

Exploring the experiences of patients with breast cancer from
diagnosis through management

Danielle-Kirsty Daniels

Full Thesis submitted in fulfilment of the requirements for the degree
MA (Psychology) in the Department of Psychology, Faculty of
Community and Health Sciences, University of the Western Cape



UNIVERSITY *of the*
WESTERN CAPE

November 2011

Supervisor: Dr. N. Roman

ABSTRACT

Breast cancer has become a life-threatening disease for women. Whether breast cancer is in the initial or advanced stage, it can be devastating to receive such a diagnosis. However, the effective treatment of this disease may depend on the communication process between the physician and the patient, from the time a diagnosis is made. The information transmitted by the physician is vital as it includes explanations of breast cancer, and of the treatment options.

Good communication is essential in the treatment of women with breast cancer. The aim of this study is to explore the role of communication between the physician and women with breast cancer, and to examine women's coping mechanisms from diagnosis through the management of the illness to its resolution. A qualitative methodology was utilised, with purposive sampling of participants from a public hospital in the Western Cape. A semi-structured interview was used to gather the data, after which a thematic analysis was conducted. The findings reveal the information exchange between physician and patient was clear, direct and understandable.

Furthermore, the participants coped by accessing and using support from family and friends, by recourse to spirituality and prayer (bargaining with God, questioning of God), and by developing a positive attitude, with hope for recovery and acceptance. There were also emotional and psychological reactions from women in the sample when they received their diagnoses. This study may provide valuable insights into the experiences of women with stages I to III of breast cancer.

DECLARATION

I declare that *Exploring the experiences of patients with breast cancer from diagnosis through management* **is my own work, that it has not been previously submitted for any degree or examination, and that all sources have been acknowledged.**

Danielle-Kirsty Daniels

November 2011



Signed:.....

UNIVERSITY *of the*
WESTERN CAPE

DEDICATION

I dedicate this study to a woman of strength who lost her fight against cancer, my late Grandmother; **Susan Vollenhoven Ada**; she was the motivation for this study. She was a mother, friend, mentor, confidant, and my pillar of strength: I gather my strength and inspiration from you. You were always there for me. Thank you so much for your love, care, guidance and support over the years. I know that you are proud of me. I miss and love you!

Your memories are a shield to my heart and will



ACKNOWLEDGEMENTS

The completion of this study is owed to my heavenly Father, Jesus Christ.

I am fully indebted to Him. Through all the adversity that I have faced, I realised that my time is not God's time. God is never too late, never too early, He is always on time. When my wings became too tattered to fly, You repaired them, so that I could continue. Thank you, Father God, for you know the plans you have for me.

To my late Grandmother, Susan Vollenhoven Ada. Thank you, Lord for blessing me with such a wonderful woman in my life. No words can describe the fullness of what she meant to me. I have closure now and this study has given me the opportunity to understand what she was enduring at the time of her illness. Till we meet at Jesus feet.

To my parents, Errol and Maureen Daniels, a huge thank you for nurturing and moulding me into the beautiful and intelligent woman that I am today. I am blessed and grateful.

To my partner, Freddie Felix, who has always been there for me and still is. Thank you so much for standing by me and having the patience to allow me to focus on my studies. You have played a role in my achievements. Thank you for understanding and supporting me when I felt like my world was falling apart. You believed in me and my abilities.

My sister, brothers, niece and nephew: Mandy, Cleavon, Charlton, Tarryn and Ashton: I thank you for your prayers and words of encouragement. Now you can stand firm and be proud of your sister and aunt.

To my supervisor, Dr. N. Roman who took me under her wing at short notice. We have produced so much together in such a short space of time. Thank you for your guidance, commitment, support, encouragement and your constructive criticism. It was an immense joy, honour and pleasure to work with you. You kept me on my toes.

To Doctors and Staff of Groote Schuur Hospital and the Radiation Oncology Department: for allowing me to conduct the interviews at the hospital. Your warmth and friendliness made me comfortable and gave me a pleasurable working experience.

[please refer to Appendix A]

Finally, an act of determination, achievement and gratitude to all.

[Her Majesty the Queen's wave]



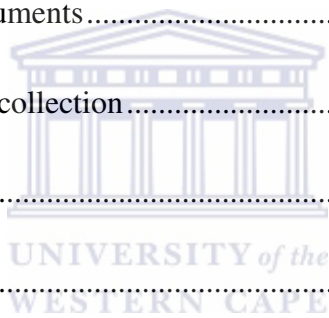
Table of Contents

CHAPTER 1	GENERAL ORIENTATION.....	1
1.1	Background and Rationale for the Research.....	1
1.2	Problem Statement	7
1.3	Research Questions	8
1.4	Aims and Objectives	9
1.5	Theoretical Framework	9
1.6	Definitions and Descriptions of Key Concepts and Terms.....	10
1.7	Motivation for the study.....	12
1.8	Significance of Study	13
1.9	Ethics of the Research.....	14
1.10	Structure of the Dissertation.....	15
CHAPTER 2	COMMUNICATING THE DIAGNOSIS OF BREAST CANCER ...	17
2.1	Introduction	17
2.2	The concept of communication.....	17
2.2.1	Verbal Communication.....	18
2.2.2	Non-verbal Communication.....	18
2.3	Medical language	19
2.4	Communication Processes.....	20
2.5	Breast cancer	21

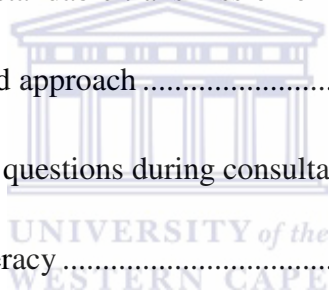
2.5.1	The concept of breast cancer.....	21
2.5.2	Stages of breast cancer.....	21
2.5.3	Treatment for stages I and II.....	22
2.5.4	Treatment for Stage III.....	23
2.6	Factors contributing to effective communication between physician and patient.....	25
2.6.1	Closed questions	26
2.6.2	Socio-economic status of the patient	27
2.6.3	The use of medical language during the diagnosis	29
2.6.4	Lack of communication skills by the physician.....	32
2.6.5	Physicians who do not disclose information.....	33
2.7	Factors contributing to good communication.....	34
2.7.1	The Physician's communication style	34
2.7.2	The Physician's character traits	35
2.7.3	Patients' active participation: asking questions	36
2.8	Advantages of good communication.....	37
2.9	The influence of effective communication on health outcomes	38
2.10	Conclusion	39
CHAPTER 3	MANAGING THE STRESS OF BREAST CANCER	41
3.1	Introduction	41

3.2	Defining stress and coping	41
3.2.1	The concept of stress.....	41
3.2.2	The concept of coping.....	41
3.3	Historical approaches to stress and coping	42
3.4	Folkman and Lazarus's stress and coping theory	45
3.5	The Link between Coping, Appraisal and Adaptation.....	48
3.5.1	The link between coping and appraisal.....	48
3.5.2	The relationship between coping and adaptation.....	49
3.5.3	The link between appraisal and adaptation	50
3.6	The stress of breast cancer	51
3.6.1	Coping with breast cancer.....	53
3.7	Behavioural problems experienced by patients during a consultation.....	55
3.7.1	Behavioural disengagement	55
3.7.2	Self-Distraction	55
3.8	Managing a diagnosis of breast cancer	56
3.8.1	Coping mechanisms used by women with breast cancer when dealing with a diagnosis.....	58
3.9	The role of helplessness and hope.....	62
3.10	The relationship between hope and coping	64
3.10.1	Avoidance Coping: Denial.....	64

3.10.2	Spirituality/Religion.....	66
3.10.3	Accepting the diagnosis	68
3.11	Conclusion	70
CHAPTER 4	RESEARCH METHODOLOGY	71
4.1	Introduction	71
4.2	Qualitative Research	71
4.3	The social constructivist research approach.....	72
4.4	Participants	75
4.5	Data collection instruments.....	76
4.6	Procedures and data collection.....	77
4.7	Data analysis	78
4.8	Reflexivity.....	79
4.9	Trustworthiness	81
4.10	Conclusion.....	82
CHAPTER 5	RESULTS.....	84
5.1	Introduction	84
5.2	Description of Participants.....	84
5.3	Themes and sub-Themes.....	86
5.3.1	Theme 1: Communication from the physician.....	88
5.3.2	Theme 2: Reactions to the diagnosis	97



5.3.3	Theme 3: The stress of the diagnosis.....	100
5.3.4	Theme 4: Coping with a Breast Cancer diagnosis.....	105
CHAPTER 6		
	DISCUSSION.....	119
6.1	Introduction.....	119
6.2	Summary of results.....	119
6.3	The reactions to a breast cancer diagnosis	120
6.3.1	Emotional and psychological distress.....	120
6.4	Physician’s style of communication and patient satisfaction.....	122
6.4.1	Clear and understandable transmission of information	123
6.4.2	A person-centred approach	124
6.4.3	The use of open questions during consultation.....	125
6.5	Patient’s medical literacy.....	126
6.5.1	Breast cancer and mammograms	127
6.5.2	Adjuvant Therapy	127
6.6	Coping Mechanisms used by women with a breast cancer diagnosis.....	128
6.6.1	Social support.....	128
6.6.2	Optimism.....	130
6.6.3	Acceptance.....	131
6.6.4	Hope.....	133
6.6.5	Denial.....	133



6.6.6	A spiritual relationship with God.....	134
6.7	Limitations of the study.....	136
6.8	Recommendations	137
6.9	Conclusion.....	139
	References.....	144

Appendix A		i
Appendix B		ii
Appendix C		iii
Appendix D		iv
Appendix E		v



CHAPTER 1

GENERAL ORIENTATION

1.1 Background and Rationale for the Research

**The words “woman/women with breast cancer” and “patient” have been used interchangeably in this study as the study is of a sensitive nature.*

One of the most common female cancers is breast cancer. It accounts for a high proportion of the deaths that occur from illness among women. This type of cancer is a major health concern for South African women (Vorobiof, Sitas & Vorobiof, 2001). In 1998, breast cancer was considered to be the second most common type of cancer in South Africa, and in 1999 it became the leading cause of mortality from cancer (National Cancer Registry of South Africa, 1998-1999). According to the latest (2000-2001) National Cancer Registry of South Africa, one in 29 women are affected by breast cancer. The Medical Research Council (MRC) reported that in 2000, 3206 women died of breast cancer. Breast cancer is now the most common form of cancer (16.6%) occurring in South African women (Vorobiof, et al., 2001).

Despite the high incidence of breast cancer, and the high mortality rate in South Africa, Fallowfield (2008) states that one of the most urgent challenges for medical practitioners is the communication of information between physicians and patients. According to Carmack (2010) simple communication errors often occur, and are the eighth leading cause of mortality among patients, higher even than breast cancer and HIV/AIDS combined. Women who are diagnosed with breast cancer often have difficulty understanding the information they receive from physicians and this limits

their understanding of their disease (Davis, Williams, Marin, Parker & Glass, 2002).

The effective communication of information during consultation is seen as an important step in delivering a high quality of patient care.

The initial consultation between physician and patient is followed by a number of further consultations (or phases) during which the following information will be communicated: (i) the nature of the illness, and its history and prognosis; (ii) treatment; (iii) diagnostic tests; (iv) maintenance care; and (v) psychosocial reactions (Fallowfield, 2008). At each phase of the consultation different information needs to be communicated to the patient. However, the communication of information can present challenges.

The misunderstanding of breast cancer by patients is recognised as a major problem (Davis, et al., 2002). Merriman, Ades and Sefrin (2002) similarly indicate that the lack of understanding of the illness has an effect on the incidence of cancer, on the mortality rate and on the quality of life of the patient. An inability to understand medical terms makes it difficult for patients to gain a clear understanding of the nature and extent of their illness as well as of the prospects for improvement. Both Davis et al. (2002) and Merriman et al. (2002) state that a lack of understanding of breast cancer can present difficulties for patients and may account for the high number of deaths resulting from cancer. This is consistent with what the previously mentioned findings by Carmack (2010), who stated that medical error is the eighth leading cause of mortality in medical treatment. According to Carmack (2010) medical error does occur, and includes misdiagnosis and communication errors (National Patient Safety Foundation, 1997). This confirms the findings of Vorobiof et al. (2001) and Carmack

(2010) that medical mistakes may contribute to the high mortality rate among breast cancer patients.

According to the World Medical Association Medical Ethics Manual (2009:42)

The patient has the right to the information necessary to make his/her decisions. The patient should understand clearly what the purpose of any test or treatment is, what the results would imply, and what would be the implications of withholding consent.

This implies that the patient has the right to be given information about his or her condition its possible consequences in a clear and detailed manner. According to the World Medical Association Medical Ethics Manual (2009) communication is a priority for physicians. This means that physicians need explain medical terminology in plain layman's terms to ensure that the information communicated during consultations is understood. One can imagine how anxious and confused a patient would be on receiving a diagnosis of breast cancer, especially if he or she did not understand the information communicated by the physician. Effective communication between physician and patient plays an important role in reducing this anxiety and in assisting these women to cope with breast cancer.

While physicians are obliged to communicate information about their disease to their patients an additional challenge is the reluctance of some patients to ask for information; this may stem from their own poor communication skills (Iserson, 2001). Often patients with breast cancer find it difficult to understand medical language. A common barrier to understanding the information communicated by the physician is use of medical jargon. Whatever the patient's background, if he or she is relatively uneducated then the information may not be understood. The physician has more

power and the responsibility to ensure that the patient understands what breast cancer is.

Effective communication between physician and patient is important so that disease-related anxiety can be reduced (Fallowfield, 2008). This requires a good physician-patient relationship, where the physician communicates on the same level as the patient and listens to their concerns, so that trust can be established between them (Barraclough, 2000).

The need for effective communication between physician and patient is obvious.

Arora (2003) states that quality of this communication contributes (directly or indirectly) to the enhanced health of the patient. It can be stated that communicating information in a clear and understandable way will assist the patient to understand her breast cancer diagnosis and will improve her health.

Similarly, Street, Makoul, Arora and Epstein (2009) report that communication between physician and patient can enhance health in various ways. These include: (i) through the availability of care; (ii) by improving patients' knowledge and understanding; (iii) by providing therapy for the patient and her family; (iv) by improving patients' emotional health; (v) by providing support structures; (vi) by improving the quality of medical choices; and (vii) by accepting the agency of the patient (Street et al., 2009). The processes outlined by Street et al. (2009) are all relevant to establishing effective communication between physician and patient.

Recognition of (i) the need to improve patients' knowledge and understanding; (ii) the need to attend to patients' emotional health; and (iii) the need to improve the quality

and range of available medical options is crucial to understanding the relationship between diagnosis and health outcomes.

One may ask how the three processes mentioned by Street et al. (2009) can contribute to the relationship between diagnosis and health outcomes. Firstly, a woman with breast cancer may not have sufficient knowledge and information about her illness. It is the task of both physician and patient to interact and understand each other's points of view and to develop the ability to impart and receive information (Epstein, Alper & Quill, 2004). Once this is achieved, the path to effective information is established, and satisfaction (on the part of both physician and patient) increases (Davidson & Mills, 2005): the patient interacts with the physician (Charles, Gafni & Whelan, 1999) and the patient is able to deal with the illness (Hagerty et al., 2005).

Secondly, according to Ryan et al. (2005) a patient with health concerns may be more vulnerable to emotional instability and their health can be affected. Physicians can assist patients to deal with their emotions by providing information in a clear manner; this will give them a sense of hope and assist them to cope (Schofield, Butow, Thompson, Tattersall, Beeney & Dunn, 2003). Physicians may not be able to observe what a patient is feeling, but they can assist the patient to deal with emotions by communicating information in a clear and honest manner (Fujimori, Parker, Akechi, Sakano, Baile & Uchitomi, 2007), by showing empathy for their patients (Fujimori, Akechi, Morita, Inagaki, Akizuki, Sakano & Uchitomi, 2007), and by listening to their needs (Zachariae, Pedersen, Jensen, Ehrnrooth, Rossen & Von der, 2003).

Thirdly, patients may also be faced with the challenge of understanding medical information. Physicians may not be able to contextualise that information in a way

that meets the needs of the patient (Street *et al.*, 2009). A lack of shared understanding between physician and patient may lead to medical mistakes and adversely affect a patient's response to therapy (Gattellari, Voigt, Butow & Tattersall, 2002). In essence, patients will experience better health when physician-patient consultations are based on mutual understanding, where differences are set aside and each understands the others' viewpoints (Street *et al.*, 2009).

A study conducted by Boehmke and Dickerson (2006) aimed to understand the post-diagnosis experiences of women with breast cancer. They concluded that the manner in which women approached their diagnosis had an impact on their well-being. Their study suggested that women with breast cancer would be likely to feel lonely or anxious and fear death – or experience a variety of other emotions that could affect their personality and outlook (Boehmke *et al.*, 2006). It is very possible that the diagnosis of breast cancer will have a negative effect on a patient's well-being. Merriman *et al.* (2002) emphasise that people who cannot understand medical terms experience various forms of stress. The way in which the diagnosis is conveyed by a physician plays an important role in determining how women with breast cancer will deal with it. However, if a physician communicates in a manner which makes it difficult for a woman with breast cancer to understand her condition, this may impact negatively on her health outcome.

The current study attempts to address three gaps identified by Thompson *et al.* (2008) in their research into breast cancer. These are (i) the need to find ways of communicating medical information effectively, and the need to evaluate the personal experiences of women with breast cancer, and (ii) the need to examine the relationship between diagnosis and health outcomes (Boemke & Dickerson, 2006).

The research currently being done on breast cancer focuses mainly on risk factors, and on prevention, early detection, treatment and quality of life: little is said about the survival stages of breast cancer and how these affect the ability to cope as the cancer progresses. Research has indicated that the effect of a breast cancer diagnosis is linked to the stage of the illness (American Cancer Society, 2008). Further study is needed to investigate the impact that a diagnosis of breast cancer can have on the different stages of breast cancer. This study will assist in understanding the relation between communication and a patient's ability to cope with stages I to III of the illness.

1.2 Problem Statement

Breast cancer has become a disease that is feared by many women. Few studies have explored communication between oncologist and patient and the impact this has on the patient's ability to cope (Eide, Graugaard, Holgersen & Finset, 2003) and more research on managing cancer is needed (Tanner & Myers, 2002). When communication barriers (such as miscommunication or non-communication) are present this impairs the relationship between physician and patient, and makes mutual understanding more difficult. Physician-patient communication is an interpersonal and reciprocal process and is an integral part of a relationship of focused care (Kenny et al., 2010). Physicians should not assume that all their patients are on the same level or have the same values and experiences. These differences create a basis for misunderstanding between physician and patient (Sutherland, 1958). Research suggests that medical error results in 12% of deaths among patients (Carmack, 2010; National Patient Safety Foundation, 1997). Failure to communication is considered a medical error and is the eighth leading cause of mortality among patients; it seriously affects the well-being and recovery of the patient (Carmack, 2010). For women

diagnosed with breast cancer, the challenge is to receive and understand as much information as possible in order to cope with the disease. Stages I to III of breast cancer are often referred to as the “early stages or primary stages” because when treatment is administered during these stages there is a good chance of recovery. Early diagnosis and treatment are important for the patient’s recovery, as are ways of managing the illness. It is the responsibility of the physician to find the frame of reference for each patient he/she is dealing with. This will make it easier for the physician to explain the diagnosis to the patient and to communicate effectively with the patient. Communication of information between physicians and patients is a challenge that requires urgent attention in the medical field (Davis *et al.*, 2002; Fallowfield, 2008). This may be because each stage of breast cancer has different requirements in terms of the patients’ coping strategies. If the patient is well-informed, she will know what to expect and therefore know how to manage each stage. The physician plays an important role in this communication process. This study provides important information to assist in understanding the role of communication between the physician and the patient. This study also fills existing knowledge gaps by contributing to breast cancer research in a South African context. It provides qualitative research with regard to breast cancer, and the importance of effective communication with patients who have been diagnosed with stage I-III breast cancer.

1.3 Research Questions

- How was the diagnosis communicated to the patient by the physician?
- How do women cope when diagnosed with breast cancer?

- How does the role of communication between physician and patient influence the way women cope with breast cancer?

1.4 Aims and Objectives

The aim of the study was to:

- explore the role of communication between physician and women diagnosed with breast cancer, from diagnosis through the course of treatment for breast cancer.

The objectives were to:

- explore and describe the role of communication between the physician and women who have been diagnosed with stage I-III breast cancer;
- explore the coping mechanisms used by women diagnosed with stage I-III breast cancer from diagnosis through management.

1.5 Theoretical Framework

The stress and coping theory of Folkman and Lazarus (1986) was used to explore the role of communication between physician and patient, specifically in relation to the coping mechanisms of women diagnosed with stage I-III breast cancer. This theory discusses how a diagnosis of breast cancer is perceived as stressful and, how certain coping mechanisms can be used to manage the patient's condition and environment. These coping mechanisms influence the way in which women with breast cancer respond to their diagnosis, which acts as a stressor. However, understanding the stages of the breast cancer is important for the patient, as different coping mechanisms

are appropriate for each stage of the illness. This theory is discussed further in the subsequent chapters.

1.6 Definitions and Descriptions of Key Concepts and Terms

Breast Cancer– refers to a tumour of the breast (Reddy, 2011).

Communication – Communication is defined as a process of transmitting information from one individual to another (Debanjan, 2010). Adejimola, Ayenigbara and Tunde (2010) state that communication is a means of sending, disseminating and receiving information. Communication “involves the encoding of thoughts and feelings, by the initiator of a message, into patterns of behaviour leading to the transmission of that message, via one or more of a range of potential communication channels, to one or more recipients. Decoding of this transmission exerts influence over the thoughts and feelings of the recipient(s), leading to an encoded feedback response to the transmission source” (*Key Concepts in Nursing*, 2008).

Coping – Coping has been defined as a behavioural way of managing demands that are regarded as stressful for an individual (Folkman, 1992). The concept of coping is also defined as managing something difficult (*Concise Oxford English Dictionary*, 2004).

Coping Mechanism – also known as coping strategies; these are ways of dealing with anxieties or with the sources of the stress (*The Penguin Dictionary of Psychology*, 2009)

Diagnosis- a condition resulting from an illness which is identified by examining the symptoms (*Concise Oxford English Dictionary*, 2004).

Exploring- is a word used in qualitative studies to refer to examining and discussing some topic in detail (*Concise Oxford English Dictionary*, 2004).

Experience – refers an encounter or event which has a lasting impact on a person (*Concise Oxford English Dictionary*, 2004).

Management – refers to the control or treatment of illnesses or the care of people suffering from an illness (*Concise Oxford English Dictionary*, 2004).

Patient – refers to an individual with a medical problem or condition who is receiving treatment for the illness (*Pharmaceutical Medicine Dictionary*, 2001).

Physician – refers to a specialist or a medical doctor. The name is given to a person who has achieved a Doctorate of Medicine (MD) degree and who is recognised as a practitioner of medicine under the rules and regulations of the country in which he/she practices (*Webster New World Medical Dictionary*, 2003).

Staging – Staging categorises the severity and the extent to which the breast cancer has progressed (*Clinical Reference Systems*, 2008). The stage of the breast cancer depends on the size of the tumor as well as on how far the cancer has spread (*Clinical Reference Systems*, 2008). Knowledge of the staging process will assist physicians to provide the necessary treatment, thereby increasing the chances of survival.

Stress – According to Selye (1955:626), the term stress may be defined as “a non-specific deviation from the normal resting state; it is caused by function or damage and it stimulates repair”. Selye (1955) states that the non-specific causation of the change has been chosen as its most dominant feature; a non-specific change is defined as one that can be produced by many agents, as opposed to a specific change, which is

elicited only by one or a few agents. Selye (1955) differentiates between non-specific and specific concepts by stating that a non-specific agent acts on many targets, while a specific one acts on only a few targets. A stressor is an agent that causes stress. In other words, stress is a non-specific response by the human body to demands that are placed upon it. Laposa, Lynn, Fullerton and Vancouver (2003) describe stress as a psychobiological response of the body caused by physical and psychological demands that could harm or deplete an the individual's resources. In addition, stress is defined as a condition of psychological and emotion tension in an individual (*Concise Oxford English Dictionary*, 2004).

1.7 Motivation for the study

As the researcher, I have often been asked what the motivation was for this study. When I was younger, I would confront by people saying that their loved one or someone they knew had died of cancer. However, I did not know of someone close to me with this illness. When I was confronted with the news that my grandmother had been diagnosed with oesophageal cancer, this came as a shock to me. All I could think of was death. I knew that people with cancer died. But I kept my hopes high and my faith was strong, so I only wished for the best. A worse scenario was being told that my grandmother had only six months to live. Amidst the confusion and sadness, I kept praying, asking God to give my grandmother another chance. As her condition deteriorated, I saw from the look in her eyes that she still had the will and courage to continue living. Sadly, one morning at her bedside, she asked me what cancer was. What was this illness? As I was thinking of a topic for my thesis, I realised that my grandmother did not have information about what cancer was, or she did not understand what the physicians were saying to her when they diagnosed her. She was

a person with limited education (Grade 4) and she was not fluent in English. I came to understand that these two factors played a role in her asking me that question. I wondered if she was the only person with this experience. This led me to realise that there are many cancer patients in her position who may have experienced difficulty in understanding the information conveyed by the physician. This provided the motivation and the focus for my study.

I focussed on breast cancer in particular, as it is more common among women and because of my interest in women's health issues. Another driving force behind the study is that communication between physician-patient in oncology is an under-researched area. Physicians are challenged to communicate diagnostic information to patients in a clear and understandable manner, so that this may contribute to the general well-being of their patients. There was a need to establish how such communication could assist women with breast cancer to cope with their illness and how this might improve their health.

1.8 Significance of Study

This study will be of significance to four groups of people : (i) women with breast cancer; (ii) women who do not have breast cancer; (iii) the partners/family/friends of women with breast cancer; and (iv) physicians. This study is informative and educational for both groups of women. Women with breast cancer will benefit from this study because they will learn that they are not alone in their experience of breast cancer. They will realise that there are other women with breast cancer who go through the same experiences as them. The group of women who do not have breast cancer will also benefit from study as it is informative and educational. They can

learn what women with breast cancer endure and also, if they are one day faced with breast cancer themselves, they will know what to expect. Thirdly, it will also be helpful to the partners, family, and friends of women with breast cancer. This information will help these people to understand the experience of women with breast cancer and assist them to offer comfort and support. Fourthly, it will also be beneficial to physicians. This study will help physicians to understand the psychological and emotional effects of breast cancer on women, and how they cope with this illness. An important feature of this study relates to the communication between physician and patient. This study will help physicians to identify problem areas in their communication with patients; it will help to make the experience and treatment of breast cancer less painful and stressful for the patient. The study will assist physicians to learn what is expected of both patients and doctors, and it will help them to improve on their communication strategies.

More broadly, this research will aid in understanding the issues that influence coping (on the part of patients) and will show how communication barriers prevent people from understanding the information they receive from physicians. By understanding the importance of communication with breast cancer patients, physicians will be better able to offer support and assist these women to cope with their illness.

1.9 Ethics of the Research

*Due to the sensitive nature of this topic, this section is included in this chapter rather than Chapter 4.

The interviews were conducted at a public hospital in the Western Cape. A social worker acted as the gatekeeper and assisted the researcher in recruiting the women with breast cancer. The social worker identified ten suitable women with breast

cancer who were willing to participate in the study. Before the women agreed to be interviewed, the social worker explained the nature of the study to them. Prior to conducting the interviews, the researcher also explained to them the content of the study. The participants were asked to give their written consent to participate in the research. They were assured of confidentiality and anonymity. The interviews were conducted in an environment that suited the participants. They were also informed that they could withdraw at anytime from the process, without any repercussions. Privacy was guaranteed and it was respected. They were given the assurance that all interviews would be conducted in the strictest privacy and that their names would not be disclosed. Numbers were used to protect the identities of the participants. Information acquired through this research study will be shared with the participants prior to public dissemination. The hospital made provision for a social worker to be available both during the interviews and afterwards to offer counselling and support to those patients who might need it. Permission to audio-record the sessions was granted by the patients. A digital voice recorder was used to record the data and it was transcribed afterwards. All recordings will be locked in a safe place for a period of at least seven years.

1.10 Structure of the Dissertation

Chapter 1 is an introduction to the area of breast cancer treatment and provides a context and background for the study. It also looks at the research questions, aims, objectives, theoretical background, definitions, motivation, the significance of the study and ethical questions.

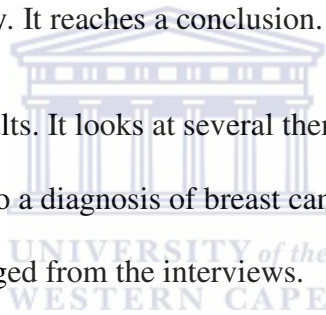
Chapter 2 examines the processes involved in communicating the diagnosis of breast cancer, beginning with the consultation. Literature on breast cancer staging and treatment, on the factors contributing to good or bad communication, and on the advantages of good communication and its influence on health outcomes is explored.

Chapter Three discusses the literature on stress and on coping mechanisms, and includes a theoretical framework for the discussion of stress and coping.

Chapter Four describes the research design and methodology. This includes qualitative research with a social constructivist approach, and discusses sampling, procedures and data collection, data-analysis, and the issues of reliability, validity, generalisability and reflexivity. It reaches a conclusion.

Chapter Five presents the results. It looks at several themes and sub-themes related to communication, to reactions to a diagnosis of breast cancer, the stress of a diagnosis and ways of coping that emerged from the interviews.

Chapter Six presents the discussion which is supported by findings of other studies. It presents the conclusion of the study, indicates its limitations and makes recommendations.

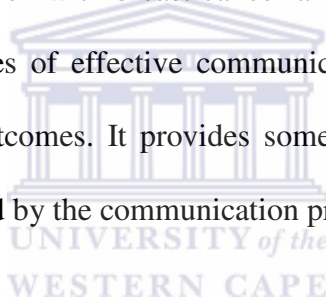


CHAPTER 2

COMMUNICATING THE DIAGNOSIS OF BREAST CANCER

2.1 Introduction

The following section deals with communicating a diagnosis of breast cancer to patients within the physician-patient setting. It includes information about the communication process as well as information about issues relating to breast cancer, in an attempt to give better insight into the disease and its management. It discusses factors contributing to miscommunication as well as factors leading to good communication between women with breast cancer and physicians. This is followed by a discussion of advantages of effective communication and of the influence of communication on health outcomes. It provides some insight into the way women with breast cancer are affected by the communication process.



2.2 The concept of communication

Sperber and Wilson (1995:1) define communication as “a process involving two information- processing devices”. They distinguish between these two devices by stating that the one adapts to the surroundings of the other, while the second device creates depictions similar to the one stored in the first device (Sperber & Wilson, 1995). This means that in order to communicate information there needs to be a sender and receiver so that the message which is transferred can be interpreted and understood. In the context of this study, the communication process involves a physician communicating information about the diagnosis of breast cancer and its treatment to a patient.

2.2.1 Verbal Communication

During the consultation, the physician and woman with breast cancer communicate by exchanging verbal information. This is called interpersonal communication. It is regarded as a good way of communicating information as it involves face-to-face communication between two or more people (Hybels & Weaver, 2004) and includes of all the components of the communication process. Each person acts as speaker or hearer, and both verbal and non-verbal signs are used. Sight and sound are the channel of communication and this is regarded by all as the best method of exchanging information (Hybels & Weaver, 2004). Both the sender and receiver are at an advantage in that they are in control of the conversation and can ensure that the information is understood correctly (Hybels & Weaver, 2004). Therefore, it can be stated that interpersonal communication is effective in a consultation between physician and patient as both communicate verbally and face-to-face. The conversation takes place in the consultation room and benefits both physician and patient as they can interact verbally; should uncertainty arise, clarity can be given.

2.2.2 Non-verbal Communication

Non-verbal communication refers to aspects of communication that are non-verbal.. These include facial expressions and gestures which help to communicate meaning. This type of communication is used during the face-to-face consultation between physician and patient.

Communication between physician and patient relies mainly on verbal communication, but also makes use of non-verbal communication, such as gestures and facial expressions. These may, for example, express a patient's confusion and

lack of understanding. However, non-verbal cues such as eye contact and facial expressions should be observed with feedback to assist physicians to improve their involvement with patients (World Health Organisation, 1993). This will give patients the idea that physicians are listening to them (World Health Organisation, 1993). Shaw, Ibrahim, Reid, Ussher and Rowlands (2008) suggest that the face-to-face encounter between physician and patient is the most effective way of transmitting information. This is important for those patients whose verbal skills are limited (Shaw *et al.*, 2008), as they expect the physician to help them understand.

2.3 Medical language

Specialisation refers to as a set of specialised words which are only used in a specific language environment or context (Hybel & Weaver II, 2004). For instance, an electrician says that you require a 'breaker', or a psychologist diagnoses 'Obsessive Compulsive Disorder' (OCD). Both the electrician and the psychologist use words that are only understandable to someone with specialist knowledge. Hybel and Weaver II (2004) state that most occupations use a standard linguistic set that is understandable to them. An example is the language used by physicians. Physicians are professionals and work within a medical frame of reference. They have their own specialised medical language which is understandable to them and not to non-professionals. This is why if effective communication is to take place individuals should consider their audience. We are constantly changing roles and as we change roles, we also change our language environments (Hybel & Weaver II, 2004). Language is effective when both the receiver and the context of the communication are taken into account; language is ineffective if there is no adaptation to the environment (Hybel & Weaver II, 2004).

2.4 Communication Processes

The communication process consists of six components: sender-receiver, the message, the channel of communication, noise, feedback, and setting (Hybels & Weaver II, 2004). These components are intrinsically linked to one another and cannot function independently. For instance, people who communicate want to share information, ideas and feelings (Hybels & Weaver II, 2004).

In order for information to be shared, there has to be a sender who sends the message and a receiver who receives it. The message consists of ideas or feelings that are to be imparted (Hybels and Weber II, 2004). In order for the message to reach the receiver it must be picked up by the senses. An example of this is a face-to-face conversation, in which both sound and sight are used (Hybels & Weber II, 2004). Once the messages has been sent, the sender-receiver expects feedback to confirm that the message has been received and understood (Hybels & Weber II, 2004).

Misunderstandings may occur because of interference, or “noise”. Hybel and Weaver differentiate between three types of noise: (i) external noise; (ii) internal noise; and (iii) semantic noise.

External noise refers to noise from the environment which prevents the information from being heard or understood (Hybel & Weaver II, 2004). Examples of this kind of noise are trains passing by or a television’s volume that is too high. Internal noise happens in the mind of the sender or receiver, when their thoughts are focused on something other than the conversation taking place between them. (Hybel & Weaver II, 2004). Semantic noise refers to information that is offensive, or which evokes negative reactions from people (Hybel & Weaver II, 2004). This can interfere with the

information being transmitted (Hybel & Weaver II, 2004). Communication can be influenced by its setting or context, such as the place where it occurs, and this can reflect the role of power in a communicative relationship (Hybel & Weaver II, 2004).

2.5 Breast cancer

2.5.1 The concept of breast cancer

Breast cancer is a life-threatening disease which takes the form of a tumour in one or both breasts (Breast Cancer Online, 2009). Breast cancer can either be classified as non-invasive (confined to one site) or invasive (spreading) (Breast Cancer Online, 2009). Examples of non-invasive breast cancer include Ductal carcinoma *in situ* and Lobular carcinoma *in situ* (Breast Cancer Online, 2009). These types of breast cancers are early-stage cancers, but may become invasive, if left untreated (Breast Cancer Online, 2009). Most early-stage breast cancers are diagnosed when there are no signs of invasion (Breast Cancer Online, 2009). Invasive breast cancers occur when cancer cells reach beyond the basement membrane and start to spread rapidly (Breast Cancer Online, 2009). Other types of invasive breast cancer are invasive ductal carcinoma and invasive lobular carcinoma (Breast Cancer Online, 2009).

2.5.2 Stages of breast cancer

Various levels of emotion are experienced by women with breast cancer and the intensity of these emotions depends on the stage of the cancer (Miedema, Hamilton & Easley, 2007). There are particular coping mechanisms that play a role during each stage of the breast cancer. A process called 'staging' begins once a diagnosis of breast cancer has been made. Staging is when the stages of breast cancer are monitored

according to the type of treatment needed. Stage 0 (100% survival) is the early stage of breast cancer. This is treatable, but if left untreated can spread to other parts of the body. During Stage I (98% survival), the cancer is approximately 2cm in length and has not yet spread. Stage II (88% survival) is subdivided into substages A and B, depending on whether the cancer has increased in size or has spread to the lymph nodes. Stage III is also subdivided into two substages, A and B. In stage III A (56% survival) the cancer has increased in size, but is less than 5cm, and has spread to about nine lymph nodes. In stage III B (49% survival) it becomes evident that the cancer cells are spreading quickly to the breast, skin, ribs and chest. Stage IV (16% survival) is the final stage of the cancer; here the cancer has spread to all other parts of the body (National Breast Cancer Foundation, 2009).

In the following section Juhn, M.T.P.W, Eltz and Stacy (2007) describe the type of treatment that is recommended for the different stages of breast cancer.

2.5.3 Treatment for stages I and II

There are three treatment options for women with stages I-II breast cancer. These are: (i) a lumpectomy, followed by radiation treatment; (ii) a mastectomy, which may include breast reconstruction; or (iii) the use of radiation treatment for lymph nodes (Juhn *et al.*, 2007). Certain factors are taken into consideration when deciding on the choice of treatment. These include the size and position of the lump, the size of the breast and the characteristics of the cancer (Juhn, *et al.*, 2007). If the lump is less than two centimetres in diameter, then the first option, a lumpectomy with radiation, is considered (Juhn, *et al.*, 2007). If the lump is between two and five centimeters, then a lumpectomy or mastectomy would be considered. However, when the lump is over

five centimeters, most physicians will advise that a mastectomy may be necessary (Juhn *et al.*, 2007).

2.5.4 Treatment for Stage III

During this stage of the breast cancer, the lump increases in size, to five centimeters or more (Juhn *et al.*, 2007). There are three types of treatment option for women with this stage of breast cancer. According to Juhn *et al.* (2007) they are: (i) a mastectomy with radiation, combined with either chemotherapy or hormonal therapy; (ii) radiation treatment following surgery, depending on whether there four or more lymph nodes are affected; and (iii) chemotherapy and stem cell transplant, the use of hormonal or biological medicines, or therapy using taxanes in combination with radiation.

According to Conlin and Seidman (2007) taxanes are drugs which are used in the early stages of breast cancer and have shown to be effective in the treatment of breast cancer. Conlin and Seidman (2007) add that taxanes have played a very important role in the management of many solid tumors, particularly those found in breast cancer.

Women who undergo chemotherapy experience side-effects such as weight loss, loss of hair and fatigue (Juhn *et al.*, 2007), while those who have radiation treatment experience, *inter alia*, fatigue, nausea and loss of appetite (Juhn *et al.*, 2007).

Radiation treatment, chemotherapy and mastectomy are used to manage the spread of breast cancer. Radiation treatment entails the use of beams of X-rays to get rid of the cancerous cells and also to reduce the size of the lump (Juhn *et al.*, 2007). This method works by slowing down the growth of the cancerous lump, and also provides symptomatic relief (Juhn *et al.*, 2007). Two types of radiation treatment are used to eliminate breast cancer cells. These are external beam radiation and brachytherapy.

External beam radiation is administered four to six weeks after surgery by an X-ray machine (Juhn *et al.*, 2007); to decrease the risk of recurrence patients receive this treatment on an ongoing basis for up to six weeks (Juhn *et al.*, 2007). Brachytherapy is a relatively new and less common type of treatment (Juhn *et al.*, 2007). It involves radiation in the form of implants (Juhn *et al.*, 2007). Women with breast cancer will benefit from this treatment as it takes less time and is advantageous from a cosmetic point of view (Juhn *et al.*, 2007).

Chemotherapy is available as a pill or as an intravenous injection (Peacock, 2002). Chemotherapy uses strong drugs to kill cancer cells in the human body (Peacock, 2002). Chemotherapy may also be used prior to surgery to reduce the size of the tumour (Peacock, 2002). Intravenous chemotherapy requires the insertion of a needle into the patient's arm; the needle is attached to a tube and a bag which contains the drug (Peacock, 2002). The drug enters the patient through the needle and the tube (Peacock, 2002). The chemotherapy lasts from two to six hours (Peacock, 2002).

Another method of receiving chemotherapy is through a device called a port, which is placed in a larger vein (Peacock, 2002). This method is used in situations when the veins of the patient have been regularly used or when the patient refuses intravenous chemotherapy (Peacock, 2002).

The function of chemotherapy is to eliminate the breast cancer cells (Juhn *et al.*, 2007). Adjuvant chemotherapy is administered before radiation treatment and after surgery over a period of three to six months (Juhn *et al.*, 2007).

A mastectomy is performed when there is no other way to conserve the breast (Juhn *et al.*, 2007). According to Juhn *et al.* (2007) there are two kinds of mastectomies, a total

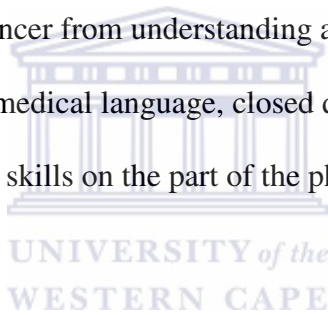
mastectomy and a radical mastectomy. A total mastectomy is a procedure whereby the whole breast is removed; in some cases lymph nodes under the armpits are also removed (Juhn et al., 2007). A radical mastectomy is a very rare procedure and is performed when the cancer is at an advanced stage. The entire breast, as well as the lymph nodes, chest muscles, fat and skin are removed (Juhn et al., 2007). There is no survival benefit with this procedure, so the total mastectomy is usually performed (Juhn et al., 2007).

Breast cancer is regarded as a life-threatening illness. The stages which categorise the degree to which the cancer has progressed in certain parts of the body illustrate the severity of the illness. However, further treatment is recommended to minimize the risks of the cancer spreading to other bodily organs. It is important for the patient to be informed about staging and the treatment options when they are diagnosed with breast cancer, as this prepares them for what may lie ahead. This information needs to be communicated by the physician in charge if the treatment. This information is often quite complex, and the physician may resort to the use of a specialised medical language (as previously discussed).

2.6 Factors contributing to effective communication between physician and patient

The purpose of consulting with the physician is to acquire information and gain an understanding of the illness, its consequences and treatment options. A consultation loses its purpose if there is misunderstanding or a lack of communication, as this creates confusion and anxiety amongst breast cancer patients. Street, Gordon and Haidet (2007) have tried to understand the roles of the physician, the patient and the

other factors that influence the physician-patient relationship. They adopted the ecological approach which is generally used in the study of communication in medical situations (Street et al., 2007). According to this approach, in any medical situation there are processes that affect the way in which physicians and patients perceive each other and communicate (Street et al., 2007). There are four processes which have a direct influence on the physician's ability to communicate: (i) the physician's communication style; (ii) the patients' characteristics; (iii) the physician-patient demographic concordance; and (iv) the patients' ability to communicate (Street *et al.*, 2007). The following section deals with some of these processes and lists six factors which contribute to miscommunication between physician and patient and which prevent women with breast cancer from understanding and interpreting their diagnoses. These factors are: medical language, closed questions, socio-economic status, lack of communication skills on the part of the physician, and non-disclosure of information to the patient.



2.6.1 Closed questions

The content of cancer consultations was examined by Ford, Fallowfield and Lewis (1996) in situations where the patient did have cancer. They concluded that biomedical information communicated from physician to patient played a major role in these consultations (Ford *et al.*, 1996). It was stated that although the patients received a great deal of information from their physicians, they were not allowed sufficient time to respond to this information (Ford *et al.*, 1996). Physicians relied on closed questions during consultation (Ford et al., 1996) and this placed limits on patients' responses and also discouraged them from disclosing personal information. An example of a closed question is one that requires a 'yes or no' answer while an

open question is helpful in that it provides patients with the opportunity to explain or express themselves, thereby providing more information (World Health Organisation, 1993). However, the use of open questions gave patients an opportunity to respond (Ford *et al.*, 1996). Ford *et al.* (1996) state that Cline (1983) warns against the use of closed questions during consultations as these cause patients to react defensively and discourage further interaction with the physician. Patients often withdrew from further participation in consultations because they felt they could not express themselves properly when closed questions were asked (Ford *et al.*, 1996).

The example given by Ford *et al.* (1996) is characteristic of poor communication with the patient. An example of a closed question within a physician-patient interview would be “Has the mastectomy been painful?”, but it would be useful to rather use an open question such as “Please tell me about your pain?”. The use of closed questions by a physician to explain a diagnosis will inevitably discourage the patient and reduce the chance that she will interact with the physician and participate in consultations. Physicians need to use open questions in order to encourage participation.

2.6.2 Socio-economic status of the patient

The difficulty in understanding the physician’s explanations may also be related to the socio-economic status of the breast cancer patient. Siminoff, Ravdin, Colabianchi and Sturm (2000) grouped the factors of race, income and education into two clusters, namely ‘higher education, high income, white race’ versus ‘lower education, low income and non-white race’. These clusters revealed that white women had a high socio-economic status, while non-white women had a rather low socio-economic status. According to Siminoff *et al.* (2000), educational levels have an effect on a

patient's ability to understand and benefit from the medical explanations provided by the physician during consultation. They were able to determine, for example, that patients with a higher education were able to understand the medical term 'adjuvant therapy' (Siminoff *et al.*, 2000). Many people in this category were academics who had a great deal of knowledge. This suggests that breast cancer patients with a higher level of education are better able to understand medical terminology, while those with less education will find it difficult to understand this terminology. Of course, if less well educated patients also exhibit feelings of anxiety, there is an even greater chance that the consultation will create misunderstanding and dissatisfaction (Siminoff *et al.*, 2000).

In a breast cancer study conducted by Bennett, Compas, Beckjord and Glinder (2005) low literacy levels were found to be associated with low socio-economic status and with age. Patients with low levels of literacy are less likely to obtain information from written material or from discussions with their physician. (Doak, Doak & Meade, 1996). These patients live in silence through not understanding what was communicated to them about their illness. Having a low level of education places them at a disadvantage. There is a stigma attached to individuals with a low level of education, as some people associate this with failure, stupidity and laziness. Because of this association, breast cancer patients with a low levels of education often choose not to participate in discussion with the physician or ask questions, for fear of being thought stupid. They would rather sit and listen passively to what the physician is saying, nod their heads, and leave the consulting room without understanding the diagnosis or knowing whether their condition is treatable or not. Doak et al. (1996) comment that people who lack health literacy know little about their bodily structure

and do not understand cancer. Furthermore, patients with other forms of cancer who have low levels of education often find themselves at a disadvantage, for the same reasons, and are left puzzled and perplexed (Doak, Doak & Friedell, 1998).

In response to Bennett et al. (2005) and the association between low levels of literacy and low socio-economic status, Bettencourt, Schlegel, Talley and Molix (2007) express a concern about the adequacy of oncological and medical information given to the disadvantaged women with breast cancer. They suggest that there is a greater chance that such women will misunderstand medical information. This is revealed in a survey by White, Given and Devoss (1996) who state that 73% of women with late-stage breast cancer and 49% of women with early-stage breast cancer lacked sufficient knowledge of breast cancer. Women with late-stage breast cancer lacked knowledge about chemotherapy, while the women with early-stage breast cancer lacked general information about cancer (White *et al.*, 1996). McGrath, Patterson, Yates, Treloar, Oldenburg and Loos (1999) mention that rural women with breast cancer are unaware of the stage of their breast cancer. This lack of information about breast cancer can be addressed by ensuring that accessible information is provided to women with breast cancer.

2.6.3 The use of medical language during the diagnosis

Understanding the information conveyed by the physician to the patient during consultation is an important component of medical care. However, many patients are faced with the use of unfamiliar medical language by physicians, whose explanations are misunderstood or lead to information overload (Iserson, 2001). In particular, the use of medical terms and specialised language by physicians causes misunderstanding

and confusion among patients. The use of such terminology by physicians can be experienced by patients as overwhelming; they prefer plain, clear, conversational language that is easy to understand (Merriman et al., 2002).

One of the most important challenges facing women with breast cancer is an inability to understand and comprehend information given by the physician. According to Davis et al., (2002) patients who who lack health literacy struggle to understand unfamiliar terms or phrases, such as *screening, colon, tumour, lesion* and *curve* (Davis et al., 2002). This lack of understanding of medical terminology is an ever-increasing problem. The elderly patients are among those most affected by poor health literacy (Davis et al., 2002).

Another example from Davis et al. (2002) shows that patients with colon cancer who participated in screening procedures had difficulty pronouncing and understanding terms such as *fecal, occult, blood tests, or flexible sigmoidoscopy*. Patients were also unfamiliar with the medical terms such as *polyp, growth* or *lesion* (Davis et al., 2002).

In another study, elderly women in a focus group did not understand terms such as *cervix, hysterectomy* or *menopause* (List, Lacey & Hopkins, 1994). The results of a study by Bean, Cooper, Alpert and Klipnis (1980) revealed that 46% of patients expressed the view that physicians should not use specialised medical language.

In order to understand the logic of misunderstandings of medical concepts among patients, Samora, Saunders and Larson (1961) researched patients' response to terms frequently used in physician-patient consultations. They concluded that 98% of patients knew the meaning of the word *vomit*, 35% of patients knew the meaning of the word *orally*, while only 18% understood the meaning of the words *malignant* and

terminal (Samora et al., 1961). This shows that most patients understood plain, clear and simple language, while only a minority were familiar with more specialised medical terms. A study conducted by Ford et al. (1996) investigated physician-patient interactions among cancer patients. The sample consisted of 117 outpatients with cancer and used the Roter Interaction Analysis System (RIAS) (a modification of Bale's Interaction Process System). They concluded that the information exchanged between physician and patient was "predominantly" medical-term based (Ford et al., 1996). In other words, physicians prefer to use medical terms. Physicians should in fact use language that is plain and easy to understand.

In an attempt to address this problem, Fallowfield (2008) states that it is the responsibility of physicians to provide information to patients in an understandable format: they should bear in mind that most patients are not familiar with medical terminology and may not understand the meaning of such terms. Physicians to communicate with patients using language that is familiar and understandable to them (Fallowfield, 2008).

Hagihara and Tarumi (2006) state that patients' understanding of their physicians' explanations is closely linked to patient satisfaction. If the patient understands the explanations given and interacts positively with the physician, the patient is more likely to make satisfactory progress. This is difficult to achieve with patients who have no previous knowledge of their illness. The physician has an obligation to determine the patient's ability to understand the explanations which are provided (Hagihara & Tarumi., 2006).

2.6.4 Lack of communication skills by the physician

There is often an assumption that the problem lies mainly with the patient and her lack of understanding – but to what extent are physicians also responsible?

Fallowfield (2008) states that physicians do not receive adequate training in communication skills. This helps to explain their difficulty in communicating information to breast cancer patients in ways that the patients can understand.

According to Fallowfield (2008), physicians conduct on average about 200 000 patient consultations in their lifetime. Since the literature confirms that physicians experience communication difficulties, one can imagine the scale of the problem.

Hagihara and Tarumi (2006) identified three factors which could contribute to the misunderstanding and lack of communication experienced by patients with breast cancer. Firstly, the relationship between clinical experience and communication skills suggests that physicians with more clinical experience are more skilled at providing patients with appropriate information. Secondly, senior physicians are more patient than their younger colleagues when dealing with women who have cancer. Thirdly, women are more easily influenced than men in pressure situations. One may conclude that the physician has the potential to influence a patient's understanding of her condition by providing appropriate explanations and information. The physician is in a position of authority and is (or should be) able to communicate the information in a plain and clear manner. A physician who lacks formal training in communication skills will tend to be aggressive, and this is obviously counter-productive.

2.6.5 Physicians who do not disclose information

Many women with breast cancer find that physicians do not provide sufficient information, and patients often do not understand the information that is given (Wiggers, Donovan, Redman, Sanson-Fisher, 1990). Fallowfield (1993) states that physicians may not disclose information because they think that the patient may be unable to cope with stressful information. However, these physicians are denying patients their professional guidance and denying them the opportunity to make decisions that will influence their future health (Gattellari et al., 1999). Studies by Gattellarri *et al.* (1999) and Fallowfield (1993) suggest that physicians may consider that withholding information is in the the patients' own interest. However, this may endanger their health as their understanding their condition will be flawed. In a study by Gattellarri *et al.* (1999), physicians stated that they did not provide their patients with prognostic data in cases where the outlook was not favourable. This places limits on the patients' ability to make informed choices and disempowers them. The fact that physicians may choose not to divulge important information to the patient places a question mark over their role as the provider of medical care.

All these factors contribute to miscommunication in the physician-patient relationship and increase the vulnerability in women with breast cancer, thereby contributing to anxiety, distress, lack of participation in consultations and confusion. Whether the problem lies with the physician or the patient, both should acknowledge the need to establish a system of effective and successful communication.

2.7 Factors contributing to good communication

There are many ways of improving the communication process between physician and patient. Although there are no set guidelines, the following factors may contribute to the overall communication process, thereby reducing misinterpretation and poor communication.

2.7.1 The Physician's communication style

According to Fallowfield (2008), physicians should allocate sufficient time for consultations, communicate on the same level as the patient and deliver information in a paced manner that avoids information overload. The pacing of information is an important skill for physicians to acquire. Although many physicians lack this skill, it is necessary if they are to communicate information that is appropriate to the stage of the breast cancer. Many breast cancer patients experience anxiety upon receiving their diagnosis. Therefore information overload at the initial consultation should be avoided, as this can have an impact on the patients' psychological and emotional well-being, their health outcomes and their quality of life.

The consultation between physician and patient needs to be patient-centred rather than physician-centred, since the manner in which physicians interact with their patients has an effect on the patients. According to Dowsett *et al.*, (2000, a patient-centred approach involves behaviour that displays openness, expression and comfort, and there is greater patient interaction with regard to decision-making. In the physician-centred style, the physician is focused on the consultation at hand, and is likely to be domineering and less understanding (Dowsett *et al.*, 2000). A patient-centred

approach would seem preferable in the context of a consultation between a physician and a woman with breast cancer.

Ford *et al.* (1996) concur that physicians should use a patient-centred approach to enable patients to participate during consultations. This approach allows the patients to express themselves, and enables them to speak openly (Ford *et al.*, 1996). The literature suggests that physicians should make use of a patient-centered approach in order to facilitate good physician-patient communication.

2.7.2 The Physician's character traits

A study by Mager & Andrykowski (2002) has found a link between cancer patients' perceptions of physicians and the patients' mental health. It concludes that physicians who are warm and caring and possess good communicative and interpersonal skills are more likely to benefit the health of their patients (Mager & Andrykowski, 2002). This means that the therapeutic skills of the physician play an important role in the promoting the patient's health. Bean *et al.* (1980:258) reported that the patients preferred physicians with "compassion, reassurance, understanding, openness and warmth". Such behaviour towards their patients resulted in greater patient satisfaction. Rowland-Morin and Carroll (1990) mention five behaviours that are responsible for high levels of patient satisfaction. These are: (i) warmth and courtesy; (ii) concern and interest; (iii) providing information that is appropriate to the patient; (iv) offering explanations based on the progress of the illness; and (v) establishing trust by providing emotional support.

2.7.3 Patients' active participation: asking questions

An important factor that contributes to effective communication between physician and patient is the style of communication (Street *et al.*, 2007). During the consultation the patient is required to cooperate with the physician by interacting and by asking questions. Street *et al.* (2007) state that the patient and physician influence each other. This means that physicians should respond when patients ask questions or express their fears and concerns (Street, Krupat, Bell, Kravitz & Haidet, 2003). Physicians who react positively to such interactions tend to have a better understanding of the needs and concerns of their patients (Street *et al.*, 2007). This process is known as active participation and it increases the wellbeing of patients.

If patients are to understand the information imparted by the physician, it is important that they ask questions. A study focusing on the coping mechanisms of cancer patients undergoing chemotherapy reported that at least 78% of the participants asked questions about their illness; 89% felt that they had received sufficient information from the medical staff (Bean *et al.*, 1980). These statistics suggest that the patients rated the medical staff highly in terms of delivering appropriate and useful information and their willingness to answer questions. The 22% of patients who did not ask questions explained that they considered the medical staff to be competent and felt they did not need further information about their illness (Bean *et al.*, 1980). Many patients who posed questions to the physician did so because they lacked knowledge about breast cancer. Bean *et al.* (1980) illustrate this point by showing that 81% of patients in the study had no knowledge of cancer or very little knowledge of cancer. This may account for the high percentage of patients asking questions. It is to be expected that a person who is diagnosed with an illness such as breast cancer, and

who lacks knowledge of it, would be likely to direct questions to the physician. A patient's reluctance to ask for information, or a physician's inability to provide specific information, or poor communication skills will adversely affect communication between the physician and the patient (Iserson, 2001).

On the other hand, Siminoff *et al.* (2000) concluded that many women asked questions about their illness because they were not impressed by their visit to the physician. These women may have done research on their illness prior to being diagnosed with breast cancer; if so, they would have had particular expectations regarding the information conveyed by the physician (Siminoff *et al.*, 2000). These patients felt that the physician did not adequately explain procedures, and they were dissatisfied with the information provided and with the amount of time spent during the consultation (Siminoff *et al.*, 2000). These findings not only suggest that the patient's interests are important, but also illustrate the critical pitfalls that exist in the communication process between physician and patient.

According to Siminoff *et al.* (2000) there are ways to address these problems. Their study addressed physician-patient communication patterns in breast cancer adjuvant therapy discussions. They concluded that physicians needed to become actively involved in their consultations and to encourage patients to ask questions more frequently. It is evident that active physician-patient participation is a first step towards establishing a platform for effective communication.

2.8 Advantages of good communication

Improving the communication between physician and patients can provide a range of advantages to patients. Siminoff *et al.* (2000) list the benefits as follows: (i) cognitive

– improving patients’ understanding of what is discussed by the physician and the rationale behind it; (ii) affective – increasing the level of physician-patient satisfaction and reducing anxiety; (iii) behavioural – assuring patients’ understanding of medicine procedures and commitment to consultation times; (iv) clinical – improving the lifestyle of patients as well as enhancing their survival time. These four categories show that the benefits to be derived from physician-patient interaction are closely related to establishing effective communication.

2.9 The influence of effective communication on health outcomes

Evidence confirms that misunderstandings occur and that these misunderstandings on the part of the patient have a negative impact on health outcomes (Ford *et al.*,1996). There is an association between active participation by the patient in the consultation process and positive health outcomes. According to Fallowfield (2008) the levels of participation and interaction between patient and physician are an important influence on positive health outcomes. Patients should become actively involved with discussions with the physicians by asking or answering questions to the best of their ability. This is more likely to occur if the patient has access to information about breast cancer (Fallowfield, 2008). Women with information about the risks of breast cancer are more likely to be satisfied with their choices than those who lack this information (Fallowfield, 2008). It has been shown that women who lack of information about their illness are less satisfied with themselves and tend to experience anxiety, all of which contributes to unfavourable health outcomes (Fallowfield, 2008). Fallowfield (2008) suggests that women who perceived their diagnosis as being favourable were less likely to experience anxiety and depression than those who perceived it as unfavourable. Where there was a lack of

communication, or a misunderstanding of medical terminology or denial of the diagnosis, this would have a negative impact on recovery. On the other hand, active participation with the physician during consultations, a good understanding of the medical information and acceptance of the diagnosis all contribute to positive health outcomes.

Siminoff *et al.* (2000) examined the relationship between physician-patient communication patterns and patient comprehension and satisfaction. They reported that patients who interacted with the physician by asking questions and discussing their illness thoroughly, had more awareness and increased levels of satisfaction.

Similarly, Allen, Petrisek and Laliberte (2001) state that patients who participated by interacting with the physician and who received appropriate information were more likely to be satisfied with their physician and treatment. This evidence suggests that patients who interacted with the physicians during consultations and who were able to understand the medical information were more likely to be satisfied with their treatment and their health.

2.10 Conclusion

Communication can be stressful, especially when miscommunication occurs or when one receives the bad news of a breast cancer diagnosis. Patients experience a range of emotions, such as confusion, anxiety and depression. During consultations with the physician, information is communicated to patients with breast cancer concerning the staging processes, the nature of the illness and its treatment. The success of the communication between physician and patient depends on their communication styles. Each depends on each other, neither can function separately. Interpersonal

communication is important during consultations. Where there is good communication, women with breast cancer were reported to be more satisfied with their health and their treatment, while those who could not understand the information were less satisfied. The miscommunication of information creates coping difficulties for women with breast cancer. The following chapter looks at stress and coping strategies among women with breast cancer and explores ways of managing the illness.



CHAPTER 3

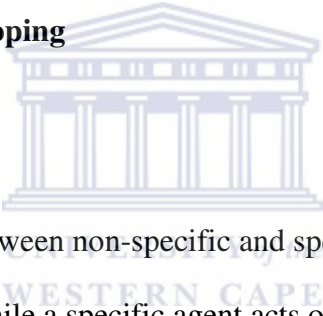
MANAGING THE STRESS OF BREAST CANCER

3.1 Introduction

This chapter argues that a both diagnosis of breast cancer as well as the way the diagnosis is communicated to patients act as a stressors which affects women's ability to cope with breast cancer. This chapter uses the Stress and Coping Theory (SCT) of Folkman and Lazarus (1986) to explore the coping abilities of women with breast cancer.

3.2 Defining stress and coping

3.2.1 The concept of stress



Selye (1955) differentiates between non-specific and specific agents. A non-specific agent acts on many targets, while a specific agent acts on few targets. A stressor is an agent that causes stress. In other words, stress is a non-specific response of the human body to demands that are on placed upon it. Lazarus and Folkman (1984) conceptualise stress as the relationship between a person and the environment. The concept of stress can be applied to this study as women diagnosed with stage I-III breast cancer experience various forms of anxiety: a diagnosis of breast cancer is often perceived as a death sentence.

3.2.2 The concept of coping

The way an individual perceives a problem will determine the coping mechanisms they will use. Coping has been defined as a way of managing demands that are

stressful (Folkman, 1992). Coping is defined by Edwards and Banglion (1993) as a means of reducing or removing the negative effects of stress on an individual. These definitions suggest that coping is a way of managing or controlling whatever is causing harm.

3.3 Historical approaches to stress and coping

The concept of stress has a variety of meanings, such as suffering and affliction, dating back to the 14th century (Lazarus, 1993). The importance of stress was first identified in the work of a physicist-biologist named Robert Hooke in the 17th century (Lazarus, 1993). Hooke was interested in the construction of bridges and how they could be designed to carry loads and also to withstand strong winds and natural forces. His interest in structures led Hooke to refine the concept of stress. *Load* refers the mass of the structure, while *stress* is the circumference of the area on which the load is situated. *Strain* is the disintegration of the construction as a result of both stress and load (Lazarus, 1993). The 20th century models of stress in disciplines such as psychology, sociology and physiology owe something to Hooke's analysis of stress and the idea of stress as an external load is still used today (Lazarus, 1993).

World War II led to an interest in emotional breakdown in response to the strains of the battlefield (Grinker & Spiegel, 1945; cited in Lazarus, 1993). During the war, the modern term "stress" was used to refer to "battle fatigue or war-neurosis" (Lazarus, 1993). This was based on a neurological rather than a psychological perspective (Lazarus, 1993). According to Lazarus (1993) another word used during the war to refer to a breakdown was "shell shock". This term was understood to refer to an

abnormal response of the brain to the explosive sound of bombs and ammunition (Lazarus, 1993).

Everyday strains and hardships resulting from (for example) exams or marriage were compared to the stresses experienced by soldiers in war (Lazarus, 1993). Human distress and abnormality became a focus of interest (Lazarus, 1993).

The concept of stress was still somewhat vague and at the time of Lazarus's emergence the term had not yet been applied to everyday life situations (Lazarus, 1993). However, in 1950 Lazarus and others revealed that stressful encounters did not produce predictable effects (Lazarus, 1993). This suggested that the level of stress experienced depended on the task at hand (Lazarus, 1993). To understand this, individual differences and motivational and cognitive variables had to be taken into account (Lazarus, 1993). Psychology moved away from stimulus-response models in favour of stimulus-organism-response models, and today these variables are used in theories of stress and emotion (Lazarus, 1993).

Hans Selye (1956) became interested in the study of the effect of steroids on the adrenal cortex, after losing interest in catecholamines of the adrenal medulla.

According to Selye's Gas Adaptation Syndrome (GAS) Theory "any agent noxious to the tissues (stressor) would produce more or less the same orchestrated physiological defence (stress reaction)" (Lazarus, 1993). Selye's physiological concept is similar to the psychological concept of coping (Lazarus, 1993). Mason, Maher, Hartley, Mougey, Perlow and Jones (1976, cited in Lazarus, 1993) found that corticosteroid might be a response to psychological stresses rather than to physiological stresses such as warmth. Although there is a relatively close connection between

psychological and physiological stress, the ways of assessing them differ (Lazarus, 1993). To differentiate between the two, Lazarus (1993) argues that the causes of physiological stress differ from the causes of psychological stress. Selye and Lazarus postulated the concept of stress (Lazarus, 1993). In 1974, Selye's understanding of stress was reflected by concepts such as 'eustress' and 'distress'. Eustress referred to a kind of euphoria that was associated with happiness, good health and optimism (Lazarus, 1993). Distress was associated with negativity and dysfunctional health states (Lazarus, 1993).

Lazarus understood stress as being harmful, threatening and challenging (Lazarus, 1993). Lazarus differentiates between the three by, (i), explaining that 'harm' implies the presence of psychological damage; (ii), stating that 'threat' involves harm that has not yet occurred but can be expected; and, (iii) stating that 'challenges' are obstacles that can be defeated by organising our coping resources (Lazarus, 1993).

It is clear that these psychological states of harm, threat and challenge are generated by different conditions and that their effects will also be different (Lazarus, 1993). An example of a harm is a diagnosis of breast cancer. Given the negative associations of breast cancer, such as dying or the loss of a breast, one would expect the patient to have an unpleasant mindset and experience psychological problems. This is because of the shock of the diagnosis, which threatens a woman's very existence. Challenges, such as the awareness of having breast cancer and fighting the illness by coping, going for treatment, changing one's diet and exercising, may put the breast cancer in remission and extend life-span by five or more years. Therefore, the ability to get beyond the harm, the threat and the challenge depends on how women with breast cancer respond to their diagnoses.

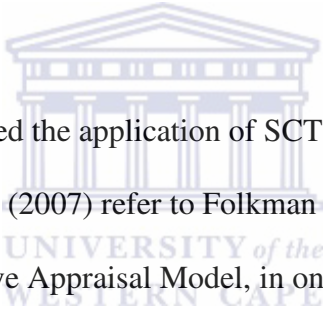
3.4 Folkman and Lazarus's stress and coping theory

The Stress and Coping Theory (SCT), developed by Susan Folkman and Richard Lazarus, is a cognitive theory of psychological stress (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). The central concept of stress has to do with the relationship between the person and his or her environment, as this is appraised or perceived by the individual (Folkman et al., 1986). Cognitive appraisal and coping help to mediate the stressful person-to-environment relationship and its consequences (Folkman et al., 1986).

According to Gurung (2006) two kinds of appraisal emerge from the experience of a stressful situation, namely primary and secondary appraisal. In the primary appraisal, the physician communicates to the patient the diagnosis of breast cancer. The woman with breast cancer must decide whether to accept the diagnosis (a positive response) or whether be in denial (a negative response). If she accepts the diagnosis, the diagnosis is seen as a stressor (Gurung, 2006). If she does not accept her diagnosis, it is regarded as harmful, threatening or challenging (Gurung, 2006). Secondary appraisal has to do with the way patient deals with her diagnosis (Gurung, 2006). Secondary appraisal refers to the way the patient adjusts to the breast cancer diagnosis. In essence, if the patient can accept and deal with the diagnosis, there will be lower levels of stress; the converse applies if the patient cannot accept the diagnosis (the diagnosis is seen as a stressor).

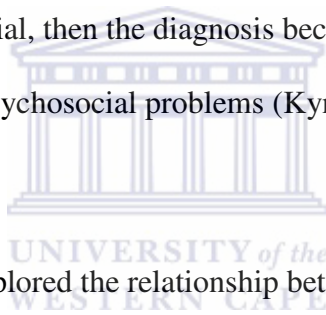
SCT specifically addresses the research questions that relate to communication and coping. SCT can be applied to a consultation between the physician and woman with breast cancer, where the physician transfers information regarding the diagnosis to the

patient. In such a setting, effective communication is essential. Information about the diagnosis can be misunderstood by women with breast cancer, as they may not understand the medical language used by the physician. It is here that SCT can be integrated into this study. The miscommunication often experienced by women with breast cancer causes stress to occur, thereby increasing anxiety levels and posing a further threat to the body. During these fluctuations in stress levels, women with breast cancer use various coping mechanisms to help them deal with the diagnosis. Women who understand the diagnostic information communicated by the physician will experience lower levels of stress and will cope better. The impact of communication on women's ability to cope with breast cancer can be explored using SCT.



Research studies have examined the application of SCT to patients with cancer. Miedema, Hamilton and Easley (2007) refer to Folkman and Lazarus's Stress and Coping Theory as the Cognitive Appraisal Model, in one of their studies. Their objective was to gain an understanding of the experiences of young adults with cancer (Miedema *et al.*, 2007). Three central themes emerged, namely delayed diagnosis, support issues and coping mechanisms (Miedema *et al.*, 2007). They chose to concentrate on coping mechanisms, as this emerged as a major theme in the analysis. Their study concluded that coping mechanisms played an integral part in the treatment of cancer. They found that the participants relied on previous life events and actions to help them cope with the cancer and its treatment. An important aspect of their findings related to coping strategies during the treatment stage. Coping during this stage is challenging and places enormous emotional and physical strain on the body and mind (Miedema *et al.*, 2007).

Boehmke and Dickerson (2006) also tried to understand the experiences of women diagnosed with breast cancer. They used the Stress and Coping Theory of Folkman and Lazarus to explain these experiences, and found that appraisal and self-view had an influence on the way patients dealt with breast cancer (Boehmke & Dickerson, 2006). Their study found that women who dealt with their diagnosis by acceptance were surely to experience better health in the future (Boehmke & Dickerson, 2006). In other words, if the patient accepted her diagnosis and was not in denial, then her chances of a recovery were improved. If the diagnosis of breast cancer caused stress and the woman with breast cancer could not accept it, then this was likely harm to the future health of the patient. Therefore, if women with breast cancer are not able accept their diagnoses and are in denial, then the diagnosis becomes a stressful encounter. This may lead to a range of psychosocial problems (Kyngas, Mikkonen, & Nousiainen, 2001).



Folkman *et al.* (1986) also explored the relationship between appraisal, coping and somatic health status. The results of this study showed that coping had an effect on women with breast cancer: being in control increased the chances of recovery. If the relationship between appraisal, coping and somatic health status was negative, then the more the stressful the diagnostic encounter, the worse the health outcome. In contrast, if the patients' health improved, they felt more in control.

Drawing on the results of these research studies, the Stress and Coping Theory of Folkman and Lazarus (1986) can be used (i) to investigate strategies of coping employed by women with stage I-III breast cancer; (ii) to examine women's responses to a breast cancer diagnosis; and (iii) to explain the role of communication in assisting women to cope with the diagnosis of stage I-III breast cancer.

3.5 The Link between Coping, Appraisal and Adaptation

3.5.1 The link between coping and appraisal

Previous studies have provided empirical evidence that there is a relationship between coping and appraisal (Folkman, Lazarus, Gruen & DeLongis, 1986). A study by Folkman and Lazarus (1985) has revealed that appraisal plays a significant part in moderating different coping mechanisms. For example, coping mechanisms that entail approaching the stressor directly, such as problem-focused efforts, are linked to appraisals of the perceived impact of the diagnosis. Lazarus's view of stress and coping is that "coping shapes emotion, as it does psychological stress, by influencing the person-environment relationship and how it is appraised" (Lazarus, 1993: 16). This indicates that coping and appraisal are connected and that both are related to psychological stress.

However, Sweet, Savoie and Lemyre (1999) suggest that there are two ways of describing the relationship between coping, appraisal and stress. The traditional account is that coping mediates the effects of appraisal on anxiety, while the contemporary account asserts that appraisal causes emotions and mediates the effects of coping on stress (Sweet et al., 1999). Researchers have preferred to base their studies on the traditional account of the cognitive-appraisal model by seeking to understand how cognitive appraisal can anticipate the choice of coping mechanisms (Sweet et al., 1999).

Folkman et al. (1986) used the traditional account of the cognitive-appraisal model and tried to find a relation between coping and the appraisal processes that occur in stressful situations. The relationship which exists between coping and appraisal

should be constant across stressful situations if such processes are to influence the adaptational status (Folkman *et al.*, 1986). Confrontation as a coping mechanism does not affect somatic health directly unless this coping mechanism is utilised by the individual repetitively (Folkman *et al.*, 1986). Similarly, self-blame will only result in depression if it occurs frequently (Folkman *et al.*, 1986). It becomes clear that in order for a coping mechanism to stabilise itself and have a positive effect on the individual, it has to occur frequently.

3.5.2 The relationship between coping and adaptation

There are numerous coping mechanisms, which have led to ways of categorising behaviour, thoughts and feelings (Sweet *et al.*, 1999). The most familiar of these categories are emotion-focused and problem-focused (Folkman & Lazarus, 1980), engagement or disengagement (Tobin, Holroyd, Reynolds & Wigal, 1989), and avoidance and approach coping (Suls & Fletcher, 1985). Endler and Parker (1990 & 1994) identify the following coping styles: task-oriented, emotion-oriented and avoidance-oriented.

Researchers have assigned various terms to describe relatively similar types of coping behaviour. For example, problem-focused, task-oriented, engagement and approach coping are representative of approaches that provide solutions to problems and enlist social support (Sweet *et al.*, 1999). On the other hand emotion-focused, emotion-oriented, and disengagement and avoidance coping mechanisms (for example, denial) draw attention away from the stressor (Sweet *et al.*, 1999). Coping efforts which draws attention away from the stressor are regarded as forms of avoidance, while

efforts that direct attention to the stressor are regarded as approach-type strategies (Suls & Fletcher, 1985).

Some researchers have studied the effectiveness of coping strategies in maintaining the health of the patient. The literature shows that certain types of coping can influence an individual's level of health, but that the approaches that produce these changes vary. Some research suggests that avoidance -type coping mechanisms (such as denial) are positively related to levels of psychological and somatic health (Commerford, Gular, Orr, Reznikof, & O'Dowd, 1994). In addition, approach-type coping mechanisms have been shown to reduce symptoms associated with illness (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992). Avoidance-type and approach-type coping strategies are usually seen as separate approaches, and this may assist the task of identifying different approaches to mental or emotional stress.

3.5.3 The link between appraisal and adaptation

The link between appraisal and adaptation has been researched thoroughly in an attempt to find a relationship between appraisals, such as negativity, uncertainty and threat, and an individuals' somatic and psychological health (Folkman *et al.*, 1986). On both conceptual and empirical grounds, the appraisal is seen as having an impact on the encounter itself. Folkman *et al.* (1986) conducted a study to find if a relationship exists between cognitive appraisal, coping and the outcome of stressful situations. The results suggested that the type of coping strategy used would depend on what was at stake (primary appraisals) and what the coping choices were (secondary appraisals). For instance, individuals whose self-confidence is low would make use of confrontational coping and escape-avoidance strategies. More directed or

organised problem solving was sometimes used to avoid procrastination. More organised problem solving was used in situations where individuals were capable of transforming the situation for their self-improvement, while distancing was used in situations where such transformation was impossible or unlikely (Folkman *et al.*, 1986). Their study showed that there was a link between coping strategies and health outcomes, but that there was no such link between appraisal and health outcomes (Folkman *et al.*, 1986). In conclusion, confrontational coping and distancing, produced unsatisfactory outcomes, while satisfactory outcomes resulted from organised problem solving and positive reappraisal (Folkman *et al.*, 1986).

3.6 The stress of breast cancer

A diagnosis of breast cancer is a something that every women fears as it is associated with a life-threatening illness. One the most important factors influencing a patient's health is the way she copes with this diagnosis. In general, the word 'coping' is associated with stress, anxiety, and the presence of underlying problems. Devlin, Maguire, Phillips and Crowther (1987) regard a diagnosis of cancer as stressful. There are many ways in which breast cancer can cause stress. Breast cancer can cause physical fatigue, anxiety, pain and poor psychological health states in a patient immediately after the diagnosis has been received. These causes of stress are not only related to physical changes caused by treatment, but also to hearing the diagnosis and to poor communication. Since both breast cancer as well as poor communication can be seen as stressors, one needs to ask further questions. How does poor communication cause stress in a woman with breast cancer?. If the physician who gives the woman the diagnosis of breast cancer uses medical language, this is likely to increase levels of stress. The very use of medical terms such as *mastectomy*, *adjuvant*

therapy or *chemotherapy* is likely to cause confusion, anxiety and stress in the patient. Not only are these words likely to be unfamiliar to her, but she also has to cope with being told that she has breast cancer.

The use of medical language by the physician, when conveying the diagnosis, as well as the diagnosis itself, can be regarded as stressors. It is also true that women diagnosed with breast cancer experience different stressors at different stages of the illness. This is a cause for concern because the different stresses will have either a negative or positive effect on the patient's coping mechanisms. In the light of Lazarus and Folkman's theory (1986), a physician who uses plain, clear and understandable language to convey a diagnosis of breast cancer will assist the patient to understand her illness and will enable her to interact verbally with the physician. The more she understands the information communicated to her, the better she will be able to cope with the breast cancer. If a physician who uses scientific language to inform the patient that she has breast cancer, she will experience problems in understanding the information, and this will be further exacerbated by the diagnosis itself. A combination of poor communication and patient misunderstanding will make it more difficult for a patient with breast cancer to cope with her illness. This may lead to a breakdown in the relationship with the physician, which will adversely affect their interactions. Because women with breast cancer encounter these stressors on a daily basis, these women will be able to provide further information about stress and coping strategies, and the effect of (mis)communication between physician and patient

3.6.1 Coping with breast cancer

In order to understand how breast cancer affects women's ability to cope, we need to remember that a diagnosis of breast cancer presents many challenges for the patient, as she needs to process with a lot of unfamiliar information and respond to the diagnosis. This study explores this problem.

A woman with breast cancer who understands the diagnosis and the information communicated by the physician, will be able to cope more effectively with her illness. For this to happen, the information must be conveyed to the patient in a clear and understandable way. Patients with low levels of literacy often do not see the need for detailed medical information by (Doak *et al.*, 1998).

Lazarus (1990:3) states, "Once a person has appraised a transaction as stressful, coping processes are brought into play to manage the troubled person-environment relationship, and these processes influence the person's subsequent appraisal and hence the kind and intensity of the stress reaction". A woman with breast cancer who finds it difficult to understand what the physician is saying will experience her situation as stressful and will have to find appropriate ways of dealing with this.

Where stress is present, some coping mechanism is needed, irrespective of whether it is effective. Lazarus (1990:11) states that the outcome of stressful encounters will depend on whether the coping process is effective or ineffective, on whether it is problem-focused or emotion-focused, on whether it is appropriate for the person (in terms of her coping style), and on whether it is a contextual response".

In an effort to understand whether different types of coping are variable or stable, Folkman and Lazarus (1980) reported that individuals are more variable than stable in

their reliance on problem- and emotion-focused coping across thirteen stressful situations. On the other hand, Aldwin (1994) evaluated eight different coping mechanisms and found that wishful thinking and positive reappraisal were used more often than self-blame. Stone and Neale (1984) reported a different trend: they found that individuals who coped with the same type of stress on a daily basis were more consistent in their use of coping strategies.

Folkman *et al.* (1986) showed that individuals who experienced unsatisfactory diagnostic encounters were most likely to be affected psychologically. The connection between coping and psychological symptoms was limited to problem-focused types of coping. Directed problem solving had a negative effect, while confrontational coping had a positive effect. In conclusion it is suggested that problem-solving is form of adaptive coping (Folkman *et al.*, 1986). Hence, it is imperative to consider the context in which a certain form of coping is used (Folkman *et al.*, 1986). For instance, studies focusing on cancer and tuberculosis suggest that confrontational coping is the more adaptive form (Folkman *et al.*, 1986).

The Stress and Coping Theory of Folkman and Lazarus shows that appraisal influences coping and coping influences encounter outcomes (Folkman *et al.*, 1986). Therefore, coping may influence the individual's appraisal of what is at stake and what the coping options are. However, it is more likely that coping strategies, such as positive reappraisal, will influence the outcome of the encounter, rather than vice versa (Folkman *et al.*, 1986). Previous studies have shown that appraisal plays a role in the way individuals manage anxiety-provoking situations by establishing that threatening levels of stress would be experienced, in cases where a diagnosis of breast cancer is given (Folkman *et al.*, 1986).

The following sections describe different ways of coping with a breast cancer diagnosis.

3.7 Behavioural problems experienced by patients during a consultation

3.7.1 Behavioural disengagement

According to Lerman, Daly and Walsh (1993) research has found a relationship between coping style and the difficulty of communicating with physicians. Coping styles such as behavioural disengagement, self-distraction or the venting of emotions (Collie *et al.*, 2005) are associated with communication problems during consultations.

Behavioural disengagement happens when an individual invests less effort in dealing with a stressor, displays signs of withdrawal and avoids contact with other people (Collie *et al.*, 2005). This coping strategy has been linked to negative health outcomes (Epping, Compas & Howell, 1994). This means that breast cancer patients who use behavioural disengagement as a coping strategy may not be able to respond appropriately in consultations with the physician. This can have a negative impact on their health.

3.7.2 Self-Distraction

The other coping strategy outlined by Carver (1997) is self-distraction. Self-distraction includes day-dreaming and sleeping in an attempt to block the stressor (Carver, 1997). It has shown that breast cancer patients experience difficulty in concentrating during consultations with the physician (Collie *et al.*, 2005).

Therefore, behavioural disengagement and self-distraction may be regarded as coping mechanisms which may further complicate the relationship between the physician and

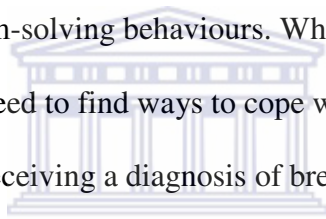
the woman with breast cancer; they may even cause distress, and distress can contribute to bad health. Research has shown that negative emotional stress is not associated with positive health outcomes (Culver, Arena, Antoni & Carver, 2002). Unhealthy emotional states in women with breast cancer impede communication and hinder the development of a good relationship between physician and patient (Collie *et al.*, 2005). Behavioural disengagement and self-distraction should therefore be avoided as they may contribute to unhealthy outcomes.

The following section looks at ways of coping with a breast cancer diagnosis which lead to healthier outcomes.

3.8 Managing a diagnosis of breast cancer

The coping mechanisms used by a woman with breast cancer depend on how she appraises or perceives her condition. Coping has been defined as a behavioural means of managing stress (Folkman, 1992). There are two types of coping, problem-focused and emotion-focused coping (Folkman *et al.*, 1986). Examples of problem-focused coping include aggressive attempts to change the situation, as well as attempts to resolve the situation. Emotion-focused coping strategies include seeking social support, distancing, self-controlling, escape-avoidance, accepting responsibility and positive reappraisal (Folkman *et al.*, 1986). Women with breast cancer respond differently to the stressful encounter of a diagnosis and therefore their coping methods will vary. Women with breast cancer have their own coping styles and their surroundings help them to define what is important for their well-being (Folkman *et al.*, 1986).

Stress caused by receiving confirmation of a breast cancer diagnosis and poor communication by the physician can give rise to a variety of emotions, and these may disrupt normal functioning and coping with breast cancer. Appraisal creates emotions, and emotion influences coping (Folkman & Lazarus, 1988). Folkman and Lazarus (1986) do not link specific coping mechanisms to stress. However they mention that coping is an emotional response (Folkman & Lazarus, 1988). This means that emotion will affect the normal functioning of cognition as well as coping (Folkman & Lazarus, 1988). The way to manage these emotions and minimize the disruptive effect is through coping mechanisms. Valliant (1977, in Folkman & Lazarus, 1988) states that coping consists of mechanisms such as denial, repression, suppression, intellectualisation and problem-solving behaviours. When women with breast cancer are faced with anxiety, they need to find ways to cope with their emotions. The literature suggests that after receiving a diagnosis of breast cancer, between 23% and 56% of women experience emotional problems (Vos *et al.*, 2004).



WESTERN CAPE

Some women use various coping mechanisms, such as denial, repression, suppression, confrontation, avoidance, problem-focused behaviour, active-coping and distancing to help them deal with the distressing news and poor communication. The following section looks at the coping mechanisms used by women when receiving a diagnosis of breast cancer.

3.8.1 Coping mechanisms used by women with breast cancer when dealing with a diagnosis

3.8.1.1 Planful Problem-Solving

Folkman & Lazarus (1988) have studied the effect of coping strategies on emotions. They concluded that planful problem-solving had a significant effect on emotion (Folkman & Lazarus, 1988). Planful problem solving was related to a healthy emotional condition, meaning there was a decrease in stress levels and an increase in feelings of optimism (Folkman & Lazarus, 1988). For example, a physician who gives a diagnosis of breast cancer and who uses scientific language to communicate information to the patient will cause stress and anxiety in the patient, particularly if she has no previous knowledge of breast cancer. The patient will feel better if she asks the physician to use plain, clear and understandable language. This strategy can improve the communicative relationship between physician and patient. A woman with breast cancer who approaches her problem directly by asking questions will understand what breast cancer is and participate more frequently in discussions with the physician. Her well-being will also improve. By identifying what the problem is and approaching it directly, the patient is able to deal more effectively with the stressor. Folkman and Lazarus (1988) confirm in their study that planful problem-solving produces a healthy relationship to the environment, and this leads to positive emotional responses. This is supported by Folkman *et al.*, (1986), who link planful problem-solving to encounter outcomes.

In addition, planful problem solving is also associated with a positive attitude, or what Folkman and Lazarus (1988) describe as a feeling of optimism when approaching a

problem that is causing stress. Many women with breast cancer maintain a positive attitude to assist them to cope with the breast cancer. Wilson, Anderson and Meischke (2000) confirm that a positive attitude is used as a coping mechanism by rural breast cancer survivors. The advantage of optimism as a method of coping is illustrated by Stanton and Snider (1993) who reported that women experienced increase levels of vigour when focusing on the positives. This supports with the model of self-regulation proposed by Carver and Scheier (1990) who state that the utilisation of optimism when approaching a problem will result in positivity.

According to the literature, optimism can be regarded as a normal response to problems and people tend naturally to have a positive outlook towards the future (Matthews & Cook, 2009). Optimism can take three forms: optimistic bias, dispositional optimism, and unrealistic optimism (Matthews & Cook, 2009). Optimistic bias involves a generally positive outlook towards life; dispositional optimism suggests that the individual anticipates positive outcomes; unrealistic optimism implies that an individual's personal expectations are not objectively justified (Matthews & Cook, 2009). A feature of dispositional optimism is positive behaviour that protects the patient from the unfavourable side-effects of cancer and its treatment (Matthews & Cook, 2009). A study by Schou, Ekeberg, Sandvik, Hjermsstad and Ruland (2005, cited in Matthews & Cook, 2009) showed that positivity was linked to human wellness at diagnosis and for a year after surgery. Matthews & Cook (2009) state that women with breast cancer use optimism as a method of coping with their diagnosis.

3.8.1.2 Active Coping

Women in the initial stages of breast cancer use active coping as a coping mechanism (Vos *et al.*, 2004). Active coping includes information-seeking, confronting the illness, and seeking social support (Vos *et al.*, 2004). These forms of coping are said to have a positive effect on women with breast cancer and they improve person-to-environment relationships.

Seeking social support by interacting with family and friends is also a form of coping used by women with breast cancer. Pieterse *et al.* (2007) report that seeking social support reduces anxiety and assists the health of the patient Pieterse *et al.* (2007) state that seeking social support improves the overall well-being of the patient. Friedman *et al.* (2006) state that seeking social support may assist women with breast cancer to deal with their diagnosis.



3.8.1.3 Confrontational Coping

According to Folkman and Lazarus (1988) confrontational coping worsens the emotional condition of the patient. This involves expressing anger and aggression that supposedly brings relief in the individual (Folkman & Lazarus, 1988). For example, a woman with breast cancer who does not understand the information conveyed by the physician will experience feelings of frustration, anger and confusion. She may repress her feelings for a time, hoping that the physicians will recognise her predicament. If this does not happen, she may confront the physician by yelling and crying hysterically and telling him she does not understand what his scientific words mean; she may demand that he uses more understandable language. However, expressing these pent-up emotions is likely to make the patient feel worse. Folkman

and Lazarus (1988) confirm this. Research indicates that the higher the level of stress in a person, the more confrontational the response is likely to be (Folkman & Lazarus, 1988). The converse also applies: the lower the level of stress in a person, the less confrontational will be the coping strategies (Folkman & Lazarus, 1988). This means a woman with breast cancer who represses her emotions for a long period of time will use confrontational coping mechanisms, while a woman with breast cancer who understands the information conveyed from the physician will be less likely to resort to confrontation.

3.8.1.4 Hope as a mechanism of coping

Another coping mechanism used by women with breast cancer is hope. Hope is defined as “the state of mind resulting from the positive outcome of ego strength, religion, perceived human family support, education and economic assets” (Obayuwana & Carter, 1982:232). According to the literature an individuals with hope are goal orientated, are likely to act on their plans and are determined to achieve what they have set they minds to (Stanton, Danoff-Burg & Huggins, 2002). There are three ways in which hope plays a significant role in adjusting to a cancer diagnosis (Stanton *et al.*, 2002). Firstly, hope and coping mechanisms may function separately to adjustment each resulting in distinctive effects (Stanton et al., 2002). Secondly, where there is an association between hope and adjustment, suggesting that the person’s levels of hope influences the choice of coping mechanisms, this in turn influences adjustment (Stanton et al., 2002). Thirdly, hope works together with coping to predict stress (Stanton et al., 2002). A study conducted by Stanton, Danoff-Burg and Cameron (2000) for early-stage breast cancer found that hope worked relatively well as an approach-focused method of coping to predict mental and bodily

adjustments to breast cancer. This means that women with breast cancer who had high hopes and were using emotional expression as a coping mechanism experienced lower levels of stress. Stanton *et al.* (2002) carried out a longitudinal study of 70 women with breast cancer and tested the suitability of situation-specific coping mechanisms and whether hope could be considered as a coping mechanism to deal with a diagnosis of breast cancer. They concluded that both coping mechanisms as well as hope influenced the adjustment in the first year after diagnosis (Stanton *et al.*, 2002).

Equally important is the use of hope in studies where women with breast cancer relied on spirituality as a resource for coping. Some examples of this are the belief that God will cure the breast cancer, hence the hope that the breast cancer will disappear. They may hope that it is all a dream and that the breast cancer will be gone. The feeling of hope reduces anxiety and helps the person to cope better (Obayuwana and Carter, 1982). Hope can be seen as a fighting spirit, or as the will to live. A study of early breast cancer patients found that a fighting spirit decreased anxiety (Classen *et al.*, 1996).

In summary, the evidence shows that the hope helps to maintain a fighting-spirit and the expectation of better things to come. It is difficult to imagine how a person without hope will cope in times of distress.

3.9 The role of helplessness and hope

Studies have confirmed that women with breast cancer use hope as a way of dealing with their diagnosis. However, such women may also feel helpless and despairing and unable to cope with the diagnosis. Helplessness is “a feeling of inability to cope [and] forms the central feature of the "giving-up-given-up complex” (Obayuwana *et al.*,

1982:230). Hope, on the other hand, is defined as “the feeling [that] what is desired is also possible” (Obayuwana *et al.*, 1982:229). One can only imagine what role hopelessness would play in this context. Hopelessness can be understood as the opposite of hope, meaning there is no fighting spirit or no will to live. Kübler-Ross (1969:123) provides a brilliant description of hopelessness as an “imminent death”. In her experience, many patients who had no hope died within twenty-four hours (Kübler-Ross, 1969). Classen, Koopman, Angell and Spiegel (1996) mention Watson’s finding (1991) that hopelessness increases anxiety and depression. Without hope there is way to cope. Hopelessness may seem similar, but Stanton *et al.* (2002) claim that people who are helpless may find comfort in spirituality. In addition, hopelessness may occur both at the start of the illness and before death (Obayuwana *et al.*, 1982).

Engel (1967) listed five stages of loss of hope. These are ego-strength, human family support, religion, education and economic assets. These five stages were referred to as the “giving-up-given-up” complex. This is a hopeless state of mind which is found at the onset of an illness (Engel, 1967). The following features are present in this complex: self-depreciation, helplessness, loss of sense of continuity, loss of gratification, and memories of not being able to cope (Obayuwana *et al.*, 1982).

Kübler-Ross (1969) lists the following five stages: denial, anger, bargaining, depression, and acceptance to retain hope. Both Engel and Kübler-Ross discuss hope and hopelessness. The difference between them is that Kübler-Ross deals with the dying patient, while Engel is concerned with start of the illness. Their work is complementary because with hope there are possibilities, while with hopelessness there are impossibilities.

According to Kübler-Ross (1969: 236), “No matter the stage of illness or coping mechanism used, all our patients maintained some form of hope until the last moments”. This suggests that irrespective of the phase of the illness many patients still have a will to overcome the illness.

3.10 The relationship between hope and coping

The literature suggests that hope and coping influence the process of adaptation to cancer in three ways (Stanton et al., 2002). Firstly, hope and coping can function separately and can produce distinctive results. Secondly, coping intervenes between hope and adaptation. This suggests that women who demonstrate feelings of hope or hopelessness have specific methods of coping which influences adaptation. Thirdly, hope may work together with coping to increase stress. Therefore, women with hope as well as those who are hopeless need to find specific ways of coping. A study of women with early-stage breast cancer who had completed treatment found that women who had hope used approach-oriented coping, and this resulted in mental and bodily adaptation to breast cancer (Stanton et al., 2002).

3.10.1 Avoidance Coping: Denial

Research suggests that avoidance coping or denial increases the risk and danger for the individual (Stanton *et al.*, 2002). However, in some circumstances avoidance-coping can be advantageous. Suls and Fletcher (in Stanton & Snider, 1993) state that "If a stressful life occurrence is relatively brief and has no serious consequences, then avoidance should be a very useful means with which to cope". Given that breast cancer is a chronic illness with serious health implications, avoidance-coping is not appropriate. However, if breast cancer was considered to have no severe implications

and the illness gradually disappears, then this kind of coping might be appropriate. Avoidance-coping can have devastating effects on women with breast cancer because it interferes with action (Stanton *et al.*, 1993). In addition, the diagnostic phase of breast cancer requires the patient to make decisions about her health (Stanton *et al.*, 1993). With avoidance-coping this is less likely (Stanton *et al.*, 1993).

Research has shown have stated that this coping mechanism has shortcomings in that it can affect the individual's mental and physical capacity (Stanton *et al.*, 1993).

Avoiding thoughts about the diagnosis may increase the intensity of the prior knowledge that the patient has breast cancer (Wegner, Shortt, Blake & Page, 1990).

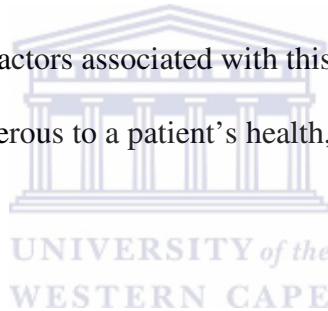
A common form of avoidance coping is denial. Women with breast cancer often refuse to accept the diagnosis and resort to the coping mechanism of denial. However, denial may sometimes help women with breast cancer to deal with the illness. This claim is supported by Vos *et al.*, (2004) who argue that denial is an effective coping mechanism following a diagnosis of breast cancer.

Denial can have a positive influence under certain circumstances and a negative influence in other circumstances (Vos & de Haes, 2006). Denial is regarded as an effective coping mechanism if it improves psychological functioning. Vos *et al.* (2006) outline three positive perceptions of denial (i) The use of denial as a strategy may indicate an understanding on the patient's part that she has cancer. (ii) It may be a way of refusing to let the cancer control the patient's life. (iii) It may help to create a positive outlook. Vos *et al.* (2006) found that some strategies of denial had a negative effect on psychological functioning. This happened where the patient refused to accept the diagnosis, and where indulging in foods and drink (or giving them up)

made the patient feel better. These strategies of denial can have the effect of lowering self-esteem.

Denial can have a positive effect in the first stage of coping after a diagnosis has been established as it reduces stress (Sprah & Sostaric, 2004). Meyerowitz (1983, cited in McCaul, Sandgren, King, O'Donnell, Branstetter & Foreman, 1999) supports this claim in his study of 113 women who received treatment for breast cancer. He reported that cancer-specific denial decreased stress levels. Denial can, however, have negative effects by delaying the treatment process, delaying an understanding of the illness or causing a breakdown in personal relationships (Sprah & Sostaric, 2004). Therefore, while the coping mechanism of denial can be used to reduce the effects of stress, but there are also risk factors associated with this. While some researchers report that denial can be dangerous to a patient's health, others claim the opposite.

3.10.2 Spirituality/Religion



Most of the research on coping with breast cancer includes spirituality as a means of helping women cope with their illness (Stanton *et al.*, 2002; Matthews, Lannin & Mitchell, 1994). Al-Azri, Al-Awisi, Al-Moundhri (2009) confirm that spiritual faith as a coping response is used by breast cancer patients. It is a fact that spirituality helps patients to cope, and also brings people closer to God. Matthews and Larson (1995) are in agreement with this. Shapiro *et al.* (2001) who reviewed 200 articles, found there was a correlation between spirituality and coping. A qualitative study conducted by Gall and Cornblat (2002) showed a link between women with breast cancer and spirituality. They concluded that some of the women coped with breast cancer through reliance on their spiritual beliefs, and that this helped to lower their

stress levels. Women use prayer as way to find strength and deliverance. Spirituality also gave women with breast cancer with “a sense of control, comfort, ability to find meaning, and intimacy and belonging” (Stanton *et al.*, 2002). Utterances such as ‘I put my trust in God’; ‘I seek God’s help’; ‘I try to find comfort in my religion’ (Stanton *et al.*, 2002) reflect spirituality and a belief in a higher authority.

Studies confirm that spirituality is used as a coping mechanism and that it produces better health results (Shapiro *et al.*, 2001). Nairn and Merluzzi (2003) reported that cancer patients who used spirituality to help them cope displayed a sense of acceptance, optimism and high levels of self-esteem.

Some patients found strength and reassurance in their religion (Hamrick & Diefenbach, 2006). This suggests that spirituality enhances coping by camouflaging the effects of breast cancer. These findings also indicate that spirituality has a positive effect on health. According to Oman and Thoresen (2005) effective support and healthy psychological conditions are mechanisms through which spirituality impacts on health. These may reduce anxiety levels. Many sources confirm that cancer patients with strong religious beliefs experience less anxiety (Hamrick & Diefenbach, 2006; Gall & Cornblat, 2005).

However, some researchers disagree with the view that a cancer diagnosis brings people closer to God (Hamrick & Diefenbach, 2006). Doyle (1992; in Hamrick & Diefenbach, 2006) argues that being diagnosed with cancer eventually leads to crisis of faith: the person with cancer feels she has been let down by God and that God has failed her. The opposite view, reflected by Doyle (1992) and Stanton *et al.*, (2002), is that cancer patients will either be drawn closer to God, or will drift away from God.

3.10.3 Accepting the diagnosis

A study by Carver and others has established that coping through acceptance of the diagnosis lowered stress levels in 59 women with early-stage breast cancer (Stanton et al., 2002). Acceptance is the recognition or acknowledgment of the diagnosis of breast cancer. Kübler-Ross (1981:48) describes acceptance as “a feeling of victory, a feeling of peace, of serenity, of positive submission to things we cannot change”. Kübler-Ross and Kessler (2005) describe the stage of acceptance of the loss of a loved one as follows: the family accepts that their beloved has passed on and family members need to live with this loss. Coming to terms with the loss of a loved one eases the grieving process. Acceptance should not, however, be regarded as a joyful stage (Kübler-Ross, 1969). This stage is characterised by perceptions that the suffering is past, but it usually calls for support and understanding. However, healing and adaptation are central to acceptance (Kübler & Ross, 2005). The anger that may have been caused by the diagnosis of breast cancer, the tendency to blame God, and the refusal to understand reach closure, and the healing process can begin. Many patients do not reach this stage of acceptance: they battle with the illness in the hope that they will recover (Kübler-Ross, 1969). Kübler-Ross’s five stages of dying represents death as a process of coming to terms with the reality of the illness. The first stage is denial and the final stage is acceptance. If acceptance were the first stage, how would people adjust to dying? The stage of denial suggests that the initial situation is appropriate. Stanton and others disagrees with this view (Li & Lambert, 2007). They conducted a study on women with stage I and stage II breast cancer and reported that acceptance at the time of the diagnosis allowed the patient to adapt to the illness (Li & Lambert, 2007), while avoidance caused fears of reoccurrence. Studies

by Stanton and others (Li & Lambert, 2007) and by Kübler-Ross's (1969) challenge the idea that acceptance is useful at the time of diagnosis or at the final stage. A longitudinal study of early-stage breast cancer revealed that a positive approach to the illness was associated to acceptance of the illness and with lower levels of stress (Classen et al., 1996).

Women with breast cancer often use acceptance, avoidance and spirituality as coping mechanisms to deal with the illness. This claim is supported in by Stanton *et al.* (2002). Accepting that one has breast cancer leads to better health outcomes (Stanton *et al.*, 2002). According to Stanton *et al.* (2002) acceptance is mostly found among women recently diagnosed with breast cancer. Their study proves that patients who accepted their illness showed better adjustment to the illness in the long run. This suggests that early acceptance of breast cancer can allow the patient to participate actively in treatment, thus assisting adjustment to the illness. An acceptance of breast cancer at a late stage may have negative implications (Stanton *et al.*, 2002). Stanton *et al.* (2002) state that feelings of optimism may trigger the acceptance of breast cancer. A positive outlook may help to create feelings of peace and hope within the individual. This suggests that there is an association between optimism and acceptance. Women with breast cancer also use acceptance, avoidance and spirituality as coping mechanisms to deal with breast cancer. This claim is supported in the results of the study by Stanton et al. (2002). Accepting that one has breast cancer will lead to a better health outcome (Stanton et al., 2002).

3.11 Conclusion

It is evident from the literature that the Stress and Coping Theory may be used together with explorations of the role of communication among women diagnosed with stage I-III breast cancer. Communicating a diagnosis of breast cancer may be stressful as the information is difficult to understand and this may cause women with breast cancer to become emotionally charged. However, the literature indicates that women who receive a diagnosis of breast cancer resort to mechanisms of denial, planful problem-solving, active coping, confrontational coping, hope, avoidance and spirituality in an effort to cope with the illness. The evidence suggests that some coping mechanisms have a positive effect on the well-being of women with breast cancer, while others have a negative effect.



CHAPTER 4

RESEARCH METHODOLOGY

4.1 Introduction

This chapter details the methodology used to conduct this research study. This chapter focuses on the use of a qualitative methodology to collect the data, using a social constructivist approach. Reflexivity and trustworthiness are considered and discussed.

4.2 Qualitative Research

According to Henning (2004: 5), a qualitative methodology is defined as “an inquiry representing a research form or approach that makes way for different opinions and views of a theme that is studied, and whereby the participants have an open-ended way of expressing their views and actions”. Henning (2004) states that a qualitative methodology is used to gather information where participants need to have the freedom to express themselves. A qualitative methodology has been used to understand how the role of communication between physician and patient affects patients’ ability to cope during the diagnostic phase of Stage I-III breast cancer. These are the stages most commonly experienced by breast cancer patients, which made it easier to recruit a sample of women for this study. There are four stages of the breast cancer cycle: stage I represents an early stage and stage IV a more advanced stage, and different levels or strategies of coping are associated with each stage of the illness. The use of qualitative methodology will enable the researcher to gain a better understanding of the experience of breast cancer patients (Henning, 2004: 5). The

researcher should be receptive to the accounts of the participants as they express themselves. The thoughts and emotions are expressed by the participants provide a clear indication of their experience during the diagnosis and treatment of stage I-III breast cancer. A qualitative approach enables one to understand how people who are diagnosed with breast cancer learn to cope with this disease.

According to Strauss and Corbin (1990), qualitative research has three aims. Firstly, a qualitative approach provides an in- depth and detailed investigation of the research area without manipulating the research environment. Secondly, qualitative research enables one to answer to questions on areas about which little is known. Thirdly, qualitative research involves face-to-face contact with the participants. One can conclude that qualitative research is the ideal method for researching the experiences of women with stage I-III breast cancer.

4.3 The social constructivist research approach

The social constructivist approach was adopted for this study in order to understand the role communication plays during consultations between physicians and breast cancer patients. This social context is foregrounded in this approach, as it takes into account differences in social status between physician and patient. Although these differences exist, the physician tries to construct a language that makes it easier for the patient to understand the diagnosis. In this way both physician and patient help to construct meaning in the consultation process. A social constructivist approach can improve our understanding of this interaction by taking into account cultural and contextual factors. It helps to reveal what individuals regard as important and how their view of reality may influence and be influenced by their illness.

Gergen and Gergen (1991:78) explain the social constructionist approach as follows:

The constructionist approach] draws attention to the manner in which the conventions of language and other social processes (negotiation, persuasion, power etc.) influence the accounts rendered of the 'objective' world. The emphasis is thus not on the individual mind but on the meanings of people as they collectively generate descriptions and explanations in language.

This implies that in order to understand the experiences of individuals in a particular group (in this case, those who have been diagnosed with breast cancer) it is best to derive knowledge and understanding from them, and to look at both their collective and their individual experience. Social constructivism takes into account the need of both the physician and patient to interact with each other. What is important are the dynamics of communicative interaction. Their communication needs to be effective and individuals should share some common ground. In terms of this approach it is important to look at the way the way language is used by both physician and patient in the consulting room.

However, the work of Lev Vygotsky provides us with a clearer understanding of social constructionism and the role of development on an individual (Shaw, 1994).

Vygotsky developed a social/cultural approach to understanding the role of cognition in child development (Shaw, 1994). He uncovered the importance of social and cultural relations and their effect on cognitive functioning (Shaw, 1994). In essence, Vygotsky believed that, unlike animals, humans have a need to communicate in a social and cultural context in order to develop intellectually (Shaw, 1994). In terms of Vygotsky's approach, language plays a crucial role in early childhood development

(Shaw, 1994). Human development takes place in phases and relies on cooperative activity to alter or adapt to the social environment (Shaw, 1994).

Language is a symbolic system that makes possible the social construction of meaning (Hall, 2003). During consultations with their physicians women with breast cancer try to make sense of the language spoken by the physician in the hope of gaining a clearer understanding of their illness. According to Parker (1998) social constructionists claim that in order to understand the world around us, we must have the linguistic ability to make sense of and explain the world to others and to ourselves.

Another argument advanced by the social constructionists is that language works as a coercive force (Berger & Luckmann, 1967). Language is a shared system which is humans need if they are to cooperate and communicate with each other. Power relations and conventions influence the way we understand others and interact socially (Berger & Luckmann, 1967). Social constructionists believe that in order to understand the social environment, one must take interpersonal and linguistic behaviour in a particular social environment into account (Berger & Luckmann, 1967). According to Held (1997) what we experience is in reality inter-personal (Held, 1997). Language and social development create meanings which are constructed socially but are often seen as 'objective' or 'real' (Gergen & Gergen, 1991). Finally, inter-personal language constructs our awareness of our social surroundings and influences the way we respond to those surroundings (Berger & Luckmann, 1967). Therefore, if women with breast cancer are to understand their illness, physicians need to recognise that each patient is unique: cultural differences set them apart from one another, and physicians should learn to acknowledge and embrace these differences.

In conclusion, social interaction is an important aspect of language use and influences the kind of communication that takes place in the consultation room. In order for physicians to communicate effectively, they need to know exactly on what level the patient in terms of her knowledge and understanding of breast cancer, so that they can process new information in a meaningful way. Knowledge is constructed through the interaction between physician and patient.

4.4 Participants

Purposive convenience sampling was used to recruit 10 women diagnosed with stage I-III breast cancer. All were being treated in the Oncology Clinic at a public hospital in the Western Cape. The selection of the participants took into account their individual qualities and their suitability in terms of the research topic (Henning, 2004). Purposive sampling allows for the selection of interviewees whose qualities and experience are relevant to the research topic (Henning, 2004).

The following criteria were used for the selection of participants: (i) they should be women aged between 21 and 40 years; (ii) they should have been diagnosed with stage I-III breast cancer; (iii) they should be receiving radiation treatment, or chemotherapy or should have undergone a mastectomy. Participants who fitted these criteria were recruited for the sample. The result was a fairly heterogeneous group of participants. The final sample of participants consisted of 10 women of various races diagnosed with breast cancer. The racial classification for the 10 women was as follows: six women were 'coloured', three were 'black' and one was 'white'. Of the 10 women, six were diagnosed with stage III breast cancer and four with stage II

breast cancer. One of the participants with stage III breast cancer had undergone a bilateral mastectomy. The ages of the women ranged from 27 to 42 years.

4.5 Data collection instruments

Open-ended questions were used, in keeping with a social constructionist approach. The interview consisted of a set of open-ended questions in which I attempted to capture the experiences of women living with breast cancer. An open-ended interview schedule was used, with 10 open ended questions. The following aspects were covered: (i) biographical information; (ii) history of the disease; (iii) personal understanding of the disease; (iv) experience of the diagnosis; (v) experience of the disease; (vi) communication between physician and patient; and (vii) support and coping. The interviews was recorded and transcribed.

Semi-structured interviews were used in this study to give researchers the opportunity to provide guidance during the interview, while allowing participants to lead the interview in another direction if necessary (Terre Blanche & Durrheim, 1999).

Fontana and Frey (2000:645) add that “interviewing is one of the most common and powerful ways in which we try to understand our fellow human beings”. According to Babbie (2001) interviews are used to investigate emotions, feelings and experiences and give individuals the opportunity to talk about sensitive issues. Open-ended interviews are more flexible as they allow for gaps in women’s experiences to be explored.

According to Huysamen (1994) semi-structured interviews involve the participation of both researcher and participant in attempting to understand and make sense of the participants’ human experience. An important aspect of this kind of interview is that

participants are able to express themselves freely: no limits are placed on their ability to express themselves (Kvale, 1996).

4.6 Procedures and data collection

The study was approved and permission granted by the Ethics Committees at the Oncology Clinic at a public hospital in the Western Cape and at the university where I was registered (UWC). The resident social worker and staff in the Oncology Clinic assisted with recruiting participants who met the inclusion criteria. The social worker first consulted with the breast cancer patients and asked if they would be willing to participate in the interviews on a voluntary basis. She explained the nature of the interview to them, and once they agreed to participate, they sat in the waiting room. The social worker accompanied the participant and introduced her to me. I discussed the background to the study with the participant and her rights as a participant. I then produced a letter of consent which the participant signed. Thereafter, the interview began. This procedure occurred each time I interviewed a new participant.

A semi-structured interview was conducted and the duration of each interview was at least forty-five minutes to one hour. The interviews were conducted in a private room in the Oncology Clinic to maintain privacy and confidentiality. The first languages of the participants were English, Afrikaans and isiXhosa, but one of the criteria for inclusion was that the interviews should be conducted in English and/or Afrikaans. The fact that Xhosa-speaking participants were willing to participate suggested that they were able to speak and understand English. A tape recorder was used to record the data. This was transcribed afterwards and will be locked in a safe place at least for seven years. At the end of each interview, the participants were thanked for their input

and willingness to participate in the research; it was guaranteed that the research findings would be made available to them.

4.7 Data analysis

The recorded interviews were transcribed and thematic analysis was used to analyse the data from the interviews. It was the task of the researcher to transcribe interviews, which were audio-recorded and then transcribed (Seidmann, 1998). A thematic analysis is a flexible approach to analysing data and enables patterns or themes to be identified (Braun & Clarke, 2006). It is a process which reflects reality by reporting and examining the experiences of the participants and their construction of meaning (Braun & Clarke, 2006). Braun and Clarke (2006) outline six steps for thematic analysis: (i) familiarising yourself with the data by transcribing and reading it; (ii) generating codes in an organized way and coding points of interest in the data; (iii) searching for themes by collating codes into themes; (iv) reviewing themes in relation to the coded extracts; (v) defining and naming the themes as part of an ongoing analysis, and refining the specifics of each theme; (vi) producing the report. The report is the final analytical step. It consists of extracts and examples from interviews, and relates the analysis to the research questions and the relevant literature (Braun & Clarke, 2006). The final report should be logical, non-repetitive and argumentative (Braun & Clarke, 2006). Once the themes had been extracted from the transcriptions, the researcher analysed and discussed the information, using direct quotes from the participants as well as from the supporting literature. Arguments relating to the validity of the information were presented.

4.8 Reflexivity

The concept of reflexivity is explained by Nightingale and Cromby (1999:228):

Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgment of the impossibility of remaining 'outside of' one's subject matter while conducting research. Reflexivity then, urges us to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research.

Nightingale and Cromby (1999:228) argue that reflexivity is consistent with Hall and Hall's (2004) concept of reflection, which involves clear and constructive thinking about ways to improve the research study. This allows researchers to describe and analyse their feelings as the research progresses. Reflection allows researchers to evaluate themselves and identify their strengths and limitations. Reflexivity implies that the researcher should be aware of how the methods used to collect the information might influence the research findings (Mays & Pope, 2000). As the researcher, I have made every effort not to influence the findings, but there is always the possibility of being influenced by one's prior knowledge and expectations, rather than by the reported experiences of the participants. Demographical traits such as age, gender, social class, and occupational status can also influence the information which is collected as well as the relationship between the researcher and the participants (Mays & Pope, 2000).

As the researcher, I have used the methods described above and applied them to my study. Initially, I was anxious about conducting the interviews with the participants as this might trigger an emotional response, reminding me of my own grandmother who died of oesophageal cancer. However, as the interviews progressed, I became more

comfortable and less anxious. Memories of my late grandmother faded and I was able to proceed without any challenges. Some of the participants felt the need to express themselves openly as they felt comfortable speaking to me. As a researcher who has lost a loved one to cancer, there were no boundaries between myself and the participants who were interviewed. Although my late grandmother experienced issues that were similar to those experienced by the participants, the opportunity to complete this research gave me closure and brought acceptance of my grandmother's death. It is, however, possible that my empathy for the participants, based on a previous family encounter with cancer, may have influenced the research process and also the research outcome.

Another relevant aspect with regard to reflexivity was while that the participants were women from diverse cultures and backgrounds, most of them came from disadvantaged socio-economic backgrounds. They were courageous in reporting on their experiences with breast cancer and in placing their trust in me. I believe that my role as a female researcher played a significant part in this because they felt comfortable speaking in my presence. This also helped me to relate to the participants in an empathetic way. There was no need for me to meet the participants prior to the interview, as they already placed their trust and confidence in the researcher. The research participants may have perhaps viewed me as a kind of psychologist or social worker because they disclosed personal information; they may have seen the interview session as an opportunity to receive counseling.

These women are to be highly commended for the manner in which they coped with breast cancer. Initially, they were afraid when they heard that their diagnosis for breast cancer was positive, but they gathered inner strength and relied on their faith in

God to overcome the challenges by using a range of coping mechanisms. The most important factor was that these women had a positive attitude to their illness and this helped their recovery and acceptance of the illness. My background in psychology may also have influenced my interpretation of the interviews. The research participants may have regarded me as a medical professional, and on this account may have been reluctant to disclose information that might place other medical professionals in a bad light.

4.9 Trustworthiness

Guba and Lincoln (1985) have proposed four concepts for judging the reliability of qualitative research.

(i) *Credibility* is the term used as an equivalent for the concept of internal consistency and validity (Guba & Lincoln, 1985). Two important criteria are used to ensure that the qualitative findings are (a) credible and (b) believable from the viewpoint of the participants. It can be argued that credibility of the findings is determined by the participants, as the researcher is seeking to understand their human experience.

Credibility within this study was ensured because the interviews that were conducted with the women patients and relied on their own accounts of physician-patient communication and their own experience of coping with breast cancer. This focus on the first-hand responses of the participants brought credibility to the study and the findings.

(ii) *Transferability* is the qualitative equivalent for the quantitative concept of external validity (Guba & Lincoln, 1985). This concept requires that the findings can be generalised and applied to other research frameworks. In order to ensure

transferability, it is the task of the researcher to provide detailed accounts of the area being studied. It is the responsibility of the researcher to ensure that the findings can be generalised. This is done in the results and discussion section of this study.

Information from other sources supported the findings and suggested that they could have general application. If the findings of two or more studies are similar, then this enables generalizations to be made regarding that specific topic of research.

(iii) *Dependability* is the qualitative equivalent for the quantitative concept of reliability (Guba & Lincoln, 1985). This requires the researcher to be aware of any transformations which may occur in the context of the research study. If transformations do occur, it is the responsibility of the researcher to explain how these may have affected the research. No transformations occurred within the context of this study as the researcher kept strictly to the aims and objectives of the study.

(iv) *Confirmability* is the qualitative equivalent of the quantitative concept of objectivity (Guba & Lincoln, 1985). This concept involves the confirmation of the findings of others. This means that the researcher should ensure that the research literature has been consulted. Confirmability was ensured in this study as the researcher drew on literature and references from other sources to support the findings of the study. This confirmed the findings of this study of breast cancer, with regard to communication and coping.

4.10 Conclusion

The experiences of the participants were highlighted and this placed them at the forefront of this research, thus ensuring that their voices heard. The study gave these women the chance to express and define themselves. This resulted in improved levels

of confidence and self-esteem on the part of the participants. The next section will interpret the findings.



CHAPTER 5

RESULTS

5.1 Introduction

Four main themes have emerged: (i) communication between physicians and women with breast cancer; (ii) the reactions to a diagnosis; (iii) the stress caused by a breast cancer diagnosis; and (iv) the coping mechanisms used to manage breast cancer. These four main themes also have sub-themes. Some of the themes which emerged were pre-determined. The main purpose of this section is to provide a greater insight and understanding into the communicative and coping experiences of women with stage I-III breast cancer.

5.2 Description of Participants

Individual details of the participants are as follows:

a) Participant 1

This participant is an Afrikaans-speaking, coloured woman aged 29 years old. She has stage III breast cancer. She has a Grade 12 education. She lives in Belhar, is a housewife and has one child.

b) Participant 2

This participant is a Black Xhosa-speaking woman who is 40 years old. She has stage III breast cancer and is on chemotherapy. She has a Grade 8 education. She lives in Delft, is a domestic worker and has two children.

c) Participant 3

This participant is a bilingual (English and Afrikaans) coloured woman who is 42 years old. She has stage III breast cancer and is on chemotherapy. She resides in Bonteheuwel. She has a Grade 10 education, works as a cleaner and has two children.

d) Participant 4

This participant is a white English-speaking woman who is 39 years old. She has stage III breast cancer and has had a bilateral mastectomy. She resides in Lakeside. She has a Grade 12 education and diploma. She is an internal accounts executive and has two children.

e) Participant 5

This participant is a black Xhosa-speaking woman who is 40 years old. She has stage II breast cancer and is on chemotherapy. She resides in Philippi . She has a Grade 12 education, is a sales assistant and has two children.

f) Participant 6

This participant is a coloured Afrikaans-speaking woman who is 40 years old. She has stage II breast cancer and is on chemotherapy. She has a Grade 12 education. She resides in Grassy Park, is unemployed and has three children.

g) Participant 7

This participant is a coloured Afrikaans-speaking woman who is 27 years old. She is the youngest of the participants. She has stage III breast cancer and is on

chemotherapy. She resides in Lavender Hill. She has a Grade 8 education, is unemployed and has one child.

h) Participant 8

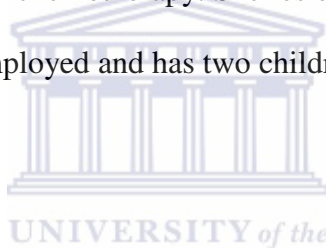
This participant is a black Xhosa-speaking woman who is 40 years old. She has stage II breast cancer and is on radiotherapy. She resides in Fish Hoek. She has a Grade 10 education, is unemployed and has one child.

i) Participant 9

This participant is a coloured Afrikaans-speaking woman who is 35 years old. She has stage II breast cancer and is on chemotherapy. She resides in Mitchells Plain. She has a Grade 10 education, is unemployed and has two children.

j) Participant 10

This participant is a coloured Afrikaans-speaking woman who is 39 years old. She has stage III breast cancer and is on radiotherapy. She resides in Heideveld. She has a Grade 12 education, is a machinist and has two children.



5.3 Themes and sub-Themes

The following themes and sub-themes emerged. Sub-themes are listed using bulleted points.

5.3.1 Theme 1: Communication from the physician

- Knowledge of breast cancer
- Content of information

- Language style of physician
- Knowledge is power
- Professionalism of the physician

5.3.2 Theme 2: Reactions to the diagnosis

- Distress
- Anger
- Shock
- Denial
- Regret



5.3.3 Theme 3: The stress caused by a diagnosis of breast cancer

- Fear of death
- Treatment side effects
- Communicating the news of breast cancer

5.3.4 Theme 4: Coping with a breast cancer diagnosis

- Support from family and friends
- Spirituality and Religiosity
- Positive attitude

- Hope to recover
- Acceptance

5.3.1 Theme 1: Communication from the physician

Six questions were asked pertaining to the participants' understanding of breast cancer and the way the information was transferred from the physician. The aim of these questions was to gain a better understanding of the communicative relationship between physician-patient. The responses by the participants suggest that their relationship with the physicians was positive. There was a level of understanding and interaction between both physician and patient during the communication process. Consequently, there was effective physician-patient communication. The sub-themes of communication are presented as expressed by the participants.

5.3.1.1 Knowledge of Breast Cancer

During the interview the participants were asked about their understanding of certain terms used during the diagnosis of breast cancer. They were asked to describe what the following words meant: *breast cancer*, *mammogram* and *adjuvant therapy*. These medical terms are used on a daily basis by medical staff in communicating with women with breast cancer in order to explain their illness, the tests that needed be done and further treatment. Obviously, it can be assumed that women with breast cancer have some understanding of these terms even if at a basic level. This would indicate some understanding of their illness, acquired from physicians or from the available medical literature.

The participants demonstrated a clear understanding of what *breast cancer* referred to. Whether they understood breast cancer as “a lump, cancerous cells or a disease” they certainly had some knowledge of it. In some cases the participants were equipped with only a basic knowledge, probably based on information which they received from the physician.

“When you get a lump in your breast and then you have to go through a lot of steps.... My perspective, for me cancer is a terrible illness.” (Participant 1)

“Breast cancer is a lump in the breast. In the lump, in the breasts, sometimes spread the whole body.” (Participant 2)

“Uhm...well..breast cancer is cells that go haywire in your breasts and multiply and go and take over your body....and you gotta cut them out...chemo them to get rid of...just in case cells” (Participant 4)

“Some kind of disease.....is like the saying the cancer is in my body...something that reacts it..and then it grows..uhm...and it's treatable and but uhm....uhm...finding out that it comes from generation to generation..” (Participant 5)

These responses reveal that some of the women understood what breast cancer was, although they provided rather narrow definitions.

Most of the participants knew what a *mammogram* was as all of them had experienced one. They all knew that a mammogram was a machine which tested for breast cancer.

“And mammogram is when they put your breast in that machine, flatten it like a pumpkin.” (Participant 1)

“It's when you test, your breast. It's like, uhm... Mammogram is when your breasts is being scanned.” (Participant 3)

“That’s the X-ray that they do of your breast” (Participant 4)

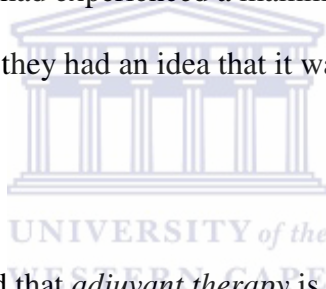
“A mammogram is what you have for your breasts, when you go for the tests, almost like a snackwich... Looking where the cancer is.” (Participant 6)

“but I know it’s where they put my breast in the machine and then they push the machine in...” (Participant 8)

“I had one, it’s... uhm... Not sore or anything, but it’s uncomfortable, they put your breasts between two, uhm, whatever they call it, then they press it so tight. It’s very uncomfortable.” (Participant 9)

“Mammogram is for...for when you go for the breasts to..that was Monday I go for that...that machine..just to see...To see the lump...the cancer is” (Participant 10)

Since they all the participants had experienced a mammogram before being diagnosed, it was evident that they had an idea that it was a medical procedure to test for breast cancer.



Thirdly, it should be explained that *adjuvant therapy* is a type of treatment similar to chemotherapy. *Adjuvant therapy* is just another word for chemotherapy. It was found that nine of the ten participants did not have an understanding of what this meant and some have never heard the term before. This might be because they had not yet experienced the treatment, or it may simply reflect a lack of health literacy. The following excerpts are examples of the participants’ responses to this term.

“I never heard that.” (Participant 5)

“I have no idea what that is.” (Participant 6)

“Don’t know” (Participant 8)

“No” (Participant 9)

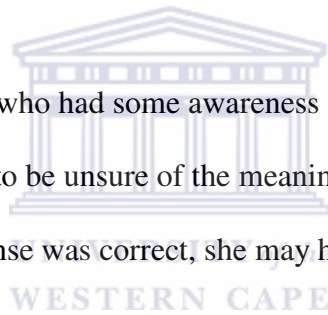
“Is that now theexercise... No..I don’t know what’s it” (Participant10)

Another reason for their lack of familiarity with this term might be that the physicians prefer to use words that are easier to understand to refer to chemotherapy treatment.

One of the ten participants attempted to answer by asking whether *adjuvant therapy* was actually chemotherapy.

“Adjuvant therapy is the chemotherapy right?” (Participant 1)

This was the only participant who had some awareness of what *adjuvant therapy* was. Even this participant seemed to be unsure of the meaning, as she asked a question in response. Although her response was correct, she may have been taking a guess.



5.3.1.2 Content of information

The extracts below show the level of communication that exists between physician and patient. It clearly shows that physicians are interacting effectively with their patients. That is, they are communicating with their patients in a clear and understandable way.

“And he went through everything with me. A biopsy and everything, he explained to me step by step...Cause I always under...understand what he said” (Participant 1)

“Yes. Physician explain to me about the cancer and he explain the cancer.”

(Participant 2)

“They alright, they okay here. They speak to you, they answer you...They speak to me as I can understand.” (Participant 6)

The responses showed the physicians communicated the diagnosis of breast cancer to the participants, in a way that was clear and understandable. The patients stated that they understood the physician at all times. When they did not understand, they asked questions so that they could gain a better understanding of breast cancer. The physicians did not make use of medical terminology while consulting with the patients. They used plain, clear and understandable language. If the patient spoke a language other than English or Afrikaans, the hospital provided an interpreter. This was to ensure that the information being communicated was understood.

5.3.1.3 Language style of physician

The ten participants were asked whether the physicians communicated in a way which was clear and understandable to the patient. Eight of the ten participants confirmed that this was the case.

“Yes. He did. Actually he did.” (Participant 1)

“Yes. I understand the doctor” (Participant 2)

“Clear” (Participant 3)

“Very straight-forward and....no frills and fancy words...very direct, ja”
(Participant 4)

“Ek het verstaan” (Participant 7)

“Yes...I did understand” (Participant 8)

“He was very clear about everything...so that I can understand...I did understand him...ja I did understand him...So far..I’ve understood everything” (Participant 9)

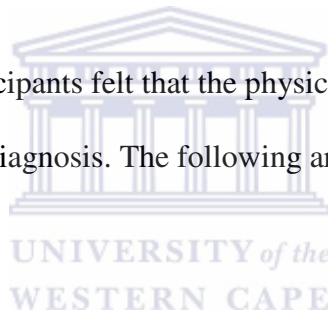
“Directly.” (Participant 10)

The responses indicate that the physicians wanted to ensure that the participants understood the information that was being communicated. The participants stated that the physicians explained the information clearly, directly and understandably.

The participants felt that the context for the communication of information was important. A following excerpt illustrates that the physicians were doing their best:

“He was very clear about everything.” (Participant 9)

However, two of the ten participants felt that the physicians did not provide clear explanations regarding their diagnosis. The following are excerpts from these participants:



“No, he just told me ‘your results are positive for cancer.’ I just said yes, and, uhm. He just explained me how the treatment is gonna work. I didn’t even know what is the chemo. He never explained to me how it’s injection or if it’s a kinda of... I thought maybe I going to... they were going to put me in some kind of machine. You know? I didn’t know it’s those drips... you know?” (Participant 5)

“Aargg, like I said, I read between the lines... I read between the lines that side and that’s when... They didn’t told me straight out.” (Participant 6)

The response from participant 5 indicates that the physicians did not provide sufficient information with regard to chemotherapy treatment. Participant 5 was clearly misinformed as she was under the impression that this treatment involved placing her in a machine. Another example of misinformation is given by participant 6. This participant mentioned that the physician was not being straight, direct and open with her about the results of her breast cancer tests. This participant mentioned that the physician did not inform her of the results of her breast cancer tests. She had to figure this out for herself and assume that she had breast cancer. In her case, it could be said that the physician withheld information from the participant.

5.3.1.4 Knowledge is power

Participants who did not understand what the physician was saying stated that they told the physician this and asked the physician to provide a clearer explanation. The participants were not afraid to ask the physician questions.

“I tell I don’t understand.....I tell him if I don’t understand. I tell him, ‘doctor I don’t understand,’ and sometimes they call another lady to explain.” (Participant 2)

“No...I do ask.” (Participant 3)

“I’ve always understood. I ask questions If I don’t.” (Participant 4)

“I do ask the meaning of what you say.” (Participant 5)

“I do ask questions.” (Participant 6)

“Ek vra...ekke..dan sé ekke uhm ek verstaan nie...dan verduidelik hy vir my.”

[I ask...I then say I...uhm...I don’t understand...then he explains to me]

(Participant 7)

“..because even if I want to ask something... I’m asking..” (Participant 8)

“I ask questions..If I wanna know something...I ask it... And if I don’t understand...he just have to explain it till I..” (Participant 9)

“Then I tell him...I don’t understand..He must explain it.” (Participant 10)

Many patients are reluctant to ask questions . Patients fear that asking questions about their health might give the physician the impression that they are stupid. However, it is clearly important to ask questions when doubt, uncertainty and confusion arise. The willingness to ask questions shows a level of active involvement and derives from the need of women with breast cancer to gain more information about their condition.

5.3.1.5 Professionalism of the physician

The participants were very impressed with the work carried out by the physicians as well as the nursing staff, and provided positive feedback. The participants described the physicians as:

“honest...cool...patient...awesome...dedicated...trusted...friendly...great...angels... nice...helpful...sensitive...straightforward.”

These responses suggest that the physicians have been working hard to achieve patient satisfaction, and they highlight the quality of service and care rendered to patients by their physicians. The responses show that the participants have placed their trust and lives in the hands of physicians.

“I actually respect them for being honest with me” (Participant 1)

“But after that I trusted the doctors help me....I think he is doing his job”

- (Participant 2)
- “...nice..no problem” (Participant 3)
- “..but he was quite cool....The doctor’s here have been great and patient.....
Oncology unit, everybody here have been awesome...I think they very dedicated bunch
and they work hard, and they do the best that they can, with what they have... And
I’ve been quite impressed.” (Participant 4)
- “but they nice...anyway... They so friendly.” (Participant 5)
- “I like being here...it’s nice they cool...they straight forward...you can ask them
questions....they answer you....Oh..they angels here....they treat you well here.”
- “I have no problem so far with no doctor...they haven’t discouraged you in any
way...they help you make decisions.” (Participant 6)
- “Die dokter doen sy werk.” (Participant 7)
- [The doctor is doing his job] (Participant 7)
- “They are speaking nicely to me...I just think that....they have have helped me...
they are very helpful.” (Participant 8)
- “People is very nice and the nurses are nice and they treat you nicely...they
friendly....they all nice and sensitive...they treat you well.” (Participant 9)
- “The doctor is just doing his job...He’s giving his best for me..really.” (Participant
10)

The medical staff in this unit clearly provide a high standard of care. The responses from the participants suggest that the physicians are friendly, helpful and dedicated. These positive responses are indicative of good physician-patient relationships.

5.3.2 Theme 2: Reactions to the diagnosis

This theme relates to the emotional reactions of patients to a breast cancer diagnosis. Questions were asked relating to this theme and there were commonalities among the participants. The women with breast cancer in this study experienced emotional and psychological responses to the diagnosis of breast cancer. Their responses show that a diagnosis of breast cancer evoked a range of emotions and feelings, as the participants were faced with what they believed to be a life-threatening illness. Many of these emotions stemmed from a fear of dying, as many participants associated breast cancer with death. They may have heard stories or experienced the death of friends or family members from breast cancer, and naturally the thought arises that they might be next. Often the initial response was one of sadness, accompanied by crying. Other emotions included anger, shock and regret. These emotions, thoughts and feelings often persisted during the initial stages of the illness. In other words, these women felt like this for a period of time before moving towards acceptance.

The following excerpts express the feelings of participants on being told they have breast cancer. The responses often included feelings of anger, shock and regret.

5.3.2.1 Distress

The participants were asked what their initial response was to the breast cancer diagnosis. Some reported feeling very emotional and crying as a response to the shock of hearing the bad news.

The following extracts convey these responses:

“I cried, in front of my daughter.”

(Participant 1)

“Lotsa tears. Lotsa tears. Very emotional, uhm, scared for lotsa reason”

(Participant 4)

“It’s very emotional, for me, it was very emotional. I thought I was going to die.”

(Participant 6)

“Ek’t upset gevoel. Ek’t begin te huil... Ek was baie upset gewees...baie by die huis in die kamer ga sit en huil.”

(Participant 7)

[I was upset. I began to cry... I was very upset.....frequently at home in the room I was sitting and crying]

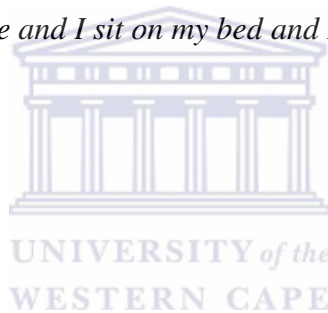
(Participant 7)

“I was crying in front of the doctor...I was not little upset...I was very sad...because I was crying all the way from Groote Schuur to the station...like all the way to Fish Hoek...I just come in the house and I sit on my bed and I’m crying...and I cried and I cried.”

(Participant 8)

“I was crying. I was upset.”

(Participant 9)



5.3.2.2 Anger

Another common response to a breast cancer diagnosis was anger. Participants were often angry at themselves, for not taking proper care of their health.

“I was angry.” (Participant 1)

“I feel angry. I feel down.” (Participant 2)

“That’s why I, I was so angry.” (Participant 8)

A person who is angry must have been hurt by someone or something. In this situation, the feeling of anger was triggered by receiving the devastating diagnosis of

breast cancer. However, participants did not vent their anger in obvious ways. In other words, they did not hurt themselves or others in any way

5.3.2.3 Shock

At the time of the diagnosis, participants often reacted with shock. They could not believe that what was happening to them. They always thought that it could happen to others, but not them.

“It’s just a huge shock, huge shock. So I thought I’d dodge a bullet.” (Participant 4)

“I couldn’t believe it anyway.” (Participant 5)

“I was shocked. Shocked...” (Participant 6)

“...and then I was just shocked a little bit.” (Participant 8)

“And I was devastated.” (Participant 9)



Shock was clearly a common response to the diagnosis of breast cancer. This feeling of shock or disbelief was registered in the initial stages of the illness.

5.3.2.4 Denial

On analysing the initial response to the diagnosis, it emerged that the participants also experienced denial. Shock and disbelief are forms of denial, where the participants remain silent. One participant said:

“I was shocked, shocked. I don’t think in denial!” (Participant 6)

This passage indicates that the participant was experiencing shock, but she denied being in denial. She may have thought that shock and denial were two separate reactions. Participants used denial in order to protect themselves from the pain and distress of hearing the breast cancer diagnosis.

5.3.2.5 Regret

Regret was often expressed by participants during their interviews. One participant felt that if she had taken precautions earlier and not neglected her health, then the illness could have been prevented:

“Maybe if I had acted earlier onwards, but...Earlier, I could have prevented it.”

(Participant 1)

Regret may also be linked to guilt. The participant quoted in the excerpt above took full responsibility for the breast cancer, but she wished that things could have been different. Many participants wished that they had discovered the lump earlier and had checked their breasts more regularly. It is interesting to note that that the lump was often not recognised by the women themselves, but by their husbands and/or partners. One participant said her lump was discovered by her husband as she was coming out of the shower. He noticed a green lump on her breast, and this persuaded her to go for a breast check up.

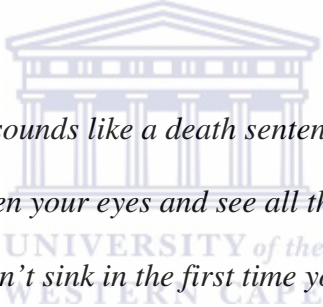
5.3.3 Theme 3: The stress of the diagnosis

A diagnosis of breast cancer is stressful; it causes anxiety and leads to an increase in stress levels. The following sub-themes are associated with stress as a response to being diagnosed with breast cancer.

5.3.3.1 Fear of death

Although breast cancer is a life-threatening illness, one can recover from it through treatment. However, many women diagnosed with breast cancer believe that it is a death sentence. Fears of dying contribute to anxiety and was a common response among the participants. Women in the study expressed their fears. Fear was an initial response to the diagnosis , but as time progressed and treatment was administered, the participants realised that they were not the only ones with breast cancer, and they recognised that some women do survive breast cancer.

The following excerpts illustrate the fear of death:



“Aargg....hectic..it was uhm..sounds like a death sentence when you hear it...you know but..then you have to open your eyes and see all the other people around you..but it still doesn'tdoesn't sink in the first time you...you...it's very emotional...for me it was very emotional.....I thought I was going to die...like..you think of your children...you think of everything and you start crying and all that...but then you have to...I guess you have to focus on life so to speak...cause then..I look at my children and I think...yor..I can't be here...I have to move up..I have to..can't sit and sulk you know and self-pity...look at the other ladies...and you think..aarrgg..you not the only one in the boat...So ja the first time I hear it...it was hectic...It took me about a week....I think to get out of it....to realise you not the only person.. it's not the death sentence.”

(Participant 6)

“That's why I was so shocked and I was so angry cause I did think maybe I was going to die...”

(Participant 8)

5.3.3.2 Treatment side effects

Participants who were diagnosed with breast cancer were advised about the appropriate treatment options for their stage of breast cancer. As a result of this information, many participants were apprehensive. They often complained that the treatment caused them to gain weight, as well as to lose hair.

“Weight! I picked up a lot of weight, about 10kg’s.” (Participant 1)

“The chemo has been hell...I mean..I’m in bed for a week..I’m very weak...uhm...very tired...constant tiredness..the loss of hair is horrid...uhm...The weight gain is awful.

Buying bigger jeans is awful.” (Participant 4)

“My hair fall out.” (Participant 2)

“The physician told me my hair was gonna fall out.” (Participant 10)



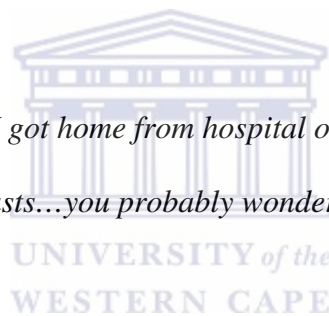
In spite of being told about the side effects of the treatment, participants frequently complained about weight gain and loss of hair after treatment. Some were under the impression that weight gain was as a result of consuming too much food during this period, while others thought that it was simply a side-effect of the treatment. Some of the participants had to buy new clothes. While the loss of hair affected some, others were not unduly concerned by this. Women who did not like to be bald preferred to wear wigs. Many of participants prepared themselves in advance for the hair loss. Those with long hair also shaved their hair prior to the treatment, so that they would not have to deal with having clumps of hair falling out.

The weight gain and hair loss experienced by the participants, it did not prevent them from fighting to survive. They accepted the fact that they would feel sick, gain weight and lose hair as side-effects of the treatment. This was necessary if they were to get better. The participants in this study showed a determination to overcome breast cancer; each participant displayed strength and courage.

Some participants also had to undergo surgery as part of their treatment, and this caused them further distress.

The following excerpts illustrate the how anxiety manifests itself during and after treatment.

“Be honest with you....when I got home from hospital on the Friday...I cried. To see the first time I’m without breasts...you probably wondering why?. (Participant 1)



“Well, I am here today. This is my last chemo...and I am here to tell my doctor, I’m not having my breasts removed... Yes. It was suggested that I have my breasts ...but my argument is...uhm....why put me through all this suffering by having chemo...and having the lump shrunked..then you want to remove my breasts....why didn’t you just in the beginning..uhm...before I went for chemo...remove the breasts? That’s my argument. Uhm...now you put me through suffering andI wouldn’t say suffering...but I mean..chemo is mos now....something that you go through..uhm...you having it shrunked....why do you want to remove it afterwards..so my argument is...I would just like to have the lump removed. If the lump has shrunked....just have the lump removed....not the whole breast.” (Participant 3)

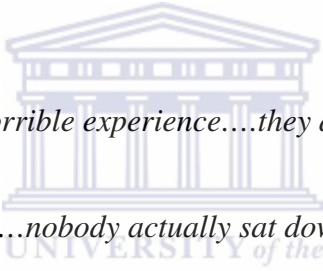
5.3.3.3 Communicating the news of the diagnosis

Further anxiety was caused by the feeling on the part of some participants that the physicians did not communicate information about the illness clearly enough.

The following excerpt indicates the distress that miscommunication can cause:

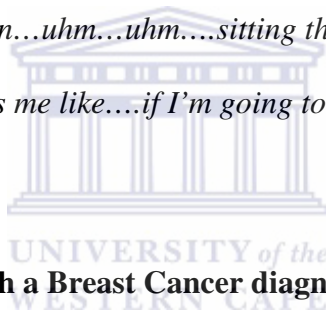
“I didn’t even know what is the chemo..... He never explained to me how it’s injection or if it’s a kinda of...I thought maybe I going to...they were going to put me in some kind of machine..... You know? I didn’t know it’s those drips...you know?”

(Participant 5)



*“(deep breath)..It was a horrible experience....they didn’t actually tell me. I figured out between the lines...nobody actually sat down with me..and say..okay *Gabi you have breast cancer...no body done that....the clinic where I was...so uhm...there going for all the stuff...asking questions... Ja...so nobody actually saidso when they wanted to send me tosee a counsellor...so I asked...what for?...why must I see her?...and they still doesn’t tell me straight out...because you have breast cancer....you so sick...so I’m....just put one and one together...Aargg...this is uhm.... They never told me straight out...the first doctor I saw...he felt...and he said okay you going to the next one....so I ask him why...he said you just have to go and see the next doctor...and then...coming to the next doctor I see all the needles and stuff and I ask like what the heck...(giggling) and he say...no we taking a sample of out of your breast of the lump...ek vra why...uhm...uhm...what happening...say no..we..we going to see if it is cancer...they gonna tell....they gonna*

see if it is cancer..fine...okay coming from there they send me to the next room...they said go wait...then the nurse...then the one doctor tells me to come in....talking to her she says.. do you know what's happened?.....I...have an idea...I have an idea putting one and one together because ...you all look so serious..and on the folder they write...."Urgency"...so everything must be serious...if it's urgently...so then she told me wait....you must see....while we spoken...she asking me questions...then she asks me did you see...the...the...psychiatrist yet... I said no I have'nt seen nobody...she said okay go sit outside....and wait...now I asking why...you need to speak to somebody...I say...what must I speak to somebody about cause then I'm already working myself up..and I am a very emotional person...I react to my emotions..(giggling)...and then...uhm...uhm.....sitting there then the nurse asks me...the nurse...the sister asks me like....if I'm going to see one...I say no why must I see one..." (Participant 6)



5.3.4 Theme 4: Coping with a Breast Cancer diagnosis

In this analysis, the theme of coping is discussed. This section outlines ways in which participants cope with breast cancer. A breast cancer diagnosis is often devastating for many women, yet they have to find ways to deal with it. Three questions relating to coping were asked. The responses from the participants were generally positive, but showed that some women questioned God or bargained with God about their health status.

5.3.4.1 Support from family and friends

Many participants stated that they received most support from family and friends. Coping styles based on help from family and friends seemed to be common.

“My, actually, it’s my in-laws that support me.” (Participant 1)

“Church families. Yes. My church families help me.” (Participant 2)

“Well. I do have my mother’s support, ’cause I’m living with her.” (Participant 3)

“I have awesome family and friends, support. My sister has been my rock. You know, we’ve held hands together. And, ja, it’s been awesome and I have been very lucky.”

(Participant 4)

“I only told one friend...she’s well supported ... My family...my sisters and my brothers”. (Participant 5)

“Physically my husband is there...I mean my husband helps me a lot.”.

(Participant 6)

“Is ma net my kind se ouma wat nou belangstel....sy vra vir my wat se die dokters elke dag wat ek gaan....Hy is daar...hy’t gesé hy wil eendag saam kom...want ek praat nie...ek hou alles in...en wil uitvinne wat...hoe ver is dit en wat gaan aan.”

(Participant 7)

[*“It’s now only my child’s grandmother who is interested....she ask’s me everyday what the doctor’s say, everyday that I go...He is there...he told me that he wants to come with oneday....because I don’t talk...I keep everything in...and wants to find out...how far it is and what is going on.”*] (Participant 7)

“As well ja...and my family...Whereas my family is not here....but when I speak’s like..on the phone...they are...sometimes they are sms’ing me...some messages.. he is also the one who is supporting me...from the first day..that I hear..I told him that I went to hospital and I got a breast cancer..ever since then he supporting me”

(Participant 8)

“ But I had the support...my family.” (Participant 9)

“A lot of family support ...Friends and family.”

(Participant 10)

These excerpts reveal that the participants rely on their families and friends for support and encouragement. All the participants received some kind of support, whether it was from a grandmother, brother, sister, husband, friends, the in-laws, or even just an sms from family members who wanted to share words of inspiration and encouragement.

Whether it was words of encouragement, a lift to the hospital, a phone call or an sms, this support helped the participants. Just knowing there was someone out there thinking about them meant that they were not alone in dealing with their illness. Reliance on support from family and friends as a coping method seemed to be importance to the women in the study. The moral support and encouragement they received helped them not to give up.

In the excerpts, participant 7 mentions how her grandmother and boyfriend supported her through her illness. She says that her grandmother always showed concern for her by asking her questions about her visits to the physician. She explains that her boyfriend liked to accompany her to the hospital to find out more about her illness. These kind and caring gestures assisted the participant to cope through knowing that there were people who were offering moral support.

While most women received support from their family and friends, one participant lacked support from her immediate family. Her response stood out, in that no one except her grandmother and boyfriend were interested in her well-being, not even her own mother.

“Actually is my ma... Hulle stel nie belang nie...hulle vra nie vir my wat sé die dokters ie.”

[“Actually it’s my mother... They are not interested...they don’t ask me what the physicians say.”]

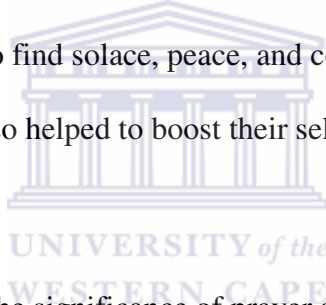
(Participant 7)

Her comment reflects a sad reality, but this situation only occurred once throughout the interviews. The circumstances surrounding this participant are unusual, as mothers generally show concern for and interest in the lives of their daughters, especially if the daughter has breast cancer. There should be no excuse for this mother’s lack of support for her daughter. Although women with breast cancer do not want to be pitied, they deserve to be treated in a compassionate manner, especially by their mothers and close relatives. The reasons for the mother’s lack of concern in this case were not clear. Obviously, a relationship where there is no communication of concern between mother and daughter is problematic, and may suggest unresolved issues within the family. Where there is a breakdown in communication between two people, it is likely that the relationship will turn sour and that misunderstandings will occur.

This response evoked empathy in me for this participant, as I realised that she may be experiencing difficulties in her life. Her responses led me to start thinking about what would drive a mother not to show concern for a daughter who had been diagnosed with breast cancer. It seems that even without the usual support structures this participant may be moving on with her life. The participant did not exhibit much concern at this lack of support. She did however comment that her boyfriend and her grandmother supported her.

5.3.4.2 Spirituality and religiosity

The theme of spirituality was discussed by the participants. Many participants stated that their relationship with God helped them to deal with their breast cancer. The participants reported that they trusted, prayed and believed in God, and felt that He would carry them through this illness. Their diagnosis in fact brought them closer to God. Those who had no previous relationship with God now formed a close bond with Him. Throughout the interviews the participants mentioned that God and/or spirituality played a huge role in their recovery. Therefore, it can safely be stated that spirituality was a factor in the healing process. Initially most of the participants were shocked and angry on hearing their breast cancer diagnosis, but forming a spiritual bond with God helped them to find solace, peace, and contentment within themselves. This relationship with God also helped to boost their self-esteem and remove uncertainty.



The participants emphasised the significance of prayer and church attendance. This showed that they regard God as an important factor in their recovery.

“I have faith, and I also go to church every Sunday and I have people that’s praying for me.” (Participant 1)

“I need God now, yes.” (Participant 2)

“to stand more on faith...” (Participant 6)

“Vertrou op die Here. En ek het gebid en vertrou op die Here.” (Participant 7)

[*“Trust in God. And I trusted and prayed to God,”*]

“...but at the same time I trust God... It’s praying...I was just praying like that.”

(Participant 8)

“ Church...yes...pray and a lot of support....”

(Participant 9)

“I’m more closer to God now.”

(Participant 10)

One participant remarked that God worked through the physician to heal her.

“Even the doctor is doing what God wants him to do.”

(Participant 8)

This participant told the physicians who were going to operate on her:

“You must pray first before you do my body.”

(Participant 8)

This participant also prayed before she went into theatre and asked for God’s hand of protection over the physicians who were operating on her.

“...Please God, they must do what you want you to do in my body.” (Participant 8)

This participant’s constant reference to God during her times in theatre, as well as prior to sedation, suggests a belief that God was working through the physician to heal people. It is not the physician himself who heals people, but God who assists the physician to carry out the operation successfully.

This theme also relates to the angry reactions on the part of some of the women in the study.

“I blame God. God. Because I have the breast cancer.”

(Participant 2)

“In the beginning it’s just, I was against God. Why God? All this”

(Participant 6)

“Yes. I did blame God ’cause I did ask what God make to me. Because... it’s the high blood pressure at the same time as the breast cancer.”

(Participant 8)

These are examples of a coping strategy that can cause a rift between God and the patient. It was quite a common response to place the blame for their breast cancer on God. Some felt that they had let God down in some way, such as by being disobedient, and that this was His way of punishing them. One participant could not make sense of what was happening to her. First, she was diagnosed with high blood pressure, then with breast cancer. She thought that this was punishment from God and did question Him about it.

In addition to participants blaming God for their breast cancer, it was evident that some of the participants had a spiritual relationship with God. Some entered into a plea bargain with God by asking God to spare them for some time.

One participant even suggested to God that she was doing her part by going for treatment and seeking help; God must also do his part to heal her.

“I’m doing my part here, Lord. I’m doing my part Lord. So you do your part, like that.”

(Participant 6)

One participant became ill on her way from Cape Town to Eastern Cape – she was intending to visit her mother during the December holidays. She pleaded with God not to let her die on the bus, but rather when she arrived in the Eastern Cape, in front of her mother:

“Just ask God, please God don’t take me now... Wait for me till I am in Eastern Cape, in front of my mum. Then you can take me. I was just praying like that.”

(Participant 8)

This participant asked God if there was anything she could do for Him, hoping that in return He would heal her breast cancer. This participant felt that the breast cancer was a punishment from God and directed questions to Him, thinking that she had failed Him in some way. The participant felt that she had not done enough to please God.

“I ask God; ‘What do you want me to do for you?’” (Participant 8)

Although the participants may have been brought closer to God by the diagnosis of breast cancer, they also began to question God about their breast cancer. One participant felt that she was obedient to God and could not make sense of His inflicting breast cancer on her:

“En dan sit ek en bid ‘verhoekom eke?’ Ek issie ‘n drinker nie. Ek issie ‘n rooker nie. Ek doenie drugs nie.”

[“And then I sit and pray ‘why me?’ I’m not a drinker. I’m not a smoker. I don’t do drugs.”] (Participant 7)

The extracts below also show that participants questioned God and believed that the illness was punishment for some wrongdoing.

“I asked God, ‘What did you do to me?....What did you do wrong to me?’” (Participant 8)

“I asked God, ‘Why me?’” (Participant 9)

These responses indicate that spirituality was an integral part of these women’s coping strategies. The use of faith as a coping method is confirmed by other researchers. Most of the participants used spirituality as a way of coping. Many

believed in a higher power, and it was their faith that gave them the ability to trust that they would survive. In some cases the breast cancer diagnosis brought the participant closer to God, and led to the establishment of a relationship with Him. These women also began praying and attending church on a regular basis. Their diagnoses brought about drastic changes, drawing them closer to God and towards a trust that He would heal them.

The tendency to blame or question God was as a response to the feeling that the cancer was a punishment from God. Participants prayed to God' wanting to understand why He had given them breast cancer. One participant felt that she was being punished "for nothing". She felt that she was obedient to God because she was neither a smoker, nor a drinker nor a drug user. This participant assumed that women, who engaged in such activities, would be punished and 'get' breast cancer. This is, however, not true. Anybody can get breast cancer and there are a number of factors that make this more likely – such as genetic inheritance, weight, diet, lifestyle and so on.

When participants resort to blaming God or bargaining with Him or questioning Him, this implies that He is the cause of their breast cancer. For many people God is an all-powerful authority. Questioning God implies that these participants experience some form of spiritual conflict as they try to reconcile their belief in God with the diagnosis of breast cancer. The participants' responses suggest that they were filled with anger because they did not expect to be affected by breast cancer.

5.3.4.3 Positive attitude

Six of the ten participants interviewed said they approached their breast cancer diagnosis with a positive attitude. They believed that this influenced their well-being in a positive manner.

“As long as you can breathe, you must say thank you. You can still get up in the morning, breathe the fresh air. That’s, that’s positive thinking....Start thinking positive. ‘Cause, uhm, it’s just temporary. It’s not forever” (Participant 3)

“Laughing, chatting, that’s my mood everyday. I don’t mope and groan, no... It’s how you take it. And to me, it’s... I take everyday, irrespective breast cancer... to me it’s like I don’t have breast cancer. That is how I see it. And that is how I go through life.” (Participant 3)

“So definitely, I think being positive, just helps with everything. It helps with the whole mentally-physically feeling.” (Participant 4)

“..nous ek heppi....ek wil vorentoe kyk want ek’t ‘n kind. Want as ek agentoe is...as ek nie vorentoe gaan kyk nie..gaan ek nog siekere raak.” (Participant 7)

[Now I’m happy...I want to look forward because I have a child. Because if I’m backwards....if I don’t look forward...I’m going to get more sick.]

“omdat ekki aan dink nie....vir my is it..ek’t hetti kenser nie.” (Participant7)

[Because I don’t think about it...for me it is...I don’t have cancer anymore.]

“I just tell myself that I...that I am still going to survive because I am not the first person who got a breast cancer...I didn’t give up...because it’s not the end of the

day..so I go to survive for a long time...and it's not the end of the day...I'm not giving up...it's not the end of the world...." (Participant 8)

"I feel positive...And I appreciate life more.....but I'm positive..cause I don't think I'm going to get sick any time now...so I feel positive and I don't feel sick...Like I said I am positive...I don't feel sick...." (Participant 9)

"..But I'm more positive because uhm...my little girl will always tell me...mommy kiss your breasts... And that is fine..it keeps me going." (Participant 10)

The feedback from these participants suggests that a positive attitude provides them with the assurance of survival.

Many participants they accepted their breast cancer diagnosis with a positive attitude. Women with breast cancer who reacted to their diagnosis with negativity, fear and anxiety were harming their chances of making a good recovery. Six participants in this study believed that being positive was the key to their recovery and to a healthier lifestyle. Positivity included laughing, chatting, and taking pleasure in waking up and being alive. Some of the participants regarded breast cancer as a temporary illness, in the belief that it would be cured through treatment.

Many excerpts reveal what one might call a 'fighting-spirit'. In this context, this is synonymous with 'the will to live': the participants are willing to adapt or adjust to having breast cancer. Individuals with a fighting spirit tend not be worried about anything. This is illustrated by this response from one participant:

"I don't mope and groan... no." (Participant 3)

The excerpts suggest that the six participants used a positive mindset as a coping strategy.

“To me it’s like I don’t have breast cancer... Laughing, chatting.” (Participant 3)

One participant hinted that what she was enduring was only temporary. This suggests a belief that the breast cancer will go away and everything in her life will return to normal.

However, four participants did not approach their illness with a positive attitude.

5.3.4.4 Hope to recover

The hope to recover emerged as a theme in this study, and can be regarded as a product of a positive attitude. The participants felt that if they didn’t have hope, then they would not be able to survive and overcome breast cancer. Many feared death but hoped for the best, and believed that they would recover soon. Hope was an integral part of their path to recovery. Many felt that had it not been for hope, they would not be alive to participate in the study.

The following excerpts illustrate how hope functioned as a coping mechanism for the participants:

“I do. That’s why, I won’t survive ’cause I won’t sit here if I didn’t have hope.’Cause if I didn’t have hope, I would have felt like... I don’t need to come for all this. I might as well stay at home and uhm, you see, accepted that... No, but I do have hope.”

(Participant 3)

“It’s not like you going to die like tomorrow. There is hope.” (Participant 9)

Hope is linked to the participants' fighting spirit. One participant also expressed a sense of strength amidst adversity. She referred to breast cancer as an illness that manifests itself in stages, so that immediate death is unlikely. Therefore, such a mind-set suggests a determination to overcome breast cancer. The coping mechanism of hope occurs throughout the breast cancer process, from the first stage of diagnosis to the point of receiving treatment. Hope gave these women the will to fight breast cancer and allowed them to cope with their condition. From the excerpt, it is clear that the participant has followed the prescribed treatment in an effort to recover. Willingness to undergo treatment is itself a positive sign, and implies hope for recovery.

Women with breast cancer who refuse treatment and stay at home lack hope and feel despair. A woman with breast cancer becomes hopeful after speaking to her physician, or after a few sessions of treatment. The physician gives the patient the assurance that everything will work out positively, and describes the treatment as an important part of the recovery process. The patient absorbs the information communicated by the physician and places her trust and confidence in the physician. Hope is often an outcome of the consultation with the physician.

5.3.4.5 Acceptance

Eventually, the participants accepted that they had breast cancer. They did not accept this immediately, on being given the diagnosis for the first time. Gradually, as they returned for follow-up consultations and treatments, they realised that they had breast cancer. This followed *acceptance* of the breast cancer diagnosis. The following responses from the participants indicate their acceptance of breast cancer.

“But, afterwards, I did accept it. I’ve accepted it already.” (Participant 1)

“So I went back home and they told me to come back for the chemo...so I accepted it anyway.” (Participant 5)

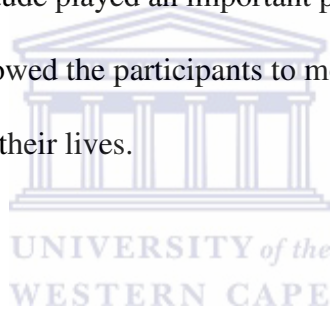
“Sure, you can’t otherwise. But, it’s in your face.” (Participant 6)

“Yes. Whereas I did, I accepted it later, but I did accept it.” (Participant 8)

“Uhm...since I had my operation in March...I’ve accepted it already.”

(Participant 9)

The participants’ positive attitude played an important part in their acceptance of breast cancer. Acceptance allowed the participants to move away from the darkness of the diagnosis and get on with their lives.



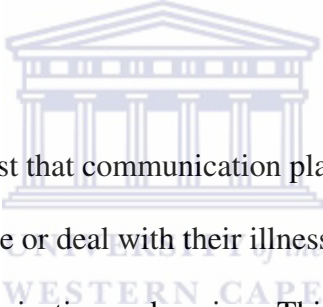
CHAPTER 6

DISCUSSION

6.1 Introduction

This section provides a discussion of how communication between physician and patient influences the coping mechanisms of women who have been diagnosed with stage I-III breast cancer. The discussion will integrate the research findings and also refer to literature that supports of the findings of this study. The chapter also includes a discussion of limitations, recommendations and conclusion.

6.2 Summary of results



The qualitative findings suggest that communication plays an important role in the way breast cancer patients cope or deal with their illness. The literature shows that there is a link between communication and coping. This study has shown that medical discourse that is clear and understandable to the patient will impact positively on their well-being and help them to cope effectively with the diagnosis of breast cancer. The following results were found to be common across studies:

- (1) The exchange of information between physician and patient is important for women's understanding of breast cancer.
- (2) Women with breast cancer understood information when physicians used plain and clear language to explain their diagnoses.
- (3) Women with stage I-III breast cancer are stressed about the possibility of dying, and also by the side-effects of their treatment and by miscommunication regarding their diagnoses.

4) Coping mechanisms such as social support, acceptance, spirituality, hope, denial and optimism are frequently used by women diagnosed with stage I-III breast cancer.

The following discussion will provide support from the relevant literature.

6.3 The reactions to a breast cancer diagnosis

The women often experienced emotional and psychological distress in response to a breast cancer diagnosis; the illness was regarded as harmful to the patient's health.

6.3.1 Emotional and psychological distress

The views expressed by the participants supported the Stress and Coping Theory (Folkman *et al.*, 1986), where stress is a function of the relationship between the patient and her environment, and it is appraised by the person. Stress is a response to anything that causes harm or threat or that challenges the health of an individual (Lazarus and Folkman, 1984). In the context of this study, the stressor is the communication of the diagnosis of breast cancer. In other words, receiving a diagnosis of breast cancer causes emotional distress. Breast cancer is a life-threatening disease, and the way in which the diagnosis is communicated can cause further harm and anxiety to the patient. In addition, distress was also caused by the fear of dying, by the side effects of the cancer treatment and by miscommunication.

When confronted with the diagnosis, patients were often distressed, angry, shocked, in denial and regretful. The manner in which a diagnosis is communicated to women with breast cancer can increase stress levels.

According to Maxwell (1969), a diagnosis of cancer can produce a range of emotions, including shock and anger. Patients often react by crying. This was the case was with

the participants in this study, many of whom they started to cry when told about their breast cancer. Some of them reacted by crying immediately, in front of the physician, while others cried when they got home and had to tell their relatives about their diagnosis. One reason for this reaction is the stigma associated with breast cancer, and the fear that it may prove fatal. One can easily imagine the overwhelming feelings experienced by the participants on being told that they have breast cancer. Their distress suggests that they often could not believe what they were told. Many of these women became afraid and did not know what to expect. Linver (2009) remarks that crying is a normal response among patients. Physicians should be prepared for this, and should offer the patient tissues. At this time, the patient will require support from family or friends. This will help to give the patient a sense of belonging, and the reassurance that she is not being abandoned (Linver, 2009).

The women in this study displayed feelings of anger when told about their diagnosis. This is consistent with the findings of Sprah and Sostaric (2004), who also studied responses to a diagnosis of breast cancer. Anger manifested among the participants in this study as a reaction to hearing the diagnosis of breast cancer. This may be a natural response to being told that one has a life-threatening illness. However, the anger may also be directed at God, or at the physician or at the patient herself. Kübler-Ross and Kessler (2005) suggest that anger may indicate guilt. The participants in this study indicated that they took full responsibility of their illness. They felt the cancer could have been prevented if they had taken precautions and gone for regular check-ups. Some participants were also angry at God, feeling that their illness was a punishment of some kind. It must be noted, however, there was no resort to physical violence. The anger expressed by the participants was often a result of internal

frustration, and there was no intention to harm another person. Kübler- Ross and Kessler (2005) state that the anger will resolve itself in time.

Kübler- Ross and Kessler (2005) suggest that a response of shock indicates that the individual is in denial. In this study, some of the participants were indeed in denial, but they often did not recognise this. When questioned about this, they responded saying 'no'. Linver (1999) mentions that shock is a common reaction to a breast cancer diagnosis. The participants in this study often mentioned that they were shocked and disbelieving, but their reactions did not always support this. There was no evidence of extreme reactions, such as screaming in response to the diagnosis. However, there were often long periods of silence during which the patients were absorbing the devastating news. Linver (1999) suggests that if individuals respond by keeping quiet, this is an indication that the person is in shock. The way to handle such a situation is to allow the individual to absorb the information in her own time. Characteristics of shock include negativity, disbelief and despair (Sprah & Sostaric, 2004). These signs were evident in the responses by the study participants.

To summarise, a diagnosis of breast cancer can lead to a range of emotional and psychological responses, and can cause distress and anxiety. The following deals with the concept of communication between physician and patient.

6.4 Physician's style of communication and patient satisfaction

The physician's approach to communicating a diagnosis of breast cancer is an important influence on the patients' understanding of her illness and on her general well-being. The following are the factors which will help to ensure that patients understand their diagnoses and establish effective relationships with their physicians.

6.4.1 Clear and understandable transmission of information

Effective communication on the part of the physician will contribute greatly to the patient's understanding of breast cancer. The women in the study stated that their physicians communicated in a way that was understandable to them, and provided clear and thorough explanations. Physicians were thus communicating effectively with the women involved in this study. As a result, they were able to understand the information communicated by the physician.

These findings are consistent with those of Fallowfield (2008), who stated that physicians should give a clear explanation of the breast cancer diagnosis. The participants in this study reported that physicians showed consideration by speaking to them in a way they could understand. The ability of patients to understand the physicians' information also suggests that these physicians possessed the appropriate communication skills as well as the necessary clinical experience to enable them to communicate effectively with their patients. The literature on this subject confirms that patients should receive information from their physicians that is clear and understandable (Hagihara & Tarumi, 2006).

Another factor contributing to the women's understanding of breast cancer in this study was that they were able to participate in the consultations by asking questions if they were unable understand what the physician was saying. This is in line with Folkman's (1988) view of the importance of asking questions. However, the participants in this study seldom had to refer questions to their physicians, who were clearly skilled communicators. This study showed that physicians were making every effort to communicate with their patients and take their needs into account. Asking

questions is of course an important communication skill, and indicates that the women in question want additional knowledge and information about breast cancer.

Siminoff *et al.* (2000) confirm that the very act of asking questions impacts favourably on the awareness and satisfaction levels of breast cancer patients. Back *et al.* (2005) state that asking questions of physicians also develops their communication skills. The fact that some participants in this study asked questions about their health reflects their desire to gain more knowledge about their illness. Siminoff *et al.* (2000) conclude that by asking questions and entering into discussion with their physicians, patients raise their levels of awareness and satisfaction. The participants in this study displayed the urge to learn and rise above adversity. Many of them showed optimism and confidence in their fight against breast cancer. On the other hand, Siminoff *et al.* (2000) also report that patients who asked questions about their illness were often not impressed by their consultations with their physicians. This contradicts the results of this study, where patients who did ask questions about their illness expressed satisfaction with their consultations. In fact, none of the participants had any complaints regarding the service provided by their physicians.

6.4.2 A person-centred approach

Another finding of this study relates to the patients' perceptions of their physicians. This study reveals that the participants had positive perceptions of their physicians. They regarded the physicians as being very helpful, dedicated and committed to their work. They suggested that the physicians were striving to do their best to meet the needs of women with breast cancer, and by helped to make their treatment as comfortable and pleasant as possible.

This finding is supported by Roberts *et al.* (1994), who found a link between patients' perceptions of physicians and with their psychological health. The description given of their physicians by the participants in this study was similar to the given by participants in the study by Roberts *et al.* (1994).

Throughout the interviews, the participants' responses showed that the physicians were utilising person-centred approaches rather than physician-centred approaches. According to Ford *et al.* (1996), a patient-centred approach is effective in promoting good physician-patient relationships. The responses from these participants suggested that their physicians were open and expressive and interacted willingly with their patients. This is characteristic of person-centred approaches, according to Dowsett *et al.* (2000). None of the participants felt that their physicians were domineering or that they lacked sympathy and understanding (Dowsett *et al.*, 2000).

A patient-centred approach involves interactions between two individuals, in this case the physician and the patient. Each depends on the other for the transmission of information, and each also relies on the other for understanding. Each needs the other to share in the communication of information as active participants.

6.4.3 The use of open questions during consultation

Physicians who relied on closed questions placed limits on their patients' responses (Ford *et al.*, 1996). Cline (1983) states that physicians should refrain from using closed questions while consulting with patients, as this causes them to become defensive or inhibited. They could not express themselves freely when closed questions were asked (Ford *et al.*, 1996). There was no evidence in this study of physicians using closed questions during consultations with the participants. The use

of closed questions would have caused the participants to withdraw from interactions with the physicist during consultations (Ford *et al.*, 1996). Open questions were utilised by the physicians in the study, and the participants' responses reflected that they were able to express themselves and interact verbally with the physicians. Ford *et al.* (1996) mention that open questions give patients the opportunity to respond promptly to the physician's requests. According to Allen *et al.* (2001), the general health and well-being of patients who participated actively in consultations improved dramatically.

In summary, the style of communication used by physicians to explain a diagnosis of breast cancer enabled the women in this study to understand the information conveyed by the physician. Information was transmitted in a clear and understandable manner by the physicians, who used a person-centred approach and open questions. As a result, the women with breast cancer were satisfied with the physician's style of communication: they were able to interact comfortably with their physicians by asking questions when they did not understand. The physician's style of communication determines whether or not their patients will understand their diagnoses.

6.5 Patient's medical literacy

An understanding of breast cancer as an illness as well as of certain terms associated with breast cancer is important if patients are to be well-informed about their illness and its treatment. The participants in this study understood the meaning of most of the relevant medical terms, as they had encountered them before. If a term was unfamiliar terms, they were unable to give its meaning.

6.5.1 Breast cancer and mammograms

The findings suggest that the women with breast cancer understood the terms *breast cancer* and *mammogram*. Although their definitions were not scientifically-based, they were evidence of a basic understanding.

6.5.2 Adjuvant Therapy

It became evident that the women interviewed did not understand the term *adjuvant therapy*. According to Davis *et al.* (2002), the main reason why patients do not understand medical terms is a lack of health literacy. This may be true to a certain extent. One should also consider a patient's general level of education. A person with a primary education will not understand certain words, while a person with tertiary education will have a wider vocabulary and be more likely to understand medical terms. Siminoff *et al.* (2000) reported that people with a higher education were able to define the term *adjuvant therapy*.

The educational background of most of the participants in this study was Grade 10 or less; only one participant had a Grade 10 education and a diploma. Individuals from poor socio-economic backgrounds usually had low levels of education (nine out of ten participants had Grade 10 or less). Doak *et al.* (1998) found that low-income patients with breast cancer often had a limited or incorrect knowledge of their illness. These participants did not understand a term like *adjuvant therapy*.

In conclusion, the study demonstrated the crucial role of good communication between physicians and patients. In general the physicians used clear understandable English and avoided the use of a specialised medical terminology. When

communication is ineffective, misunderstandings occur, as patients are uncertain of what is meant. The responses of the participants in this study showed no evidence of this. This supports the hypothesis of the social constructivist approach that interpersonal communication is important for the construction of meaning and for effective communication.

The following section focuses on the coping mechanisms used by participants in the study.

6.6 Coping Mechanisms used by women with a breast cancer diagnosis

In this section, evidence-based literature is presented to support the findings of this study. Active coping strategies entail seeking information and adopting a confrontational approach to the illness as well as seeking social support (Vos *et al.*, 2004). This study confirms that the coping mechanisms most often used by women with breast cancer are support from family and friends, a positive attitude, spirituality, acceptance and hope.

6.6.1 Social support

Firstly, as part of an active approach to coping, support from family and friends as well as spirituality are important. Most of the women with breast cancer in this study stated that they relied on family and friends for support. Pieterse *et al.* (2007), find that support from family and friends lowers anxiety levels and benefits the health and the well-being of patients. The link between support from family and friends and the lowering of anxiety levels is significant in that the patients benefit from feelings of self-esteem and optimism, which are directly linked to their health. Folkman and

Lazarus (1988) state that there is an association between social support and positive emotions. The benefits of social support for the general well-being of a person have been shown by Pieterse *et al.* (2007). They add that women with breast cancer who have excellent social support have a better chance of surviving the illness. Participants reported that the support of family, friends, in-laws and the church gave them the strength to carry on, and also to appreciate life. The participants mentioned that it was usually a mother, sister, aunt or female friend who provided the support, rather than a man. However, one participant did mention that her boyfriend provided support and showed concern for her. Breast cancer is seen as an illness that affects women, so it is not surprising that those showing compassion and support should be women. Women tend to display more sensitivity and empathy in such situations like, and society has socialised men to control their emotions. Women who show empathy for women with breast cancer may feel that one day they might have to deal with the same illness themselves. However, there was no evidence in the interviews to suggest that traditional gender roles were being challenged. The partners of the participants were very supportive throughout the whole ordeal. It would seem that women are acting in keeping with their normative gender roles by showing concern and empathy.

Bettencourt *et al.* (2007) state that women with breast cancer in their study did not rely on family and friends for moral support. This was because they did not want to place further strain on family members. However, this finding is not in keeping with the results of this study. The women with breast cancer in this study relied on their families for support and appreciated their care and concern during their ordeal. They mentioned that their family members and friends supported them in a number of ways, such as by phoning them, sending messages or visiting them. This is in keeping

with the study by Bettencourt *et al.* (2007), which showed that family and friends showed their support through calls, visitations and food parcels.

6.6.2 Optimism

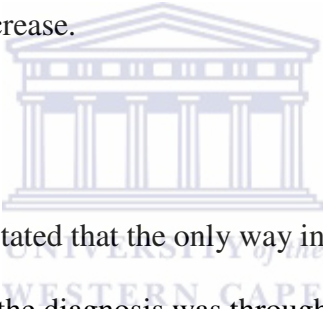
In this study women with breast cancer confronted their illness with optimism and positivity. This is consistent with the findings of Folkman and Lazarus (1988) who state that planful problem-solving is a healthy emotional condition which reduces stress levels and increases feelings of optimism. An individual is more likely to be optimistic when approaching and dealing proactively with the problem that is causing the stress (Folkman & Lazarus, 1988).

A positive attitude is a form of planful problem-solving. The women with breast cancer in this study reported that they approached their illness with optimism and attempted to start thinking positively, and to laugh. They also felt that this approach would increase their chances of recovery. This is confirmed by Folkman and Lazarus (1988), who show that planful problem solving produces healthy person-to-environment relationships, which in turn lead to positive emotional responses.

Gurung (2006) concluded that approaching a problem with optimism results in better health outcomes. This is supported by Carver and Scheier (1990) in their study of self-regulation: they found that women who are fearful of the outcome of a biopsy are more likely to show symptoms of anxiety; while those who are optimistic are less anxious. These findings are consistent with the responses of participants in this study, and confirm that a positive attitude is essential when dealing with a breast cancer diagnosis.

Positivity and optimism can be linked to the theoretical framework of Lazarus and Folkman (1984), who note that there are two kinds of appraisals, primary and secondary. Primary appraisals describe the extent of a threat or challenge, while in secondary appraisals the individual evaluates the changes and her ability to control the situation (Folkman and Lazarus, 1984). In this study, the participants adopted a positive and optimistic approach to their breast cancer diagnosis by finally accepting it. Although this was not the case with the participants in this study, those who approach their diagnosis negatively are more likely to experience harm, threat and challenges. In essence, what these examples show is that when the patient has a positive attitude, then anxiety levels will decrease. If an individual lacks the resources to do this, stress levels will increase.

6.6.3 Acceptance



The participants in this study stated that the only way in which they could move on with their lives and cope with the diagnosis was through acceptance. Acceptance as a method of coping with breast cancer implies the realisation, recognition and acknowledgement that one has breast cancer. A longitudinal study of early-stage breast cancer has revealed that a positive approach to the illness is associated to acceptance of the illness and lower levels of stress (Classen *et al.*, 1996).

According to Stanton *et al.*, (2002), acceptance is recognised as coping mechanism by women who have just found out that they have breast cancer. This finding supports the emphasis placed on acceptance by many of the participants in this study.

Acceptance of the breast cancer diagnosis gave the participants a reason to be proactive and go for the necessary treatments in order to speed up their recovery. The

optimism of the study's participants enabled them to approach their breast cancer positively. This suggests that there is a link between optimism and acceptance: in order for women with breast cancer to be optimistic, they first need to accept their diagnoses.

The following example may clarify this. Imagine a pessimistic woman diagnosed with breast cancer. The chances of this woman accepting her diagnosis are very slim. But then imagine a woman with optimism. The chances of this woman accepting her diagnosis are much greater. The research findings suggest that acceptance will not be effective without optimism, and that pessimism is not compatible with acceptance. This is because it is very unlikely that a woman with a negative approach to breast cancer will immediately accept her illness.

According to Stanton *et al.* (2002), women in the initial stages of cancer who accepted their diagnosis had a greater chance of recovering and adjusting; those who only accepted their diagnosis later on did not have the same results. Acceptance is understood by Shapiro *et al.* (2001) as a way of being in control. Shapiro, Schwartz and Astin (1996) state that the more control an individual has, the better the outcome (Shapiro *et al.*, 1996). This links with the ability of women with breast cancer to be assertive and accepting of their diagnoses; this results in favourable psychosocial adaptation (Astin *et al.*, 1999).

A further finding relates to the fact that most of the participants were religious. The implication is that there is a relation between spirituality and acceptance. This is supported by Nairn and Merluzzi (2003), who state that cancer patients who relied on

God as a method of coping had a better chance of achieving acceptance, optimism and self-esteem.

6.6.4 Hope

This study shows that women with breast cancer relied on hope as a method of coping. Obayuwana and Carter (1982) state that hope is the state of mind which results in ego strength. The truth of this becomes evident if one considers the psychological effect of a breast cancer diagnosis, and the need to remain hopeful. A previous example has shown that hope and optimism are closely linked. Snyder *et al.* (1999) support this by suggesting that hope provides an individual with the drive and the belief that they can achieve anything.

A study of early breast cancer has found that a fighting spirit reduces anxiety (Classen *et al.*, 1996). The advantage of hope is that it places less strain on the participant's emotions and feelings. Obayuwana *et al.* (1982) agree, stating that hope can reduce anxiety, thereby by allowing the person to cope better with her illness.

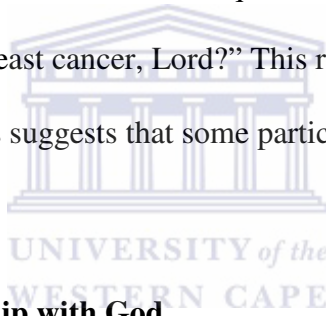
Snyder *et al.* (1999) confirm that individuals with hope are more determined to achieve their goals. The goal of a woman with breast cancer is to recover completely by going for her treatments. She understands that completing the course of treatment is a necessary part of the recovery process.

6.6.5 Denial

The evidence suggests that shock is a form of denial. Classen *et al.* (1996: 435) provide an example of this from a patient diagnosed with cancer: "I really don't believe that I have cancer". The participants in this study stated that they had never

expressed any kind of denial: they accepted that they had cancer. However, Kübler-Ross and Kessler (2005) suggests that shock is closely linked to denial, and that one may be in denial without knowing it.

Denial is in fact a common response to a breast cancer diagnosis. Heishman (1999) reports that rural women used denial as a method of coping. Here denial means not believing that you have breast cancer. According to Kübler- Ross and Kessler (2005) denial assists patients to cope and may take the form of form of questioning reality. Examples of denialist questions are, “Is this true?” and “Is this really happening to me?” (Kübler- Ross & Kessler, 2005). Some of the responses by the participants in this study suggested an element of denial in the questions they posed to God, such as, “Why did you give me this breast cancer, Lord?” This resembles the question, “Is this really happening to me?” This suggests that some participants did not recognise that they were in denial.



6.6.6 A spiritual relationship with God

The women in this study reported that spirituality was an important part of their coping strategy. If this is true, one would expect other studies to confirm this. The link between spirituality and health has been explored by Koenig, McCullough and Larson (2001), who confirm that attending church on a regular basis is associated with an increase in social involvement: that is, church attendance facilitates access to support networks within the church. This finding by was confirmed by participants in this study who reported that they regarded the church as ‘family’. One participant stated that her pastor and his wife were very supportive, and invited her to prayer meetings. Such participation in the church-related activities meant that this patient was

surrounded by positive energy in the form of these support groups. Involvement in prayer meetings also helped the participants to acknowledge that there were people who cared for them. It meant that they did not have to try and cope alone.

These participants believed that their health and ability to cope improved as a result of their spiritual relationship with God. This can be linked to findings from Matthews and Larson (1995), who confirm that in the 200 studies which they reviewed, there was a positive relationship between spirituality and coping. Some women gained inner strength and their relationship with God grew stronger and closer. This gave these women “a sense of control, comfort, ability to find meaning, intimacy and belonging” (Stanton *et al.*, 2002). Some felt that God was responsible for them having breast cancer. This confirms Doyle’s (1992) finding that a diagnosis of cancer is often regarded as punishment from God by those who felt they had been disobedient to Him.

The following responses from participants were noted in this study: (i) blaming God; (ii) bargaining with God; and (iii) questioning God. Koenig and Pargament (1998) found that some people experience what may be called ‘negative religious coping’ by regarding their illness as a punishment from God. Some of the participants in this study blamed God for their breast cancer. This usually happened in response to the initial diagnosis, and faded as the participant received treatment.

Bargaining with God was used as a coping mechanism used by participants in this study. This is linked to Kübler-Ross’s (1969) “Five Stages of Dying”, and corresponds to the third stage of the dying process. It is difficult to ascertain at what point the participants resorted to this, but it did occur as a coping strategy. The plea

usually takes the form of a request to God to relieve pain or remove the breast cancer. These plea bargains were directed to God, a finding which is supported by Kübler-Ross (1969), who mentions that most plea bargains involve God. This suggests that the participants had faith in God and that their beliefs were strong. According to Kübler-Ross (1969) and the “Five Stages of Dying”, the dying cancer patient wants relief from the pain and asks God to intervene, in exchange for promises of good behaviour. However, this suggests that the participants were bargaining for more time to live. This points to a negative feature of this reliance on spirituality, namely, a questioning of God. Some of the participants questioned God about their health status, wanting to know if this was a punishment for something they had done wrong, or wanting to know why God chose them to have breast cancer, and not someone else.

6.7 Limitations of the study

It should be emphasised that there were limitations to this study. One limitation was that I should have specified among the criteria for selecting participants, that their first language was to be English (and not just that they could speak English). Alternatively, I should have made arrangements for an interpreter. However, I only encountered a language barrier with one woman whose first language was isiXhosa. She struggled to understand what I was saying. I tried my best to simplify the questions, as well as to provide examples and explanations, she still struggled to understand. The other participants whose language was not English, understood the questions and answered them to the best of their ability.

Another limitation related to instances when, as the interviewer, I had to ask supplementary questions, especially when the patients responded with a simple ‘yes’

or 'no'. The reason for this was that some patients were not giving me adequate answers. They may not have understood the questions, even when these were simplified.

6.8 Recommendations

The following recommendations are made, based on the findings of this study.

1. The women with breast cancer showed that they understood the information conveyed by the physicians. It is recommended that in future physicians, both locally and internationally, should follow in the footsteps of the medical staff at this public hospital, where communication with patients was considered a priority. This will enable to the establishment of healthy relationships between physician and patient.
2. The physicians in the public hospital's Oncology Clinic demonstrated a professional work ethic in terms of their role, their performance and the skills when they utilised when communicating with their patients. It is recommended that physicians who lack the necessary communicative skills should embark on a course of training to ensure that they gain the necessary insights and skills.
3. Some participants regarded their breast cancer journey as "educational". This indicates a desire to gain knowledge. It is recommended that if this was indeed a learning experience for these women, then this should be included in literature, such as pamphlets, and should be made available in hospital waiting rooms so that other women with breast cancer might benefit.

4. The main objective of this study was to understand the role played by the communication of information from physician to patient. It is imperative that the patient should understand what breast cancer is, and should be able to deal with the illness. Cancer support organisations should distribute pamphlets and other literature on breast cancer that are easy to read and understand, and are suited to the needs of the many patients who do not understand medical terminology.
5. At least two participants complained of poor service from social workers. One social worker was not suited to that kind of work, while the other participant simply had a bad experience with a social worker. It is recommended that at the initial consultation, when informing the patient of her breast cancer diagnosis, the physician should recommend the services of both a primary social worker and an alternative social worker, in case things do not work out.
6. Further research on breast cancer is needed, especially with regard to communication and coping strategies.
7. Physicians and medical staff should take cognisance of the fact that women with breast cancer are psychologically affected by the diagnosis. They should recommend that they make use of the counselling services provided by counsellors, psychologists or social workers. This will help to alleviate their psychological distress.
8. Oncology Clinics should provide literature about breast cancer, as this would help to educate women in general about the illness.

9. Support groups are important as they give the women with breast cancer the opportunity to share their experiences with other women who have experienced the same illness. It is recommended that Oncology Clinics establish support groups for women with breast cancer to assist them to deal with breast cancer as well as to allow them to share their experiences.
10. Very little research on the influence of communication on the coping strategies of women with breast cancer is available; future research should attempt to focus on this area.

6.9 Conclusion

The aim of the study was to describe the role of communication between physicians and their breast cancer patients, and to explain the coping strategies used by women with stage I-III breast cancer. It attempted to meet the following objectives:

- (i) to explore and describe the role of communication between physician and women who have been diagnosed with stage I-III breast cancer;
- (ii) to identify the coping mechanisms used by women who have been diagnosed with stage I-III breast cancer.

To achieve these objectives, the study used the Stress and Coping theory of Folkman and Lazarus and linked this to other studies.

This study confirmed that the way in which a breast cancer diagnosis is communicated influences the coping strategies of women with stage I-III breast cancer. Women who understood their diagnosis as a result of physician's use of clear and understandable language were more likely to adopt to effective methods of coping

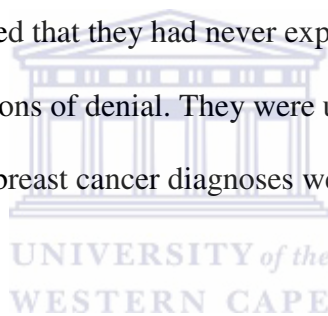
with the breast cancer. The participants in this study did not have any difficulty in understanding the information communicated by their physicians as they used clear and understandable language to explain their diagnoses. This enabled the participants to cope more effectively with their diagnoses.

However, six significant points emerged in the course of this study.

(i) An issue that emerged from the responses of participants was the importance of the transfer of information from physician to patient during the consultation process. It was established that effective communication played an important role in enabling the participants to cope with their diagnoses. The sharing of information in a clear and understanding manner helps women to cope more effectively. If the patient understands the information being conveyed, this releases a positive energy which assists her to cope with the diagnosis. In contrast, if the physicians make use of medical terminology in their explanations, this would influence the patient in a negative way. Poor communication often causes the patient to misinterpret the information, thereby causing anxiety and confusion. In this study physicians communicated effectively with their patients. In general, they understood each other.

(ii) The fact that these women with breast cancer understood the information imparted by their physicians made it easier for them to adopt appropriate methods of coping. Consistent with other studies, five types of coping were strongly associated with women's responses during the diagnostic phase of stage I-III breast cancer. These were: social support, spirituality, optimism, acceptance, denial and hope. All these coping mechanisms helped the participants to deal with the distressing news that they had breast cancer; these strategies also helped them to cope with the treatment.

Coping was viewed as having twelve facets: planning, acceptance, denial, use of social support, positive reframing, active coping, suppression of competing activities, restraint, religion, behavioural disengagement, use of humour and self-distraction (Deimling, Wagner, Bowman, Sterns, Kerchner & Kahana, 2006). Their study of breast cancer patients reveals that acceptance, positive reframing and religion are the most commonly used coping mechanisms, while denial and behavioural disengagement were the least used (Deimling *et al.*, 2006). This finding is consistent with the results of this study and with the coping mechanisms used by the participants. It was found that acceptance, optimism and spirituality were common coping mechanisms, while denial also featured as a possible coping mechanism. Although the participants stated that they had never experienced denial, some their responses resembled descriptions of denial. They were unaware that some of their feelings and responses to the breast cancer diagnoses were in fact consistent with aspects of denial.



(iii) *Social Support* was a significant coping strategy. Family support was identified as important by all the participants. In particular, the participants stressed the importance of support from partners, husbands, friends, church members, and members of their immediate or extended families. *Spirituality* was also identified as an important coping mechanism by the participants. It gave them a sense of control and comfort and the ability to find meaning. The participants relied on such things as prayer, faith and repentance. Spirituality was seen as a component of the healing process.

Optimism or a *positive attitude* assisted the participants to deal with their breast cancer. This was associated with a fighting spirit and helped to reduce hopelessness.

Acceptance was most frequently endorsed as a coping mechanism by participants who

had recently been diagnosed with breast cancer. Acceptance helped to inculcate a spirit of positivity and confidence in the participants. *Hope for recovery* was also an important coping mechanism throughout the breast cancer journey. The participants relied on hope and the intention to get better. Women with stage I-III breast cancer used similar coping mechanisms to deal with their diagnosis.

(iv) The participants' overall perception of their physicians influenced their health in a positive way. Patients' perceptions of the physicians showed that they provided emotional support during consultations. High levels of patient satisfaction with physicians were reported by the participants: they understood the information imparted by the physicians and they were able to ask questions when necessary.

Patient satisfaction has been associated with the following behaviours on the part of physicians: (i) expressions of warmth and care towards the patients; (ii) information that is conveyed in a manner that takes the patient's background and knowledge into consideration; (iii) willingness on the part of the physician to provide explanations. In general, their responses showed that the participants in this study supported and trusted the physicians.

(v) An important finding of this study was the positive impact of these coping mechanisms on the participants. None of the coping mechanisms influenced the participants' health in a negative way. Stage I-III breast cancer may be considered as the beginning and intermediate phases of the cancer, but the women in this study displayed courage and strength, irrespective of the harmful effects of the treatment.

(vi) Consistent with the theories of Lazarus and Folkman (1984), appraisal and coping processes were associated with the benefits of effective communication between

physician and patient. Although it was not the case with these participants, women who felt less motivated or felt threatened experienced greater anxiety. The participants in this study were optimistic and coped by focusing on the positives. These findings are consistent with Lazarus and Folkman's (1984) theoretical models of adjustment to stress, as well as with findings on primary appraisal and adjustment in breast cancer patients. They support the view that patients' responses to stress are strongly associated with the appraisal of threat, and with their coping strategies.



References

- Adejimola, A.S, Ayenigbara, G.O, & Tunde, O. (2010). Language and health communication strategies towards effective public health communication programmes in Nigeria. *Journal Media and Communication Studies*, 2(5), 111-117.
- Al-azri, M., Al-awisi, H. & Al-Moundhri, M. (2009). Coping with a diagnosis of breast cancer- literature, review, and implications for developing countries. *The Breast Journal*, 15(6), 615-622.
- Aldwin, C.M. (1994). *Stress, coping and development: an integrative perspective*. New York: Guilford.
- Allen, S.M., Petrisek, A.C. & Laliberte, L.L. (2001). Problems in doctor-patient communication: the case of younger women with breast cancer. *Critical Public Health*, 11(1), 39-58.
- American Cancer Society. (2008). *Breast cancer facts and figures 2007-2008*. November 2011.
- [Online]. Available:
<http://www.cancer.org/acs/group/content/@nho/document/bcffinalpdf.pdf>
- Arora, N. K. (2003). Interacting with cancer patients: the significance of physician's communication behaviour. *Social Science Medicine*, 57, 791-806.
- Astin, J.A., Anton-Culver, H., Schwartz, C.E., Shapiro, D., McQuade, J., Breuer, A.M., Taylor, T.H., Lee, H. & Kurosaki, T. (1999). Sense of control and

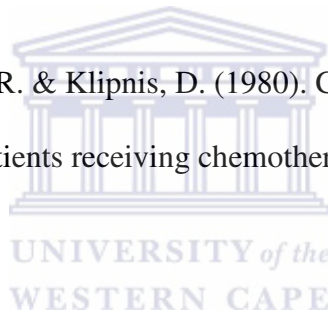
adjustment to breast cancer: The importance of balancing control coping styles.
Journal of Behavioural Medicine, 25, 101–109.

Babbie, E.R. (2001). *The Practice of Social Research*. Cape Town: Oxford University Press.

Back, A.L., Arnold, R.M., Baile, W.F., Tulsky, J.A. & Fryer-Edwards, K. (2005).
Approaching difficult communication tasks in oncology. *Cancer Journal for Clinicians*, 55, 164-177.

Barracough, J. (2000). *Cancer and emotion: a practical guide to psycho-oncology*.
London: Wiley.

Bean, G., Cooper, S., Alpert, R. & Klipnis, D. (1980). Coping mechanisms of cancer
patients: a study of 33 patients receiving chemotherapy. *Cancer Journal for Clinicians*, 30, 256-259.



Bennett, K.K., Compas, B.E., Beckjord, E. & Glinder, J.G. (2005). Self-blame and
distress among women with newly diagnosed breast cancer. *Journal of Behavioural Medicine*, 28, 4, 313-323.

Berger, P. & Luckmann, T. (1967). *The Social Construction of Reality: A Treatise on the Sociology of Knowledge*. London: Penguin.

Bettencourt, B.A., Schlegel, R.J., Talley, A.E., and Molix, L.A. (2007). The breast
cancer experience of rural women: a literature review. *Psycho-Oncology*, 16, 875-887.

Boehmke, M.M. & Dickerson, S.S. (2006). The diagnosis of breast cancer: transition from health to illness. *Oncology Nursing Forum*, 33(6), 1121.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. November 2011. [Online]. Available: <http://www.QualResearchPsych.com>

Breast Cancer Online. A.D.A.M. (2009). *Breast Cancer*. 1800755(6).

Carmack, H.J. (2010). The communicative power of the checklist. A publication for the National Communication Association: *Communication Currents* 5(1). [Online]. Available: <http://www.natcom.org/CommCurrentsArticle.aspx?id=724>

Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International Journal of Behavioural Medicine*, 4, 91–100.



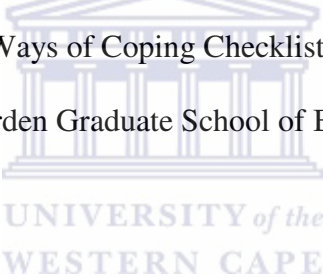
Carver, C.S. & Scheier, M.F. (1990). Origins and functions of positive and negative affect: A control-process view. *Psychological Review*, 97, 19-35.

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared decision-making model. *Social Science Medicine*, 49, 651-661.

Classen, C., Koopman, C., Angell, K. & Spiegel, D. (1996). Coping styles associated with psychological adjustment to advanced breast cancer. *Health Psychology*, 15(6), 434-437.

- Cline, R.J. (1983). Interpersonal communication skills for enhancing physician-patient relationships. *Maryland State Medical Journal*, 32, 273.
- Clinical Reference Systems. (2008). *Staging of cancer*. Health Source- Consumer Edition.
- Collie, K., Wong, P., Tilston, J., Butler, L.D., Turner- Cobb, J., Kreshka, M.A., Parsons, R., Graddy, K., Cheasty, J.D. & Koopman, C. (2005). Self efficacy, coping and difficulties interacting with health care professionals among women living with breast cancer in rural communities. *Psycho-Oncology* 14, 901-912.
- Commerford, M.C., Gular, E., Orr, D.A., Reznikof, M. & O'Dowd, M.A. (1994). Coping and psychological distress in women with HIV/AIDS. *Journal of Community Psychology*, 22, 224-230.
- Communication (2008). In *Key Concepts in Nursing*. Retrieved on 28 July 2011 from <http://www.credoreference.com.ezproxy.uwc.ac.za/entry/sageuknurs/communication>
- Concise Oxford English Dictionary. (2004). 11th Edition: Oxford University Press.
- Conlin, A.K. & Seidman, A.D. (2007). Taxanes in breast cancer: an update. *Current Oncology Reports* 9, 22-30.
- Coping mechanisms (2009). In *The Penguin Dictionary of Psychology*. Retrieved on 28 July 2011 from http://www.credoreference.com.ezproxy.uwc.ac.za/entry/penguinpsyc/coping_strategies

- Culver, J.L., Arena, P.L., Antoni, M.H. & Carver C.S. (2002). Coping and distress among women under treatment for early stage breast cancer: Comparing Africans, Americans, Hispanics and non-Hispanic whites. *Psycho-Oncology* 11, 495–504.
- Davidson, R., & Mills, M.E. (2005). Cancer patients satisfaction with communication, information and quality care in a UK region. *European Journal of Cancer Care*, 14, 83-90.
- Davis, T.C., Williams, M.V., Marin, E., Parker, R.M. & Glass, J. (2002). Health literacy and cancer communication. *A Cancer Journal for Clinicians*, 52 (3) 134.
- Debanjan, B. (2010). Mass communication: Trends, traits and theories. *Journal of Media and Communication Studies*, 2(5), 118-121.
- Deimling, G.T., Wagner, L.J., Bowman, K.F., Sterns, F., Kerchner, H. & K. Kahana, B. (2006). Coping among older adult, long term cancer survivors. *Psycho-Oncology* 15, 143-159.
- Devlen, J., Maguire, P., Phillips, P. & Crowther, D. (1987). Prospective study. *British Medical Journal*, 295, 955-957.
- Doak, C., Doak, L. & Friedell, B. (1998). Improving comprehension for cancer patients with low literacy skills: strategies for clinicians. *Cancer Journal for Clinicians*, 48, 151-162.
- Doak, L.G., Doak, C.C. & Meade, C.D. (1996). Strategies to improve cancer education materials. *Oncology Nursing Forum*, 23, 1305-1312.

- Dowsett, S.M., Saul, J.L., Butow, P.N., Dunn, S.M., Boyer, M.J., Findlow, R., & Dunsmore, J. (2000). Communication styles in the cancer consultation- preferences for a patient-centered approach. *Psycho-Oncology* 9, 147-156.
- Doyle, D. (1992). Have we looked beyond the physical and psychosocial? *Journal of Pain and Symptom Management*, 7, 302–311.
- Dunkel-Schetter, C., Feinstein, L.G., Taylor, S.E, & Falke, R.L. (1992). Patterns with coping with cancer. *Health Psychology*, 11, 79-87.
- Edwards, J.R. & Baglion A.J. (1993). The measurement of coping with stress: Construct validity of the Ways of Coping Checklist and the Cybernic Coping Scale. *Work & Stress*. Darden Graduate School of Business Administration: University of Virginia.
- 
- Eide, H., Graugaard, P., Holgersen, K. & Finset, A. (2003). Physician communication in different phases of a consultation at an oncology outpatient clinic related to patient satisfaction. *Patient Education and Counselling*, 51, 259-266.
- Endler, N.S. & Parker, J.D.A. (1990). Multi-dimensional assessment of coping: a critical evaluation. *Journal of Personality and Social Psychology*, 58, 844-854.
- Engel, G.L. (1967). A psychological setting of somatic disease: The "giving-up-given-up" complex. *P. R. Social Medicine*, 60, 553.

- Epping-Jordan, J.E., Compas, B.E. & Howell, D.C. (1994). Predictors of cancer progression in young adult men and women: Avoidance, intrusive thoughts, and psychological symptoms. *Health Psychology, 13*, 539–547.
- Epstein, R. M., Alper, B.S., & Quill, T.E. (2004). Communicating evidence for participatory decision making. *Journal of American Medical Association, 291*, 2359.
- Fallowfield, L. (1993). Giving sad and bad news. *Lancet, 341*, 478-480.
- Fallowfield, L.J. (2008). Treatment decision-making in breast cancer: the patient-doctor relationship. *Breast Cancer Research Treatment, 112*, 5-13.
- Folkman, S. (1992). Making the case for coping. In *Personal Coping: Theory, Research and Application*. Carpenter, B. (Ed.) Westport, CT: Praeger.
- Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour, 21*, 219-239.
- Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A. & Gruen, R.J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology, 50* (5) 992-1003.
- Folkman, S., Lazarus, R.S., Gruen, R.J. & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology, 50* (3) 571-579.
- Folkman, S. & Lazarus, R.S. (1988). Coping as a mediator of emotion. *Journal of Social and Personality Psychology, 54*, 3, 466-475.

- Friedman, L.C., Kalidas, M., Elledge, R., Chang, J., Romero, C., Hussein, I., Dulay, M.F. & Liscum, K. (2006). Optimism, social support and psychosocial functioning among women with breast cancer. *Psycho-Oncology* 2006(15), 595–603.
- Fontana, A. & Frey, J.H. (2000). The Interview: From Structured Questions to Negotiated Text. In N.K. Denzin & Y.S. Lincoln (Eds.) *The Handbook of Qualitative Research*. California: Sage Publications.
- Ford, S., Fallowfield, L. & Lewis, S. (1996). Doctor-patient interactions in oncology. *Social Science and Medicine*, 42(11), 1511-1519.
- Fujimori, M., Parker, P.A., Akechi, T., Sakano, Y., Baile, W.F., & Uchitomi, Y. (2007). Japanese cancer patients' communication style preferences when receiving bad news. *Psycho-Oncology*, 16, 617-625.
- Gall, T.L. & Cornblat, M.W. (2002). Breast cancer survivors give voice: A qualitative analysis of spiritual factors in long-term adjustment. *Psycho-Oncology*, 11, 524–535.
- Gattellari, M., Voigt, K.J., Butow, P.N., & Tattersall, M.H. (2002). When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *Journal of Clinical Oncology*, 20, 503-513.
- Gergen, K. & Gergen, M. (1991) Toward reflexive methodologies. In Steier, F. (Ed.) *Research and Reflexivity*. Newbury Park: Sage Publications. pp. 76-95.
- Guba, G. E. & Lincoln, Y. S. (1985). *Naturalistic Inquiry*. London: Sage Publications.

- Gurung, R.A.R. (2006). *Health Psychology: A cultural approach*. Greenbay: Thompson Wadsworth.
- Hagerty, R.G., Butow, P.N., Ellis, P.M., Lobb, E.A., Pendlebury, S.E., & Leighl, N et al. (2005). Communicating with realism and hope: incurable cancer patients views on the disclosure of the prognosis. *Journal of Clinical Oncology*, 23, 1278-1288.
- Hagihara, A. & Tarumi, K. (2006). Doctor and patient perceptions of the level of doctor explanation and quality of patient- doctor communication. *Scandinavian Journal of Caring Science*, 20, 143-150.
- Hall, S. (2003). *Representation: Cultural Representation and Signifying Practices*. London: Sage Publications/ The Open University.
- Hall, I. & Hall, D. (2004). *Evaluation and Social Research. Introducing small-scale practice*. New York: Palgrave Macmillan.
- Hamrick, M. & Diefenbach, M. (2006). Religion and spirituality among patients with localized prostate cancer. *Palliative and Supportive Care*, 4, 345–355.
- Heishman A. (1999). *Get rid of it and don't dwell on it: explanatory models and experiences of breast cancer by rural women*. Georgia State University: (Unpublished Dissertation).
- Held, B. (1997). The real meaning of constructivism. *Journal of Constructivist Psychology*, 8, 305-315.

Henning, E. (2004). *Finding your way in qualitative research*. Pretoria: Van Schaik Publishers.

Huysamen, G.K. (1994). *Methodology for the social and behavioural sciences*.

Bloemfontein: South Book Publishers

Hybels, S. & Weaver, R.L. (2004). *Communicating effectively*. (2nd ed) New York:

McGraw-Hill.

Iseron, K.V. (2001). The (partially) educated patient: a new paradigm. *Cambridge*

Quarterly of Healthcare Ethics, 10, 154-156.

Juhn, G., M.T.P.W., Eltz, D.R., Stacy, K.A. (2007). Breast Cancer Treatment.

[Online]. Available: http://www.healthcentral.com/breast-cancer/chemo-000006_7-145_2.html



Kenny, D. A., Veldhuijzen, W., Weijden, T., LeBlanc, A., Lockyer, J., Legare, F. &

Campbell, C. (2010). Interpersonal perception in the context of doctor-patient relationships: A dyadic analysis of doctor-patient communication. *Social Science and Medicine*, 70, 763-768.

Koenig, H. G., McCullough, M. E. & Larson, D. B. (2001). *Handbook of religion and health*. Oxford: Oxford University Press.

Koenig, H., & Pargament, K. (1998). Religious coping and health status in medically ill hospitalised older adults. *Journal of Nervous and Mental Disease*, 18, 513-521.

Kübler- Ross, E. (1969). *On death and dying*. London: Tavistock Publications.

- Kübler- Ross, E. & Kessler, D. (2005). *On grief and grieving: finding the meaning of grieve through the five stages*. New York: Scribner. pp 11-12.
- Kvale, S. (1996). *Interviews: An Introduction to Qualitative Research Interviewing*. California: Sage Publishers.
- Kyngas, H., Mikkonen. & Nousiainen, E.M. (2001). Coping with the onset of cancer: coping strategies and resources of young people with cancer. *European Journal of Cancer Care*, 10, 6-11.
- Laposa, J.M., Lynn, E., Fullerton, R.N. & Vancouver, B.C. (2003). Workstress and Post-traumatic Stress Disorder in ED Nurses/Personnel. *Journal of Emergency Nursing*. 23-28.
- Lazarus, R. (1990). Theory based stress management. *Psychological Inquiry*, 1(1), 3-13.
- Lazarus, R. S. (1993). From psychological stress to emotions: a history of changing outlooks. *Annual Review of Psychology*, 44, 1-21.
- Lazarus, R.S. & Folkman, S. (1984). Coping and adaptation. In Gentry, W.D. (Ed.) *The Handbook of Behavioural Medicine*. New York: Guilford. pp. 282-325.
- Lerman, C., Daly, M., Walsh, W.P. (1993). Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer*, 72, 2612-2620.



- Li, J. & Lambert, V.A. (2007). Coping strategies and predictors of well-being in women with breast cancer in the People's Republic of China. *Nursing and Health Sciences*, 9, 199-204.
- List, M.A. Lacey, L. & Hopkins, E. (1994). The involvement of low literate elderly in the development and distribution of cancer screening materials. *Family Community Health*, 17, 42-55.
- Linver, M.N. (2009). Delivering bad news: a vital skill for professionals involved in breast cancer care. *Breast Cancer Online*, 12(2), 1-3.
- Mager, W.M. & Andrykowski, M.A. (2002). Communication in the cancer 'bad news' consultation: patient perceptions and psychological adjustment. *Psycho-Oncology*, 11, 35-46.
- Mays, N. & Pope, C. (2000). Qualitative research in health care: assessing quality in qualitative research education and debate. *British Medical Journal*, 320, 50-2.
- Matthews, E.E. & Cook, P.F. (2009). Relationship among optimism, wellbeing, self-transcendence, coping, and social support in women during treatment for breast cancer. *Psycho-Oncology*, 18, 716-726.
- Mathews, H., Lannin, D. & Mitchell, J. (1994). Coming to terms with advanced breast cancer: black women's narratives from Eastern North Carolina. *Social Science and Medicine*, 38, 789-800.
- Matthews, D.A. & Larson, D.B. (1995). *The faith factor: An annotated bibliography of clinical research on spiritual subjects* (3). Rockville, MD: National Institute for Healthcare Research.

- Maxwell M. (1969). Elisabeth Kübler- Ross Revisited: A personal account of a life and transitions workshop. *Oncology Nursing Forum*, 6, 26-7.
- McGrath, P., Patterson, C., Yates, P., Treloar, S., Oldenburg B. & Loos, C. (1999). A study of post-diagnosis breast cancer concerns for women living in rural and remote Queensland. Part II: Support Issues. *Austin Journal of Rural Health*, 7, 43-52.
- Medical Research Council. (2000). [Online]. Available:
<http://www.mrc.ac.za/bod/faqcancer.htm>
- Merriman, B., Ades, T. & Seffrin, J. (2002). Health literacy in the information age: communicating cancer information to patients and families. *Cancer Journal for Clinicians*, 52, 130.
- Meyerowitz, B.E. (1983). Post-mastectomy coping strategies and quality-of-life. *Health Psychology*, 2, 117-132.
- Miedema, B., Hamilton, R. & Easley, J. (2007). From invincibility to normalcy: coping strategies of young adults during the cancer journey. Cambridge University Press, (5), 41-49.
- Molete, M. (1999). National Cancer Registry 1999. [Online]. Available:
http://givengain.com/cgi-bin/giga.cgi?cmd=print_article&news_id=31937
- Nairn, R.C. & Merluzzi, T.V. (2003). The role of religious coping in adjustment to cancer. *Psycho-Oncology*, 12, 428-441.

- National Breast Cancer Foundation (2009). Stages of breast cancer. [Online].
Available: <http://www.nationalbreastcancer.org/About-Breast-Cancer/Stages.aspx>
- National Patient Safety Foundation at the AMA: Public Opinion of Patient Safety
Issues, Louis Harris & Associates. (September, 1997). [Online]. Available:
<http://www.wrongdiagnosis.com/mistakes/common.htm?ktrack=kcplink>
[Online]. Available: <http://www.npsf.org/pdf/r/1997survey.pdf>
- Nightingale, D.J. & Cromby, J.C. (Eds.) (1999). *Social Constructionist Psychology: A critical assumption of theory and practice*. Buckingham: University Press.
- Obayuwana, A.O. & Carter, A.L. (1982). Original communications: anatomy of hope.
Journal of the National Medical Association, 74, 3.
- Oman, D. & Thoresen, C.E. (2005). Do religion and spirituality influence health? In
Paloutzian, R.F. & Park, C.L. (Eds.) *Handbook of the psychology of religion and
spirituality*. New York: The Guilford Press. pp.435–459
- Parker, I. (1998). Realism, relativism, and critique in psychology. In Parker, I. (Ed.)
Social Constructionism, Discourse and Realism. Newbury Park; California: Sage
Publications. pp. 1-9.
- Patient. (2001). In *Pharmaceutical Medicine Dictionary*. Retrieved on 28 July 2011
from <http://www.credoreference.com.ezproxy.uwc.ac.za/entry/pmd/patient>
- Peacock, J. (2002). Treatment for Breast Cancer. *Breast Cancer* (0-7368-1028-5).
Health Source: Consumer Edition.

Physician. (2003). In *Webster's New World™ Medical Dictionary*. Retrieved on 28 July 2011 from

<http://www.credoreference.com.ezproxy.uwc.ac.za/entry/webstermed/physician>

Pieterse, K., van Dooren, S., Seynaeve, C., Bartels, C.C.M., Rijnsburger, A.J., de Koning, S.J., Klijn, J.G.M., van Elderen, T., Tibben, A. & Duivenvoorden, H.J. (2007). Passive coping and psychological distress in women adhering to regular breast cancer surveillance. *Psycho-Oncology*, *16*, 851–858.

Reddy, K. B. (2011). Triple-negative breast cancers: an updated review on treatment options. *Current Oncology*, *18* (4).

Roberts, C.S., Cox, C.E., Reintgen, D.S., Baile, W.F. & Gibertini, M. (1994). Influence of physician communication on newly diagnosed breast patients' psychological adjustment and decision-making. *Cancer*, *74*(1), 336–341.

Rowland-Morin, P.A. & Carroll, J.G. (1990). Verbal communication skills and patient satisfaction: a study of doctor-patient interviews. *Evaluation and the Health Professions*, *13*, 168-185.

Ryan, H., Schofield, P., Cockburn, J., Butow, P., Tattersall, M., Turner, J., & Girgis, A et al. (2005). How to recognise and manage psychological distress in cancer patients. *European Journal of Cancer Care*, *14*, 7-15.

Samora, J., Saunders, L. & Larson, R. (1961). Medical vocabulary knowledge among hospital patients. *Journal of Health and Human Behaviour*, 83-92.

Schou, I., Ekeberg, O., Sandvik, L., Hjermland, M.J. & Ruland, C.M. (2005). Multiple predictors of health-related quality of life in early stage breast cancer. Data from

a year follow-up study compared with the general population. *Quality of Life Research, 14*, 1813–1823.

Schofield, P. E., Butow, P. N., Thompson, J. F., Tattersall, M.H.N., Beeney, L. J., & Dunn, S. M. (2003). Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology, 14*, 48-56.

Selye, H. (1955). Stress and disease. *American Association for the Advancement of Science, (122)*, 625-631.

Shapiro, D.H., Schwartz, C.E., & Astin, J. (1996). Controlling ourselves, controlling our world: Psychology's role in understanding positive and negative consequences of seeking and gaining control. *American Psychologist, 51(12)*, 1213-1230.

Shapiro, S.L., Lopez, A.M., Swartz, G.E., Bootzin, R., Figueredo, A.J., Braden, C.J. & Kurker, S.F. (2001). Quality of life and breast cancer: relationship to psychosocial variables. *Journal of Clinical Psychology, 57(4)*, 501-519.

Shaw, Alan (1994). Neighborhood Networking and Community Building. *Ties That Bind: Building Community Networks*. Steve Cisler (Ed.) May 4-6, Cupertino, CA.

Shaw, A., Ibrahim, S., Reid, F., Ussher, M. & Rowlands, G. (2008). Patients' perspectives of doctor-patient relationship and information giving across a range of literacy levels. *Patient Education and Counselling, 75*, 114-120.

Siminoff, L.A., Ravdin, P., Colabianchi, N. & Saunders-Sturm, C.M. (2000).

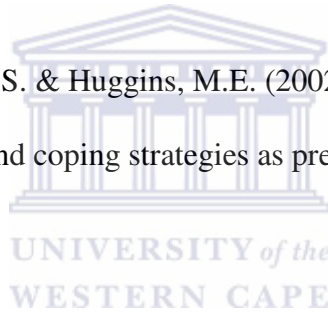
Doctor- patient communication patterns in breast cancer adjuvant therapy discussions. *Health Expectations*, 3, 26-36.

Snyder, C.R., Cheavens, J., Michael, S.T. (1999). Hoping. In Snyder, C.R. (Ed.) *Coping: The Psychology of What Works*. New York: Oxford University Press.

Sprah, L. & Sostaric, M. (2004). Psychosocial coping strategies in cancer patients. *Radiology and Oncology*, 38(1), 35-42.

Stanton, A.L., Danoff- Burg, S. & Cameron, C.L. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting Clinical Psychology*, 68, 875–882.

Stanton, A., L., Danoff-Burg, S. & Huggins, M.E. (2002). The first year after breast cancer diagnosis: Hope and coping strategies as predictors of adjustment. *Psycho-Oncology*, 11, 93–102.



Stanton, A.L. & Snider, P.R. (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology*, 12, 16–23.

Stone, A.A. & Neale, J.M. (1984). New measure of daily coping: Development and preliminary results. *Journal of Personality and Social Psychology*, 46, 892-906.

Street, R.L., Gordon, H. & Haidet, P. (2007). Physicians' communication and perceptions of patients: is it how they look, how they talk, or is it just the doctor? *Social Science and Medicine*, 65, 586-598.

- Street, R.L., Krupat, E., Bell, R.A., Kravitz, R.L. & Haidet, P. (2003). Beliefs about control in the physician- patient relationship: effect on communication in medical encounters. *Journal of General Internal Medicine*, 18(8), 609-616.
- Street, R. L., Makoul, G., Arora, N. K., & Epstein, R.M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counselling*, 74, 295-301.
- Sperber, D. & Wilson, D. (1995). *Relevance: communication and cognition* (2nd ed). USA: Blackwell Publishers.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded Theory procedures and techniques*. Thousand Oaks: Sage Publications.
- Suls, J. & Fletcher, B. (1985). The relative efficacy of avoidant and non-avoidant coping strategies: A meta-analysis. *Health Psychology*, 4, 249-288.
- Sutherland., A.M. (1958). Communication between the doctor and the cancer patient. *A Cancer Journal for Clinicians*, 8, 119-121.
- Sweet, L., Savoie, J., Lemyre, L. (1999). Appraisals, coping and stress in breast cancer screening: A longitudinal investigation of causal structure. *Canadian Journal of Behavioural Sciences*, 31(4), 240-253.
- Tanner, G. & Myers, P. (2002). Secondary-primary care communication: impressions of the quality of consultant communication with specific regard to cancer patients. *Primary Health Care Research and Development*, 3, 23-28.
- Terre Blanche, M. & Durrheim, K. (1999). *Research in Practice: Applied Methods for the Social Sciences*. Cape Town: University of Cape Town Press.

- Thompson, A., Brennan, K., Cox, Gee, J., Harcourt, D., Harris, A., Harvie, M.,
Holen, I., Howell, A., Nicholson, R., Steel, M. & Streuli, C. (2008). Evaluation of
the current knowledge limitations in breast cancer research: a gap analysis. *Breast
Cancer Research*, London.
- Tobin, D.L., Holroyd, K.A., Reynolds, R.V. & Wigal, J.K.(1989). The hierarchal
factor structure of the coping strategies inventory. *Cognitive Therapy and
Research*, 13, 343-361.
- Vorobiof, D.A., Sitas, F. & Vorobiof, G. (2001), Breast cancer incidence in South
Africa. *Journal of Clinical Oncology*, 19(18S), 125-127.
- Vos, M.S. & de Haes, J.C.J.M. (2006). Denial in cancer patients, an explorative
review. *Psycho-Oncology*, 16, 12-25.
- Vos, P.J., Garssen, B., Visser, A.P., Duivenvoorden, H.J. & de Haes, H.C.M.J.
(2004). Early Stage Breast Cancer: Explaining Level of Psychosocial Adjustment
Using Structural Equation Modeling. *Journal of Behavioural Medicine*, 27(6).
- Wegner, D.M., Shortt, J.W., Blake, A.W. & Page, M.S. (1990). The suppression of
exciting thoughts. *Journal of Personality and Social Psychology*, 58, 409-418.
- White, N.J., Given, B.A. & Devoss, D.N. (1996). The advanced practice nurse:
Meeting the information needs of the rural cancer patient. *Journal of Cancer
Education*, 11, 203–209.
- Wiggers, J.H., O'Donovan, K.O., Redman, S & Sanson- Fisher, R.W. (1990). Cancer
patient satisfaction with care. *Cancer*, 66, 610–616.

Wilson, S., Andersen, M. & Meischke, H. (2000). Meeting the needs of rural breast cancer survivors: what still needs to be done? *Journal of Women's Health Gender Based Medicine*, 9, 667–677.

Williams, J.R. (2009). *World Medical Association: Medical ethics manual* (2nd ed). The World Medical Association.

World Health Organisation Geneva. (1993). *Doctor-patient interaction and communication*. Retrieved November 2011

[Online]. Available:

http://whqlibdoc.who.int/hq/1993/WHO_MNH_PSF_93.11.pdf

Zachariae, R., Pedersen, C.G., Jensen, A.B., Ehrnrooth, E., Rossen, P.B., & Von der, M.H. (2003). Association of perceived physician communication style with patient satisfaction, distress, cancer related self-efficacy and perceived control over the disease. *British Journal of Cancer*, 88, 658-665.



Enquiries : Prof. Raymond Abratt
Telephone : (021) – 404-4265
Fax : (021) – 448-5707
E-mail : raymond.abratt@uct.ac.za
Reference :
Date : 27 September 2010

Departement van Gesondheid
Department of Health
ISebe IezeMoilo

Dear Ms Daniels,

I hereby give you permission to recruit 10 patients with Breast Cancer for a questionnaire interview for you study titled: **“The influence of communication between physician and patient influences women’s coping mechanism with the diagnosis of stage I – III breast cancer.”**

I have noted that Ethics permission has been obtained from UWC and that you have listed several corrections to the original proposal.

Please note the following requests:

- Should your work be published or presented, the input of the Radiation Oncology Department be duly acknowledged.
- The study be logged on the Vula table of active studies in L Block. Dr van Wijk will list this for you.

Hoping you well for success with your study.

Sincerely,

Prof. R. P. Abratt
Head of Dept
Division of Radiation Oncology
LD 35, Groote Schuur Hospital
Observatory, Cape Town
7925
South Africa



Groote Schuur Hospital
Private Bag,
Observatory, 7935
Telephone: 404-9111

APPENDIX A

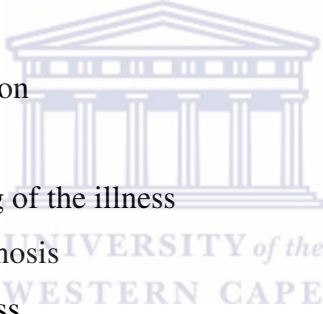
APPENDIX B
PATIENT INFORMATION DOCUMENT

Title of Research Project:

**“Exploring the experiences of patients with breast cancer from diagnosis
through management”**

I, Danielle Kirsty Daniels, a Master’s student at the University of the Western Cape, plan to perform a research study with the above title. I would like to inform you verbally of the purpose of my study, and invite you to participate.

In brief, however, this research study will involve that you agree to be subjected to an interview which will last about 1 hour, and which will involve questions about your:

- 
- 1) Biographical information
 - 2) History of the illness
 - 3) Personal understanding of the illness
 - 4) Experience of the diagnosis
 - 5) Experience of the illness
 - 6) Communication between doctor and patient
 - 7) Support and Coping

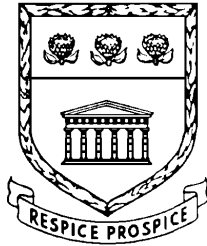
A digital recorder will be used to record the data which will be transcribed afterwards and locked in a safe place at least for seven years. I shall strive to respect and safeguard confidentiality and privacy at all times. Participants will be assured that all interviews will be held in the strictest privacy and that their names will not be disclosed to anyone. Numbers will be used to protect the identities of the participants when results are published. Participants will not receive any payment.

Participant Name: _____ Witness: _____

Signature: _____ Signature: _____

Date: _____ Date: _____

APPENDIX C



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2970

CONSENT FORM

Title of Research Project:

Exploring the experiences of patients with breast cancer from diagnosis through management

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name.....

Participant's signature.....

Witness.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the supervisor:

Supervisor's Name: Dr N Roman

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021) 959-2970

Cell: 082 877 6691

Email: nroman@uwc.ac.za

APPENDIX D

PATIENT # _____

DATA COLLECTION FORM

Of study

“Exploring the experiences of patients with breast cancer from diagnosis
through management”

Age	
Stage of Breast Cancer	
Treatment Chemo/ Radiation	
Race	
Home Language	
Language spoken by doctor when diagnosis was given	
Area	
Highest Education	
Occupation	
Number of children	

DATE : _____

PLACE : _____

PATIENT SIGNATURE : _____

RESEARCHER SIGNATURE : _____

APPENDIX E

INTERVIEW SCHEDULE

1. How did you first become aware of your illness?
2. How did your doctor tell you the first time that you had breast cancer?
3. What was your first reaction when being told that you have breast cancer?
4. How do you feel now after the diagnosis of breast cancer?
5. What has changed in your life since you discovered you have breast cancer?
6. What makes you have breast cancer?
7. How is your mood/s holding up throughout all this?
8. How do you cope with breast cancer?
9. What issues do you struggle with when coping with breast cancer?
10. How has your femininity been affected by breast cancer?
11. How is the relationship between you and the physician?
12. Since the time of being diagnosed with breast cancer, what is your impression of the doctor?
13. How was the information regarding your diagnosis communicated to you?
14. What is your understanding of breast cancer?
15. How do you feel when do not understand what the doctor is saying to you?
16. How does this affect your coping and/or health?
17. Explain what the terms 'breast cancer', 'mammogram' and 'adjuvant therapy' mean?
18. On what issues would you like to have your voice heard regarding breast cancer?
19. How has this breast cancer journey been so far?



UNIVERSITY *of the*
WESTERN CAPE