

Exploring delays to help-seeking among patients presenting late for symptomatic breast cancer at Tygerberg Hospital.

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DECLARATION

I, the undersigned hereby declare that the work contained in this thesis is my own original work, and that I have not previously in its entirety or in part, submitted it to any university for a degree.

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April 2019

Signature

Date

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ABSTRACT

The primary focus of the study was to explore the reasons women delay seeking help for symptomatic breast cancer among South African women attending a tertiary hospital. The focus was on patient delay after self-discovered breast symptoms. The study was conducted at Tygerberg hospital in Cape Town. The primary aim was to explore the personal and structural barriers to help-seeking. The participants were 25 female patients diagnosed with breast cancer. The data were collected through semi-structured individual interviews which was then analysed using Thematic Analysis. The Common Sense Model of Self-regulation in conjunction with Bronfenbrenner's Ecological Systems theory was used to frame the study's results. The results of this study showed that participants' insufficient knowledge of breast cancer, negative views of the healthcare system and social context following symptom discovery, contributed to their help-seeking delays. Structural barriers such as access to medical care, access to finance and work related constraints were not found to be contributing factors to help-seeking for the participants in this study.

OPSOMMING

Die primêre fokus van hierdie studie was om die redes te verken rondom vertraagde hulpsoek vir simptomatiese borskanker onder Suid-Afrikaanse vroue wat 'n tersiêre hospitaal bywoon. Die fokus was op pasiënt vertraging na self ontdekte bors simptome(e). Die studie was uitgevoer by Tygerberg hospitaal in Kaapstad. Die hoof doelwit van die studie was om die persoonlike en strukturele hindernisse tot hulpsoek te verken. Die deelnemende pasiënte was 25 vroue wat met borskanker gediagnoseer was. Die inligting was versamel deur middel van semi-gestruktureerde individuele onderhoude wat dan deur wyse van tematiese analise verwerk was. Die Common-Sense Model of Self-Regulation (CSM) is in samewerking met Bronfenbrenner se Ekologiese stelsel teorie gebruik as raamwerk om die resultate ten toon te stel. Die gevolgtrekking dui aan dat onvoldoende kennis oor borskanker by pasiënte, negatiewe uitkyk op die gesondheidsorg sisteem en vroue se sosiale konteks na simptome ontdekking bygedra het tot vertraging in hulpsoek. Strukturele hindernisse soos toegang tot mediese sorg, toegang tot finansiering en werkverwante hindernisse was nie bydraende faktore tot vertraagde hulpsoek in die pasiënte in hierdie studie nie.

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When I look at the sky, the moon and stars which you have set in place, who am I that you are mindful of me, who am I that you care for me? Psalm 8 v3-6.

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Chapter 1

Introduction, Rationale and Aim of the study

1.1 Introduction

The focus of this thesis was on exploring the reasons why certain women delay seeking help for symptomatic breast cancer. The main objectives were to uncover the subjective personal and structural factors which act as barriers to help-seeking. Cancer is one of the leading causes of death in the world, resulting in an estimated 8.8 million deaths worldwide in 2015 with 70% of these cancer deaths occurring in low and middle-income countries (World Health Organisation [WHO], 2017). The WHO estimates an estimated 70% increase in new cancer cases over the next two decades (WHO, 2017).

Globally, breast cancer accounts for 25% of all cancers diagnosed amongst women and it is also the leading cause of cancer deaths in women (International Agency for Research on Cancer [IARC], 2012). The WHO's IARC reported an estimated 94,378 cases of Breast Cancer and approximately 47,583 deaths in Sub-Saharan Africa in 2012 (IARC, 2012). This high incidence rate may be attributable to lifestyle changes such as unhealthy eating, physical inactivity, tobacco and alcohol intake, changes to reproductive patterns such as bearing of a first child after the age of 30 or bearing no children at all as well as ageing of the population (WHO, 2013). Breast cancer is a growing public health concern in South Africa with an increase from 6,849 new histologically (at microscopic level) diagnosed cases in 2011 to 8230 new cases in 2014 (National Cancer Registry, 2011; National Cancer Registry, 2014).

Breast cancer is typically detected through breast self-examination (BSE), mammography screening, clinical examination, Magnetic Resonance Imaging (MRI) of the breast (Orel & Schnall, 2001) and/or Fine Needle Aspiration Biopsy (FNAB) in which a fine needle is inserted into the mass in the breast to extract cellular material to be tested (Amedee &

Dhurandbhar, 2001). Women are encouraged to perform regular BSE and undergo mammography screening to aid in the early detection of breast cancer (Humphrey, Helford, Chan & Woolf, 2002).

There exists some controversy in the literature regarding the harms and efficacy of systematic mammography screening. This is because there has been little to no reduction in advanced cancers in countries that have been running mammography screening programmes for long periods (Autier & Boniol, 2017). It appears that some of the controversy is informed by results of large scale trials in countries such as Sweden which reported reductions in breast cancer mortality as a result of screening (Perrenoud, Stiefel, & Bourquin, 2018). Systematic population-wide screening programmes can lead to overdiagnosis and overtreatment of benign non-cancerous lumps which can place unnecessary physical and psychological strain on individuals (Autier & Boniol, 2017). In spite of this controversy, early detection and intervention remains important to decrease mortality rates (ACS, 2016).

The American Cancer Society (ACS) provides a guideline for 5-year relative survival rates for each stage of breast cancer as follows: stage 1 (close to 100% survival), stage 2 (93%), stage 3 (72%) and stage 4 with approximately 22% chance of survival, 5 years after diagnosis (American Cancer Society [ACS], 2016). These guidelines illustrate the importance of seeking treatment early for breast cancer.

This current study explored the reasons why women attending a breast clinic at Tygerberg hospital, delayed seeking treatment for symptomatic breast cancer. A distinction is made in the literature between different types of delays. Bish, Ramirez, Burgess and Hunter (2005) explain the term delay has two sources, namely patient delay and caregiver delay. Patient delay refers to the time between a patient discovering a lump or change in the breast to the time they seek help from a doctor. Caregiver delay is described as the time between a patient consulting with a doctor to the time when the doctor refers the patient for further treatment.

In this study I focused on patient delay. Maly, Leake, Mojica, Diamant and Thind (2011) further categorises delay into the following two groups namely delays after *patient*-detected abnormalities and delays after *system*-detected abnormalities. This study focused on delays after patient-detected abnormalities of the breast. I used the term self-discovered breast symptom(s) instead of patient-detected abnormalities.

Detecting breast cancer at an early stage, when the tumour is still small, localized to the breast, and operable, is paramount in controlling breast cancer (WHO, 2013). Coupled with early intervention, early detection is associated with increased chances for survival (ACS, 2016). A study conducted at Groote Schuur Hospital in Cape Town, found that the average delay between symptom discovery and diagnosis of breast cancer was 8.5 months (Moodley, Cairncross, Naiker & Momberg, 2015).

Richards, Smith, Ramirez, Fentiman and Rubens (1999) found that within each stage of breast cancer, women who presented within 12 weeks of symptom onset, had similar or better survival than those who delayed for 12 weeks or more. A probable explanation for this is that tumours which are intrinsically less aggressive, will not progress to an advanced stage, despite delays. Conversely, high proliferating tumours may influence metastasis. This means that the biological characteristics of certain tumours may result in an initial advanced diagnosis (Caplan, 2014; Warner, 2016).

Delays in treatment seeking places a huge burden on public health costs because a delay in treatment seeking means that diagnosis is normally done at an advanced stage of the disease (Maly et al., 2011, Coughlin, 2009). This is especially the case with low to middle income countries such as South Africa.

1.2 Rationale

Breast cancer is the most common form of cancer and one of the leading causes of cancer-related deaths amongst women globally (WHO, 2013). The WHO estimates a total of 627 000 breast cancer deaths in women in 2018 (WHO, 2018). Many of these deaths may be prevented through early medical intervention (WHO, 2018). In South Africa a total of 8230 new breast cancer cases were recorded in 2014 alone (National Cancer Registry, 2014). Breast cancer is a growing public healthcare concern. An understanding of the reasons for delays in help-seeking for breast cancer amongst women could inform the way in which awareness messages about timely treatment are disseminated within communities. Early detection and treatment of cancer remains vital to favourable disease outcomes (WHO, 2018).

According to the WHO early detection comprises of early diagnosis (awareness, clinical evaluation, diagnosis and staging and access to treatment); and mammography screening (to identify asymptomatic persons with breast abnormalities (WHO, 2018). The month of October is Breast Cancer Awareness month in South Africa with a special focus on breast health, breast cancer awareness and education as well as free screening services. We do not know whether there is an uptake of screening services during this month and whether those women who are screened and deemed to be at risk, follow on to have further tests done. There is also a paucity of research on help-seeking behaviours for breast cancer amongst South African women. In order to encourage screening practices amongst South African women, it is important to understand the perceived barriers to help-seeking as experienced by South African women. It is anticipated that this research will contribute towards the discussion on help-seeking behaviours in women and more specifically, will highlight the barriers to help-seeking for symptomatic breast cancer.

1.3 Research Aim

The aim of this study was to explore the barriers to help-seeking for symptomatic breast cancer. The objectives were as follows:

1. To examine the subjective personal barriers to help-seeking and
2. To identify the structural barriers to help-seeking.

1.4 Conclusion

Chapter one provided an introduction to this study by providing a brief overview of the breast cancer incidence rates globally. Thereafter followed an explanation of the way in which the disease can be detected and insights from literature regarding early detection and early intervention. The rationale and aim of the study brings chapter one to a conclusion. Chapter two comprises of the literature review and theoretical framework which informed this study. Chapter three outlines the methodology utilized and explains in detail the guidelines and steps taken to conduct this study. Chapter four comprises of my results and discussion, in which I report the findings of this study. Chapter five is the final chapter in this thesis and comprises of the conclusions, limitations and recommendations flowing from this work.

Chapter 2

Literature Review and Theoretical Framework

2.1 Introduction to Literature Review

This chapter is a review of the literature on patient delay as it pertains to breast cancer. I begin this chapter with an explanation of what is understood by the term ‘delay’ or ‘patient delay’ as it is used in help-seeking literature. I have grouped the results of my literature review by means of sub-headings, in such a way that it flows from initial symptom discovery of the breast symptom, to the factors which influence delayed help-seeking.

2.1.1 Definition of the term ‘delay’ in help-seeking literature

Seeking help for symptomatic breast cancer usually takes place between initial symptom discovery and the time of initial consultation with a health care provider (Unger-Saldana & Infante-Castaneda, 2011). This period between symptom discovery and help-seeking may vary and when it is extended, it is regarded as a delay in help-seeking. A delay period of less than 3 months is considered a short delay and 3 to 6 months delay is considered as a moderate delay period (Richards, Westcombe, Love, Littlejohns & Ramirez, 1999). The findings of a review of literature which focused on the impact of delays on survival showed a 7% difference in 5-year survival rate between those women with short delays (<3 months = 52%) and those with moderate delays (3 to 6 months = 45%) (Richards et al., 1999). Patient delay of more than three months is associated with late stage at diagnosis; however this association appears to be confined to poorly differentiated tumours according to a study of 287 breast patients (Arndt et al., 2002). The characteristics of poorly differentiated tumours are that they appear very different from the surrounding normal cells and tend to grow and spread faster than well differentiated tumours, which in turn look more like normal cells and grows and

spread slower (National Cancer Institute, 2018). A woman typically detects a lump or other breast symptom accidentally, during a bath or shower or by performing a breast self-examination. Some women do not report this finding immediately and thus enter into a time of delay.

More recently the term 'delay' was considered to be "value laden, pejorative and judgemental" (Dobson, Russell & Rubin, 2014, p.2). Dobson, Russel and Rubin (2014) use the term patient interval, instead of patient delay, which consists of two components. The first component is 'symptom appraisal' which Dobson, Russell & Rubin (2014) explain to be the time from symptom detection to deciding that there is a need to seek medical help. The second component is 'help-seeking', which denotes the time from deciding that help needs to be sought to the actual first consultation with a health care professional.

A review of qualitative studies, which focused on help-seeking behaviours in women with self-discovered breast symptoms, published between 1990 and 2013, revealed the following eight major themes across the relevant literature; symptom detection, initial symptom interpretation, symptom monitoring, social interaction, emotional reaction, priority of medical help, appraisal of help services and personal-environmental factors (Khakbazan et al., 2014). These are broad themes which have been included in this literature review.

2.1.2 Symptom detection

Breast self-examination, clinical breast examination, biopsy and mammograms are common ways of detecting abnormalities in the breast. Breast self-examination occurs at home whilst clinical examinations, biopsies and mammogram are performed during a scheduled hospital visit. Most women require a referral letter from a primary care medical practitioner in order to have mammography screening. According to the WHO, mammography is the most effective screening tool for Breast Cancer, however the WHO

(2014) recommends against the use of population wide screening of asymptomatic women between the ages of 40 and 49 in low resourced countries with weak health systems. This type of screening is recommended for women in this age category by the WHO in well-resourced countries which indicates an underlying problem with the cost and feasibility of such a service at population wide level.

Regular breast self-examination (BSE) is an easy and cost-free way of checking for breast lumps or any other changes in the breast (CANSAs, 2018). Women would need some general training or guidance on how to perform BSE in the correct manner. This guidance is obtained at a clinic or through print and other media campaigns. The adherence to BSE practices is low in certain settings as shown in recent studies conducted in Nigeria (Amaran & Toyobo, 2015) which found the practice of regular BSE to be as low as 5.3% out of a sample 495 participants. Similarly (Obaji et al., 2013) found that only 0.4% of 230 participants in their study performed regular BSE. These low figures may be an indication of a lack of knowledge about breast cancer risk factors which include early onset of menstrual periods, having no children or being older than 30 at first pregnancy, obesity, physical inactivity and increased risk with age (Amaran & Toyobo, 2015; Obaji et al., 2013). Low rates of BSE practice was also found to be prevalent among participants in a study of breast cancer knowledge among women living in a resource poor community in South Africa. The study by Maree, Wright and Lu (2013) found that only 5% of the 299 women who participated, reportedly practiced regular BSE.

Self-detected lumps are those discovered by a woman in her home environment. System-detected lumps are those lumps which are initially detected through mammography screening or clinical examination of the breast by a trained medical professional in a clinic or hospital setting (WHO, 2018). According to the WHO clinical breast examination is a viable approach to early detection in low resource areas (WHO, 2018). Early detection of breast lumps is an

important step in the health-seeking process. However, an American study in which 921 newly diagnosed breast cancer patients were surveyed, found that women with self-detected lumps reported greater delays than those with system-detected lumps (median interval of 80.5 days versus 31.5 days respectively) (Maly et al., 2011). This means that the practice of regular BSE might not guarantee faster help-seeking. In a hospital setting, the detection of a breast lump triggers a series of referrals for further tests, whilst a lump detected in the privacy of a woman's home gives her an opportunity to monitor the lump for visible changes which could take some time to appear. Similar findings were made in a study of patients with oral cancers which found that patients evaluated the need for medical help based on symptom severity (Scott, Grunfeld, Auyeung & McGurk, 2009).

Lack of knowledge of cancer symptoms is thus an important factor in the delay process. Women, who have prior knowledge of which symptoms to look out for, have an opportunity to evaluate the possible seriousness of their own symptoms. When such baseline knowledge does not exist it leaves women to make unqualified assessments of their own symptoms, which may lead to delays in help-seeking (McGutchan, Wood, Smits, Edwards & Brain, 2016). According to Grunfeld, Ramirez, Hunter & Richards (2002) a painless breast lump is the most commonly identified symptom of breast cancer. It is possible that limited knowledge of other breast cancer symptoms, such as dimpling of the breast or nipple discharge, may be contributing to help-seeking delays (Faccione & Dodd, 1995).

2.1.3 Symptom appraisal

Once women become aware of a breast symptom, an appraisal of the symptom takes place. Symptom appraisal constitutes approximately 70% of the total delay time (Khakbazan, Taghipour, Roudsari, Mohammadi & Omranipour, 2014). A woman has to make sense of the cause of the breast symptom and whether it is something serious or not. In their

study of 46 newly diagnosed breast cancer patients, Burgess, Hunter and Ramirez (2001), found this stage, in which women begin to identify and label their symptoms, to be the most important stage in the help-seeking process. Studies have shown that some women incorrectly appraise their symptoms as something other than cancer such as age related weight gain, breastfeeding or connected to hormonal changes (Burgess, Hunter & Ramirez, 2001 & Khakbazan et al., 2014). The lack of knowledge of non-lump symptoms such as pain, has been considered to be a reason for some women to present late (Unger-Saldana & Infante-Castaneda, 2011).

Symptoms not matching up to women's prior knowledge of breast cancer was found to promote delays among a sample of 21 Japanese breast cancer patients (Oshiro & Kamizato, 2018). In some cases a clearly defined lump is not the initial symptom that women notice. This was reported in a study of 46 women, of which 31 did not have a lump as an initial symptom, and some women indicated that if they had a definite lump they would have acted sooner (Burgess, Hunter & Ramirez, 2001).

The absence or presence of pain is controversial in the literature. A review of help-seeking behaviour of women with breast cancer noted that women perceived the presence of pain as reassuring but that in others the appearance of pain triggered help-seeking (Khakbazan et al., 2014). Among a sample of Chinese women with breast cancer, those who had painless lumps reported that they did not believe that it was sufficiently serious to warrant seeking medical assessment (Lam et al., 2008). The discovery of a painless lump was one of the factors which reportedly contributed to delays of more than 18 months (69%) in a sample of 55 Nigerian women (Dye, Bogale, Hobden, Tilahun & Deressa, 2012).

In studies done in the United Kingdom (Dobson, Russell & Rubin, 2014) and Australia (Shahid et al., 2015) it was found that women attach labels to their breast symptoms which

characterises these as benign or trivial so that they do not realise the severity of the actual symptom. Another factor in establishing the seriousness of the breast symptom are women's perceptions about whether they are at risk of developing breast cancer. These risk factors include aging, family history of breast cancer, early onset of menstrual period, late or no pregnancy, late onset of menopause, physical inactivity, excessive weight after menopause, taking certain oral contraceptives for long periods of time, using combined hormone therapy and increased alcohol use (Centres for Disease Control and Prevention (CDC), 2018).

Women's perception of low personal risk may influence delayed help-seeking. A qualitative study conducted in Cape Town at Groote Schuur hospital's combined breast clinic, in which 20 newly diagnosed breast cancer patients were interviewed, revealed that many of the women did not perceive themselves to be at high risk despite having a family history of breast cancer (Moodley, Cairncross, Naiker & Momberg, 2015).

Among 85 women in New Zealand, 42% of those with a family member with breast cancer, delayed presentation for more than a month, compared to 26% of women who had no family history of breast cancer (Meechan, Collins & Petrie, 2002). Despite suspecting that their own breast symptom might be cancerous, women with past experience of cancer in a friend or relative delayed seeking immediate medical help (Burgess, Hunter & Ramirez, 2001). A study of women with newly diagnosed breast cancer revealed that some women focus very strongly on negative memories of loved ones who suffered and died of cancer irrespective of how much time had passed since the event and were reportedly unaware of new advances in cancer treatment such as breast conservation (Burgess, Hunter & Ramirez, 2001)

Non-delayers in the study by Burgess, Hunter & Ramirez (2001) used the memory of loved ones with cancer as a trigger to help-seeking and perceived the doctor's visit to be a positive exercise that can delay any fears and provide reassurance after the breast

investigation (Burgess, Hunter & Ramirez, 2001). A study of 100 breast patients in Ireland found that having a family member or friend with cancer does not have a significant effect on delays although they do not clearly state how prevalent this finding was in their study (O'Mahony & Hegarty, 2009). Some women reported that seeking help was dependent on whether they had a friend or family member who had an early diagnosis and survived or whether the friend or family member had a late diagnosis and died (Marlow, McGregor & Wardle, 2014). Therefore, merely having a friend or family member with cancer is not an indicator of whether women will delay seeking help.

2.1.4 Symptom monitoring

There was reported uncertainty among a sample of 46 breast cancer patients on when exactly it would become necessary to report a discovered lump in their breast as women watched to see if any changes occur to the breast symptom (Burgess, Hunter & Ramirez, 2001). The discovery of a painless breast lump (Khakbazan et al., 2014) coupled with general good health, past experience with benign breast disease, and the attribution of bodily changes (Dobson, Russell & Rubin, 2014) such as weight or appetite loss to normal ageing contributed towards help-seeking delays (Moodley et al., 2015).

Some women might notice changes in their breast area and not develop a noticeable lump. The absence of a definite lump could then lead to a prolonged monitoring period. Ambiguous, non-lump symptoms such as pain or swelling of the arm, have been shown to lead to delays in the help-seeking process (O' Mahony, McCarthy, Corcoran & Hegarty, 2013). Women reportedly monitored the breast lump for periods exceeding a year and would only go seek help at the appearance of additional breast symptoms (Dye, Bogale, Hobden, Tilahun, Deressa & Reeler, 2012).

Women have also reported concerns about wasting the doctor's time or concerns about appearing to have unwarranted worry about a non-existent serious illness (Renzi, Whitaker & Wardle, 2014; Dobson, Russell & Rubin, 2014) as in some cases where women had past benign diagnosis. According to Renzi, Whitaker and Wardle (2014) women with previous false-alarm diagnoses were more likely to delay seeking help when symptoms recur as they were previously reassured by doctors that it was not something serious. A false alarm diagnosis occurs when a woman presents with a breast symptom which is assessed and diagnosed as benign by a doctor (Renzi, Whitaker & Wardle, 2014).

A study about help-seeking delays in women over 65 years of age found that older women reported that they were reluctant to bother their GP (general practitioner) and this was coupled with negative attitudes towards GP visits (Burgess, Hunter & Ramirez, 2006). Women therefore monitor their symptoms and are only alerted to its possible seriousness once the symptoms changed such as blood excretion from the nipple or enlargement of the breast lump (Lam et al., 2008). Negative attitudes toward health care providers was found to be a barrier to help-seeking for symptomatic oral cancers, these attitudes were informed by past negative experiences with health care providers (Scott, Grunfeld, Auyeung & McGurk, 2009).

Contrary to the aforementioned studies, other research found that self-discovered breast lumps are associated with prompt help-seeking as it is the most commonly identified breast cancer symptom, matching women's expectation of breast cancer (Marlow, McGreggor, Nazroo & Wardle, 2014, Bradley, 2005, Meechan, 2002 and Bish et al., 2005).

2.1.5 Social interaction

The living conditions of women are an important aspect in the delay process as women who share homes with extended family often ignore symptoms due to competing family demands. The prioritising of work and other life events, such as taking care of children or grandchildren or sick members in the family was found to be a reason why women ignored their own breast symptoms (Shahid et al., 2015; Dobson et al., 2014; Oshiro & Kamizato, 2018).

An important aspect of women's social context is the disclosure of symptoms to a trusted individual. Symptom disclosure can have an ambiguous function, depending primarily on the feedback received. A trusted individual can either acknowledge the possible seriousness of the breast symptom and encourage help-seeking or conversely downplay the seriousness of the breast symptom and dispel the concerns altogether (Moodley, 2015). A review by Bish, Ramirez, Burgess and Hunter (2005) revealed that symptom disclosure is an important step in the help-seeking process.

A New Zealand study found that marital status of women, or whether women live alone or in shared homes, did not significantly influence delays (Meechan, Collins & Petrie, 2002). The nature of the relationships in the home might have an influence on symptom-disclosure. Of the 185 women who participated in a British study, 67% of the married women disclosed their symptoms to someone, compared to 47% of the women who were either, single, divorced or widowed (Burgess, Ramirez, Richards & Love, 1998). Older women were found to be more likely to delay disclosing their symptoms possibly due to not having someone in their daily lives to confide in (Burgess et al., 2006).

2.1.6 Emotional reactions

The view of breast cancer as an incurable disease can play a huge role in delaying investigation into symptoms, especially when the person suspects that the symptoms might be linked to cancer (Chojnacka-Szawlowska, Kos´cielaka, Karasiewicz, Majkowicz & Kozak, 2013). Studies reveal that women report having felt a great sense of fear about cancer and its associated treatments (Dobson, Russell & Rubin, 2014; Lam et al., 2008 & Shahid et al., 2015). The fear of receiving a cancer diagnosis and all the treatments and procedures such as mastectomy surgery acted as a barrier to help-seeking (Shahid et al., 2017 & Lam et al., 2008). In another study, it was found that women reported fearing cancer due to its link with the inevitability of death and the fact that it could affect anyone, even those who lead healthy lifestyles (Marlow, McGregor, Nazroo & Wardle, 2014).

A Ghanaian study revealed that cancer was perceived to have supernatural causes which caused women to fear the disease (Opoku, Benwell & Yarney, 2012). Many Ghanaian women present with late stage breast cancer and die shortly after diagnosis or surgical treatment, for this reason some women associate breast cancer with death (Opoku, Benwell & Yarney, 2012). The “divine cause” (the idea of cancer being related to an act of God) attributed to cancer was also found to be prevalent among 20 cancer patients in a Malaysian study by Farooqui et al. (2011). Some women reportedly believed that cancer is present in all people and can develop at any time, that it has no geographical or racial boundaries, that it can have genetic links but also that it can be caused by unhealthy lifestyles or God’s will (Farooqui et al., 2011).

In spite of the advancements in cancer treatments and increased survival, some women believe that those who survived are “lucky” (p.751) and that recurrence of cancer will remain a reality for the survivors (Marlow et al., 2014). These fears are often based on experiences of community members which are retold within the community (Peek et al., 2008). A review focusing on the role of cancer worry in cancer screening by Hay, Buckley & Ostroff (2004) suggests that in the general population, people have fears about positive test findings which influence help-seeking delays and not about developing cancer in general. Consedine et al. (2004) conducted a review on fear, anxiety, worry and breast cancer screening and suggested that it is difficult to pinpoint exactly what it is that women fear about cancer. They suggest that the factors influencing cancer fears are complex and that perhaps it is simply that women fear everything related to cancer. These fears include a fear of receiving a positive diagnosis, fear of pain and discomfort associated with the disease, fear of embarrassment, fear of medical institutions and fear of treatments such as radiation and chemotherapy (Consedine et al., 2004).

2.1.7 Depression and anxiety

Levels of depression and anxiety are higher around time of diagnosis as shown in a sample of 222 women with early breast cancer (Burgess et al., 2005). Prevalence for depression and anxiety were measured at 33% at diagnosis and 24%, 3 months after diagnosis with a steady drop from 48% in the first year to 15% in the 5th year after diagnosis (Burgess et al., 2005). Risk factors for depression and anxiety were found to include previous psychological treatment, lack of an intimate confidante and experience of non-cancer difficulties, and longer episodes of depression and anxiety were present when coinciding with these risk factors (Burgess et al., 2005).

Elevated levels of distress and depression were found among a sample of 201 breast cancer patients reporting at an outpatient clinic in Cape Town (Kagee, Roomaney & Knoll, 2017). Body change stress and low perceived support were among the identified causal factors which influenced these elevated levels of distress and depression (Kagee, Roomaney & Knoll, 2017).

Fear emerged as the major factor influencing delays in help-seeking in Africa according to a review by Donkor et al. (2015). Fear plays an important and yet ambiguous role in help-seeking delays for patients as it can act as a prompt to help-seeking in some cases and a barrier in others (Khakbazan et al., 2014 & Dobson, Russell & Rubin, 2014; Shahid et al., 2015)

2.1.8 Appraisal of health services

The general attitude that patients have towards health practitioner visits is a factor that contributes to delays in treatment seeking (Burgess et al., 2006, Burgess, Hunter, Ramirez, 2001, Marlow et al., 2014). These attitudes may include wanting to only be seen by a female doctor (Khakbazan et al., 2014 & O'Mahony, Hegarty & McCarthy, 2011), lack of confidence in the general practitioner (de Nooijer, Lechner & De Vries, 2001) and embarrassment of breast examination (Lam et al., 2009). Women with access to health insurance had positive attitudes to GP visits and were unlikely to delay seeking treatment (Bradley, 2005). Women who are better resourced would then behave in an autonomous manner when it comes to health decisions.

Arndt et al (2005) found that women who had visited a gynaecologist or seen a medical doctor for check-ups in the 5 years prior to the breast cancer diagnosis, were more inclined to investigate breast symptoms. Studies on screening practices in America show that African-American women (Maly et al., 2011) and Hispanic women (Selvin & Brett, 2015), in low

socio-economic areas do not adhere to regular breast screening practices. The following set of factors deal with the characteristics of women and how these act as structural barriers to help-seeking: culture, family situations, education, access to finances, transport and health facilities which may contribute to help-seeking delays.

2.1.9 Cultural factors

A study conducted in Kwazulu-Natal Province, in which 70 urban and 70 rural, randomly selected women participated, found that 31.4% of rural woman reportedly knew about breast self-examination compared to 82.9% of urban women (Pillay, 2002). The term ‘urban’ was used to describe those women who had lived in cities most of their lives while the term ‘rural’ was used to describe those women who lived in outlying areas, far from major cities and with access to few services (Pillay, 2002). The urban women were recruited from a “historically African neighbourhood (Pillay, 2002 p.106)” and the survey questions were in the isiZulu language which was the first language of the participants in this study (Pillay, 2002). Of the 140 participants in Pillay’s study, it was found that 37.7% of rural women consulted a traditional healer on discovery of breast symptoms compared to only 10% of urban women (Pillay, 2002).

Cancer is believed by some people living in rural areas to have some supernatural link especially since the disease is perceived to have to clear natural cause and in a country like Ghana where patient doctor ratios are as low as 1:13 000, it is understood that traditional healers, herbalists and spiritual leaders become an important source of health information (Opoku, Benwell & Yarney, 2012).

Rural people are often cut off from big hospitals or clinics which may be far away and therefore traditional healers are important due to their close proximity to the people (Christoph, Muller & Muller, 2002). Some of the reasons why women consult traditional

healers for breast cancer include recommendations from well-meaning family members, the perceived benefit of obtaining a possible cure, compatibility between spiritual and physical healing, reservations about western practices which include surgery and the credibility of the traditional healer (Muhamad, Merriam & Suhami, 2011). A review of breast cancer delay literature on the African continent suggest that the respected place of husbands, family heads and spiritual leaders within African communities may influence the use of alternative medicines by women (Donkor et al., 2015).

The use of traditional medicines, spiritual healing, prayer and herbal therapies were found to be common on the African continent and this is so due to the belief that cancer has a supernatural rather than biological cause and for this reason the use of western medicines and treatment are perceived to be ineffective in matters of the spirit (Donkor et al., 2015). A study in Ghana found that once women consult with traditional healers there is unwillingness from the healers to refer patients onto nearby hospitals as they reportedly believe in their ability to treat every kind of illness, including breast cancer (Opoku, Benwell & Yarney, 2012). Although it is unclear whether delays are associated with adverse consequences (Caplan, 2014), it is widely accepted that early detection and treatment are beneficial for treatment outcomes (Buccimaza, 2015).

A review paper by Remennick (2006) which focused on immigrant and minority women in multicultural societies, found that certain religio-cultural beliefs may discourage women from revealing their affected breast(s) to strangers, especially males. In this regard, women from very strict, traditional religious cultures such as Islam, may be hesitant to seek mammogram screening when the physician is male and if there is no accompanying female relative available during screening (Khakbazan et al., 2014).

2.1.10 Socio-economic factors

Poverty not only robs people of access to reliable health services and affordable medication but also creates illiteracy which leaves poor people ill-informed about health risks (Kern & Ritzen, 2018). In poor families the health of the breadwinner is an important concern and the loss of income from sickness and death of a breadwinner can have devastating effects on the family (Kern & Ritzen, 2018). The health needs of women often compete with the daily responsibilities of caring for the family (Marlow et al., 2014). A UK study of Black, and Asian women reported that competing priorities was a consideration in help-seeking behaviours as some women believed that their husband and children came first and that they just have to get on with life especially at time when other family events needed more attention (Marlow et al., 2014).

Work pressures, long working hours, unemployment and language barriers were reported as barriers to help-seeking among a sample of 552 Filipino immigrants in Australia and more importantly women who have to take care of children report to have very little time to take care of health concerns (Maneze, DiGiacamo, Salamonsen, Descallar & Davidson, 2015). A study conducted in Mexico documents how lack of money and transport affects very poor women as they struggle with raising money and having to travel great distances to obtain a correct diagnosis when they notice changes in breast symptoms. These factors, coupled with illiteracy, further hamper the ability of some women to make informed decisions about discovered breast symptoms (Unger-Saldana & Infante-Castaneda, 2011).

The ability to ask clear questions and to illicit the correct answers from a health care provider is important in the help-seeking process and thus lack of confidence in the ability to get a physician to take health concerns seriously was shown to contribute to delays of more than 60 days among sample of 1869 low-income women (Maly et al., 2011). One study found

that the low socio-economic status of some women played a role in help-seeking delays (Bradley, 2005) while other studies found that socio-economic factors were unrelated to delays in treatment-seeking (Bish et al., 2005, Meechan, Collins & Petrie, 2002).

A British study in which a sample of 961 women were purposefully surveyed to include those with different education levels, found socio-economic inequalities were not related to women's ability to recognise breast cancer symptoms (Davies, Marcus, Vedsted & Whitaker, 2017). Another UK study which included both men and women, found that poor knowledge about non-cancer specific symptoms, fearful and fatalistic beliefs about cancer and emotional barriers to help-seeking were more common in people from low socio-economic groups (McGutchan, Wood, Smits, Edwards & Brain, 2016).

Factors such as ongoing racism from the dominant group, limited access to medical facilities and lack of education and employment opportunities affect 41% of Aboriginal Australians who live on the rural outskirts of society (Shahid et al., 2015). The above factors have been found to influence help-seeking behaviours amongst this group and contributed towards late delays in help-seeking for symptomatic cancer (Shahid et al., 2015). In neighbouring New Zealand a study found that delays in help-seeking were not significantly related to any socio-demographic factors and these included factors such as marital status and education (Meechan, Collins & Petrie (2002).

A potential barrier to help-seeking for those living in low socio-economic groups is access to transport. Distance from the medical facility has been found to be a barrier to help seeking (Oshiro & Kamizato, 2018 & Shahid et al., 2015). Distance from medical facilities reportedly contributed to delays in a study of 30 Aboriginal patients living in remote locations in Australia (Shahid et al., 2015). The lack of access to personal transport has also been found to play a role in delays for women in South Africa. A study that investigated the

relationship between patient distance from hospital and delays in help-seeking, found that 51% of the 1071 breast cancer patients in their study presented late with stage (III or IV) disease (Dickens, Joffe, Jacobson, Venter, Schuz & McCormack (2014). The greater the distance from the hospital, the greater the delays were. The percentage of women who presented with late stage at diagnosis increased from 50% in those living less than 20km from the hospital to 69% for those who live between 30 and 39km from the hospital (Dickens et al., 2014).

There are many complex reasons why women do not seek help in spite of their concerns regarding the possible seriousness of their breast symptoms. The above literature survey shows that research findings into this phenomenon are varied. A barrier to help-seeking in one study may act as a trigger to help-seeking in another and often these contradicting findings occur in the same study.

Early detection of breast symptoms and early access to medical intervention are important facets of disease control. It is therefore important to identify why women continue to present late for symptomatic breast cancer in spite of evidence that early detection can lead to better health outcomes and a decrease in cancer related deaths. The following section of this chapter encompasses the theoretical framework used to frame this study.

2.2 Theoretical Framework

This study was framed using the Common Sense Model of Self-Regulation (CSM) (Hale, Treharne, & Kitas, 2007) as well as Bronfenbrenner's Ecological System's theory (Bronfenbrenner, 1979). The combination of the CSM model and Bronfenbrenner's theory provided the lens through which to investigate and view the personal factors as well as the perceived structural factors which influence help-seeking delays. The CSM Model focuses on

the individual and how he/she perceives an illness whilst the ecological model offers an understanding of the interplay between the individual and his/her environment.

2.2.1 The Common-Sense Model of Self-Regulation

According to Hagger & Orbell (2003) the CSM provides a framework for understanding how individuals process information available to them about a specific illness. This is done so that the individual can make sense of the detected problem in order to plan how the problem should be managed (Hagger & Orbell, 2003). The CSM model was useful in understanding why women delayed the immediate investigation of breast symptoms since their understanding of cancer in general, and breast cancer specifically, formed the basis against which they assessed their understanding of the health threat (in this case the breast symptom). This assessment of the breast symptom as serious or not, informs whether some women delay seeking help. This model was initially formulated by Leventhal in the 1960's and 1970's to explore how fear messages might cause some people to take up health-promoting actions such as the use of seatbelts in motor vehicles and was further expanded to explore what adaptations and coping strategies are used by those experiencing chronic illness (Hale, Treharne & Kitas, 2007).

This model suggests that once a threat (for example a lump in the breast) is discovered, the individual will immediately create a cognitive representation or picture of the possible illness or disease to enable them to understand and cope with it. The creation of this mental picture invokes an immediate emotional response. The type of emotional response will influence the way in which the individual will cope with an illness and subsequently this will affect the treatment outcomes (Hale, Treharne, & Kitas, 2007).

The five key components of the CSM model are identity (an individual's interpretation of the known symptoms associated with an illness), cause (the belief about what causes an

illness), timeline (the predictive belief about how long an illness will last), consequences (the belief about the possible physical and social impact of the disease) and lastly cure/control (the belief about the curability and controllability of the disease (Hagger & Orbell, 2003, Hunter et al., 2013).

A fundamental tenet of CSM is that there is a relationship between illness cognitions/representations and illness outcomes which are mediated by coping (Hagger & Orbell, 2003). The CSM was used as a framework to aid in the understanding of what may be happening to women on a psychological level in terms of their interpretation, beliefs, and predictions about breast cancer, when they discover changes in their breast. An understanding of the perceived personal factors which influence delays is useful in explaining the help-seeking behaviours of these women with symptomatic breast cancer.

This study was framed using the Common-Sense Model of Self-Regulation (CSM) and Bronfenbrenner's Ecological Systems theory. The CSM provided a useful framework for understanding how an individual may respond to an illness threat once such a threat has been discovered, and in this study, that threat is the breast symptom. The CSM was then used to understand that the individual will have some sort of emotional response to the threat and how such an individual will create certain perceptions of what the threat could be. Using the CSM in this study helped to see how patients entered a period of assessing and monitoring while trying to figure out what to do next and how the feedback received from the breast lump, in terms of the persistence and progression, caused participants to re-evaluate the assessment and decide what future steps to take in terms of help-seeking.

2.2.2 Bronfenbrenner's Ecological Systems theory

The CSM was used in conjunction with Bronfenbrenner's Ecological Systems Theory which explains the interplay between the individual participant and her social environment. This theory was used to understand how messages about cancer and more specifically breast cancer received from the social circles of women, affects the individual woman on a personal level in terms of health behaviours. Bronfenbrenner (1979) speaks about ecological transitions which happen throughout the lifespan of an individual such as getting married or becoming a mother, and how roles are assigned to the individual which informs how the individual is treated within society with the onset of these transitions. My understanding of this is that there are certain societal understandings of the behaviours associated with both womanhood and motherhood which sees mothers for example as nurturing and almost self-sacrificial within the family structure. The combination of these two theories provided a clear and useful framework to understanding what participants faced following the discovery of a breast lump or other breast symptom(s)

Chapter 3

Methodology

3.1 Introduction

In this chapter I describe the methodology which I used to conduct the current research. Methodology refers to the steps which I took to conduct each phase of the research project. I describe the setting in which participants were recruited, the types of participants who formed part of my study, the data collection method as well as my analytical framework and ethical considerations as part of this chapter. The aim of this study was to explore the reasons why some women delay seeking help for symptomatic breast cancer.

3.2 Study setting

This study was conducted at the out-patient Breast Cancer Clinic and the Radiotherapy centre at Tygerberg Hospital in Bellville, Cape Town. Tygerberg hospital is the largest tertiary hospital in the Western Cape and the second largest hospital in South Africa. The hospital serves as a teaching hospital in partnership with the Faculty of Medical and Health Sciences of Stellenbosch University (Western Cape Government, 2016).

The Breast Cancer or Mamma Clinic as it is known, forms part of the Division of Radiation Oncology at Tygerberg Hospital. Tygerberg services a population of 3.4 million people in the greater Cape Town and surrounding areas (Western Cape Government, 2016). Each week the Mamma Clinic sees both new and returning patients who attend the clinic for various treatments and diagnostic services. The women who attend the breast clinic are from both urban and rural areas.

Returning patients generally come for follow-up treatments, which include regular mammograms as well as consultations with doctors. Other patients may need further surgery,

chemotherapy or radiation therapy depending on their individual cases. New patients presenting at the clinic may have had an initial diagnosis or screening done at private or public medical facilities in the Western Cape and referred for further investigation or treatment to Tygerberg hospital.

It is important to note that Tygerberg is a public healthcare facility and services are essentially free or low cost. At the breast clinic, pensioners and patients with disabilities are excluded from payments while the unemployed and low income earners pay approximately R75 per visit which includes services such as mammograms, x-rays and blood tests. Depending on what patients earn, they may have to pay a small fee for tests. Patients with private medical insurance also make use of services at Tygerberg hospital. The costs of services at Tygerberg cost considerably lower than those charged at private medical facilities. This information was obtained from personal conversations with administrative staff at Tygerberg hospital.

Although the cost of healthcare is low at Tygerberg hospital, patients have to wait for many hours to see a doctor or to undergo certain tests and treatments. Patients often have to wait extended times for operation dates and follow up visits are sometimes scheduled months apart. The waiting rooms are often filled to capacity with uncomfortable seating. Some patients arrive very early in the morning in the hope of being seen first.

Patients often wait for hours to see a doctor only to be sent to another area of the hospital to join another long queue. At the end of a long day patients have to queue once again at the pharmacy to collect medication. Some patients bring friends or family members along to queue on their behalf at the pharmacy while the patients navigate the long queues for tests and consultations. This is in stark contrast to private healthcare facilities where patients have

pre-arranged appointments and spend minimal time waiting for doctors in very comfortable and inviting waiting rooms.

According to Mayosi and Benatar (2014) the public health sector services more than 40 million people but is only staffed with about 30% of the doctors in the country.

Approximately 16% of the population have private medical insurance and make use of private medical facilities which are serviced by the remaining 70% of the doctors in the country (Mayosi & Benatar, 2014). Nearly 25% of the South African population who are without private medical insurance, make use of private sector medical service providers, paying for these expensive services out of pocket (Mayosi & Benatar, 2014). This may be due to the comfort and convenience of accessing private healthcare. The reality in South Africa is that if you are sick and uninsured you can be guaranteed that you will have to wait for many hours to be seen by doctors in public hospitals. These public hospitals are often dysfunctional and run down (Mayosi & Benatar, 2014).

3.3 Study design

The study is exploratory in nature using qualitative methods of data gathering.

Exploratory research is useful to uncover new insights into a specific phenomenon (Babbie & Mouton, 2002).

I employed a purposive or judgemental method to select participants for this study. This type of selection is used when the researcher has a clear idea of the characteristics which the participants need to possess in order to be eligible for participation in the study (Botma, Greeff, Mulaudzi & Wright, 2016). Not every patient who attended the clinic had an opportunity to participate in the study as I was looking for patients with specific criteria (Etikan, Musa & Alkassim, 2016). The inclusion criteria are listed in point 3.4.2 in this chapter. It was important for me to carefully select the participants as many who attended the

clinic had in fact not been officially diagnosed with breast cancer and were still awaiting test results and diagnosis. Data were collected by means of semi-structured individual interviews.

3.4 Participants

3.4.1 Participant selection

On each data collection day, I consulted with the clinic staff to ascertain the number of patients present on the day and what their reasons for attendance were. This was important because on certain days there were many new patients who were yet to be formally diagnosed and who would therefore not be eligible for participation in this study. With the help of the nursing staff I had a clear idea of the types of patients who were present for the day as well as the time available for interviews. The time availability was decided with regard to the position of the patients names on the list. Patients whose names appeared lower down the list would have more time for taking part in interviews as their waiting time to see the doctor would thus be longer than those at the top of the list. Each day I reminded the nurses and doctors about the eligibility criteria of the study and ask permission to address the patients. After consultation with clinic staff, I approached the patients who were in the waiting rooms. I then briefly introduced myself to the patients and explained the research project to them. After explaining the inclusion criteria, I invited patients who were interested in participating to either indicate this to me or to the clinic staff. In many cases the interested patients would immediately raise their hands to either ask a clarifying question or to state that they fit the criteria for the study and their wish to participate. Once a patient indicated their willingness to participate, there was always encouragement from the other patients saying that it is important to talk about their experiences.

The staff of the Mamma clinic as well as the staff of the radiotherapy centre also assisted in inviting patients to talk to me or alerted me to those patients who had breast cancer. This

was done as there were certain days when the breast clinic hosted a combined clinic day when patients with different cancers attended. Patients with various types of cancers attend the radiotherapy centre therefore it was very important to have the help of the doctors and staff to recruit patients. The staff at the radiotherapy centre would count the number of breast patients for the day based on the files they had laid out. In some cases they would indicate to me to wait in the waiting room as some patients with appointments were on their way from the hospital wards or from home. In the radiotherapy centre patients had appointed treatment times therefore it was easy to ascertain how many and which types of cancer patients were expected on any particular day. Private rooms in close proximity to the waiting areas were made available for the interviews.

The patients who agreed to participate were taken to the interview room where I explained the aims of the study in more detail. This was important as some patients reported to have delayed for only one or two weeks. These participants were not interviewed for the study as the delay period was not significant. In those cases when it was clear to me that particular patients were not eligible for participation, I thanked them for their interest in the study and explain which types of patients I needed and why this was important. Once the criteria were clearly understood and the patient agreed that it was not applicable to their personal experience then I walked the patient back to the waiting room. This happened with approximately four patients. I always made it clear that I was grateful for their willingness to participate in the study. Those who indicated a delay period of more than 3 months were included in the study. The patients who met the inclusion criteria were then invited to participate in an interview and after gaining written informed consent the interview would take place immediately. I recruited participants for this study until data saturation was reached. The final number of participants was 25.

3.4.2 Inclusion Criteria

Patients who matched the following criteria were invited to participate: they were 18 years and older and diagnosed with breast cancer. The participants had all discovered the lumps themselves and then reported to have delayed seeking help for a period of three months or more. The participants had a good understanding of either English or Afrikaans in order to participate in an interview.

3.4.3 Exclusion criteria

Patients who had system-detected lumps as well as those with a history of breast disease or other cancers were excluded from the study. System-detected lumps are detected through mammogram screening or by a medical professional during a doctors or hospital visit. Patients with other chronic illness, other than cancer, were not excluded from participating.

3.5 Data Collection

Semi-structured individual interviews were conducted with participants (see Appendix A). This type of interview allows the researcher to ask several key questions which focused on the areas being explored but also allowed the participant as well as the interviewer to deviate to explore an idea or response in more detail (Gill, Stewart, Treasure & Chadwick, 2008). Semi-structured interviews are popular in healthcare research as it offers some guidance to the participants and also allows for the uncovering and expansion of information that is pertinent but may have not been apparent to the researcher (Gill et al., 2008).

The aim of the interviews was to understand the real life experiences of women who delayed seeking help for symptomatic breast cancer. Through the interview process I aimed to uncover the personal and structural factors which contributed to delays in help-seeking and how these personal and structural factors acted as barriers to help-seeking.

I personally conducted each interview and received training on how to conduct interviews prior to data collection. The interviews were conducted in English or Afrikaans depending on each participant's preference. Most of the participants opted to be interviewed in Afrikaans. The interviews took place either before or after the patients had met with their doctor/s. The interviews were audio-recorded with permission from the participants. Each interview lasted approximately 30 to 40 minutes. The audio-recordings of the interviews were downloaded and stored onto a password-secure personal computer. The interviews took place between June 2017 and June 2018.

3.6 Data Analysis

I used thematic analysis as a method to analyse the data which I collected through my interviews. The interviews were transcribed verbatim, and uploaded to the Atlas.ti text management programme. I used Atlas.ti version 8. This is a computer-based tool which is used to manage large quantities of texts, audio, images and video and which allows researchers to transcribe and save audio-recordings and transcriptions of data electronically. Thematic analysis is a flexible analytic approach that allows the researcher to actively identify interesting themes in the data (Braun & Clarke, 2006). Thematic analysis can be described as a qualitative method used for classifying, analysing and describing patterns or themes within data (Braun & Clarke, 2006). According to Braun & Clarke (2006) there are six phases to follow in performing a Thematic Analysis. These phases are not always linear or sequential and the researcher might have to go back to previous phases and back again during the analysis process.

During phase one of the analysis process, I familiarised myself with the data by listening to the audio tapes of each interview and then reading and re-reading through the associated transcripts in order to identify themes and patterns in the data (Braun & Clarke, 2006). As I

conducted and transcribed the interviews I had a good idea of the content of each transcription. I checked the transcripts against the audio-recordings for accuracy. Each transcript was then uploaded to the Atlas.ti computer programme. Once uploaded, each transcript was labelled and interesting sections were highlighted using the Atlas.ti.

During phase two I generated the initial codes. This was done once I was familiar with the data. A provisional list of interesting elements in the data was created. These codes identified parts of the data which I found of particular interest especially as it pertained to the overall aim of the study. I worked systematically throughout the complete data set, affording careful attention to each data item. I read each line of the transcripts in order to understand what was being said and then coded these sentences as closely as possible. Certain parts of a sentence have two codes attached as what was said had more than one meaning. The interesting aspects in these data items formed the foundation for repeated patterns across the data set. Atlas.ti allowed me the ease of colour-coding and grouping related themes together in order to view them during the analysis process. I discussed the transcripts with my supervisors to clarify whether the highlighted texts were representative of the themes which were emerging during this phase of the analysis. As suggested by Braun & Clarke (2006), I coded for as many themes or patterns as were possible and included all relevant surrounding data to provide context. I also coded the themes which deviated from the dominant story as well. My supervisor worked with me looking at one transcript at a time see whether anything was missed or whether certain initial codes had the most accurate title.

During phase three of the analysis process, I categorised the various codes into themes (Braun & Clarke, 2006). Braun & Clarke (2006) suggests that it is useful to make use of visual representations such as tables or mind-maps to sort the various codes into themes. At the end of this phase I had created a collection of candidate themes and sub-themes including all coded extracts of data which related to these themes.

In phase four the themes were reviewed. This phase involved a refinement of the candidate themes identified in the previous phase (Braun & Clarke, 2006). During this phase I identified the strength of the themes by checking the amount of codes which supported these themes and how the themes related to each other using Atlas.ti. At the end of this phase I had a clear understanding of what the themes were, how they were related and the overall story that they told about the collected data. At this point I had a thematic map of the data which was generated in Atlas.ti.

The themes were identified and named during Phase 5. Once I had a suitable thematic map I was able to refine the themes even further and identify which facet of the data was captured within each theme. I then wrote a comprehensive analysis of each theme to identify the story each of the themes conveyed, how it fitted in with the overall story and, how this related to the research questions. Names were assigned to the themes which were used in the final analysis. These names give the reader a good idea of what each theme is about.

The final analysis phase was characterised by the writing-up of the report. The writing-up of the thematic analysis allowed me to tell the story of the data in a manner that illustrates to the reader, the importance and validity of the analysis. To illustrate the validity of each theme, I selected enough appropriate data extracts that supported the themes. I chose examples or extracts which adequately captures the essence of each point I was making. According to Braun and Clarke (2006) the extracts needed to be embedded within an analytic narrative that convincingly illustrates the story being told about the data and should make an argument that relates to the research question.

3.7 Trustworthiness

In order to ensure the trustworthiness of my work I provided adequate detail of the context in which I conducted my research in order for the reader to decide whether my findings can be justifiably applied to another, similar setting as suggested by Shenton (2004). Glens (2006) suggests an external audit of the work to augment the trustworthiness of the research. I worked closely with my supervisors during the analysis phase of my work, to ensure that the research process was continually examined. I provided a picture which is as close as possible to the experiences of my participants as it related to delays in help-seeking for breast cancer. I have also done this by clarifying with my participants whether my analysis is representative of what they relayed to me during the interview process. This clarifying process is called member-checking.

3.8 Reflexivity

I spent more than a year at the Mamma Clinic, first as a research assistant for another breast cancer related study and then for my own data collection. This time allowed me to form meaningful relationships with doctors, nurses and other staff at the clinic. I was careful to work alongside the doctors in terms of when I was able to interview patients. Once a patient indicated their interest to participate in my study I checked with the nursing sister whether the participant was next on the list or whether they had enough time to meet with me for the interview. In cases where the participants were close to being called by the doctor, I consulted with the patient to discuss whether we should conduct the interview after the doctor's consultation as I was always very careful not to be the cause of any further waiting delays.

My conversations with staff provided me with good insights into the workings of the clinic as well as the challenges faced by patients in terms of waiting times for follow-up dates

and especially the often hours-long waiting period to see the doctors on duty. I also witnessed the impact a reduced staff compliment had, not only on the waiting periods, but also on the mood within the waiting areas. It became clear to me whilst working at the clinic that many of the women needed a safe space to be open about what they faced and what they might possibly face in the future in terms of their breast cancer diagnosis. I tried to create a warm environment in which they could feel comfortable to openly share their stories. This meant getting to the clinic early, checking in with the staff, securing a private room for interviews, making sure that there are tissues and water at hand and that I had no other pressing issues in order to be fully present during the interview.

Many of the participants reminded me of the neighbours and aunts I grew up with and I had a good understanding of the idioms and little sayings which they expressed. As a mother, it was sometimes hard to listen to participant's accounts of how they feared death upon hearing that they had breast cancer. Their fear was mainly centred around their young children and the impact that such a diagnosis had on their family members. During my analysis I took care not to impose my own ideas regarding the meaning of certain words but to rather see it and listen to it as if it was my first time doing so. My supervisors' input during the coding of the data was useful to ensure objectivity.

What struck me the most was how much the women had to deal with in their lives in general and with cancer specifically and how they still remained positive about the future. For me the most precious moments at the breast clinic was when spontaneous laughter would erupt in the waiting room when someone would share something funny with the women, moods lifted and anxieties reduced for a brief moment. As a researcher, this has been an incredibly rewarding learning experience for me, not just in the skills I acquired during this process, but also in witnessing the strength of the human spirit as displayed by the participants in this study.

3.9 Ethics

Ethical clearance for the study was granted by the Health Research Ethics Committee of Stellenbosch University Faculty of Medicine and Health Sciences (Ref: N15/08/077) (see Appendix C) and the Western Cape Department of Health. This ethical clearance gave me access to the patients at the breast cancer clinic at Tygerberg hospital. Further permission was granted by senior medical staff at the radiotherapy centre at Tygerberg to recruit participants from this section of the hospital. I had access to the diagnostic information in the patients' medical files in order to identify eligible participants. There was however no need to search through the medical files of the participants as they were able to ascertain their own eligibility during pre-screening. The pre-screening encompassed the explanation of the inclusion criteria of the study. Participants were then able to say whether or not their circumstances matched the criteria as read out by me.

Participants took part voluntarily without coercion. Duplicate informed consent forms were available for each interview. The participants had an opportunity to read through the form. Once a participant read, understood and agreed to sign it, she was then able to go ahead and participate in the study. The participant kept one of the signed informed consent forms for her own record. No identifying information of the participants was made public in any form.

Participants were informed of their right to end the interview at any time or withdraw from participating if they so wished. No harm was brought to the participants during the interview process. In cases where the participants showed signs of emotional distress, or cases where the participants indicated their need to seek counselling, I made available the contact details of counselling services. The participants were not paid for participating in this research.

Confidentiality of participant's identifying information was guaranteed as only the investigators had access to the biographical information of the participants. Once the researcher received and processed all the relevant identifying information from the participants, such information was kept secure by storing it digitally on a password secure computer. No identifying information was labelled on any tapes or transcripts of the interviews. Pseudonyms were used to protect the identity of the participants. All paper based identifying information was kept in a locked cabinet in the researcher's office for safe record-keeping. No other persons, not involved with the study, had any access to such sensitive information. All audio-tapes will be securely stored for a period of five years and thereafter they will be destroyed.

Chapter 4

Results and Discussion

4.1 Demographic characteristics of the participants

The participants were 25 women diagnosed with breast cancer. Participants' demographic information is listed in Table 1. Their ages ranged between 36 and 72 years. When asked about their relationship status, 12 indicated that they were married, four divorced or separated, two widowed, six single or never married and one indicated that she was dating someone. Many of the women were unemployed (n=11), two were receiving a pension, one was medically boarded due to a pre-existing chronic illness and nine indicated permanent employment. When given the option of English or Afrikaans interviews, 15 chose to speak in Afrikaans while ten chose English. Of the English interviews, two women were Xhosa first language speakers who indicated that they had a good command of the English language and felt comfortable to proceed. Out of the entire sample, only one woman indicated that she had no children, three women had one child each, 11 had two children, six had three children and four women had four children. Thirteen participants indicated that they had some family history of cancer.

In terms of treatment received, the participants reported the following: 20 participants had undergone mastectomy surgery, 17 had received chemotherapy with two reporting that they refused chemotherapy and five others were not offered chemotherapy based on their individual cases. Sixteen of the women reportedly underwent radiotherapy. A small number of the women (n=2) had received only hormone tablets and no other treatment while three were given the hormone tablet in addition to the other treatments. Of the participants, only one woman had not started any treatment post diagnosis and was still awaiting treatment recommendations by the doctors. When asked whether they knew the stage of the breast

cancer, two indicated stage one, three indicated stage two and eight participants indicated stage three. Many of the participants (n=12) did not know the stage of the breast cancer while three of those indicated that they knew the tumor size which they indicated as (1cm, 5cm and 15cm).

Table 1

Demographic characteristics of participants

<i>Description</i>	<i>Number</i>
<i>Age (years)</i>	
Range	36 – 72
Mean	51
<i>Relationship status</i>	
Single	6
Married	12
Divorced	4
Widowed	2
Dating	1
<i>No of children</i>	
0	1
1	3
2	11
3	6
4	4
<i>Language</i>	
Afrikaans	15
English	10
<i>Employment</i>	
Unemployed	11
Full Time	9
Part Time	2
Pensioner	2
Medically boarded	1
<i>Disease stage</i>	
Does not know	11
Stage 1	2
Stage 2	3
Stage 3	8

<i>Treatment</i>	
Mastectomy	20
Chemotherapy	17
Radiotherapy	16
Hormone therapy	5

4.2 Description of themes

During the analysis a total of three main themes emerged that described reasons for diagnostic delay. I named these themes (1) Lack of breast cancer knowledge, (2) Healthcare: negative perceptions and past misdiagnoses, and (3) Social context following symptom discovery. Each theme consisted of sub-themes. In the following section, I will describe these themes and illustrate them using quotations/ exemplars from participants.

4.2.1 Lack of breast cancer knowledge

The participants in this study reported that they did not have sufficient knowledge of breast cancer prior to their diagnosis. Participants reported that their existing knowledge of breast cancer was obtained from information received from family and community members in general. They reported that most of this information came from family and community members about their own personal experiences or anecdotal accounts. Much of this information was reportedly based on fear and bad experiences. Some women stated that they read about breast cancer on health promotion posters and leaflets at clinics, while others stated that they heard about breast cancer on radio or other media. In general, women reported that they had a limited understanding of the symptoms, risk factors and treatment of breast cancer. Many participants reported that this lack of knowledge and information about breast cancer contributed to their late presentation of symptoms to medical professionals. When asked about their prior knowledge of breast cancer, some participants stated that they

had no knowledge about the disease as can be seen in the following statement by Deliwe, a 56 year old mother of three, diagnosed with breast cancer, stage not known:

“...to be honest I don't know nothing about cancer. ... absolutely nothing. Because it's the first time. And in my family no one had cancer. So I don't know.”

Some participants reported that they did not make a link between a breast lump and breast cancer. I asked one participant whether she knew anything about breast cancer symptoms, she answered as follows:

“Nothing. Nothing. I knew nothing about it.” (Rosie, a 61 year old mother of two, diagnosed with stage one breast cancer)(translated)

All participants stated that it took them several weeks or months to decide whether their symptom(s) warranted medical attention. Some participants reported that they had some idea of what the lump should feel like and assessed their own lump using this knowledge. Other participants struggled to pinpoint the lump in the breast and waited until it grew bigger and harder. Some participants believed that lumpy breasts or inverted nipples were normal and attributable to age related bodily changes. Participants reported that they appraised their symptoms as normal. Many of the women in this study reported that they avoided thinking about the lump, dismissed thoughts of the lump as soon as they arose, and wished that it would simply go away. Some participants reported that they did not want to acknowledge the existence of the breast symptom although they admitted that they had a nagging feeling in the back of their mind that it could possibly be something related to cancer.

“And what happened later on... if I perhaps read a book or a magazine and I read about breast cancer then I close the book. I was scared that I was going to see the same symptoms

in there that was in my breast.” (Beulah, a 50 year old mother of three, diagnosed with stage three breast cancer)

One recurring explanation for the existence of breast lumps among participants was the belief that breast lumps are actually blocked milk ducts. Some participants explained how lumps in the breast were thought to be linked to breastfeeding, pregnancy, miscarriage and blocked milk ducts. Participants believed that breastfeeding too much or too long could cause breast lumps, as described by Sandra, a 39 year old mother of 3, diagnosed with stage three breast cancer:

“The glands that are in your breasts are milk glands, if I’m correct. I also thought because our little one...he drank on me for about 2 years and I thought maybe it is that, maybe it is a milk gland” (Sandra, a 39 year old patient diagnosed with stage three breast cancer)(translated)

Due to the lack of breast cancer knowledge some participants believed that if there are no known breast cancer cases in the family that they themselves could not be at risk of developing the disease. Based on this misinformation some participants reported that they appraised their symptoms as something that was not serious. For example, a 57 year old mother of three, diagnosed with stage one breast cancer stated the following:

“To tell you the truth I am the first one in my family, we are eight sisters and I am the first one in my family that this has happened to. So I just always sat with the thing (the lump) and never thought that it is cancer.”(translated)

Some participants stated that they did not know at which point to seek help but monitored their symptoms for some time. This monitoring reportedly lasted for long periods. Maureen, a

59 year old mother of 3 diagnosed with breast cancer, stage not known, explained the following:

“But the lump sat there. I look at the lump and I feel the lump and I see that the lump is getting larger. And the lump is getting bigger and it made a hell of a big lump”(translated)

Some participants monitored their symptoms daily, noticing increases in the size of the lump or the appearance of additional symptoms such as skin dimpling and nipple excretion. Participants reported that they were alerted to the possible seriousness of the breast symptom when additional symptoms surfaced as stated by the following participant:

“Then I was in a shower one day and I got a stabbing pain again and when I looked down there was blood coming out of my nipple and I immediately knew then that it was cancer. In my heart I knew it was cancer.” (Mavs, a 58 year old mother of four, diagnosed with breast cancer, stage not known)

The findings reported above have also been reported in a study by Khakbazan et al. (2014) which found that upon discovering a breast symptom, some women try to identify what the symptom could be and why it appeared in the first place. My finding was similar to that of Khakbazan et al. (2014) that insufficient knowledge of breast cancer led to delayed help-seeking among participants. This is because participants reportedly assessed their breast symptom(s) as something insignificant and not warranting investigation. In this study, this appraisal or labelling of the symptom was based on insufficient knowledge of breast cancer. Moodley, Cairncross, Naicker and Momberg (2015) found that the women in their study, had insufficient knowledge of breast cancer and those women who had family members with breast cancer did not perceive themselves to be at an elevated risk nor did it prompt them to seek early help. In terms of symptom appraisal, Moodley, Cairncross, Naicker & Momberg (2015) found that the absence of additional symptoms like pain gave women a false sense of

reassurance about the unlikely seriousness of the symptom and some women thought that the symptom would just disappear. One very important factor in help-seeking delays is the monitoring of symptoms for persistence and progression (Khakbazan et al., 2014). Some participants in my study reported that they did not pay much attention to their breast symptom(s) as it did not cause them much concern initially. However, those women who actively monitored their symptoms, reportedly did so for prolonged periods. Studies by O'Mahony, McCarthy, Corcoran & Hergarty (2013) and Oshiro et al. (2018) found that the discovery of a breast lump was associated with prompt help-seeking as women easily recognised a breast lump as an indicator of breast cancer. However, in this study participants reportedly delayed help-seeking despite discovering a lump in their breast which means that they did not understand that a lump is associated with breast cancer or that it warranted prompt medical intervention.

4.2.2 Healthcare: Negative perceptions and past misdiagnoses

This theme is related to the perceptions that some participants had of the healthcare system prior to symptom discovery. These perceptions were mostly negative and based on personal and anecdotal accounts from significant others in the lives of the participants. This theme comprises two sub-themes related to the healthcare system. They are (1) negative perceptions of the healthcare system, and (2), secondary patient-related delay after initial help-seeking.

4.2.2.1 Negative perceptions of the healthcare system

This study was conducted at Tygerberg hospital, a state healthcare facility. Most participants only sought treatment for illnesses at state facilities, but some (n=8) reported that they had previously utilized private healthcare facilities but due to financial constraints were forced to seek treatment at Tygerberg hospital. Participants reported that their negative

perceptions about the healthcare system were shaped by personal experiences in the past and accounts of these facilities from family and friends. Some participants stated that they generally avoided seeking diagnosis and treatment from doctors for any illness. The participants who previously sought private healthcare stated that their negative perceptions of public hospitals played a central role in their avoidance of diagnosis and treatment. This is evident in the following statement by Esther, a 63 year old mother of four, diagnosed with stage two breast cancer, who reported that these negative perceptions resulted in her delaying seeking a diagnosis and treatment for nearly two years.

“And then we fell into financial difficulties and we had no more medical aid. And I was scared of the government hospitals. We heard so many horrendous things and it made me scared I didn’t want to go. So I just left it. And a year went by and another year ...” (Esther, a 63 year old mother of two, diagnosed with stage 2 breast cancer)

4.2.2.2 Secondary patient-related delay after initial misdiagnoses

In some cases, participants reported their symptoms to doctors but stated these symptoms were dismissed or overlooked by the doctors. Some of the reported feedback participants received from doctors and nursing staff, after initially seeking help, were negative test results, and misdiagnosis of lumps as abscesses or blocked milk glands. In a couple of cases the women reported that they went back to their doctors more than once and were given the same explanation for their symptoms as before, and sometimes prescribed pain medication or antibiotics. Participants stated that the reassurance given by the medical professionals left them with a sense of relief initially, and then with great disappointment when they were eventually diagnosed with breast cancer. The following quotation illustrates the frustration Maureen, a 59 year old mother of three, diagnosed with breast cancer, experienced regarding the first misdiagnosis:

“If they had told me in the first place (that it was cancer) then I would have had it done (removed). Then it might have only been a small cut in my breast. But when it (the lump) started growing then they had to remove my (entire) breast” (translated)

The following quotation from a 50 year old patient with stage three breast cancer illustrates how after a general practitioner prescribed antibiotics for the breast lump (which she had already monitored for some time), she decided to not go back again resulting in a second delay period.

“... and the 10 days passed and it was still the same and I didn't go back and I didn't tell anybody. I just kept it to myself. I just thought that I am not going to say to my husband that I need to go back. I just left it” (Beulah, a 50 year old mother of two, diagnosed with stage three breast cancer).

Some participants in this study reported that seeing a doctor for past ailments or illness was not something that they did very promptly and this hesitation was either born out of the belief that they were strong women or the fact that they generally do not like doctors and hospitals. A general mistrust of professionals in the healthcare system was found to be a barrier to help-seeking in a study by Shahid et al. (2015), which is in line with sentiments from some participants in this study.

Burgess et al. (2006) found that some women delayed help-seeking due to negative attitudes towards doctor visits, and fear of the consequences of medical procedures (Burgess, Hunter & Ramirez, 2001). In my study, participants reported negative attitudes towards doctor visits but did not report a fear of the consequences of medical procedures prior to their diagnosis.

In some cases, participants reported that their symptoms persisted and worsened but that they held on to previous negative diagnoses that they received for the breast symptoms in the past. This finding is in line with findings of a review by Renzi, Whitaker and Wardle (2014) who found among 15 studies, past benign diagnoses lead to a normalization of symptoms and this in turn cause some women to be hesitant about seeking help again for the same symptom according to Renzi, Whitaker and Wardle (2014).

4.2.3 Social context following symptom discovery

The third theme that emerged from the data is Social context following symptom discovery. The Social context consists of those perceived factors within the social world of women, which influence help-seeking delays. This theme is characterized by the daily living situations of women, their perceived role within the family, family responsibilities and perceived support. These factors influenced decisions regarding the timing of a doctor's visit, the choice on whether to tell someone about the discovered breast symptom and whether a symptom was perceived to be severe enough to alarm or upset the family.

This theme has two subthemes namely (1) Non-disclosure of symptoms, and (2) Disclosure of breast symptoms that led to further help-seeking delays.

4.2.3.1 Non-disclosure of symptoms

Disclosing the discovery of a breast symptom to trusted individuals was important for some participants and this disclosure led to friends or family members encouraging and sometimes insisting on medical intervention. Other participants however reported that they chose not to disclose their breast concerns with the people in their social circle. Reasons for this non-disclosure and delayed help-seeking are varied and some of these are discussed below:

Some participants stated that they chose to focus on other, more pressing events within the family and that they decided to focus on their breast at a later stage. These participants reported that they dedicated their time and energy into caring for others instead of investigating the problem in their breast. Taking care of sick loved ones was reported as one such reason for non-disclosure and delay. This is illustrated by the following account by Brenda, a 64 year old mother of one diagnosed with breast cancer, stage not known:

“...and at this time my husband was sick, very sick, and I took care of him with everything, I cannot still deal with my thing (breast). So I placed him first. Then I thought if I can at least help him then when he is well, he can help me again. The time wasn't right. I have to look after my husband... I'll rather remain silent and do it myself”(translated)

The sense of responsibility toward family members, especially caring for young children played a role in help-seeking delays as reported by some participants. One participant explained that she was the only one who could look after her autistic grandchild, while another had to look after her own children and two others whom she was fostering. Participants described events such as finding schools for their children to attend, helping children move to boarding school or simply just feeling a sense of being responsible for everything in the home, as it pertains to children, as being an important reason why they could not focus on their own breast symptoms at the time. Participants stated that they intended seeking medical help once they had things in place for the children. This is explained in the following statement by Jessica, a 46 year old mom of two diagnosed with breast cancer, stage not known):

“The lump just got bigger from December month and since Christmas. I thought that I would first focus on my children and make sure that they are enrolled in crèche because we

had recently moved there. When I got them place in school, then I began focusing on myself because the lump bothered me, because it grew larger”(translated)

Some participants reported that they were experiencing marital discord and had difficulty telling their partners about their symptom discovery because they reportedly thought that the partner would not understand or would not care. Other participants who were married reported that they did not tell their partners as they felt that men in general would not fully understand the situation. When partners were not available, some participants described how they tried to figure out who they could possibly tell. This type of scenario is clearly illustrated by the following statement by Sunet, a 48 year old mother of three, diagnosed with stage one breast cancer:

“Yeah who am I going to tell? Who am I telling this? My husband who is having an affair with a 30 year old girl? He’s not going to listen. My mother in law? I don’t think so. My children? – don’t upset them, its Christmas.”

Some participants described how they would sit in the company of family and friends and not mention a word about what they were experiencing. In some cases this non-disclosure was reportedly informed by a perceived deficit of people to trust and fears about rumors being spread about them within in the community.

“And I thought that I need to get to a doctor, but who am I going to take into my confidence because I don’t want people to talk about it because the one tells the other one and that one tells another and in the end its not even the correct story at all” (Brenda, a 64 year old mother of one, diagnosed with breast cancer, stage not known) (translated)

4.2.3.2 Disclosure of symptoms that led to further help-seeking delays

Confiding in someone about the breast symptom did not always have the same outcome for all participants. In a few cases, participants confided in close friends who immediately dismissed their fears and tried to reassure them that the breast symptom was not something to worry about. One participant described how she immediately informed her daughter about the lump because she had a friend who had been diagnosed not long before that and she thought that her own lump surely meant that she had cancer too:

“Like I said, my daughter said “mommy, I think you are silly. Just because aunty XXX has it (cancer), does not mean that you have it. It is all in your mind”. I left it at that...”
(Mavs, a 58 year old mom of four diagnosed with breast cancer, stage not known)

Participants reported that they described their symptoms and fears to others and that they were told that they were imagining things and that it is not something they should be worrying about. Some participants recalled how they delayed going to the doctor based on the information and reassurance they received from others. The following account illustrates how symptom disclosure can contribute towards delayed help-seeking.

“Immediately I phoned one of my friends and she said to me “oh man, don’t worry, I have had a lump (in my breast) for an entire year” and I said “are you sure?” She said, you are going to worry about nonsense”. I blocked it (the lump) out” (Delmaine, a 43 year old mother of two, diagnosed with stage two breast cancer) (translated in part)

Some participants in this study actively sought advice from those close to them, which ultimately led to help-seeking. This is in line with findings from Lam et al., 2008 and O’Mahony, McCarthy, Corcoran & Hegarty (2013) who found that symptom disclosure to another person facilitates help-seeking. However other participants in this study did not

disclose their symptoms, for various reasons, often related to family dynamics such as problematic marital situations, sick loved ones, pressing needs of children and lack of someone to confide in, which added to longer delay periods, and this non-disclosure was found to have contributed to longer delays in other studies (Oshiro & Kamizato, 2018 & Burgess et al., 2006). Participants in this study reportedly delayed seeking help when they considered their family situation at the time of symptom discovery especially in cases when these circumstances were perceived to be unfavorable to the disclosure and investigation of the breast symptom(s). A similar finding was made in a study by O'Mahony, McCarthy, Corcoran & Hegarty (2013). Burgess et al. (2006) found that non-disclosure leads to long delays especially in the case of older women. Symptom disclosure plays an ambiguous function in women's help-seeking experiences. Competing demands in the daily lives of the participants in this study created a sense that their own health needs could not be seen to immediately and this help-seeking barrier was also found in another study by Shahid et al (2015). Another group of participants confided in those close to them about their breast symptoms and reported that the feedback they received confirmed their beliefs that the breast symptom was not cancer related. This finding is in line with a finding by Unger-Saldana & Infante-Castaneda (2011) that symptom disclosure leads to the reaffirmation of the misattributed symptoms which hampers prompt help-seeking.

4.3 Using theory to make sense of the results

To develop an understanding of the above results, I used two theories as guidance. According to Leventhal, Phillips and Burns (2016) the Common-Sense Model of Self-Regulation (CSM) is a useful framework for exploring the “conceptual, behavioral and cognitive processes” involved in the self-management of illnesses or illness threats (Leventhal, Philips & Burns, 2016 p. 935). The CSM model proposes that once an individual becomes aware of an illness threat, such as the discovery of a breast lump, the individual uses

mental pictures stored in memory about what that breast lump could indicate. The mental picture of what an illness is consists of all the information gathered over the lifetime about the disease. This information comes from various experiences of the disease such as cultural and social narratives about the disease as well as information received from knowledgeable figures like health professionals (Hagger & Orbell, 2003). Once an understanding of the significance of an illness threat has been formulated the individual formulates an action plan on how to deal with the threat, such as seeking help and adhering to treatment (Leventhal, Philips & Burns, 2016).

The results show that many of the participants lacked the baseline knowledge about breast cancer against which to compare their breast symptom and therefore instead of seeking help, they entered in to a period of combined assessment and monitoring. According to Hagger & Orbell (2003) as soon as a health threat arises there is an immediate assessment of the severity of the threat. Many of the participants in this study did not appreciate the severity of the breast symptom causing some participants to believe that it would simply go away. Many of the participants also helped their understanding of their symptoms by searching for answers from individuals in their social circle. These individuals advised the participants based on their own mental pictures or understanding of what a breast lump could mean. According to Hale, Treharne & Kitas (2007) when patients embarked on a treatment plan they create an expected timeline as to when the medication should start working or when they should start to feel better. They essentially monitor the body for feedback. In the case of these participants they had some idea that the breast lump would not last long and the feedback they received in terms of persistence and progression would then inform the next action plan such as disclosing the symptoms to someone else.

Bronfenbrenner (1979) illustrates how different levels of an individual's environment interact and affects that individual. The home, school, work, community and societal

structures can all affect an individual's on a personal level (Bronfenbrenner, 1979). Breast cancer is a complex disease with many different biological and environmental contributory factors (Schettler, 2013). The WHO lists many factors which may place women at increased risk of developing breast cancer and these include, obesity, physical inactivity, late onset of menses and the use of alcohol and tobacco products (WHO, 2013). Environmental factors such as stress or lack of access to healthy food can influence the development of breast cancer. In order to be healthy one needs regular access to healthy food, safe living environment that allows for physical activities such as running or walking as well as ways to manage stress. The environment plays an important role on the health of the individual. Breast cancer is a disease of communities, not just the individual (Schettler, 2013). Schettler (2013) suggests that breast cancer is a result of the societies which we design.

Family history and genetic factors to breast cancer can predispose women to developing the disease. If this predisposition is coupled with a stressful and unhealthy lifestyle then diseases such as breast cancer can flourish. A breast cancer diagnosis can have a negative ripple effect on the patient and her immediate and wider social environment. This anticipated ripple effect may be the reason why certain women refuse to address their discovered breast symptoms. If we look at the personal-environmental or social aspects of the participants in this study from a systems perspective then one can see that many of the participants made health decisions, that is decisions about delaying help-seeking, based on what was happening in their environment, especially the home. The home environment in terms of support, marital relationships, roles and responsibilities, treatment concerns as well as fears about death and how it would affect the family, all affected participants in different ways on a personal level which led to delayed help-seeking.

4.4 Conclusion

The primary focus of this research was to explore reasons why women delay seeking help for symptomatic breast cancer. I aimed to uncover the personal and structural barriers which contribute towards such delays. This study focused on female breast cancer patients with self-discovered breast symptoms attending the outpatient breast clinic at Tygerberg hospital in Cape Town. Tygerberg hospital is a public hospital and the reality is that the breast clinic operates on a referral system and the waiting periods can be very long.

Although not the case for everyone, the majority of people who utilize services at hospitals such as Tygerberg do not have private medical cover. For this reason I initially expected to encounter many stories of financial barriers to help-seeking. I expected to hear stories about lack of transport, or work conditions which do not allow time off, or unavailability of funds to visit a doctor; however this was not the case. The participants in this study who reported that they were employed at the time of symptom discovery, indicated that they could have gone to the doctor if they had asked for time off from work. I asked the participants about barriers such as financial constraints, work constraints, distance to healthcare facilities or access to medical care contributed to help-seeking delays. Some of their responses are listed below:

“Luckily I live near the hospital. I live near to Tygerberg hospital. So I just walk there because it is something like a 10 minute walk. But luckily transport is not a problem because we have a car... and my husband has a steady job” (Marilyn, a 36 year old mother of two diagnosed with breast cancer(translated)

“No, we are close to the hospital, within walking distance and if you don't have money then the employer gives you a letter to go the doctor”(Nadia, a 45 year old mother of three disganosed with breast cancer) (translated)

“No. I am close to the doctors. Walking distance” (Bernie, a 57 year old mother of 3 children diagnosed with breast cancer) (translated)

“I could have gone (to the doctor).... It’s not the job. Definitely, the company I worked for, was very understanding “(Mavs, a mother of four, diagnosed with breast cancer)

The statements listed above exclude structural barriers such as distance to medical facility from the list of reasons why some participants did not seek help immediately. For these participants, other more pertinent reasons such as fear, misunderstanding of symptom severity and dislike of hospitals are what influenced prompt help-seeking.

Dickens et al. (2014) found that advanced stage at diagnosis increased as travel distance from patient’s homes to hospital increased however distance from hospitals and access to hospitals were not reported as factors in help-seeking delays in my study even though some participants did reside in rural areas.

Lack of breast cancer knowledge, negative attitudes toward the healthcare system and the social context of women were identified as barriers to help-seeking for the participants in this study. Participants did not know about early detection and intervention and many participants did not know that breast cancer could be cured. Such health messages had simply not reached them in any meaningful way. I concluded this chapter using the Common-Sense Model of Self-Regulation and Bronfenbrenner’s ecological systems theory to create an understanding of the results.

Chapter 5

Conclusions, Limitations, Recommendations and Further research

5.1 Conclusions

In this chapter I will provide a concluding overview of this study. I will also discuss the limitations of this study and make some recommendations for future research, practice and policy. I start the chapter by detailing the main objectives of the study.

5.1.1 The main objectives of this study

5.1.1.1 Exploring the personal barriers to help-seeking for symptomatic breast cancer

The first objective of this study was to explore the personal barriers to help-seeking for symptomatic breast cancer. I met this objective by using the interview schedule as a guide and creating a safe interview space where the participants were comfortable and forthcoming about their delay experience after the discovery of a breast symptom. The participants used this opportunity to reflect on their thoughts and actions during the delay period. For many participants it was their first time speaking about these events in a systematic way as I prompted them to remember dates and events to jog their memories. This objective was met during data collection and the evidence for this can be clearly seen in my results and discussion chapter (see Chapter Four).

Chapter four shows that most participants in this study had insufficient knowledge of breast cancer in general and breast cancer symptoms more specifically. Most participants delayed for long periods while they assessed the breast symptom for persistence and change. Many of the participants did not believe their breast symptom to be serious nor were they concerned about the presence of the symptoms. The reason why many participants were not sufficiently concerned about the breast symptom was because they had linked the cause of the

breast symptom to breast feeding, miscarriage, age, and blocked milk ducts. Most participants had difficulty deciding when to seek help. The addition of other symptoms such as changes in the appearance of the skin or excretion from the nipple alerted some women to the possible seriousness of the breast symptom(s).

Insufficient knowledge and in some cases a total lack of knowledge was a major contributor to why participants did not believe their symptoms were related to breast cancer. Misunderstanding of the risk factors led some participants to believe that they could not be at risk for developing the disease if it had never been diagnosed within their family.

Another barrier to help-seeking for some participants in the study was their own negative perceptions about the healthcare system. These perceptions were based on personal experiences which they had of past illness, operations and procedures in medical settings. Some participants reported that their negative perceptions of the healthcare system were based on what other people told them about public hospitals. Other participants, who previously had access to private healthcare, were hesitant to seek help at public medical facilities based on their negative views of such facilities.

The social context of participants was an important barrier to help-seeking. The roles women held in the family and the perceived responsibilities that goes along with those roles and responsibilities were contributing factors to late presentation. Participants considered the needs of other members in the family when making health decisions. Placing the immediate needs of family members, above their own health needs was common amongst the women in this study.

Perceived support within the immediate family and wider social circles of women were considered amongst participants when making decisions about symptom disclosure. Disclosure to trusted individuals prompted some participants to seek help. However amongst

other participants the feedback received following disclosure caused them to delay seeking help for the breast symptoms. The contribution of the social lives of women to their help-seeking delays was an important finding in this study.

5.1.1.2 Exploring the structural barriers to help-seeking for symptomatic breast cancer

The second objective of this study was to explore the structural barriers to help-seeking for symptomatic breast cancer. I had hoped to explore all those factors which were outside the control of the participants, which may have prevented them from seeking help promptly. I investigated whether structural barriers existed and contributed towards delayed help-seeking for the participants in this study. I explained to the participants what structural barriers are and found that barriers such as access to hospitals or work-related constraints were not contributing factors in their delay experience.

This study has shown that access to finance, access to hospitals, time-off from work and distance to medical facilities were not contributing factors and therefore not barriers to help-seeking for many of the participants. Two participants stated that they felt that the money spent on going to a doctor would be a wasteful expenditure and could be utilized better in the home. In these two cases, limited access to money was not the cause for the delay. Instead, participants thought that the doctor's consultation fee was a waste of money and outweighed the possible benefits of seeking help. Most participants stated that they could indeed have accessed a hospital and could have arranged time off from work to go to a doctor therefore these structural factors were not barriers to help-seeking for symptomatic breast cancer in this study

5.2 Two theories that helped to frame the research

This study was framed using the Common-Sense Model of Self-Regulation (CSM) and Bronfenbrenner's Ecological Systems theory. The CSM provided a useful framework for understanding how an individual may respond to an illness threat once such a threat has been discovered, and in this study, that threat is the breast symptom. The CSM was then used to understand that the individual will have some sort of emotional response to the threat and how such an individual will create certain perceptions of what the threat could be. Using the CSM in this study helped me to understand why patients entered a period of assessing and monitoring of their symptom(s). This assessing and monitoring allowed the participants some time to try and figure out what to do next. The changes in the initial symptom, as well as the persistence and progression of the symptom, acted as feedback which then caused participants to re-evaluate their initial assessment in order to decide what future steps to take in terms of help-seeking.

Social context following symptom discovery was an important theme which emerged during the analysis of the data. Therefore, the use of Bronfenbrenner's Ecological Systems Theory was important theory to understand the interplay between the individual participant and her social environment and how cues received from the immediate and wider social circles could have important effects on the individual on a personal level. The limited knowledge that some participants had of breast cancer was also obtained through family and community interactions. The combination of these two theories was a useful lens through which I viewed this study (see Chapter 2).

5.3 Limitations of this study

The first limitation of this study is that it was retrospective in nature and required patients to think back to the very first time they discovered a breast symptom. Many participants had gone through many tests and treatments since the symptom discovery and had to apply their minds and think back to the first time they noticed something wrong with their breast. I found most of the participants to be good historians who were able to link important dates such as birthdays and holidays to remember dates around the time of symptom discovery. However, some participants had more difficulty remembering actual dates and required more guidance in this regard.

The second limitation was that the interviews were only conducted in English and Afrikaans, which excluded those patients who spoke other languages and who were not confident or comfortable to be interviewed in these two languages.

The third limitation is that this study was only conducted at one public health facility and did not include other public and private sector breast clinics.

5. 4 Recommendations

5.4.1 Recommendations for researchers conducting similar studies

In order to mitigate recall bias from participants, future researchers, who wish to conduct studies on delayed presentation should aim to select patients who are possibly just near the end of their treatment regime and who have not had too many years since symptom discovery and the actual data collection.

To ensure that future research is more representative of the population in the Western Cape, future studies should include other African languages such as isiXhosa in order to get perspectives from African language speaking participants.

5.4.2 Recommendations for practice and policy

As a direct result of this study I suggest that greater effort needs to be made to disseminate information about breast cancer within primary health care clinics and community centers. Clear and direct messages about the various types of symptoms to look out for and what to do when such symptoms are discovered should be broadcast in simple language to both urban and rural women in languages that they can understand.

Some participants in this study reported that their negative views of the healthcare system contributed to the reasons why they delayed seeking help. Non-clinical screening facilities should therefore be made available to women. Breast screening could be done in the same way that the South African Blood Service makes use of mobile points for blood donations. Screening could take place in private rooms at libraries, shopping centers and pharmacies, which might feel less threatening to those women who struggle with hospital visits.

5.5 Further Research

Many participants in this study had insufficient knowledge of breast cancer with some claiming that they knew nothing about the disease. Negative views of the healthcare system, fear-provoking narratives about cancer within communities and incorrect diagnoses made at primary healthcare facilities, are all factors which contributed towards delayed presentation in this study. Based on the above, future research could explore the following:

The participants in this study could not make informed decisions about their breast symptom(s) as they did not possess the required knowledge to make correct assessments of the seriousness of the breast problem. Future research could explore whether current breast health campaigns are reaching the intended population?

Some participants in this study resisted going to the hospital as they had previous bad experiences with the healthcare system. In order to mitigate that fear, screening services could be moved outside of hospital settings. Future research could therefore investigate whether mobile breast screening services could be utilized to reduce help-seeking delays?

Some participants in this study sought medical help at primary healthcare clinics and were advised that their breast lumps were blocked milk ducts or abscesses, which led to further help-seeking delays. Future research could investigate whether primary health care professionals are adequately trained to perform clinical breast exams?

5.6 Conclusion

In conclusion, this study has shown that a lack of breast cancer knowledge led to delayed presentation as women tried to make sense of what their breast symptom could indicate. Secondly, participants reported that their negative views of the healthcare system deterred them from seeking help sooner. Lastly the social contexts of women following symptom discovery played a role in their delay experiences especially as it pertains to family roles and responsibilities, non-disclosure, and the feedback received after symptom disclosure.

These barriers indicate a need for focused breast cancer education programs within communities and primary healthcare facilities. The 25 women who participated in this study, delayed help-seeking after symptom discovery and were subsequently diagnosed with breast cancer. The findings of the study might provide some input to governmental policies and health promotion campaigns which aim to reduce delayed presentation for breast cancer in women.

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Appendix A: Interview Schedule

Exploring delays to seeking treatment among patients presenting late for breast cancer treatment at the Tygerberg Breast Hospital

Interview schedule

I am going to ask you a few questions about your experience with breast cancer. Please take your time to answer the questions, providing as much or as little information as you feel comfortable sharing. The information that you share will be treated as confidential. If at any time you would like to end this interview you are free to do so.

1. Can you tell me about your experience with breast cancer?
2. Can you tell me about your diagnosis?
3. What were the events that lead up to your diagnosis?
4. When did you first suspect that something was wrong? Can you tell me more about this? What were your thoughts, concerns, feelings and fears?
5. Can you tell me a bit about why you waited before consulting with a health professional about your concerns? What were the structural issues? What were the personal issues?
6. Looking back, is there anything that you wish you would have done differently relating to seeking help?

Appendix B: Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Exploring delays to help-seeking among patients presenting late for symptomatic breast cancer at the Tygerberg Hospital.

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Professor SA Kagee

CO-INVESTIGATORS: Ms. R. Roomaney and Claudia Swinny

ADDRESS: Psychology Department, Wilcox Building, Ryneveld Street, Stellenbosch, 7600

CONTACT NUMBER: 0218083442 / 0218083973

You are being invited to participate in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher or staff at the healthcare facility where you found this information leaflet any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The focus of the proposed study is to explore the reasons why women delay seeking help for symptomatic breast cancer and to understand the barriers which cause such delays. This will be the focus of the interview in which you will take part.

The research project will be conducted at Breast Clinic and the Radiotherapy Centre in the Division of Radiation Oncology at Stellenbosch University and Tygerberg Hospital. If you agree to participate, you will be asked to participate in a confidential interview as part of the study. The interview will be conducted by a trained research assistant and will be audio recorded. The interview will take between 30 and 60 minutes to complete. All information will be confidential.

Who may participate in this study?

In order to participate in the study you should be able to speak and understand English well enough to allow for informed consent and be interviewed. Interviews may also be conducted in Afrikaans, should you wish to do so. You also need to be diagnosed with breast cancer and be receiving treatment at the breast clinic. Patients diagnosed with any other serious acute or chronic illness may not participate in the study. You should be 18 years or older in order to participate.

Will you benefit from taking part in this research?

There are no direct benefits associated with participating in this study.

Are there in risks involved in your taking part in this research?

There are no known risks to participating in this study. Should you have any concerns do not hesitate to contact the researcher. Should you feel distressed during the interview, please inform the interviewer who will refer you to a counselling centre. If you feel distressed after the interview then please contact the numbers for support given below.

Who will have access to your medical records?

The researchers will have access to your medical records. Cancer-specific information will be obtained from chart notes and consultation with the oncology staff. This information will include staging of cancer, date of diagnosis, occurrence and date of detected metastases and recurrences, treatment plan, current treatment stage, prognosis and medication prescription across the course of treatment.

This study is being conducted independently of the healthcare facility through which you are recruited and does not in any way affect your ongoing treatment at the facility.

All information collected will remain confidential. Only the researchers will have direct access to the data. All persons handling data will be required to sign confidentiality agreements. Any information that may lead to the identification of participants will be removed when disseminating the research. The Stellenbosch University researchers will be working with a researcher at the Free University of Berlin, Professor Nina Knoll. In the event that data from this study will be shared with Professor Knoll, all names and identifying information will be removed.

Will you be paid to take part in this study and are there any costs involved?

You will not be paid to take part in the study.

Is there anything else that you should know or do?

- If you feel distressed please contact our counselling centre (Welgavallen) at 0218082944 or the Trauma Centre for Survivors of Violence and Torture at 0214657373
- If you would like more information about this study please contact the Principal Investigator (Prof. Kagee) at 0218083442 or Co-investigator (Ms. Roomaney) at 0218083973.

- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*insert title of study*).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*)

Signature of participant **Signature of witness**

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*)

Signature of investigator Signature of witness

Consent to confirm diagnosis

I hereby grant permission to the researchers to contact my doctor/nurse to obtain information form my medical records.

Signature of patient.....

Appendix C: HREC Approval



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY
Job kennisverreik • your knowledge primer

Approved with Stipulations Response to Deferral

04-Dec-2015
Kagoo, Shaheen SA

Ethics Reference #: N15/08/077

Title: Psychosocial aspects of breast cancer treatment.

Dear Prof Shaheen Kagoo,

The Response to Deferral - (*New Application*) received on 03-Nov-2015, was reviewed by Health Research Ethics Committee 1 via Committee Review procedures on 03-Dec-2015.

Please note the following information about your approved research protocol:

Protocol Approval Period: 03-Dec-2015 -02-Dec-2016

Present Committee Members:

Abulfaizi, Ahmed AA
Els, Petrus PJJS
Farris, William WF
Hall, David DR
Hook, Kim KGP
Keams, Elaine E
Lachman, Anusha A
Philander, Cynthia C
Potgieter, Sumita S
Rohland, Elvira EL
Weber, Franklin CFS
Welzel, Tyson T
Werely, Cedric CJ

The Stipulations of your ethics approval are as follows:

Kindly note that when data is shared with another institution there should be an agreement in place to protect your intellectual property rights.

Please remember to use your **protocol number** (N15/08/077) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rdc and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes

2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthrec@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rda

If you have any questions or need further assistance, please contact the HREC office at 0219389657.

Included Documents:

Budget
 Interview schedule 2
 Duke functional social support questionnaire
 Application form_signature page
 Declaration N Knoll
 Demographic information
 FACT_B Version 4
 Declaration J Githaiga
 Flyer
 Hopkins symptom checklist
 CV N Knoll
 Center for Epidemiologic Studies Depression Scale
 Medical Information extraction form
 20151103 DEF Protocol
 20151103 DEF Consent quantitative study
 CV R Roomaney
 CV S Kagee
 Interview schedule 4
 Checklist
 CV J Githaiga
 Declaration R Roomaney
 Patient questionnaire
 Protocol
 Payment exemption request
 Benefit finding scale for breast cancer
 Article - brief cope
 Consent form quantitative study
 Brief pain inventory
 20151103 DEF Consent qualitative study
 Brief illness perception questionnaire
 Application form
 Breast cancer therapy adherence questionnaire
 20151103 DEF Cover letter
 Breast impact of treatment scale
 Questionnaire
 Declaration S Kagee
 Interview schedule 3
 Consent form qualitative study
 Interview schedule 1
 Protocol Synopsis

Sincerely,

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.

2. Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.

3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.

4. Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur**. If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.

5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.

6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HREC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating Procedures www.sun.ac.za/portal/Agency/Health_Sciences/Eng/Hub/Centres/20/vars/PS/20/Institutions/Research_Development_Support/Ethics/Application_package. All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.

7. Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC.

8. Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.

9. Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.

10. Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.

11. On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

Appendix D: HREC Extension Letter



HEALTH RESEARCH ETHICS COMMITTEE
HEALTH RESEARCH ETHICS COMMITTEE

Ethics Letter

30 January 2018

Ethics Reference #: N15/08/077

Title: Psychosocial aspects of breast cancer treatment.

Dear Prof Shaheen Kagee

The Health Research Ethics Committee reviewed and approved the annual progress report you submitted through an expedited review process.

Progress Report dated 16 January 2018

The approval of this project is extended for a further year.

Approval date: 30 January 2018

Expiry date: 29 January 2019

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation:

Kindly submit **ONE HARD COPY** to Elvira Rahlenc, RDSU, Room 5037, Teaching Building and **ONE ELECTRONIC COPY** to ethics@sun.ac.za.

Please remember to use your **protocol number (N15/08/077)** on any documents or correspondence with the HREC concerning your research protocol.

Federal Wide Assurance Number: 00001372

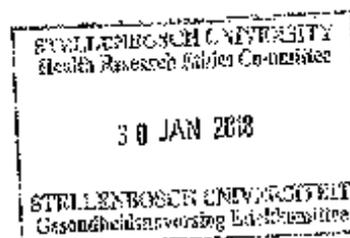
Institutional Review Board (IRB) Number: IRB0005240 for HREC1

Institutional Review Board (IRB) Number: IRB0005239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles, Structures and Processes 2015 (Department of Health).

Yours sincerely,

Ashleen Fortuin
HREC Administrator
Health Research Ethics Committee 1



Fakulteit Geneeskunde en Geesteswetenskappe
Faculty of Medicine and Health Sciences



Modelle van Nursingontwikkeling en -Opleiding, Research Development and Support Opleiding

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