher to use a language that is sensitive and insightful in recording and relaying human experience. The researcher was afforded the opportunity to observe and study participants in their usual environment and could attempt to understand the phenomena of breast cancer in terms of the meaning women ascribe to it. With this approach it was possible to give each participant the opportunity to express themselves and not be restricted by rigid questions and in this way in-depth information was gathered. (Bless, Higson-Smith & Kagee, 2006:43-44; Denzin & Lincoln, 2011:3; Royse, 2011:269).

2.2 Type of research

Applied research is designed to put knowledge into action with the assumption that some group or society as a whole will gain specific benefits from it. Applied research can be “immediately useful” for organisations or programme goals (Babbie, 2011:26; Alston & Bowles, 2003:31; Monette, Sullivan & DeJong., 2002:5). Breast cancer can cause social issues in the lives of women and their families and there is a need for

intervention for those affected by this illness. Research can assess the social functioning of women with breast cancer within the context of the different roles these women fulfil and practical issues that they deal with while receiving chemotherapy. This study expands the knowledge of social workers and other professionals in the oncology field and assists them in their work with patients living with breast cancer. For this reason, this study falls into the category of applied research.

3. Research methods

3.1 Research design

A case study research design was followed in order to establish a comprehensive understanding of how people make meaning of a single instance of social phenomenon. Collective case studies were used so that a comparison could be drawn between the experiences of women living with breast cancer. By exploring different aspects of social functioning, using collective case studies, the researcher was able to find similarities and differences between how women experience breast cancer. The concrete experiences of women with breast cancer was compared (Babbie, 2010:309; Nieuwenhuis, 2007a:75; Fouché, 2005:272; Flick, 2000:147).

3.2 Population, sample and sampling method

3.2.1 Population

A population is the “total number of units from which a sample is selected” (*New Social Work Dictionary*, 1995:45). The population in this study was made up of women who have been diagnosed with breast cancer and are receiving chemotherapy for the disease, as well as receiving services from CANSA Potchefstroom, North West Province.

3.2.2 Sampling method and technique

Non-probability sampling, specifically, purposive sampling was used in order to meet the specific criteria of the study. In purposive sampling, it is believed that a particular group is important to the study because they hold the data necessary to perform the study and the participants must have specific homogeneous characteristics (Royse,

2011:204-205; Nieuwenhuis, 2007a:79; Alston & Bowles, 2003:90). The criteria for the women were as follows:

- ❖ Between the ages of 30-70 years.
- ❖ Diagnosed with breast cancer.
- ❖ Currently or recently undergone surgical, radiation or chemotherapy treatment for the disease.
- ❖ Residing in the Potchefstroom area.
- ❖ Currently part of the client system of CANSA Potchefstroom.

The director of CANSA Potchefstroom provided the researcher with contact details of women who fit the criteria. The first 10 women whom the researcher contacted and who met the criteria were selected. They were invited for an interview where the researcher explained the research study by means of a letter of informed consent. Once they had signed, the interviews were arranged.

3.2.3 Sample

A sample is a small subset of the population which is selected to be studied because it is impractical to research the entire population (Nieuwenhuis, 2007a:79; Kirk, 1999:367). A sample of 10 women was selected for this study and after the interviews were completed, the researcher was realised that data saturation has been reached.

3.3 Data collection method

Interviewing is a method of gathering personal and social information by asking questions during a dialogue and specific topics are pursued (Babbie, 2011:340; Jupp, 2006:157). Face-to-face interviews using semi-structured interviews were used as the data collection method for the study. The semi-structured interview gave a detailed picture of the women's lives while they are living with breast cancer. It gave the researcher flexibility to probe and explore as the interview takes new directions and the interview could be guided by the researcher (Greeff, 2011:351-352; Nieuwenhuis, 2007a:87). Face-to-face interviews with eight participants from CANSA were conducted using semi-structured interviews. These interviews were held (with only the researcher and the participant present) at the participants' homes, at a

predetermined time that suited the participants. An interview schedule guided the interviewer when conducting an interview (Fowler, 2004:518). Themes in the interview schedule focused on the social functioning of women with breast cancer. The primary theme was divided into three categories: social functioning in her life world, social functioning in her family and social functioning in her community and environment. In terms of life world, sub-themes focused on her relationship with herself, her relationship with her family as a mother, daughter, wife and caregiver and lastly the relationship with her work, friends and community. Interviews were recorded with an electronic voice recorder with the permission of the participants and were transcribed afterwards. The pilot testing interviews were transcribed by the researcher but the main study interviews were transcribed professionally with the verbal permission of the participants. The recordings and transcriptions will be kept in storage at the University of Pretoria, Department Social Work and Criminology, for 15 years.

Monette et al. (2002:9) describe a pilot study as a small-scale dress rehearsal of all the procedures planned for the main study. Within a qualitative research approach, a pilot study is used to test the questions/themes of an interview schedule to ensure that the necessary data can be gathered (Strydom & Delpont, 2011:395). The pilot study tested the interview schedule to ensure that the questions/themes elicit an appropriate response from participants. Two participants were sampled in the same way as the main study and they met the same criteria. They were interviewed using the semi-structured interview schedule to test the data collection instrument and these participants were not part of the main study. Corrections were made to the interview schedule, venue, settings on the voice recorder, time taken to conduct interviews, quality of recordings, the interview process and method of transcription of interviews as relevant issues arose from the pilot testing.

3.4 Methods of data analysis

Data analysis unlocks the information that is hidden in raw data and converts it into something significant. Coding entails placing observations in categories this develops during the data collection with the purpose of simplifying words and their meanings in order to measure and develop a theory (Monette et al., 2002:9; 442-443). The data collected from the semi-structured interviews were transcribed and coded according to themes that arose from the interviews.

3.4.1 Steps in data analysis

Schurink, Fouché and De Vos (2011:403) combined the theories of Cresswell and Marshall and Rossman to create a linear process of data analysis which the researcher used during the research process. To explicate the process, the steps are combined according to the outline described by Schurink et al. (2011:403-419):

- ❖ Planning for recording data, data collection and preliminary analyses

During the first phase of data collection, the researcher developed a unique plan for recording data that is appropriate for the study (Schurink et al., 2011:404). Data was recorded using an electronic voice recorder along with field notes made by the researcher during the semi-structured interviews with participants. The recordings were transcribed and notes were typed to make reading easier. As data was collected from participants, preliminary analysis took place in order to evaluate the data that was collected. This guided the questions and probing of the researcher and assisted in reaching saturation point in data collection.

- ❖ Managing data and reading

Field notes and transcriptions of each interview were organised together so that a holistic view of experiences of breast cancer could be formed. Data was organised into computer files as well as hard copies in folders. The transcriptions and field notes of each interview were read as a whole to gain a complete picture of the phenomenon. An electronic version of the data was saved on a separate storage device to ensure that data will not be lost. To gain insight the data was thoroughly examined. Notes were made during this process which assisted the researcher in the next step (Todres, 2005:112).

- ❖ Generating categories, themes and patterns and coding data

In this step, the researcher developed patterns from the data. It is a synthesis of the meaningful units into themes that are present in the different experiences of the participants (Todres, 2005:113). Themes were subdivided into units of analysis which are more comprehensible. These themes were divided into three main themes that included the social functioning of women in terms of their life world; social functioning of women in terms of their family and the social functioning of women in terms of their community. Once these categories and themes were generated, the

researcher coded each theme in each transcript. Using specific colours for a theme was the most effective way of coding the data.

❖ Testing understandings and searching for alternatives

The researcher challenged the themes that seemed evident (Schurink et al., 2011:416). During this process, the researcher tested preconceptions about the field and data. New insights were made, misconceptions changed and some concepts were strengthened. When understandings were challenged, the researcher searched for alternative meanings and explanations. This elicited critical thinking and a literature review to make sense of new findings.

❖ Representation

The purpose of representation is to communicate the collected data of the research process (Neuman, 2011:550). This was the last step in the data analysis process where the coded data was organised in a written form. Visual representations such as tables were used to make logical sense of information, categories and sub-categories.

3.4.2 Trustworthiness

In order to ensure **trustworthiness of data**, findings were confirmed with participants (Nieuwenhuis, 2007b:113-114). The researcher used clarification in an information session to confirm findings with participants. These interviews were conducted after the initial interviews were transcribed and themes had been generated. The truth value of data, as described by Lincoln and Guba in De Vos (2005:346-347), is established by the following four aspects: credibility, transferability, dependability and conformability. The **credibility** of data is established by a number of complex of variables (such as the experiences of the participants) that are supported by the data collected and **transferability** of data is created by consulting and comparing the findings of similar studies done in different contexts. **Dependability** of data rests on certain assumptions (such as the typical roles that women fulfil) and means that due to a changing social world, a study cannot be replicated (De Vos, 2005:346). The last aspect, **conformability**, asks the question “does the data help confirm general findings?” which was assessed after

data was collected (De Vos, 2005:347). From the representation, descriptions were made and conclusions were drawn.

4. Ethical issues

Ethics pertain to the ways in which a person should behave. Ethical concerns in health care are normative in nature and relates to the way a researcher ought to act (Iphofen, 2005:17). The following ethical issues were taken into consideration during this research study:

❖ Informed consent

Informed consent is a fundamental ethical right which entails that participants must become aware of what they are getting involved in by reading and signing a statement, thereby giving informed consent (Neuman, 2003:124). The letter of informed consent was compiled by the researcher and stipulated the goal, objectives and procedures of the study, including the use of a voice recorder and the possibility of further research in the future. This guaranteed that participants were informed about the process and ensured confidentiality in the study. This letter was signed by the participants voluntarily in order to include them in the research study.

❖ Confidentiality, anonymity and privacy

Privacy refers to the participants' right to have control over when, where and to whom they share their beliefs, values or behaviours. Anonymity means that no one can link the participant with the data that they provided. Confidentiality means that data collected will not be made public in a way that can link the individual with the data offered and limits others' access to the private information (Monette et al., 2002:59-60; Strydom, 2011:119-121).

The anonymity of the population was ensured through the sampling process. The participants remain anonymous to each other and to others, but not to the researcher. The head of CANSA Potchefstroom was trained by the researcher to assist in the sampling of participants. The head of CANSA Potchefstroom assisted the researcher in recruiting participants through the purposive sampling method and kept the identities of the patients who did not want to participate, anonymous. The selected participants' confidentiality was ensured as their names were not used, and

only the researcher knows which set of data is linked to which participant. The researcher assigned numbers for each participant in the transcriptions. Privacy was ensured by allowing the participants the freedom to keep certain information to themselves and not forcing them to share information that they were not comfortable with sharing.

❖ Deception of participants

Deception of participants was avoided by adopting the principle of transparency, which entails being free from pretence (*Merriam Webster Dictionary*, 2010). Monette et al., (2002:58) sites Erikson in his expression that deception should be avoided at all costs seeing that it is unethical to consciously deceive another human being. Participants were made aware of the purpose of the study, how data will be collected and what will be done with the data and final research writings. An opportunity was also given for any questions at the beginning, when the letter of consent was explained, during and after the research process so participants could have clarity about the project.

❖ Debriefing of participants

Debriefing is used to give participants an opportunity to work through their experiences in order to minimize any possible harm caused by the research process (Strydom, 2011:122). After completion of data gathering, a debriefing interview was conducted with each participant to ensure that their emotional needs are met. This was the last opportunity for participants to ask questions and have their emotions heard. If a need for counselling was observed or verbalised, counselling services were made available by the CANSA staff or by Dr. Humpel, a health care social worker at Potchefstroom Hospital. After completion of the research paper, the findings were made available to all participants as well as CANSA Potchefstroom.

❖ Harm to participants

Psychological or emotional harm can be caused in qualitative interviews where emotional and personal information is shared. Participants were asked to share information that is uncomfortable to share or can endanger their family life, friendships or jobs (Babbie, 2011:68). Harm cannot be prevented but the researcher did observe participants during the data gathering process for distress and ensured

that participants understood that they can express any distress. Participants were informed that they are allowed to withdraw from the interview at any time (Iphofen, 2005:31). Participants were debriefed after the interviews, but if distress was observed or expressed, participants were referred to the head of CANSA Potchefstroom who would assist patients with an opportunity to connect with their group counsellor. Emotional distress was observed with one participant and this was followed up by counselling from a social worker at Potchefstroom Hospital.

5. Research findings

This section is a representation of the data that was collected during the research process. Data that is presented in the form of a profile of the participants and a thematic analysis of the themes generated from the researched.

5.1 Profile of participants

The demographic information of the participants is described in the following table:

Table 2: Demographic of participants

Participant	Age	Relationship status	Children	Grandchildren	Employed
1	68	Married	Yes	Yes	No
2	62	Married	Yes	No	No
3	57	Married	Yes	Yes	No
4	41	Divorced and in a relationship	No	No	Yes
5	64	Married	Yes	Yes	Yes
6	69	Divorced	Yes	Yes	Yes
7	37	Single	No	No	Yes
8	70	Married	Yes	Yes	No

The participants' ages range from 37 to 70 with the average age being 58.5 years old. Five participants are married, one is in a relationship, one is divorced and one single. Six of the participants have children and five have grandchildren. Four participants were employed at the time of the interview.

All participants were diagnosed with breast cancer and some had breast cancer that had metastasised to other areas of the body. The diagnosis and treatment options of the participants are described in the following table:

Table 3: Diagnosis and treatment options

Participant	Diagnosis	Surgery which includes biopsy, lumpectomy and mastectomy	Chemotherapy	Radiation therapy	Hormone therapy
1	Metastasised breast cancer	√	√	√	√
2	Metastasised breast cancer	√	√	√	-
3	Metastasised breast cancer	√	√	√	√
4	Breast cancer	√	√	-	√
5	Breast cancer	√	-	√	√
6	Breast cancer	√	-	√	-
7	Breast cancer	√	√	√	-
8	Breast cancer	√	-	√	√

All participants received some form of surgery including biopsy, lumpectomy, lymph node removal and mastectomy. Five participants received chemotherapy and seven received radiation therapy. Five participants were receiving hormone therapy at the time of the interviews. The profiles of the participants show similarities and differences and this helped to put the data collected in perspective.

5.2 Themes and sub-themes

Research findings are discussed according to the themes that were identified and divided into sub-themes and then a thematic analysis is done. Verbatim quotes are

used from the transcribed interviews to support these themes, which are also substantiated with literature from chapter two.

Table 4: Themes and sub-themes of research

Themes	Sub-themes
Cancer This theme explored different aspects of cancer including the participants understanding of cancer, their feelings at the time of diagnosis and treatment as well as the side-effects experienced during treatment.	Understanding cancer Feelings at time of diagnosis Feelings during treatment Side-effects experienced
Social functioning in the context of life world	Changes experienced in personality Feeling like a woman Changes experienced with regard to spiritual aspects Changes with regard to self-image
Social functioning in the context of family	Changes in relationship with significant other Changes in sexual identity Changes in role as mother Changes in role as caregiver Changes in role as daughter Changes in role in extended family
Social functioning in the context of community	Changes experienced in work life Changes experienced as a community member Changes experienced in social network

5.2.1 Theme 1: Cancer

This section focuses on the aspects of cancer including the participants' understanding of cancer, their feelings at the time of diagnosis and treatment and how they experienced the treatment's side-effects.

❖ *Sub-theme 1.1 Understanding cancer*

Many participants' understanding of cancer was that it is a common illness and something that can be treated.

“algemene siekte van die dag”/ *“common illness of the day”*

“dis deesdae so algemeen”/ *“nowadays it’s so common”*

“dis nog steeds vir my ‘n siektetoestand wat dringend aandag nodig het”/ *“to me, it’s still an illness that urgently needs attention”*

“oorwinbaar”/ *“beatable”*

“dis behandelbaar, afhangende van hoe vroeg dit is”/ *“it is treatable depending on how early it is”*

This is contrary to the research by Venter (2008:23) where participants stated that being diagnosed with cancer is a death sentence and that if you have cancer you die. One participant described cancer as “onnodig”/“unnecessary” and after the interview was completed, that people “romanticise cancer”, but another participant had a more positive outlook on cancer, describing it as:

“siekte om te hê maar ek dink daar is wat baie erger is en soos ek voorheen vir jou gesê het, my ervaring van die kanker was nie alles negatief nie”/ *“an illness to have but I think there are things that are worse and like I said to you before, my experience with cancer wasn’t all negative”*

The participants that had metastasised cancer knew their staging but other participants only knew they were diagnosed with breast cancer. They did not know their staging but did know the size of the tumour removed. Knowledge of cancer staging assists with understanding and helps patients and families to be realistic. People need information regarding the meaning of being diagnosed with cancer and such detailed information helps to alleviate fear (Venter, 2008:29).

Overall, participants did not link cancer with death but rather saw it as a manageable illness and chose to take positive things out of the cancer experience. This does, however, not mean that there aren’t intense emotions linked with the diagnosis of cancer. The diagnostic phase is marked by shock, uncertainty, disbelief, fear and numbness (Edwards & Clarke, 2004:562; Fitch et al., 1999).

❖ *Sub-theme 1.2 Feelings at time of diagnosis*

Literature shows that people experience intense feelings at the time of diagnosis. Most of which is shock or denial (Edwards & Clarke, 2004:562; Fitch et al., 1999; Friedman et al., 2006:595; Montgomery & McCrone, 2010:2388). The participants expressed their feelings at the time of diagnosis as follows:

“mens is maar verpletter”/ *“you are crushed”*

“jy is geskok, dis nie iets wat jy regtig wil hoor nie”/ *“you are shocked, it’s not something that you really want to hear”*

“blunt”/ *“blunt”*

“geskok, hartseer, emosioneel”/ *“shocked, sad, emotional”*

“ek kon dit nie glo nie omdat daar geen familie geskiedenis is van kankers nie”/ *“I couldn’t believe it because there is no family history of cancer”*

From the quotes, it is clear that participants experienced a mixture of emotions that can be overwhelming at times. Most of the emotions were shock, disbelief and sadness. This is similar to research that found shock, disbelief, anger, numbness, depression and devastation at the time of diagnosis (Fitch et al., 1999). During the diagnosis participants had to undergo a biopsy which is associated with emotional turmoil and the diagnostic phase was shown to interfere with daily living and their ability to receive important health care information (Montgomery & Crone, 2010:2388). One participant experienced different emotions with regard to her diagnosis.

“Ek het dit aanvaar. Ek was, ek het myself eintlik positief gemaak deur te sê dis iets van my wat ek, dit gaan my nie iets doen nie, jy weet. Dit sou erger gewees het as dit my arm of my been of my oog of iets moes gewees het.”/

“I accepted it. I was, I made myself positive through saying it’s something of mine that, it’s not going to do something to me, you know. It would have been worse if it was my arm or my leg or my eye or something.”

The experience of cancer and diagnosis is a subjective one and as in the case of this one participant, she chose to be positive and consider that there are worse things that could have happened to her. This mind set is shared by research performed in China where women want to make the best of their cancer diagnosis and cancer treatment (Fu, Xu, Liu & Haber, 2008:158).

Two participants were confronted with the concept of death. The one participant has stage IV cancer that metastasised to the skeleton. Early stage breast cancer has a

better prognosis and stage IV cancer is advanced cancer with a poorer prognosis. (American Joint Committee on Cancer, 2010).

“’n Mens moet rasideel wees. En my tellings het bly opgaan, dit het darem nou weer ‘n bietjie af gegaan. So dit wys vir jou die siekte vererger, of dis nog nie heetamal onderdruk nie...so jy weet, jy moet aan die dood dink.”/

“A person has to be rational. And my counts kept going up, lately it did go down a bit again. So it goes to show that the illness is worsening, or it’s not completely suppressed yet...so you know, you have to think about death.”

When discussing the spiritual aspect, this respondent stated that:

“mens lees meer oor die dood en goed op”/ *“a person reads more about death and stuff”*

Another respondent was not diagnosed with terminal phase cancer, but was still confronted with the concept of death.

“Mens dink mos nou maar aan baie dinge, kinders, kleinkinders, ek dink aan hom (man), hoeveel jaar het jy nog oor, wat gebeur hierna.”/ *“A person thinks about a lot of things, children, grandchildren, I think about him (husband), how many years do you have left, what’s going to happen after this.”*

This participant also expressed fear of recurrence and according to research by Vivar et al. (2009:726) the fear or recurrence is the most frequently expressed emotion among cancer survivors.

“’n Mens wonder nou maar, jy weet. Oktober gaan ek weer vir my mammogram, so, dit bly mos nou maar hier (wys na agterkop – gebaar wat verwys na onderbewuste), jy weet...jy het ‘n siekte wat ‘n probleem is, wat vir jou vorentoe ‘n probleem kan wees, so...”/

“A person wonders, you know. October I’m going for my mammogram again, so, it stays right here (indicates to back of head – gesture that implies the subconscious), you know...you have an illness that is a problem, that can be a problem for you in the future, so...”

This fear can be based on the medical diagnosis of terminal stage cancer or on a subjective fear regarding cancer apart from staging and prognosis. This is confirmed by the literature review Edwards and Clarke (2004:564) where the perceived seriousness of an illness is linked to stress and anxiety.

❖ *Sub-theme 1.3 Feelings during treatment*

The time when a person receives treatment can be a time consuming process as well as a time marked by uncertainty with regards to treatment related side-effects. Some participants experienced intense emotions when receiving treatment:

“gehuil”/ *“cried”*

“daai sense of loss”/ *“that sense of loss”*

“dit is maar ‘n bietjie traumaties om te gaan vir ‘n operasie”/ *“it is a bit traumatic to go for an operation”*

“onsekerheid”/ *“uncertainty”*

“‘n groot hap uit jou lewe uit gevat”/ *“took a big bite out of your life”*

“geskok...ongeloof”/ *“shocked...disbelief”*

Treatment starts so quickly that it leaves little time for psychological adjustment to the cancer diagnosis (Coyne & Borbasi, 2009:11). There are a lot of negative emotions and experiences linked with receiving cancer treatment. Participants feeling uncertain, shocked, traumatised or having a sense of loss. Treatment has the ability to impact the emotional and practical aspects of a person’s life (Forrest et al., 2009:101). But other participants had positive experiences:

“wat moet ek hieruit leer...vaste sekerheid gehad van daars ‘n groter prentjie, waar dit inpas”/ *“what must I learn from this...firm belief that there’s a bigger picture that this fits into”*

“vreeslik kalm...[geweet] presies wat met my gaan gebeur, was ek baie rustig en baie kalm”/ *“very calm...[knew] precisely what would happen to me, I was very peaceful and very calm”*

“daai rit Klerksdorp toe was vir my so salig”/ *“I experienced that ride to Klerksdorp as very serene”*

“ek het vrede gemaak daarmee”/ *“I made peace with it”*

“aanvaar dinge”/ *“accept things”*

These participants felt calm because they knew what was coming or made peace with the circumstances they were in. Choosing to see the experience as part of the bigger picture or taking a moment to rest on the way to treatment were strategies used by the participants to cope with cancer treatment. Research has shown that successful cancer coping strategies include communication, complementary therapies and involvement in spirituality (Knott, Turnbull, Olver & Winefield, 2012:557).

❖ *Sub-theme 1.4 Side-effects experienced*

The side-effects experienced by the participants varied in type and intensity. Six participants experienced fatigue, five experienced nausea, five lost their hair and four experience skin problems. Other side-effects experienced include being prone to infections, change in taste, sensitive eyes, headaches, pain, constipation, memory problems and hot flushes due to the hormone treatment. Research shows that chemotherapy can affect a woman’s daily functioning (Prigozin, Uziely & Musgrave, 2010:417). Participants experienced the symptoms as follows:

“dit krap jou hele lewe om, jy kan nie doen wat jy voorheen gedoen het nie”/ *“it disrupts your whole life, you can’t do what you used to do before”*

“die simptome was, dit was, dit was vicious”/ *“the symptoms were, it was it was vicious”*

“dit het ‘n groot impak in mens se lewe”/ *“it has a big impact on a person’s life”*

“baie onaangenaam”/ *“very unpleasant”*

“mens moet aanpassings maak...sulke aanpassings is die grootste wat mens moet maak, jou fisiese vermoëns”/ *“a person has to make adjustments...such adjustments are the biggest a person has to make, your physical abilities”*

One participant expressed her negative experience with the side-effects of the hormone treatment stating that:

“die hormoonbehandlings het ‘n moerse invloed op jou...menopause...hot flushes maak my dood”/ *“the hormone treatments have a huge impact on you...menopause...hot flushes kill me”*

One participant had an issue with being naked in front of people and the breast cancer treatment required of her to take her clothes off for different medical personnel which she found difficult.

“So een van die simptome wat ek vir myself ook elke dag moes sê is maar kom net oor dit, om elke dag jou klere uit te trek. Veral met, die bestralingspersoneel het ook gewissel. So dit was nie konstant dieselfde mense nie, so een van die simptome vir my was nogal, jy weet, kom net oor daai skaam gevoel van naaktgeid voor ander mense.”/

“So one of the symptoms that I had to say to myself ever day was just get over taking your clothes off every day. Especially with, the radiation personnel kept changing. So it was not constantly the same people, so one of the symptoms for me was, you know, just to get over that shy feeling of being naked in front of other people.”

The side-effects experienced throughout the process were negative and disruptive to their lives. The side-effects of the breast cancer treatment had a greater influence on the person than the cancer itself. Patients will have to manage numerous side-effects at a time and learn to adjust in the short and long term (Kulik & Kronfeld, 2005:38; Semple & McCance, 2010:1285).

❖ Discussion of theme 1

Participants saw cancer as a common and manageable illness but two participants had negative meanings associated with cancer, specifically with death and recurrence. This is a subjective experience seeing that two other participants had metastasised cancer but did not consider death.

Participants had mixed emotions with regard to cancer diagnosis and treatment such as shock, denial and sadness but in the midst of these emotions they were able to

have a positive outlook. The side-effects of the treatment was experienced as negative by all participants but this depended on the severity of the side-effect.

5.2.2 Theme 2: Social functioning in the context of life world

This theme is focused on the participant herself and her personal experience with cancer. This theme is divided into four sub-themes namely changes in personality; feeling like a woman; changes in spiritual aspect and self-image.

❖ *Sub-theme 2.1 Changes experienced in personality*

A person's identity can be described as follows (Little, Paul, Jordens & Sayers, 2002:171):

[the] sense of being *this* person, with attributes, acquisitions and capabilities which condition interactions between the person and the social systems in which he or she lives.

Participants were given the opportunity to discuss the possible changes that they experienced in their personality.

“Jy worry nie meer so erg oor klein nitty gritty stuff nie, waaroor jy jou gewoonlik sou ontstel het of iets...don't sweat the small stuff.”/ “*You don't worry so much about the small nitty gritty stuff anymore, stuff that would normally have upset you or something...don't sweat the small stuff.*”

“Ewe skielik is ander goeters net nie belangrik nie. Daar is belangriker dinge in die lewe.”/ “*All of a sudden other stuff is not as important. There are more important things in life.*”

“nie meer krag en genade vir verspottigheid en vir kleinlikheid nie”/ “*don't have the energy and grace for silliness and pettiness*”

All eight participants confirmed that the breast cancer diagnosis and treatment impacted their personality. Some felt that they started focusing more on the important things in life. Participants' stated that they had no more grace for petty things and this supports the discussion by Bell (2009:43) who stated that pain or illness had a way of making people honest. The realisation of mortality cause self-awareness which leads people to find courage, strength and self-expression (Carpenter, Brockopp & Andrykowski, 1999:1405-1406). These changes are

supported by research that found that after a period of contemplation, people are able to make positive lifestyle shifts within family values and priorities in life (Semple & McCance, 2010:1286).

Other participants felt that breast cancer made them more emotional people:

“raak depressief”/ *“get depressed”*

“sagte persoon en ‘n emosionele persoon”/ *“soft person and an emotional person”*

“bietjie meer emosioneel”/ *“a bit more emotional”*

Some participants experienced the emotional change as positive but there was one participant that saw this shift in a negative light and stated that she feels “morose”. Cancer can bring about personal growth such as appreciating the small things in life, being able to see positive things in negative experiences, being less critical towards others and realising what is important in life (Venter, 2008:24). Changes in personality can mean that there are changes in how a person perceives his/her roles or chooses to fulfil those roles. As the description of identity given above explains, an identity influences a person’s interaction with the social system (Little et al., 2002:171).

❖ *Sub-theme 2.2 Feeling like a woman*

All the participants felt that they were still women throughout the process of cancer treatment and that the diagnosis and treatment didn’t change their identity as women.

“dit (borskanker) het glad nie my, my vroulikheid aangetas nie”/ *“it (breast cancer) dit not affect my, my femininity at all”*

“[‘n] vrou is soos ‘n porseleinpop...ek dink ek is nou ‘n beter porseleinpop”/ *“[a] woman is like a porcelain doll...I think I’m a better porcelain doll now”*

“voel meer soos ‘n vrou”/ *“feel more like a woman”*

The findings of this study are contrary to those of other studies that depict the loss of femininity and sexuality experienced by women who lose their breasts due to breast cancer intervention (Klaeson & Berterö, 2008:188; Skrzypulec et al., 2008:614). On

the question of ‘what is a woman?’ the one participant stated very adamantly “definitief nie net twee tieties nie”/“*definitely not just two breasts*”. Because the participants did not experience a change in their identity as women, it would not change their fulfilment of roles linked with being women.

❖ *Sub-theme 2.3 Changes in spiritual aspects*

Seven of the eight participants belong to the Christian faith and felt a change in their spiritual lives. One participant is not of the Christian faith but stated that she is spiritual but did not experience any change in the spiritual aspect of her life.

“betoen meer dankbaarheid”/ *“show more thankfulness”*

“my geloof het baie sterker geword”/ *“my faith became a lot stronger”*

“verdieping in my geestelike aspek...op ‘n ander geestelike vlak”/ *“deepening in my spiritual aspect...on another spiritual level”*

One of the participants expressed, that even when she is fighting with God, it is also part of growing in her spiritual life.

“n Mens het nou maar bietjie nader gegaan en jy weet, vra hoekom, jy weet, en baklei...ek het baklei met die Here.”/ *“A person does go closer and you know, ask why, you know and fighting...I did fight with the Lord.”*

Another participant felt that the spiritual aspects were an important part of coping with cancer and believes that all people need God in their lives. People can draw strength from their faith or relationship with God which positively affects their ability to cope (Venter, 2008:27). Religious coping predicts changes in psychological adjustment with patients diagnosed with breast cancer (Gall, Guirguis-Younger, Charbonneau & Florack, 2009:1173). This is confirmed by research by Venter (2008:27-28) where cancer patients also expressed a deepening in their spiritual life and see religion was a way of coping with cancer. A literature review by Lin and Bauer-Wu (2003:78) shows that positive psycho-spiritual well-being leads to hope and “meaning in life” for patients diagnosed with cancer.

❖ *Sub-theme 2.4 Changes with regard to self-image*

Self-image can be affected by cancer treatments due to the physical impact of surgery, chemotherapy and radiation therapy. Some participants experience a change, either positive or negative while others didn't experience any changes.

"bietjie leliker geword"/ "became a little uglier"

"...daarom dink ek het ek 'n bietjie 'n swakker selfbeeld, omdat ek nou emosioneel ook raak"/ "...that's why I think I have a bit of a weaker self-image, because now I get emotional"

"dis 'actually' beter...want jy voel jy't iets oorkom"/ "it's actually better...because you feel you have conquered something"

"in 'n positiewe manier...soveel komplimente gekry oor my haarstyl...vreeslike boost gekry"/ "in a positive way...got so many compliments about my hairstyle...got a great boost"

Some participants felt that they are uglier due to the side-effects of treatment, whether it was physical or emotional changes, but some felt a positive change due to the side-effects of treatment. Feelings that you've overcome something or receiving compliments from strangers influenced the participants' self-image.

Some participants' way of coping with the physical changes was wearing a wig or changing their clothes or making an effort with make-up.

"Maar ek probeer nou, jy weet, my netjies aantrek...die pruik ook. Dit help jou om meer normal te voel."/ "But now I'm trying, you know, dress neatly...the wig as well. It helps you to feel more normal."

"pas maar net die styl van jou klere aan"/ "you just adjust the style of your clothes"

"Ek het net besluit ek gaan nie, ek gaan nie die pruik opsie vat nie, dit gaan my uhm, dit gaan nie vir my werk nie. Maar ek het, voor die tyd het ek sekere keuses geneem van ek gaan dan my grimering bietjie aanpas en my juweliersware en alles."/ "I decided that I'm not, I'm not going for the wig option, it's going to make me uhm, it's not going to work for me. But I did"

make certain decisions beforehand, that I'm going to adjust my make-up a bit and my jewellery and everything."

Some participants expressed no changes in their self-image stating that they don't feel different.

"nee ek voel nie anderste nie"/ "no I don't feel different"

"nog dieselfde"/ "still the same"

What can be deducted from the sub-theme of self-image is that not everyone has a change in their self-image, but that if there is a negative change, there are things that can be done to a person's appearance to assist in self-image issues. This is somewhat contradictory to research by DeFrank, Mehta, Stein and Baker (2007:4), which indicated that 16-54% of women reported a dislike of their body image. Because of the feelings of shame and embarrassment as well as changes in sexual functioning and intimacy that is associated with changes in body image, it is an important issue to be assessed and addressed (Kayser & Sormanti, 2002:404; Venter, 2008:26).

❖ Discussion of theme 2

All participants experienced a change in their personality, most of which was either becoming more emotional or focusing on the important things in life. The spiritual life of participants improved and deepened which is also an aspect of their lives that assists in coping with the cancer. Participants did not experience a change in their self-concept regarding their femininity but some did experience a lowered self-image. Loss of hair can have a negative effect on a person's self-image but due to either wearing wigs or positive feedback from the community, it did not weigh down the participants' self-image.

5.2.3 Theme 3: Social functioning in the context of family

Theme 3 is about the social functioning of participants in their family. This theme is divided into six sub-themes namely changes in the relationship with their significant other, changes in sexual identity, changes in role as mother, changes in role as caregiver, changes in role as daughter and changes in roles linked with extended family.

❖ *Sub-theme 3.1 Changes in relationship with significant other*

Six participants were in relationships at the time of the interviews. All participants experienced their significant other as being supportive.

“baie supportive gewees”/ “was very supportive”

“hy’t my baie moed ingepaat en geondersteun”/ “he was very encouraging and supportive”

Some experienced their relationship with their significant other as becoming better through the cancer diagnosis.

“dit het ook verdiep”/ “it also deepened”

“maar ons is nou nog nader aan mekaar”/ “but we are now closer to each other”

Although the significant others were supportive of the women with breast cancer, it was a difficult experience for them as well. When participants were asked how their husbands were taking the diagnosis, they replied:

“baie sleg, dis nog steeds vir hom ‘n probleem”/ “very bad, it is still a problem for him”

“hys nogal ook bekommerd oor my dink ek”/ “he’s worried about me too, I think”

Cancer not only affects the woman but her significant other as well and this should not be overlooked when dealing with families of people who are diagnosed with cancer. It was found that significant others experienced trauma at the diagnosis of cancer and experienced fear at the idea of losing their loved one (Lethborg, Kissane & Burns, 2003:80). Even small things that seem insignificant can influence the relationship as one respondent stated after the interview was completed, that because she is prone to infections, her husband has to be extra careful not to get sick because then he will make her sick as well.

One participant found it difficult to understand her husbands’ experience because he is not a talkative person and she is unsure what he is thinking about and this makes her worry. Her feelings are supported by research that found expressiveness in

families to be linked with lower levels of depression and conflict (Edwards and Clarke, 2004:570).

“Jy weet nie wat in my man se kop aangaan nie. Hy sê hy’s oraaï, maar ek meen, ek weet nie hier nie...ek is nogal bekommerd, wat in sy kop aangaan...ons het nie ‘n clue wat in mekaar se koppe aangaan nie.”/

“You don’t know what’s going on in my husband’s head. He says he’s fine but I mean, I don’t know here...I am relatively concerned, what is going on in his head...we don’t have a clue what’s going on in each other’s heads.”

Although a cancer diagnosis is difficult to deal with, the support offered by the significant others encourage and carry the participants through the difficult times of diagnosis and treatment. When women feel supported it impacts their ability to navigate their role as a cancer patient (Hirschman & Bourjolly, 2005:18). The support from the significant others assisted the participants in maintaining their role as wife in the relationship. Research shows that breast cancer in itself is not a risk for relationship distress but the coping strategies used by the couple is a factor that can cause relationship problems (Hinnen, Hagedoorn, Ranchor & Sanderman, 2008:750).

❖ *Sub-theme 3.2 Changes in sexual identity*

Most of the participants did not experience any changes in their sexual identity, including the participants who have undergone mastectomies.

“Ons het altyd ‘n baie goeie seksuele verhouding gehad, en dit, dit gaan nog steeds so voort, maar net minder dikwels.”/ *“We always had a very good sexual relationship, and it, it still continues, just less frequen.t”*

“My seksuele identiteit het nie verander nie. Dis net ‘n mens se seksuele funksionering word geaffekteer.”/ *“My sexual identity didn’t change. It’s just that a person’s sexual functioning its affected.”*

“In die begin, ‘n ou was moeg en goeters gewees maar ek bedoel my man verstaan dit en soos ek sê, jou antidepressante is ‘n onderdrukker so van beide kante pla dit ons nou nie.”/ *“In the beginning, one tired and stuff but I*

mean, my husband understands that and like I said, the antidepressants are a suppressor so it doesn't bother us from both sides."

Cancer treatment did affect the sexual functioning and energy of the participants but it didn't change their sexual identity. This is contrary to research that indicated that women with breast cancer feel less attractive, that their sexual identity is threatened and that the husbands' response to the loss of a breast was a large indicator of marital distress (Mak Wai Ming, 2002:28). But the research by Klaeson and Berterö (2008:191) shows that 5 out of 6 women in their study had improved intimate relationships after cancer diagnosis. Their significant others were supportive and understanding and as the one respondent stated regarding their sex life:

"het daaronder gely, ja, maar dit het nie tot sitlstand gekom nie"/ "did suffer, yes, but it didn't come to a standstill"

Participants and their significant others were able to navigate the consequences of cancer treatment on the sexual front, make adjustments and still continue with a healthy sex life. Cancer treatment has harmful effects on sexual functioning and part of adjustment is for patients to differentiate between sexuality and physical sexual abilities or performance (Monga, 2002:288-290).

❖ *Sub-theme 3.3 Changes in role as mother*

Six participants had children and of those, most relationships were supportive and the relationships improved. The participants were able to maintain their role as mother and grandmother within the family system.

"ek is nog ma en ek is ouma"/ "I'm still mom and I'm still grandmother"

"hulle is baie baie baie naby nou"/ "they are very, very, very close now"

"hulle het my baie ondersteun"/ "they supported me a lot"

Some of the children experienced very strong emotions regarding the diagnosis

"skok"/ "shock"

"hy (seun) was nogal bietjie opgestres"/ "he (son) was a little stressed"

"dis vir hulle moeilik om te aanvaar"/ "it is difficult for them to accept"

One participant explained that due to her son not talking about how he experiences her cancer diagnosis, it makes things difficult for her.

“hy praat nie, so ek weet ook nie wat in sy kop is nie”/ “he doesn’t talk, so I don’t know what is in his head”

This caused her to feel that she doesn’t want to upset her son therefore she decided to pretend to be strong. This is not a new tendency because women are prone to “be strong” in an attempt to maintain normalcy in the family system (Coyne & Borbasi, 2009:11).

“...dan sal ek nou maar in die sterker rol ingaan....en so hier agteraf is jy nou nie fine nie, maar voor is jy fine. Dis hoe dit werk.”/ “...then I’ll take on the stronger role...and so here behind the scenes you aren’t fine but there upfront you are fine. This is how it works.”

This shows the importance of communication and the expression of emotions within a family system. A family’s ability to express feelings openly can lower the risk of depression (Edwards & Clarke, 2004:570).

❖ *Sub-theme 3.4 Changes in role as caregiver*

The participants had to care for either themselves or their households. Most participants felt that they were too tired or didn’t have enough energy to do the household chores. They also experienced difficulty in cooking due to either feeling nauseous or having an altered sense of taste.

“maar my taak nou is baie afgeskaal want my man doen baie”/ “but now my chores have decreased a lot because my husband does a lot”

“moenie iets verwag nie, alles is ‘n bonus”/ “don’t expect anything, everything is a bonus”

“kry nie goeters gedaan nie...want ‘n mens is te moeg”/ “don’t get stuff done...because a person is just too tired”

“dit was selfs vir my moeilik om ‘n snytjie brood te smeer”/ “it was even difficult for me to spread a slice of bread”

“het nie die fisiese krag gehad nie”/ “did not have the physical strength”

Some participants who had limited side-effects due to treatment felt that they were able to attend to the chores that they did before the diagnosis.

“nee, ek maak kos”/ *“no, I prepare the food”*

“ek doen alles wat daar te doen is...ek was wasgoed en so aan”/ *“I do everything that needs to be done...I do the washing and so on”*

“ek kon skottelgoed was”/ *“I could wash dishes”*

The functional status in terms of the role of caregiver was affected by the severity of the side-effects experienced but most participants preferred to attend to household chores as before. Some did scale down the intensity with which they attended to household chores. This links strongly with the theoretical foundation of role theory where women feel obligated to fulfil their roles in the house. It could be that by completing household chores, the person feels validated and this reminds the person that they are valued and loved (Brennan, 2004:94). Being useful for family members could increase the persons' feelings of being a capable person (Luoma & Hakamies-Blomqvist, 2004:734)

Role theory posits that in everyday life, people occupy particular social positions that require of them to behave in a certain way or fulfil a certain role (DeLamater & Myers, 2011:7; Hindin, 2007:3951). The contradictory requirements of the sick role and the role as caregiver could cause role conflict within some women. Role conflict occurs when a person occupies numerous roles with different requirements and demands that are difficult to reconcile (Bruce & Yearley, 2006:264; Franks, 2007:3945). Role conflict can lead to stress in the person and this can cause them to want to still continue with their tasks even though they are feeling too sick (Biddle, 1986:82).

Research by Bourjolly et al. (1999:15) found that the ability to perform household responsibilities affects the woman's self-esteem which could be why it was such an important aspect for these women. Due to the support received from their significant other and family, women are more capable to function and carry out their social roles such as caregiver, housekeeper, employee and community participant (Hirschman & Bourjolly, 2005:18). When women feel that breast cancer doesn't hold them back

from what they want to do, it made it possible for them to have better social functioning (Bourjolly et al., 1999:13).

❖ *Sub-theme 3.5 Changes in role as daughter*

Most participants' parents have passed away or are elderly or ill and unaware of the cancer diagnosis. The participants whose parents were still alive indicated that it was difficult for their parents but that the relationship was supportive.

“dis seker nie lekker vir haar om te weet nie”/ *“it’s probably not nice for her to know”*

“baie goed”/ *“very good”*

“verdiep”/ *“deepened”*

This shows that cancer gives the opportunity for deeper relationships within a family system. Even though families can experience turmoil due to cancer diagnosis and treatment regimens, there has been reports of positive changes such as more time for family activities and family members growing closer (Brennan, 2004:100).

❖ *Sub-theme 3.6 Changes in role in extended family*

All participants had extended family that supported them through the process. Even though the family was supportive, they were also very concerned about the participants. The extended family is a source of support to the women in this study, which assisted in their ability to cope because a woman's ability to take on the new role as a breast cancer patient is affected by the support she receives (Hirschman & Bourjolly, 2005:18).

“my familie is baie ondersteunend en wil altyd weet hoe dit gaan”/ *“my family was very supportive and always wanted to know how its going”*

“hulle is baie ondersteunend”/ *“they were very supportive”*

“vir hulle is dit baie swaar want ek is die ousus in die huis”/ *“for them it was very difficult because I’m the eldest daughter in the house”*

“my sussie het die baie erg gevat”/ *“my sister took it very badly”*

“erg geskok gewees”/ *“very shocked”*

“baie bekommerd”/ *“very worried”*

One participant felt that due to the family history of cancer, it made her family more worried and anxious.

“jy weet ons het baie kanker in ons familie en dit is die idée wat by haar [suster] vassteek, almal gaan dood daarvan in ons familie...ek het bietjie hulle persepsie verander”/ *“you know we have a lot of cancer in our family and that’s the idea that stuck with her [sister],, everyone dies of it in our family...I changed their perspective a bit”*

Participants had to deal with their family’s reactions towards cancer, one participant experienced her extended family’s reaction as draining and found it difficult to deal with.

“mense se reaksies is nog steeds so sterk oor kanker...nog met hulle issues ook deal”/ *“people’s reactions to cancer are still so strong...had to deal with their issues too”*

Effects of breast cancer include having to cope with others unhelpful beliefs, expectations and emotions while you are dealing with your own issues regarding cancer (Beatty et al., 2008:335). Another participant was worried about her family members’ health seeing her brother has a heart problem and she felt that if he stressed about her illness it would make him sicker.

“...my broer wat jonger is, ek was baie besorg. Baie bekommerd...want hy’s ook maar nie gesond nie, hy’t ‘n hartprobleem...hy moet hom nie so bekommer daaroor nie.”/ *“...my younger brother, I was very concerned. Very worried...because he isn’t healthy either, he has a heart condition...he should not worry about this.”*

One participant preferred to be alone and deal with the cancer on her own and not expose her family to it.

“Ek het gevoel ek moet my liggaam laat rus dat hy die bestraling kan hanteer en uhm, ek moes vroeg opstaan om werk toe te gaan...ek wou nie my vreinde sien nie ek wou nie my familie sien nie uhm, ek was so introvert soort van daai tyd en wou net dit self hanteer.”/ *“I felt I had to give my body a chance to*

rest to be able to handle the radiation and uhm, I had to get up early to go to work....I didn't want to see my friends, didn't want to see my family uhm, I was like an introvert during that time and wanted to handle it by myself."

❖ Discussion of theme 3

Social functioning within the context of the family is an issue for most participants who experienced mixed emotions and numerous adjustments had to be made. The relationship with their significant others was marked by support and a deepening in the relationship, even though they were worried about the participants. But as one participant expressed, there is a need for open communication within the relationships. The sexual relationship between the couples continued despite the side-effects of treatment but the frequency decreased.

The participants who had children experienced the relationship with their children as closer after cancer, but their children found the diagnosis difficult to accept. The need for communication was emphasised here as well to prevent people from putting on a mask of "I'm fine" for their children. The participants' roles as caregivers within the household changed and they had to decrease their tasks due to the side-effects of treatment, like fatigue and a lack of physical strength. But the participants still wanted to be able to contribute to the household and chose to continue with certain household chores.

The participants whose mothers were still alive experienced the relationship as deepening. The relationships with the extended family were experienced as supportive, but unfortunately had several issues as well. Participants feel that they are unable to deal with the issues that the family members are experiencing due to the cancer diagnosis. Another participant feels that her diagnosis is making people worry and that can cause a worsened health status for these family members.

Even though some issues were present, the support received from family and the positive adaption to circumstances assisted the participants in having satisfactory social functioning during this time.

5.2.4 Theme 4: Social functioning in the context of community

Theme four focuses on the community that the participants are a part of. This theme is divided into three sub-themes, which specifically focuses on the changes in the

work life of participants, changes experienced as a community member and changes experienced within their social support network.

❖ *Sub-theme 4.1 Changes experienced in work life*

Four participants were employed at the time of their cancer diagnosis and treatment and experienced support and understanding in the workplace. They did not experience any difficulty in taking time off for treatment or recovery or to have their workload decreased during that time.

“baie pragtig ondersteun”/ *“supported very beautifully”*

“hulle het my baie goed, tegemoet gekom”/ *“they accommodated me very well”*

“ek het dit nou net op ‘n stadiger manier gedoen totdat my steke uit is”/ *“I just did things at a slower pace until my stitches came out”*

“begrip was regtig wonderlik gewees”/ *“the understanding was really wonderful”*

“verantwoordelikhede van die werk af weggevat”/ *“responsibilities at work were taken away”*

One participant’s work requirement is giving counselling and she stated that:

“...die kliente het nog steeds aangekom en dan voel ek, weet jy ek is besig met my eie battle en jy kom kla met my oor ‘n bevelvoerder wat lelik is met jou...besef ek kan nie berading doen soos altyd”/ *“... the clients still came and I felt that, you know I’m busy with my own battle and you come to complain about a commander who is not being nice towards you...realised I couldn’t do counselling as always”*

From the interviews, it is evident that employers are very cooperative, understanding and supportive of employees during the cancer treatment phase. Employers were flexible and able to shift things around at work to accommodate the participants. This assisted the participants to continue their role as employees and productive members of society. Research found that 30-93% of patients returned to work due to a supportive work environment (Kulik & Kronfeld, 2005:51). Being able to work or

return to work leads to improved psychological well-being (Semple & McCance, 2010:1286).

❖ *Sub-theme 4.2 Changes experienced as a community member*

Many participants are involved in their church and had to downscale their involvement but still experienced a lot of support from the church members. There was a change in the roles the participants were able to fulfil within their church.

“hulle is baie positief, hulle besoek my, hulle bel my”/ “they were very positive, they visited me, they phoned me”

“ek is nie in die vroue diensgroep of iets nie, mens het nie die krag nie”/ “I’m not in the woman’s group or something, you don’t have the energy”

“...goeie verhouding met almal, almal vra altyd jy weet, hoe gaan dit en stuur groete...ek glo daar is baie wat vir my bid.”/ “...good relationship with everyone, everyone always asks you know, how are you and they send regards...I believe there are a lot praying for me.”

“ek is nie meer op die bestuur van die kerk nie”/ “I’m no longer on the management of the church”

“baie ondersteunend, ek het reregig gevoel ek word geestelik versorg”/ “very supportive, I really felt that I was spiritually cared for”

When participants went to town or the local shopping centre, they experienced support and positive feedback from community members.

“die swart mense sal jou vreeslik komplimenteer en sê jis hulle hou van jou kaalkop”/ “the black people complimented me a lot and said, wow they really like my shaved head”

“Baie mense het na my toe gekom en gevra, vreemde mense wat gevra het...hoor hierso kry jy behandeling en so voorts en sommer ‘n geselsie aangeknoop het.”/ “Many people came to me and asked, strange people that asked...listen here are you receiving treatment and so forth and just started a conversation.”

“dit was eintlik met ope arms...ontvanklik”/ “it was actually with open arms...receiving”

It would seem that the community as a whole is very supportive of cancer patients and didn't make these participants feel like out-casts. The church is a great support system for the participants during this time and they continue to support and pray for participants. Congregation members are a valuable source of support (Venter, 2008:27). Religious beliefs assist people to feel part of a larger community of people with shared beliefs that will be available for support (Howsepian & Merluzzi, 2009:1076-1077). The participants had to limit their role in the church but their changed role in the church did not change the support they received.

❖ *Sub-theme 4.3 Changes experienced in social network*

The participants experienced their social network as very supportive.

“die het ook nader gekom, baie beslis ja”/ “they also came closer, most definitely yes”

“ek kry die wonderlikste ondersteuning van my vriende”/ “I get the most wonderful support from my friends”

“ons het baie vriende gemaak”/ “we made a lot of friends”

“behulpsaam”/ “helpful”

“gekry waar mense die vrymoedigheid gehad het om my iets oor kanker te vra”/ “got it to where people had the freedom to ask me something about cancer”

“bekommerd”/ “worried”

The social network of friends was supportive throughout the cancer process and none of the participants felt that people were avoiding them. Other research found that people lose friends and loved ones when these people perceive themselves as unable to support the patient (Venter, 2008:21). Research by Landmark, Strandmark and Wahl (2002:219) discovered that women receive support from people that they did not perceive as “close friends” which supports the finding that people are able to gain friends. Women, who receive support from friends, were able to deal with the

impact of breast cancer on their life better (Hirschman & Bourjolly, 2005:24). The influence of positive social support is described by Kayser and Sormanti (2002:403) when they state that:

the quality of women's close relationships plays an important role in their psychosocial adjustment, not only during periods of high stress associated with the diagnosis and treatment of a life-threatening illness but throughout their lives.

❖ Discussion of theme 4

Overall the participants enjoyed great support from different areas in their lives. The support and cooperation received from the employer assisted the participants to continue in their role as a productive employee as well as receive treatment for cancer. The church was a great source of support and prayers for the participants and participants expressed their gratitude for this support. The community did not shun the participants but was supportive, concerned and interested in the lives of the participants. Some of the reactions of community members caused positive changes within the participants. Even though the social support network was worried about the participants, they continued to show support and encouragement towards the participants.

5.3 Issues raised by participants that were not covered in themes

The participants expressed their feelings and thoughts concerning other issues not covered by the themes that were interesting and are noteworthy. Many participants expressed their gratitude towards the medical personnel that assisted them during diagnosis and treatment. Research by Venter (2008, 22) found that some people found the medical personnel as being supportive and helpful while others experienced them as being insensitive and incompetent.

"...medici toe gegaan by die borskliniek, en almal was baie behulpsaam...jy raak soos familie...baie simpatiek...baie sag op jou as person."/ "..."went to medical staff at the breast clinic and everyone was very helpful...you become like family...very sympathetic...very soft towards you as a person."

“Personeel by hospitaal is vriendelik, gesels maklik, almal is positief, maak dit lekker en maklik.”/ *“Staff at the hospital are friendly, easy to talk to, everyone is positive, makes it nice and easy.”*

“personeel was baie baie gaaf en behulpsaam”/ *“staff was very, very kind and helpful”*

“almal is baie dierbaar en gaaf en vriendelik”/ *“everyone is very nice and kind and friendly”*

Even though the participants are positive about the medical personnel, two participants expressed their negative experiences of getting contradictory medical advice from different doctors. This leaves the person torn in two and unsure which way to go. Detailed information helps to dissolve fears (Venter, 2008:29).

“die chirurg wat my gedoen het het gesê stop die hormone onmiddelik, toe ek by die uroloog kom toe sê hy vir my....jou blaas het hormone nodig”/ *“the surgeon that operated on me said to stop the hormones immediately, when I got to the urologist, he said to me...your bladder needs hormones”*

“julle dokters maak mens eintlik deurmekaar...dis ‘n spesialis teenoor ‘n spesialis”/ *“you doctors make people so confused...it’s a specialist against a specialist”*

“Wie vertel die waarheid? Wie jok? Wat makeer ek? Verstaan. Al daai tipe van goeters. Hoekom sê die een vir my so en die een sê vir my so?”/ *“Who is telling the truth? Who is lying? What is wrong with me? Understand. All those type of things. Why does the one say this and the one says that?”*

From these quotes it is evident that patients feel confused and frustrated when they get contradictory medical advice from doctors.

Two participants mentioned the financial implication of cancer treatment which was very worrying to them. The financial implication of cancer can be very expensive (Venter, 2008:29).

“dit was net sleg vir ons om vir ses weke elke dag Klerksdorp toe te ry...brandstof is duur”/ *“it was just bad for us to drive to Klerksdorp every day for six weeks...petrol is expensive”*

“Mense, en veral jong mense, nie besef dat dit ‘n siekte is wat jong mense ook aantast nie en hulle maak nie mediese voorsiening nie. Jy weet baie van hierdie ouens het mediese fonds opsies wat dit nie dek nie...jy weet kanker behandeling is duur.”/ *“People, and especially young people, do not realise that it’s an illness that affects young people as well and they do not make medical provisions. You know a lot of these people have medical aid options that do not cover it...you know cancer treatment is expensive.”*

Lastly, one participant expressed the need for counselling throughout the process and emphasised the need for social work services in the oncology field.

“lets wat ek net sal sê, wat vir my nogal baie belangrik was was uhm, en dit besef mens meer eers as mens deur die hele proses is maar die berading voor die tyd. As mens...ek sal net graag wou sê dat wanneer ‘n mens ‘n kanker diagnose het, moet daar iewerste in die hele spektrum van spesialiste wat met jou werk, sal ek sê, met daai eerste, eintlik jou, wanneer jy die diagnose kry van kanker moet daar eintlik berading beskikbaar wees. Wat vir ‘n mens mooi die, jy weet, die emosionele en die sosiale impak kan verduidelik.”/

“Something that I will say, that was kind of very important was was uhm, and this you only realise when you go through the whole process is that the counselling prior to. If you...I just would have like to say that when a person gets a cancer diagnosis, that somewhere in the whole spectrum of specialists that work with you there must, I would say with that first, actually when you get the diagnosis of cancer there must actually be counselling available. That can really explain to you the, you know, that can explain the emotional and the social impact.”

“hanteringsvermoë van die hele kanker kan anders wees”/ *“coping ability of the whole cancer can be different”*

“So dis vir my daai, daai kombinasie van die berading om te sê, hoe gaan jy jou familie hanteer, hoe gaan jy met jou eie goeters ‘cope’ en dan ook hoe gaan jy fisies met hierdie omstandighede ‘cope’. So daar is vir my ‘n leemte in die proses.”/

“So for me it’s the, the combination of the counselling to say, how you are going to cope with your family, how are you going to cope with your own stuff and then also how are you going to physically cope with these circumstances. So there is a gap in the process for me.”

The views of this participant shows the need for social work intervention with women diagnosed with breast cancer and the continuum of intervention needed from diagnosis to the conclusion of treatment.

6. Summary

Overall four themes were discussed to assess the social functioning of women with breast cancer. The social functioning of women in the context of her life world is affected by cancer diagnosis and treatment. Personality changes are present that are positive in that it helps the person focus on the important things in life and not trivial matters. Their spiritual lives improved and deepened and they still feel like women despite the breast cancer. Even though some experienced negative self-image issues they could be fixed by subtle changes to style, other participants had a self-image boost due to positive feedback from the community.

The social functioning of women in the context of their family was positive due to all the support they received from their significant others, children, parents and extended family. Most of the relationships improved through the cancer process, deepened and became closer. As seen from one participants account, a lack of communication causes worry and uncertainty within family relationships. Participants’ functioning was affected in such a way that they had to shift the responsibility for chores at home, but they all wanted to continue to fulfil their roles at home.

The community was supportive throughout the cancer process towards all participants where even strangers offered support when seeing a participant in the

local mall. The employers were cooperative and the participants that were employed at the time of treatment were able to have sick leave and attend to their work and be productive. The church was a great source of support to participants and continued to enquire about their well-being, praying for them and visiting participants. The social support network was worried but supportive and none of the participants felt that they were being avoided.

The following chapter will focus on the conclusions and recommendations.

Chapter 4

Summary, Conclusions and Recommendations

1. Introduction

The final chapter summarises the research study to ascertain if the research goal and objectives were met and to what extent. It also aims to answer the research question that was demarcated into three sub-questions. Conclusions are drawn according to the key findings from the four themes and sub-themes from the research. Lastly, recommendations are made for practice and for future research according to the themes.

2. Summary

2.1 The objectives of the study

To attain the goal of the research study, the following objectives were pursued:

- ❖ To conceptualise the phenomenon of breast cancer, including diagnosis, treatment and recovery and aspects of the social functioning of women from the theoretical framework of role theory.
- ❖ To explore how breast cancer affects the functioning of a woman as an individual, mother and wife.
- ❖ To explore how breast cancer affects the functioning of a woman as a member of the community.
- ❖ To provide guidelines for social work practice with female breast cancer patients for health care social workers.

2.1.1 Objective 1: To conceptualise the phenomenon of breast cancer, including diagnosis, treatment and recovery and aspects of the social functioning of women from the theoretical framework of role theory

This objective was achieved through an in-depth literature review that was conducted and presented in chapter two. The literature review gave a description of medical terms and key concepts used in the literature review and the empirical

study. The theoretical foundation of role theory was described as well as the concepts of cancer, breast cancer, cancer treatment and reactions to cancer. Furthermore, focus was given to the gender roles in South Africa, the concept of social functioning from a social work perspective as well as social work in the oncology field. The literature review gave a better understanding of breast cancer, its treatment, role theory and social functioning so that the empirical research could be viewed in context.

2.1.2 Objective 2: To explore how breast cancer affects the functioning of a woman as an individual, mother and wife

This objective was achieved through the literature review and the empirical research conducted. The literature review in chapter two described breast cancer, staging and its genetic foundation. Cancer treatment include surgical intervention, radiation therapy, chemotherapy and hormone therapy with possible side-effects that patients can experience. The empirical research indicated changes in personality and spiritual aspects of the individual. The research showed the participants' understanding of cancer as a manageable illness and their emotions during the time of diagnosis and treatment. The side-effects experienced from cancer treatment were researched as well as how the participants cope with side-effects. The research showed the support that the participants received from the family that assisted participants' roles as wives. The role of mother could not be researched as participants did not have dependent children.

2.1.3 Objective 3: To explore how breast cancer affects the functioning of a woman as a member of the community.

This objective was achieved through the literature review and empirical research conducted. The sub-themes that were explored during the empirical research include experiences in work life, experiences as a community member and experiences in the social network. The research showed that the community was very supportive towards the participants which aided their ability to fulfil their roles in the community. The participants that are employed were able to continue their work to the best of their abilities. The church and the social support network was a great source of support.

2.1.4 Objective 4: To provide guidelines for social work practice with female breast cancer patients for health care social workers.

This objective was achieved and is discussed at the end of the current chapter. The recommendations are discussed focusing on practice and future research. Recommendations will assist with the manner in which interventions are planned for women with breast cancer.

2.2 The goal of the study

The goal of the study was to explore the social functioning of women with breast cancer, and it was accomplished in the following way:

The literature chapter focused specifically on the theoretical foundation of role theory and how society expects people to fulfil certain roles and the conflict that arises when these roles cannot be fulfilled. The concept of cancer was conceptualised, specifically looking at the cellular changes that take place in the human body and the staging process used by oncology personnel. Breast cancer was described with special considerations made for staging and genetic foundation. Cancer treatment including surgical intervention, radiation therapy, chemotherapy and hormone therapy was discussed including with the possible side-effects that patients can experience. The important aspect of “reaction to cancer” was conceptualised focusing specifically on diagnosis, treatment, survivorship, recurrence and issues regarding the end of life. The gender role of women in South Africa was discussed so that the framework of the life world of women in South Africa can be understood. Social functioning from a social work perspective was conceptualised and it looked at the specific areas where social functioning can be assessed. Lastly, social work in the oncology field was discussed with the scope of practice of the Association of Oncology Social Work.

From the empirical research the following themes were generated: concept of cancer, social functioning within the life world of a woman with breast cancer, social functioning within the family of a woman with breast cancer and social functioning within the community of a woman with breast cancer. Each of these themes were divided into sub-themes. The theme of cancer had four sub-themes including understanding cancer, feelings at time of diagnosis, feelings at the time of treatment and side effects experienced. The theme of social functioning within the life world

was divided into four sub-themes including changes in personality, feeling like a woman, changes in spiritual aspect and changes in self-image. The theme of social functioning within the family has six sub-themes, which include the relationship with significant other, changes in sexual identity, role as mother; role as caregiver, role as daughter and the role in the extended family. The participants had to adjust to role conflict between their previous roles and the sick role they needed to fulfil, this includes the expectations they have for themselves in terms of their functionality and they also had to manage role expectation. The last theme of functioning within the community has three sub-themes which are changes in work life, changes as community member and changes in social network.

2.3 The research question

In the context of this study, the following research question was asked:

How does breast cancer affect the social functioning of women?

The data collected during the in-depth interviews with the participants revealed themes and sub-themes related to the social functioning of women who were diagnosed and receiving treatment for breast cancer. These themes and sub-themes were discussed in chapter three. The research question was demarcated into specific areas which are the main themes of the study. Thus the answer to the research question can be seen in the following themes generated from the study, which shows that breast cancer does affect the social functioning of women to a certain degree.

Table 4: Themes and sub-themes of research

Themes	Sub-themes
<p>Cancer</p> <p>This theme explored different aspects of cancer including the participants understanding of cancer, their feelings at the time of diagnosis and treatment as well as the side-effects experienced during treatment.</p>	<p>Understanding cancer</p> <p>Feelings at time of diagnosis</p> <p>Feelings during treatment</p> <p>Side-effects experienced</p>
<p>Social functioning of women with breast cancer within the context of life world</p>	<p>Changes experienced in personality</p> <p>Feeling like a woman</p> <p>Changes experienced with regard to spiritual aspects</p> <p>Changes with regard to self-image</p>
<p>Social functioning of women with breast cancer within the context of family</p>	<p>Changes in relationship with significant other</p> <p>Changes in sexual identity</p> <p>Changes in role as mother</p> <p>Changes in role as caregiver</p> <p>Changes in role as daughter</p> <p>Changes in role in extended family</p>
<p>Social functioning of women with breast cancer within the context of community</p>	<p>Changes experienced in work life</p> <p>Changes experienced as a community member</p> <p>Changes experienced in social network</p>

3. Conclusions

The conclusions are based on the key findings of this study, which are the key findings of each theme. The researcher is of the opinion that the findings cannot be generalised, but that the findings are transferrable to a similar population. The data analysis of this study was done according to qualitative processes.

The qualitative approach using collective case studies and in-depth face-to-face interviews, proved to be the appropriate research design, seeing that the information gathered was in the form of descriptions and words which gave meaning to the experiences of women with breast cancer. The researcher was able to obtain first-hand information through the use of the semi-structured interview and an interview schedule (Appendix 1) as it allowed some flexibility to explore certain topics further during the interviews. It can consequently be concluded that the semi-structured interview schedule, as a method of data collection used in interviewing, worked effectively in answering the research question. The researcher can recommend these methods to future researchers who are aiming to explore experiences of women with breast cancer. The collective case study design was appropriate, as the researcher was able to expand her understanding of the experience of women with breast cancer and these findings were presented in the common themes and sub-themes generated.

3.1 Theme 1: Cancer

The research showed that the participants experienced differing emotions during the diagnosis and treatment of cancer. The side-effects of breast cancer negatively affected the participants but they chose to have a positive outlook with regard to cancer.

❖ *Sub-theme 1.1: Understanding cancer*

The concept of cancer has changed from people linking it with death to seeing it as a common disease of the day. Participants in this research thought of cancer as manageable and none of the participants linked cancer diagnosis with death. This shift can bring about a more positive outlook on cancer and make people more hopeful during treatment.

Although the participants knew they were diagnosed with breast cancer, most were unsure of the staging of their illness, only the participants that were diagnosed a second time with metastasis knew the detail of their cancer staging. This could be due to the shock and denial people experience during the diagnostic phase of cancer where a person struggles to take in all the information given to them. The speed of onset of treatment can also make it difficult for patients to deal with the diagnosis.

Knowledge of cancer and staging assists with understanding cancer and their own prognosis. Knowledge of the prognosis is important to give realistic hope and to prevent unrealistic fear. This was evident when comparing the two participants that did consider death, one with stage IV metastatic cancer, where treatment is not going well and the other with stage I breast cancer who needed radiation therapy. One participant was realistic with regard to her prognosis where the other participant with stage 1 breast cancer, was unrealistic with regard to her prognosis. This shows the importance of understanding cancer and the appropriate knowledge for cancer patients.

❖ *Sub-theme 1.2: Feelings at time of diagnosis*

Participants' were unable to give detailed information about their diagnosis possibly due to the emotional distress associated with the diagnostic period. Participants experienced mixed emotions including feeling crushed, shocked, blunt, sad and in disbelief. These emotional responses were also found in the literature discussed in chapter two.

Even though cancer has negative emotions connected to it, the participants were able to find the positive in the cancer experience. This type of mind set assists with adjustment to cancer diagnosis and treatment. But this mind set does not mean that patients do not have certain fears. One of the fears that arose during this section of the research was the fear of recurrence. One participant experienced the fear of death even though her prognosis did not indicate a risk of death. This could either show a new thought process regarding her own mortality or a subjective fear regarding cancer and death, which is apart from prognosis.

❖ *Sub-theme 1.3: Feelings during treatment*

Treatment is an important part of the cancer patients' life and as described by one of the participants, "it takes a big bite out of your life". Although there were some

participants who expressed their negative emotions related to treatment, including uncertainty and a sense of loss, there were also those participants who were able to find a positive attitude. Participants' were able to find a moment of peace on the trip to the hospital for treatment or they have a firm belief that this fits into the bigger picture of what God has in store for their lives. Participants felt calm when they knew what to expect, this highlights the importance of the need for medical personnel to prepare the patients for treatment so as to diminish unrealistic fears people have towards cancer treatment.

❖ *Sub-theme 1.4: Side-effects experienced*

The side-effects of treatment can be mild or severe depending on the person and the treatment that is given. All participants had negative experiences with the cancer treatment, seeing it as vicious or having a big impact on your life. Participants had to learn to adapt to treatment side effects and their diminished capacities. Diminished capability affects a person's functioning, which in turn impairs their role functioning. Participants had to shift from the role of diligent caregiver, healthy person, hardworking employee or dedicated community member to the role of cancer patient who is experiencing side-effects of treatment and who is too weak to fulfil her roles. As one participant described it, it is the adjustments that are most difficult. Another participant described her difficult adjustment to having to taking her clothes off. She explained that a patient is expected to take their clothes off for medical examinations and certain treatments which infringes on her privacy that was a very difficult adjustment to make.

The hormone treatment also has a big impact on the participants, especially the younger participants who have to deal with premature menopause and hot flushes. As described in chapter two, there are numerous side-effects to chemotherapy, radiation therapy and hormone therapy that patients need to adjust to and deal with. It is possible that the side-effects experienced due to cancer treatments can have a greater influence on the persons' functioning than the cancer itself.

3.2 Theme 2: Social functioning in the context of life world

The life world of the woman entails her personality, her spiritual aspect, her identity as a woman and her self-image. Research showed that there were changes

experienced in these aspects but that most of the changes were positive. This emphasises the participants' ability to take the positive from a negative situation.

❖ *Sub-theme 2.1: Changes experienced in personality*

Changes in terms of personality can also link with changes in terms of identity. Personality changes were present in this research where participants experienced a shift in their focus as they started to focus on the important things and no longer focused on trivial things. As a participant described it: "don't sweat the small stuff". A change in personality can cause a change in how a person perceives and chooses to fulfil their roles. Research showed a change in the emotional side of participants as they became more emotional or depressed. The change of becoming more emotional was seen as a positive change because it made them a "softer person" who is able to empathise with others more. Cancer diagnosis and treatment does affect a woman's personality and causes certain changes. Whether the changes are positive or negative depends on the person.

❖ *Sub-theme 2.2: Feeling like a woman*

The participants in this research either felt no changes in their femininity or felt more like women after cancer treatment. An unchanged sense of femininity can indicate that their roles pertaining to femininity were not affected. As discussed in chapter three, participants felt stronger because they had overcome something and did not feel like their femininity was linked to their breasts. It is beneficial that the participants' sense of femininity was not affected by breast cancer or even cancer treatment. Even the participants that received a lumpectomy or mastectomy didn't feel their womanhood was affected. Participants were able to distinguish their femininity from their physical appearances or the attributes that society sees as feminine (breasts and hair).

❖ *Sub-theme 2.3: Changes experienced with regard to spiritual aspects*

Religion played a very important role in the participants' lives and seven out of eight participants felt that through the cancer process there was a deepening in their spiritual aspect. Participants were able to draw on their faith for support and hope and they received support from their church. Even the participant that admitted to fighting with God about her cancer diagnosis, described a deepening in her relationship with God. This aspect gave participants peace during an emotionally and

physically challenging time in their lives. This research study confirms the importance of religion and how participants are able to see the “bigger picture” due to their relationship with God.

❖ *Sub-theme 2.4: Changes with regard to self-image*

This sub-theme had mixed results where some women did have a lowered self-image but had coping mechanisms such as wigs or a change in style and other participants had an improved self-image due to compliments from community members or no change whatsoever. Self-image can be a sensitive issue but these participants were able to address this issue successfully. Self-image is a subjective issue and depends on the side-effects of treatment and the individual’s personality.

3.3 Theme 3: Social functioning in the context of family

The research showed that throughout the process of cancer and cancer treatment the participants enjoyed support from the entire family system, which assisted with their ability to cope and function. Their sexual identity was unchanged as well as their role as daughters. Their relationships with their significant others, children and extended family improved. Their ability to continue their tasks as caregivers to their families were, however, hindered somewhat.

❖ *Sub-theme 3.1: Changes in relationship with significant other*

Support is essential to the persons’ ability to cope with cancer and this research study showed that the participants had abundant support from their significant others. Participants experienced improved relationships with their significant others, which assisted with their ability to adjust to cancer and manage cancer treatment. The support experienced from the significant other assisted the participants in maintaining their role in the relationship, such as the role as wife. The participants also expressed that their significant other was worried about them and struggling to with coming to terms with the diagnosis. This worry, however, did not keep them from being supportive, which in turn assisted in the growth of the relationships. One participant did express her need for communication during this time with her significant other. The lack of expressiveness was found to either be linked to a cultural aspect of keeping emotions private or a couple that have not yet dealt with such a situation and were feeling ill-equipped to express themselves.

❖ *Sub-theme 3.2: Changes in sexual identity*

The participants did not experience any changes in their sexual identity and could still experience a healthy sex life. The sex life of the participants had to adapt to changes in energy and side-effects of hormone treatment, but the couples were able to adjust positively. The positive adjustment to sexual functioning changes and unchanged sexual identity was greatly due to the support and understanding of the significant others. This aided the participants' ability to maintain their role as wife, woman and sexual partner.

❖ *Sub-theme 3.3: Changes in role as mother*

The participants experienced improved relationships and positive support from children, which can be due to the fact that the children were adults with their own families. The participants' role as mother was not changed by the cancer diagnosis or treatment. The children were possibly more able to cope and had a better understanding of cancer than school aged children. But the age of their children did not diminish their need to protect their children, as one participant stated that she had to "go into the stronger role" so as to not upset her children. The children experienced emotions such as shock, stress and finding it difficult to accept the diagnosis. Open communication with children and dealing with the emotions associated with cancer is needed to assist with effective functioning in families.

❖ *Sub-theme 3.4: Changes in role as caregiver*

Women continue to fulfil their household duties, just at a slower pace and some of the chores were transferred to their significant other. The participants saw this as supportive but still wanted to do their share in the house. This study showed the balance that participants had to keep between dealing with side-effects of treatment and still being a productive member of the household. Women want to fulfil their roles in the house and feel productive and they do not want their significant other to have to do everything in the house. The significant others were very supportive in this matter and allowed the participants to rest and do small things in the house while they take up bigger or more difficult tasks. Participants had to manage the possible role conflict experienced between the role of caregiver and role of cancer patient.

❖ *Sub-theme 3.5: Changes in role as daughter*

The relationship with parents improved and deepened for the participants in this research study. Parents were supportive throughout the process of cancer even though the parents found it difficult to know their child has cancer. Positive family relationships were maintained. The participants did not experience a change in their role as daughter.

❖ *Sub-theme 3.6: Changes in role in extended family*

The extended family was a form of support for the women in this study. Unfortunately not all family relationships are marked by support; some are marked by having to deal with other people's reactions and feelings about cancer. One participant stated that her family view cancer as a death sentence and she was able to change their view point regarding cancer. Another participant felt emotionally unable to deal with her extended family's emotions regarding cancer. Unfortunately, cancer patients need to deal with their own and their family's emotions regarding cancer, which can become emotionally taxing for the individual. One participant explained that she preferred to be alone when dealing with the side-effects of treatment so she is able to give her body a rest and deal with the cancer in her own way in her own time. This participants' family respected her wishes which helped this particular participant to cope with cancer in her own way. Even though participants did experience negative aspects in their relationships with their extended family, all felt that they were supported by their family which assisted them to cope with cancer. Participants were able to continue their role in their extended family but some had to take up new roles such as dealing with family members' emotions regarding cancer. Such a role was found to have a negative influence in her life by one participant.

3.4 Theme 4: Social functioning in the context of community

This theme discussed the participants' work life, experiences as a community member, church member and relationships within the social support network. The research showed that the participants' received overwhelming support from these different entities throughout the process of cancer diagnosis and cancer treatment. This support assisted in the participants' ability to adjust and balance the work role and sick role.

❖ *Sub-theme 4.1: Changes experienced in work life*

This research study showed that employers are very supportive and accommodating towards patients who need to receive treatment for cancer. Participants were awarded sick leave without difficulty and their work load was lightened during this time. The participants were able to attend to their work and receive treatment which caused them to feel like productive members of society and keep a sense of normalcy in their life. Participants were able to maintain their role as an employee and productive member of society.

❖ *Sub-theme 4.2: Changes experienced as a community member*

Participants experienced the overall community as supportive and strangers even came up to them to enquire about their health and ask questions about cancer. As one participant described it, she made friends during this time. The church was an important support system for the participants and knowing that people cared and prayed for them helped the participants cope with cancer.

Strangers out of the community gave compliments to the participants on their appearance, which lead to positive self-image changes. Due to the shift in seeing cancer as being a “death sentence” to seeing it as a common illness that is manageable, people are more willing to approach cancer patients in public areas. None of the participants felt shunned by the community or alone, but felt included and supported.

❖ *Sub-theme 4.3: Changes experienced in social network*

Friends are an important source of support throughout a person’s life. The relationships the participants had with their friends were very supportive and they also experienced a deepening in those relationships. Their friends were worried about them, but also more willing to ask questions about cancer. None of the participants lost friends during this process, but rather made friends.

4. Recommendations

4.1 Recommendations for practice

Medical personnel working in the oncology field need to be aware of the emotional turmoil patients go through during the cancer diagnosis and treatment process.

During the diagnostic phase there is a lot of fear and uncertainty that needs to be recognised and addressed. Patients can still be in denial during this stage, therefore it is important to remember that information may need to be repeated and clarification may be necessary to ensure that patients and families understand. It is important that patients are aware of their staging and prognosis so that they can have realistic hopes and do away with unrealistic fears. During the treatment phase, it is important that patients are prepared for the treatment because this helps keep them calm and reduce any fears they may have with regard to the treatment. Dealing with side-effects of treatment is an important issue that should receive attention in practice.

As the participants mentioned, the personnel at the oncology departments are supportive and become like family to the patients. This needs to continue and therefore training for health care professionals is needed, which can include empathy training, stress management and the ability to relay difficult subjects or bad news to patients and family. Some participants received contradictory information from doctors which left them feeling confused. That is why multidisciplinary and interdepartmental communication within the health care setting is so important. When that can be done, patients will receive the same information and all specialists and team members are on the same page and working towards the same goal.

The importance of social workers in this field is appropriate because of their understanding of personal and family functioning and the interventions they can use to assist the patient and family. Social workers in the health care field can identify factors that influence functioning and their interventions can focus specifically on how to assist patients' adjustment to role changes within themselves, their family and the community. Services that social workers can assist with in the oncology field can include marital and sexual adjustments, encouragement to expressing emotions within the family, continued open communication in the family throughout the cancer process, the disclosure of the diagnosis and assessing understanding of cancer and treatment.

Depending on the side-effects of treatment and the personality of the person, certain self-image issues can become distressing for the person. Patients need to be counselled and prepared for these changes and different ways of dealing with self-

image issues can be discussed. Ways of dealing with self-image issues, as found in this study, was wearing a wig or changing fashion. During counselling it is also important to assist the patient and significant other in distinguishing between self-worth and physical appearance.

Support groups can be a great source of support, solidarity and information for patients and families. Discussing symptoms, side-effects and coping strategies with fellow patients is recommended to assist patients and families.

4.2 Recommendations for research

Future research can focus on a larger sample in order to test results. Using this research as a platform, future research can focus on the communication within the family, such as ways that family communicate about cancer and possible intervention strategies from a social work perspective. The role of religion/spirituality was important for this sample and could be a possible research topic to assess the influence of religion on cancer patients. The side-effects of treatment were the most difficult for patients to deal with and research can focus on possible ways of coping with side-effects.

4.3 Recommendations according to themes

❖ *Theme 1: Cancer*

It is important for patients to know their staging and prognosis to ensure that they have a realistic idea and hope. Medical personnel and social workers in the oncology field should be advised for future practise. Practise should focus on coping with side-effects of treatment and finding the positive aspects of living with cancer.

❖ *Theme 2: Life world*

Social workers in the oncology field should focus on preparing patients for possible personality changes and self-image changes, including ways of coping with hair loss and a mastectomy in the case of breast cancer. Seeing that spirituality is such an important aspect for patients, it will be important to ensure that they receive support from their church.

❖ *Theme 3: Family*

Social workers working in the oncology field should assist patients in dealing with role changes within the family, especially in the role as caregiver. Family counselling could be appropriate for families to promote communication, as well as giving ways of dealing with changes within the sex life of a couple. Lastly, the patient should be assisted in dealing with their own emotions and the emotions of the people in their life.

❖ *Theme 4: Community*

Education programmes in the community is needed to keep the support that patients enjoy. These programmes should focus specifically on the church, seeing that it is a great source of support to these participants.

Closing statement

Breast cancer is seen as a manageable illness and women choose to have a positive outlook on the diagnosis and treatment of cancer. Breast cancer affects the social functioning of women in different areas of their lives. Changes are experienced in their personality along with a deepening in spiritual aspects, which is a way of coping with cancer. Women experience changes in their physical abilities and adjustments were made with regard to their roles in the household as well as their sexual life with their significant other. The relationship with the significant other experienced a deepening and women experience abundant support from their significant others, their extended families, their friends, their employers, their church and the greater community. The support assisted these women in coping with cancer and bringing about positive changes in their social functioning.

Reference List

- Adams, K.B. 2010. Late adulthood. In Ashford, J.B. & LeCroy, C.W. (Eds). *Human behaviour in the social environment: a multidimensional perspective*. 4th ed. Belmont: Brooks/Cole, Cengage Learning.
- Alberts, A.S. 2012. *Knowledge beats cancer*. Singapore: Marula Books.
- Alston, M. & Bowles, W. 2003. *Research for social workers: an introduction to methods*. 2nd ed. Australia: Allen & Unwin.
- American Joint Committee on Cancer. 2009. *Breast cancer staging*. 7th ed. Available: <http://www.cancerstaging.org/staging/oster/breast8.5x11.pdf> (Accessed 2013/06/24).
- American Joint Committee on Cancer. 2010. *What is cancer staging?* Available: <http://www.cancerstaging.org/mission/whatis.html> (Accessed 2013/06/24).
- Apffelstaedt, J. 2008. The status of breast health management in South Africa. Available: <http://www.bizcommunity.com/article/196/335/24909.html> (Accessed 2013/07/06).
- Ashford, J.B. & LeCroy, C.W. 2010. *Human behaviour in the social environment: a multidimensional perspective*. 4th ed. Belmont: Brooks/Cole, Cengage Learning.
- Association of Oncology Social Work. 2013. *Scope of practice*. Available: <http://aosw.org/scope-of-practice/> (Accessed 2013/09/06).
- Babbie, E. 2010. *The practice of social research*. 12th ed. Belmont: Wadsworth.
- Babbie, E. 2011. *The basics of social research*. 5th ed. Belmont: Wadsworth.
- Banton, M. 2004. Role. *The social science encyclopedia*, 2:891-894.
- Barker, R.L. 2003. *The Social Work Dictionary*. 5th ed. Washington, DC: NASW Press.
- Beatty, L., Oxland, M., Koczwara, B. & Wade, T.D. 2008. The psychosocial concerns and needs of women recently diagnosed with breast cancer: a qualitative study of patient, nurse and volunteer perspectives. *Health Expectations*, 11(4):331-342.

Bell, R. 2009. *Drops like stars*. Michigan: Zondervan.

Bernacki, R.E. & Meier, D.E. 2012. Principles of palliative care. In McKean, S.C., Ross, J.J., Dressler, D.D., Brotman, D.J. & Ginsberg, J.S. (Eds). *Principles and Practice of Hospital Medicine*. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/resourceTOC.aspx?resourceID=749> (Accessed 2013/07/09).

Biddle, B.J. 1986. Recent developments in role theory. *Annual review of sociology*, 12:67-92.

Biddle, B.J. 1992. Role theory. *Encyclopedia of sociology*, 3:1681-1685.

Billhult, A. & Segesten, K. 2003. Strength of motherhood: nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Science*, 17:122-128.

Blaauw, L. 2012. Personal interview with Dr Blaauw, Oncologist at Wilmed Park Oncology. 26 March. Klerksdorp.

Blakely, T.J. & Dziadosz, G.M. [Sa]. Social functioning: a sociological common base for social work practice. Available: <http://www.questia.com/read/5027338089?title=Social%20Functioning%3a%20A%20Socialogocal%20Common%20Base%20for%20Social%20Work%20Practice> (Accessed 2013/06/21).

Bless, C., Higson-Smith, C. & Kagee, A. 2006. *Fundamentals of social research methods: an African perspective*. 4th ed. Cape Town: Juta and Co.

Bourjolly, J.N., Kerson, T.S. & Nuamah, I.F. 1999. A comparison of social functioning among black and white women with breast cancer. *Social Work in Health Care*, 28(3):1-20.

Brannon, J. & Feist, L. 2010. Health Psychology

Brennan, J. 2004. *Cancer in context: a practical guide to supportive care*. New York: Oxford University Press.

Bruce, S. & Yearley, S. 2006. *The SAGE dictionary of sociology*. London: SAGE.

Bryant, W. 1995. Cancer of the breast. In Pervan, V., Cohen, L.H. & Jaftha, T. (Eds). *Oncology for health-care professionals*. Kenwyn: Juta.

Byrnes, R.M. 1996. South Africa: a country study. Washington: GPO for the Library of the Congress. Available: <http://countrystudies.us/south-africa/58.htm> (Accessed 2013/02/21).

Cambridge Advanced Learner's Dictionary. 2010. Cancer. Cambridge University Press. Available: http://dictionary.cambridge.org/dictionary/british/cancer_1 (Accessed 2010/09/29).

CANSA. 2010. *Breast Cancer*. Available: http://www.cansa.org.za/cgi-bin/giga.cgi?cmd=cause_dir_news&cat=822&cause_id=1056 (Accessed 2010/09/27).

Carpenter, J.S., Brockopp, D.Y. & Andrykowski, M.A. 1999. Self-transformation as a factor in the self-esteem and well-being of breast cancer survivors. *Journal of Advanced Nursing*, 29(6):1402-1411.

Cheville, A.L., Troxel, A.B., Basford, J.R. & Kornblith, A.B. 2008. Prevalence and treatment patterns in physical impairments in patients with metastatic breast cancer. *Journal of Clinical Oncology*, 26(16): 2621-2629.

Commission on Gender Equality. 2000. *A framework for transforming gender relations in South Africa*. Available: <http://www.info.gov.za/view/DownloadFileAction?id=70346> (Accessed 2013/06/13).

Coyne, E. & Borbasi, S. 2009. Living the experience of breast cancer treatment: the younger women's perspective. *Australian Journal of Advanced Nursing*, 26(4):6-13.

Davis, C. 2004. Psychosocial needs of women with breast cancer: how can social workers make a difference? *Health & Social Work*, 29(4):330-334.

DeFrank, J.T., Mehta, C.C.B., Stein, K.D. & Baker, F. 2007. Image dissatisfaction in cancer survivors. *Oncology Nursing Forum*, 34(3):1-6.

DeLamater, J.D. & Myers, D.J. 2011. *Social Psychology*. 7th ed. Belmont: Wadsworth.

De Vos, A.S. 2005. Qualitative data analysis and interpretation. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for the social sciences and human service professionals*. 3rd ed. Pretoria: Van Schaik Publishers.

Denzin, N.K. & Lincoln, Y.S. 2011. *The SAGE handbook of qualitative research*. 4th ed. Los Angeles: SAGE Publications.

Diekman, A.B. 2007. Roles and role theory. *Encyclopedia of social psychology*, 2:762-764.

DuBois, B. & Miley, K.K. 2005. *Social work: an empowering profession*. 4th ed. Boston: Pearson Education.

Education and Training Unit. 2007. *Gender and development*. Available: <http://www.etu.org.za/toolbox/docs/organise/gender.html> (Accessed 2013/02/21).

Edwards, B. & Clarke, V. 2004. The psychological impact of cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology*, 13:562-576.

Ehrlich, A. & Schroeder, C.L. 2009. *Medical terminology: for health professions*. 6th ed. Australia: Delmar Cengage Learning.

Engel-Hills, P. 1995. Radiation therapy. In Pervan, V., Cohen, L.H. & Jaftha, T. (Eds). *Oncology for health-care professionals*. Kenwyn: Juta.

Fitch, M.I., Bunston, T. & Elliot, M. 1999. When mom's sick: changes in a mother's role and in the family after her diagnosis of cancer. *Cancer Nursing*. Available: http://0-ovidsp.tx.ovid.com.innopac.up.ac.za/sp-3.8.1a/ovidweb.cgi?&S=NEBMFPINAJDDECNBNCOKNEJCDCPPAA00&Link+Set=S.sh.18.19.23.27%7c11%7csl_11143804 (Accessed 2013/07/08).

Flick, U. 2000. Design and process in qualitative research. In Flick, U. (Ed.), Von Kardorff, E. & Steinke, I. *A companion to qualitative research*. London: SAGE Publications.

Franks, D.D. 2007. Role. *The Blackwell encyclopedia of sociology*, 8:3945-3948.

Friedman, L.C., Kalidas, M., Elledge, R., Chang, J., Romero, C., Husain, I., Dulay, M.F. & Liscum, K.R. 2006. Optimism, social support and psychosocial functioning among women with breast cancer. *Psycho-Oncology*, 15:595-603.

Forrest, G., Plumb, C., Ziebland, S. & Stein, A. 2009. Breast cancer in young families: a qualitative interview study of fathers and their role and communication with their children following the diagnosis of maternal breast cancer. *Psycho-Oncology*, 16:96-103.

Fouché, C.B. 2005. Qualitative research designs. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delpport, C.S.L. *Research at grass roots: for the social sciences and human service professions*. 3rd ed. Pretoria: Van Schaik Publishers.

Fowler, F.J. 2004. Interview schedule. *The SAGE encyclopedia of social science research methods*, 2:518-519.

Fu, M.R., Xu, B., Liu, Y. & Haber, J. 2008. 'Making the best of it': Chinese women's experiences of adjusting to breast cancer diagnosis and treatment. *Journal of Advanced Nursing*, 63(2):155-165.

Gall, T.L., Guirguis-Younger, M., Charbonneau, C. & Florack, P. 2009. The trajectory of religious coping across time in response to the diagnosis of breast cancer. *Psycho-Oncology*, 18:1165-1178.

Giuliano, A.E. & Hurvits, S.A. 2013. Breast disorders. In Papadakis, M.A. & McPhee, S.J. (Eds). *Current Medical Diagnosis & Treatment 2013*. 52nded. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=8538> (Accessed 2013/06/24).

Greeff, M. 2011. Information collection: interviewing. In De Vos, A.S., Strydom, H., Fouché, C.B. & Delpport, C.S.L. (Eds.). *Research at grass roots: for the social sciences and human service professions*. 4th ed. Pretoria: Van Schaik Publishers.

Heppner, P.P., Tierney, C.G., Wang, Y.W., Armer, J.M., Whitlow, N.M. & Reynolds, A. 2009. Breast cancer survivors coping with lymphedema: what all counsellors need to know. *Journal of Counselling & Development*, 87:327-338.

Hindin, M.F. 2007. Role theory. *The Blackwell Encyclopedia of sociology*, 8:3951-3954.

Hinnen, C., Hagedoorn, M., Ranchor, A.V. & Sanderman, R. 2008. Relationship satisfaction in women: a longitudinal case-control study about the role of breast cancer, personal assertiveness, and partners' relationship-focused coping. *British Journal of Health Psychology*, 13:737-754.

Hirschman, K.B. & Bourjolly, J.N. 2005. How do tangible supports impact the breast cancer experience? *Social Work in Health Care*, 41(1):17-32.

Howsepian, B. & Merluzzi, T.V. 2009. Religious beliefs, social support, self-efficacy and adjustment to cancer. *Psycho-Oncology*, 18:1069-1079.

Hunt, K.K., Newman, L.A., Copeland, E.M. & Bland, K.I. 2010. The breast. In Burnicardi, F.C., Andersen, D.K., Billiar, T.R., Dunn, D.L., Hunter, J.G., Matthews, J.B. & Pollock, R.E. (Eds). *Schwartz's Principles of Surgery*. 9thed. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=5021163> (Accessed 2013/06/24).

Iphofen, R. 2005. Ethical issues in qualitative health research. In Holloway, I. (Ed). *Qualitative research in health care*. New York: Open University Press.

Jackson, J. 1998. Contemporary criticisms of role theory. *Journal of occupational science*, 5(2):49-55.

Jaftha, T. & Brainers, J. 1995. Surgery. In Pervan, V. (Ed.), Cohen, L.H. & Jaftha, T. *Oncology for health-care professionals*. Kenwyn: Juta.

James, R.K. 2008. *Crisis Intervention strategies*. 6th ed. Australia: Thomson Brooks/Cole.

Jim, H.S. & Andersen, B.L. 2007. Meaning in life mediates the relationship between social and physical functioning and distress in cancer survivors. *British Journal of Health Psychology*, 12:363-381.

Jupp, V. 2006. *The Sage Dictionary of Social Research Methods*. London: Sage Publications.

Kayser, K. & Sormanti, M. 2002. A follow-up study of women with cancer: their psychosocial well-being and close relationships. *Social Work and Mental Health*, 35:391-406.

Kilroe, M.C. 2009. *An exploration of young women and men's perceptions of gender roles and their impact on relationships*. Johannesburg: University of Witwatersrand. (MA Dissertation).

Kimberley, D. & Osmond, L. 2011. Role theory and concepts applied to personal and social change in social work treatment. In Turner, F.J. (Ed.) *Social Work Treatment: interlocking theoretical approaches*. 5th ed. New York: Oxford University Press.

Kimmick, G.G. & Muss, H.B. 2009. Breast disease. In Halter, J.B., Ouslander, J.G., Tinetti, M.E., Studentski, S., High, K.P. & Asthana, S. (Eds). *Hazzard's Geriatric Medicine and Gerontology*. 6thed. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=5129678> (Accessed 2013/06/24).

Kirk, S.A. 1999. *Social work research methods: building knowledge for practice*. Washington, DC: NASW Press.

Kissane, D.W., McKenzie, M., McKenzie, D.P., Forbes, A., O'Neill, I. & Bloch, S. 2003. Psychosocial morbidity associated with patterns of family functioning in palliative care: baseline data from the family focused grief therapy controlled trial. *Palliative Medicine*, 17:527-537.

Klaeson, K. & Berterö, C.M. 2008. Sexual identity following breast cancer treatments in premenopausal women. *International Journal of Qualitative studies on Health and Well-being*, 3:185-192.

Knott, V., Turnbull, D., Olver, I. & Winefield, A. 2012. A grounded theory approach to understanding the cancer-coping process. *Journal of Health Psychology*, 17(3):551-564.

Kornegay, E. 2000. South Africa's national policy framework for women's empowerment and gender equality. Available: <http://www.info.gov.za/otherdocs/2000/gender.pdf> (Accessed 2013/06/13).

- Kralik, D., Brown, M. & Koch, T. 2001. Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing*, 33(5):594-602.
- Kreitler, S. 2003. Psycho-oncology. In Cohen, L.M., McChargue, D.E. & Collins, F.L. (Eds.). *The health psychology handbook: practical issues for the behavioural medicine specialist*. Thousand Oaks: Sage Publications.
- Kulik, L. & Kronfeld, M. 2005. Adjustment to breast cancer: the contribution of resources and causal attributions regarding the illness. *Social Work in Health Care*, 41(2):37-57.
- Landmark, B.T., Strandmark, M. & Wahl, A. 2002. Breast cancer and experiences of social support: in-depth interviews of 10 women with newly diagnosed breast cancer. *Scandinavian Journal of Caring Sciences*, 16:216-223.
- Lang, E. 1992. Role Conflict. *Encyclopedia of sociology*, 3:1676-1677.
- Leon, E., De Jager, S. & Toop, J. 1995. Chemotherapy. In Pervan, V., Cohen, L.H. & Jaftha, T. (Eds). *Oncology for health-care professionals*. Kenwyn: Juta.
- Lethborg, C.E., Kissane, D. & Burns, W.I. 2003. 'It's not the easy part': the experience of significant others of women with early stage breast cancer, at treatment completion. *Social Work in Health Care*, 37(1):63-85.
- Lin, H.R. & Bauer-Wu, S.M. 2003. Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. *Journal of Advanced Nursing*, 44(1):69-80.
- Lippman, M.E. 2012. Breast cancer. In Longo, D.L., Fauci, A.S., Kasper, D.L., Hauser, S.L., Jameson, J.L. & Loscalzo, J. (Eds). *Harrison's Online*. 8th ed. McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/resourceTOC.aspx?resourceID=4> (Accessed 2013/06/24).
- Little, M., Paul, K., Jordens, C.F.C. & Sayers, E.J. 2002. Survivorship and discourse of identity. *Psycho-Oncology*, 11:170-178.
- Lo Castro, A.M. & Schlebusch, L. 2006. The measurement of stress in breast cancer patients. *South African Journal of Psychology*, 36(4):762-779.

Longo, D.L. 2012. Approach to the patient with cancer. In Longo, D.L. (Ed.), Fauci, A.S., Kasper, D.L., Hauser, S.L., Jameson, J.L. & Loscalzo, J. *Harrison's Online*. 8th ed. McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=9114033> (Accessed 2013/06/24).

Luoma, M.L. & Hakamies-Blomqvist, L. 2004. The meaning of quality of life in patients being treated for advanced breast cancer: a qualitative study. *Psycho-Oncology*, 13:729-739.

Mak Wai Ming, V. 2002. Psychological predictors of marital adjustment in breast cancer patients. *Psychology, Health & Medicine*, 7(1):37-51).

Malan, H. 2012. Personal interview with Dr Malan, health care social worker at Wilmed Park Oncology. 26 March. Klerksdorp.

Mandal, A. [Sa]. History of breast cancer. Available: <http://www.news-medical.net/health/Histroy-of-Breast-Cacner.aspx> (Accessed 2013/06/21).

Mayeaux, E.J. 2009. Paget's disease of the breast. In Usatine, R.P., Smith, M.A., Chumley, H., Mayeaux, E.J. & Tysinger, J. (Eds). *The Colour Atlas of Family Medicine*. McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?alD=8203793> (Accessed 2013/06/24).

Medical Dictionary for Allied Health. 2008. Boston: McGraw Hill Higher Education.

Meric-Benstam, F. & Pollock, R.E. 2010. Oncology. In Burnicardi, F.C., Andersen, D.K., Billiar, T.R., Dunn, D.L., Hunter, J.G., Matthews, J.B. & Pollock, R.E (Eds). *Schwartz's Principles of Surgery*. 9thed. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=5021163> (Accessed 2013/06/24).

Merriam Webster Dictionary. 2010. Transparency. Available: <http://www.merriam-webster.com/dictionary/transparent?show=o&t=1285777448> (Accessed 2010/09/29).

Merriam Webster Dictionary. 2013. Woman. Available: <http://www.merriam-webster.com/dictionary/woman> (Accessed 2013/10/22).

Minne, F. 2011. Personal interview with a professional nurse and the head of CANSA Potchefstroom. 19 October. Potchefstroom.

Monette, D.R., Sullivan, T.J. & DeJong, C.R. 2002. *Applied social research: a tool for the human services*. 5th ed. Australia: Wadsworth/Thompson Learning.

Monga, U. 2002. Sexual functioning in cancer patients. *Sexuality and Disability*, 20(4):277-295.

Montazeri, A., Vahdaninia, M., Harirchi, I., Ebrahimi, M., Khaleghi, F. & Jarvandi, S. 2008. Quality of life in patients with breast cancer before and after diagnosis: an eighteen months follow-up study. *BMC Cancer*, 8:330.

Montgomery, M. & McCrone, S.H. 2010. Psychological distress associated with the diagnostic phase for suspected breast cancer: systematic review. *Journal of Advanced Nursing*, 66(11):2372-2390.

National Cancer Registry. 2004. *Summary statistics of cancer diagnosed histologically in 2004*. Available: http://www.cansa.org.za/cause_data/images/1056/Cancer_Registry_2004.pdf (Accessed 2012/10/09).

Neuman, W.L. 2003. *Social research methods: qualitative and quantitative approaches*. 5th ed. Boston: Pearson Education Inc.

Neuman, W.L. 2011. *Social research methods: qualitative and quantitative approaches*. 7th ed. Boston: Pearson Education Inc.

New Social Work Dictionary. 1995. Terminology Committee of Social Work. (Eds.) Cape Town: CTP Bookprinters (Pty) Ltd.

Nieuwenhuis, J. 2007a. Qualitative research design and data gathering techniques. In Maree, K. (Ed). *First steps in research*. Pretoria: Van Schaik.

Nieuwenhuis, J. 2007b. Analysing qualitative data. In Maree, K. (Ed.) *First steps in research*. Pretoria: Van Schaik.

Ortega, Y. 2010. *Finding hope for your journey through breast cancer*. Michigan: Revell.

Oxford Concise Medical Dictionary. 2010. 5th ed. Oxford: University Press.

Palitza, K. 2008. Gender-South Africa: 'a real man does provide care'. Inter Press Sercie News Agency. Available: <http://www.ipsnews.net/2008/12/gender-south-africa-39a-real-man-does-provide-care39/> (Accessed 2013/06/13).

Patel, S.P., Buzdar, A.U. & Hunt, K.K. 2011. Early-stage and locally advanced breast cancer. In Kantarjian, H.M., Wolff, R.A. & Koller, C.A. (Eds). *The MD Anderson Manual of Medical Oncology*. 2nded. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=8307513> (Accessed 2013/07/01).

Parrish, M. 2010. *Social work perspectives on human behaviour*. Maidenhead: Open University Press.

Pervan, V., Cohen, L.H. & Jaftha, T. 1995. *Oncology: for health-care professionals*. Cape Town: Juta & Co.

Pretorious, J. 1998. The Portrayal of Women on TV in South Africa. Available: www.ifuw.org/seminars/Portrayal.pdf+g (Accessed 2013/06/24).

Prigozin, A., Uziely, B. & Musgrave, C.F. 2010. The relationship between symptom severity and symptom interference, education, age, marital status, and type of chemotherapy treatment in Israeli women with early-stage breast cancer. *Oncology Nursing Forum*, 37(6):411-418.

Rees, G. 2004. *Understanding cancer*. Dorset: Family Doctor Publications.

Ross, E. & Deverell, A. 2004. *Psychosocial approaches to health, illness and disability: a reader for health care professionals*. Pretoria: Van Schaik Publishers.

Ross, E. & Deverell, A. 2010. *Health, illness and disability: psychosocial approaches*. 2nd ed. Pretoria: Van Schaik Publishers.

Royse, D. 2011. *Research methods in social work*. 6thed. Brooks/Cole: Cengage Learning.

Sausville, E.A. & Longo, D.L. 2012. Principles of cancer treatment. In Longo, D.L., Fauci, A.S., Kasper, D.L., Hauser, S.L., Jameson, J.L. & Loscalzo, J. (Eds).

Harrison's Online. 8th ed. McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/resourceTOC.aspx?resourceID=4> (Accessed 2013/06/24).

Schultz, P.N., Stava, C.J., Habra, M.A. & Vassilopoulou-Sellin, R. 2011. Adult long-term follow-up. In Kantarjian, H.M., Wolff, R.A. & Koller, C.A. (Eds). *The MD Anderson Manual of Medical Oncology*. 2nded. The McGraw-Hill Companies, Inc. Available: <http://0-accessmedicine.com.innopac.up.ac.za/content.aspx?aid=8315918> (Accessed 2013/07/01).

Schurink, W., Fouché, C.B. & De Vos, A.S. 2011. Qualitative data analysis and interpretation. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for the social sciences and human service professions*. 4thed. Pretoria: Van Schaik Publishers.

Semple, C.J. & McCance, T. 2010. Experience of parents with head and neck cancer who are caring for young children. *Journal of Advanced Nursing*, 66(6):1280-1290.

Serfontein, W. 2010. *Gediagnoseer met kanker! Wat nou? Wat elke pasiënt en dokter moet weet*. Rosslyn-Pers.

Siddiqi, A., Given, C.W., Given, B. & Sikorskii, A. 2009. Quality of life among patients with primary, metastatic and recurrent cancer. *European Journal of Cancer Care*, 18:84-96.

Skrzypulec, V., Tobor, E., Droszol, A. & Nowosielski, K. 2008. Biopsychosocial functioning of women after mastectomy. *Journal of Clinical Nursing*, 18:613-619.

South African Medical Research Council. 2010. *What are the top causes of death due to cancer in SA?* Available: <http://www.mrc.ac.za//bod/faqcancer.htm> (Accessed 2011/07/25).

Stiffler, D., Barada, B., Hosei, B., & Haase, J. 2008. When mom has breast cancer: adolescent daughters' experiences of being parented. *Oncology Nursing Forum*, 35(6):933-940.

Strydom, H. 2011. Ethical aspects of research in the social sciences and human service professions. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport,

C.S.L. *Research at grass roots: for the social sciences and human service professions*. 4th ed. Pretoria: Van Schaik Publishers.

Strydom, H. & Delport, C.S.L. 2011. Sampling and pilot study in qualitative research. In De Vos, A.S. (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots: for the social sciences and human service professions*. 4th ed. Pretoria: Van Schaik Publishers.

Todres, L. 2005. Clarifying the life-world: descriptive phenomenology. In Holloway, I. (Ed). *Qualitative research in health care*. Open University Press.

Tulman, L. & Fawcett, J. 2007. Development of the comprehensive inventory of functioning – cancer. *Cancer Nursing*, 30(3):205-212.

Van Schalkwyk, D. 1995. Counselling and support of patients and family. In Pervan, V., Cohen, L.H. & Jaftha, T. (Eds). *Oncology for health-care professionals*. Kenwyn: Juta.

Venter, M. 2008. *Cancer patients' illness experiences during a group intervention*. Potchefstroom: North West University. (MA Dissertation).

Vivar, C.G., Canga, N., Canga, A.D. & Arantzamendi, M. 2009. The psychosocial impact of recurrence on cancer survivors and family members: a narrative review. *Journal of Advanced Nursing*, 65(4):724-736.

Vorobiof, D.A., Sitas, F. & Vorobiof, G. 2001. Breast cancer incidence in South Africa. *Journal of Clinical Oncology*, 19(18): 125-127.

Werner-Lin, A. & Biank, N.M. 2006. Oncology social work. In Gehlert, S. & Browne, T.A. (Eds). *Handbook of Health Social Work*. New Jersey: John Wiley & Sons, Inc.

World Health Organisation. 2008. *Are the number of cancer cases increasing or decreasing in the world?* Available: <http://www.who.int/features/qa/15/en/ondex.html> (Accessed 2013/06/11).

World Health Organisation. 2012. *Cancer prevention and control*. Available: <http://www.afro.who.int/en/clusters-a-programmes/dpc/non-communicable-diseases-managementndm/programme-components/cancer.html> (Accessed 2013/06/11).

World Health Organisation. 2013a. *Cancer*. Available: <http://www.who.int/mediacentre/factsheets/fs297/en/index.html> (Accessed 2013/06/11).

World Health Organisation. 2013b. *Breast cancer: prevention and control*. Available: <http://www.who.int/cancer/detection/breastcancer/en/index.html> (Accessed 2013/06/11).

Zastrow, C.H. & Kirst-Ashman, K.K. 2004. *Understanding human behaviour and the social environment*. 6th ed. Belmont: Brooks/Cole Thompson Learning.

Zastrow, C.H. & Kirst-Ashman, K.K. 2013. *Understanding human behaviour and the social environment*. 9th ed. Andover: Cengage Learning.

Appendix 1: Ethical approval letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

8 February 2013

Dear Prof Lombard

Project: The social functioning of women with breast cancer: a social work perspective
Researcher: J van Wyk
Supervisor: Dr CL Carbonatto
Department: Social Work and Criminology
Reference number: 10598783

Thank you for your response to the Committee's letter of 6 December 2012.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 8 January 2013. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Sakhela Buhlungu
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: sakhela.buhlungu@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof S Buhlungu (Chair); Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof A Mlambo, Dr C Panebianco-Warrens; Prof GM Spies; Prof E Taljard ; Dr FG Wolmarans, Dr P Wood

Appendix 2: Permission letter from CANSA



Toll-Free 0800 22 66 22
www.cansa.org.za

HEAD OFFICE
Bedfordview

+27 11 616 7662
+27 11 615 2769

26 Concorde Road West
Bedfordview, 2008

PO Box 2121,
Bedfordview, 2008

Tel
Fax
Address
Postal

26 September 2012

MsJonita van Wyk
P.O BOX 6571
BAILLIE PARK
POTCHEFSTROOM
2526

Dear Ms van Wyk

THE SOCIAL FUNCTIONING OF WOMEN WITH BREAST CANCER: A SOCIAL WORK PERSPECTIVE

Your recent application to make use of CANSA patients as respondents towards your envisaged research refers.

It gives me great pleasure to inform you that your application has been approved. You may, therefore, continue with your research project as indicated in your application.

Sincerely

Michael C Herbst (Prof)
For CANSA Research Ethics Committee



Rated as South Africa's 3rd most
trusted and admired NGO

Cancer affects us all...

Non-Executive Directors: I. Johnstone (Chairperson) | B. Pancha (Vice-Chairperson) | Prof. E. McIntosh | D. Foster | Dr C. Masuku | T. Mashaba
Executive Directors: S. Janse Van Rensburg (CEO) | E. Joubert (COO) | R. van Jaarsveld (CFO)

Reg. No. 1932/003720/08. NPO No. 000-524



Appendix 3: Interview schedule

Interview schedule

Research for MSW (Health Care)

Principle Investigator: Jonita van Wyk (10598783)

The social functioning of women with breast cancer: a social work perspective

General

- ❖ Age of participant
- ❖ Marital status of participant
- ❖ Dependent children and ages of children
- ❖ Employment of participant
- ❖ Composition of household

Cancer

- ❖ Diagnosis of participant
- ❖ Current treatment of breast cancer
- ❖ Participants understanding of disease
- ❖ Feelings at time of diagnosis
- ❖ Feelings during treatment

Individual

- ❖ Changes patient experiencing within her personality
- ❖ What constitutes a woman
- ❖ Being/feeling like a woman
- ❖ Changes patient experiencing with regards to spiritual aspect
 - What was it before
 - What is it now
- ❖ Changes with regards to self image
 - What was it before
 - What is it now

Family

- ❖ Changes in relationship with husband
 - Only if she is married or in a relationship
- ❖ Changes in sexual Identity
- ❖ Changes in role as mother
 - Relationship changes
- ❖ Changes in role as caregiver

- What tasks did respondent do before diagnosis and treatments
- ❖ Changes in role as a daughter
 - If parents are still alive
- ❖ Changes in role in extended family

Community

- ❖ Changes experienced in work life
 - Responsibilities at work
- ❖ Changes experienced as a community member
 - Responsibilities in community, including church
 - Experiences in town
- ❖ Changes experienced in her social support network
 - Focus on friends, role in friend circle

Appendix 4: Letter of informed consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

Researcher: Jonita van Wyk

Contact Details: 083 601 5532

LETTER OF INFORMED CONSENT

Title of Study: The social functioning of women with breast cancer: a social work perspective

Principal Investigator: Jonita van Wyk, MSW (Health Care) student, University of Pretoria, Pretoria

TARGET GROUP (Clients of CANSA Potchefstroom receiving chemotherapy for breast cancer)

Participant's Name:..... **Date:**.....

Purpose of the Study: To explore the social functioning of women experiencing breast cancer

Procedure: You will participate in a in-depth interview with the researcher focusing on three aspects: changes in her role in the family, changes in her role as a community member and changes in roles as an individual. Each interview will be voice recorded for the purpose of collecting data and each interview will last approximately sixty minutes. The data will be stored for 15 years according to the

prescribed standards of the University of Pretoria. The data may be used for future research.

Risks and Discomforts: No known medical risks or discomforts are associated with the participation in this study. Should you experience any emotional harm as a result of the interviews, debriefing interviews will be conducted with the researcher after completion of the interviews. If additional counselling is required, you will be referred to CANSA staff or Dr Humpel, a social worker at Potchefstroom Hospital.

Benefits: The results of this study will assist CANSA staff and health care practitioners working with patients receiving chemotherapy for breast cancer to understand how the social functioning of the woman is being influenced.

Participant's Rights: You may withdraw from participating in this study at any time and withdrawal from the study will not have any negative implications for the participant.

Confidentiality and anonymity: The data collected during the interviews using a voice recorder and field notes will remain confidential. The data will be transcribed after the interview and your name will not be used but a number or pseudonym. The data will not be linked to your name or identity, maintaining anonymity. The results may be published in a professional journal and will be part of a mini-dissertation but will never be linked to your identity.

Persons to contact: If you want to talk to anyone about the research study because you think you have not been fairly treated or think you have experienced emotional harm by participating in the study, or you have any other questions about the study, you should call the researcher, Jonita van Wyk at 083 601 5532.

I..... understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and the procedures in this study. I will receive a signed copy of this consent form.

Participant's Signature

Date

Researcher Name

Researcher Signature

Date

Appendix 5: Declaration of language editing



Co-directors: CME Terblanche - BA (Pol Sc), BA Hons (Eng), MA (Eng), TEFL
T van der Westhuizen - BA (Psyc, Eng), BA Hons (Eng), MA (Eng), PGCE

22 Strydom Street
Baillie Park, 2531

Tel 082 821 3083 / 084 404 4264
cumlaudelanguage@gmail.com

DECLARATION OF LANGUAGE EDITING

I, Therina van der Westhuizen, ID nr 861007 0057 086, hereby declare that I have edited the dissertation of Jonita van Wyk, entitled

**The social functioning of women with breast cancer:
a social work perspective**

without viewing the final product.

Regards,

T. van der Westhuizen

Cum Laude Language Practitioners (CC)

SATI reg nr: 1002991