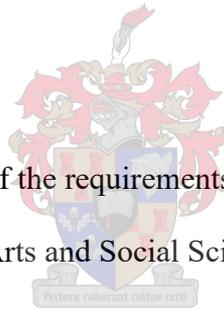


Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape

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Thesis presented in fulfilment of the requirements for the degree of Master of Arts (Psychology) in the Faculty of Arts and Social Sciences at Stellenbosch University.



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April 2022

DECLARATION

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ABSTRACT

Worldwide, breast cancer is the most commonly diagnosed cancer as well as the leading cause of cancer-related death among women. The estimated incidence of breast cancer is expected to rise, with the majority of breast cancer cases occurring among women in low and middle-income countries (LMIC) such as South Africa, where adherence to treatment for cancer remains a challenge. Adherence to treatment for cancer is essential in order for breast cancer patients to achieve optimal health and treatment outcomes. In South Africa, factors that affect adherence to intravenous chemotherapy, one of three treatment options available to breast cancer patients, have not been well-documented within the literature.

The qualitative research study reported on here is an effort to explore the factors that influence adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape, South Africa. The perspectives of breast cancer patients, family members and healthcare workers, including doctors and nurses from the breast clinic and chemotherapy unit at the tertiary hospital, have been elicited. Participants in the present study included nine breast cancer patients, three family members and eight healthcare workers. Using semi-structured interviews, data describing participants' perspectives of the adherence-related factors of patients were collected. Through the lens of the Ecological Systems Theory (EST), nine main themes and 21 sub-themes were identified and interpreted using thematic analysis and a qualitative software programme. The most salient barriers to adherence identified at the microsystem level were treatment side effects and transport and finances. The most salient facilitators of adherence to treatment were patients' self-motivation to complete treatment as well as symptom improvement as a result of chemotherapy. The most salient barriers identified at the mesosystem level was lack of social support and the most salient facilitators of adherence were shown to be social support received from relatives and

friends as well as healthcare workers. At the exosystemic level, the most salient barrier to adherence was lack of oncology-trained staff and the most salient facilitators of adherence were the fee subsidy and hospital transport.

The research study's findings demonstrated that breast cancer patients' adherence to treatment was shaped and influenced by their interactions with family, friends, healthcare workers as well as poverty-related and institution-related factors. Patients' understanding, knowledge and access to information regarding breast cancer and its treatment mechanisms also served as important determinants of adherence.

OPSOMMING

Wêreldwyd is borskanker die mees algemene kanker wat by vroue gediagnoseer word en is ook die belangrikste oorsaak van kanker-verwante sterftes. Daar word verwag dat die voorkoms van borskanker sal verhoog, met die oorgrote meerderheid van borskanker gevalle in lae- en middel inkomste (LMIL) lande soos Suid-Afrika, waar volhouding met kankerbehandeling 'n uitdaging bly. Om optimale gesondheids- en behandelingsuitkomstes vir borskankerpasiënte te bereik is behandelingsvolhouding baie belangrik. In Suid-Afrika word die faktore wat die volhouding van binne-aarse chemoterapie (een van drie behandelingsopsies beskikbaar vir borskankerpasiënte) beïnvloed nie goed in die literatuur gedokumenteer nie.

Die kwalitatiewe navorsingstuk waaroor hier verslag gedoen word is 'n poging tot die ondersoek van die faktore wat die volhouding van binne-aarse chemoterapeutiese behandeling onder borskankerpasiënte by 'n opleidingshospitaal in die Wes-Kaap in Suid-Afrika beïnvloed. Die perspektiewe van borskankerpasiënte, familieledede en gesondheidswerkers (insluitende dokters en verpleegsters van die borskliniek en chemoterapie-eenheid by die opleidingshospitaal) is vasgestel. Nege borskankerpasiënte, drie familieledede en agt gesondheidswerkers het aan die navorsing deelgeneem. Semi-gestruktureerde onderhoude is gebruik om data oor die beskrywing van die deelnemers se perspektiewe aangaande volhoudingsverwante faktore te versamel. Deur die lens van die Ekologiese Stelselteorie (EST) is tematiese ontleding met die behulp van 'n kwalitatiewe rekenaarprogrammatuur gebruik om nege hooftemas en 21 sub-temas uit te ken en interpreteer. Die opvallendste hindernis vir volhouding van behandeling op die mikrosisteemvlak blyk behandelingsnuwe-effekte, vervoer en finansies te wees. Die uitstaande fasiliteerders vir behandelingsvolhouding was die pasiënt se self-motivering om

die behandeling te voltooi asook die verbetering van simptome as gevolg van die chemoterapie.

Op die mesosisteesvlak is die mees opvallende hindernisse ten opsigte van behandelingsvolhouding 'n gebrek aan sosiale ondersteuning en die duidelikste fasiliteerders was sosiale ondersteuning van familie, vriende en gesondheidswerkers. Op die eksosisteesvlak is bevind dat die belangrikste rede vir volhoudingsversuim die gebrek aan onkologie-opgeleide personeel was en die bydraende fasiliteerders tot sodanige versuim, die tariefsubsidie en die vervoer na en van die hospitaal was.

Die bevindings van hierdie navorsingstuk toon aan dat versuim tot volgehoue behandeling onder borskankerpatiënte veroorsaak en beïnvloed word deur hulle interaksie met familie, vriende en gesondheidswerkers, sowel as deur armoede- en faktore verwant aan die behandelingsinrigting. Die pasiënte se insig in, kennis van en toegang tot inligting aangaande borskanker en die behandelingswyses daarvan, dien ook as belangrike bepalers van behandelingsvolhouding

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LIST OF ABBREVIATIONS

BP	Breast Patient
BRCA 1/2	BReast CAncer gene 1/2
CAF	Doxorubicin (Adriamycin)
CEF	Epirubicin
CMF	Methotrexate
COVID-19	Coronavirus Disease 2019
DoH	Department of Health
ER	Estrogen
EST	Ecological Systems Theory
GLOBOCAN	Global Cancer Incidence, Mortality and Prevalence
HCT	Health Care Team
HER2	Human Epidermal growth factor Receptor 2
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HREC	Health Research Ethics Committee
LMIC	Low- and Middle-Income Countries
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NICD	National Institute for Communicable Diseases
P	Participant
PR	Progesterone
REC	Research Ethics Committee
SES	Socioeconomic Status
SMS	Short Message Service

SSA	sub-Saharan Africa
VOiP	Voice Over internet Protocol
WHO	World Health Organisation

GLOSSARY OF TERMS

Adherence	The extent to which a person's behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice
Breast Cancer	Disease in which cells in the breast grow out of control.
Cancer stage (I-IV)	Describes whether the cancer has spread to the lymph nodes as well as other parts of the body and indicates the size of the primary tumour. Individuals with stage I, II and some stage III are classified as having early-stage breast cancer. Individuals with some stage III and IV are classified as having advanced-stage or metastatic cancer.
Chemotherapy	Any drug used to kill cancer cells by eliminating the cancer cells' ability to proliferate and metastasize
Core biopsy	Extraction of a tissue sample from breast mass or lump
Cytology	Examination of single or clusters of cells in order to determine cancer diagnosis
Fine Needle Aspiration	Extraction of cell or fluid sample via a needle from breast mass or lump
Histology	Microscopic examination of suspected tissue in order to determine cancer diagnosis
Intravenous chemotherapy	Intravenous chemotherapy entails the injection of chemotherapy drugs via a vein in to the patient's blood stream
Mastectomy	Surgical removal of the entire breast

LIST OF OUTPUTS

1. Kepkey, B. B., Coetzee, B. J., Edge, J., & Kagee, A. (2021, September 7-9). *Factors influencing adherence to intravenous chemotherapy amongst breast cancer patients at a tertiary hospital in the Western Cape* [Conference session]. 7th Southern African Students Psychology Conference, Virtual Conference hosted by UNISA.
2. Kepkey, B. B., Coetzee, B. J., Edge, J., & Kagee, A. (2021, October 16). *Factors influencing adherence to intravenous chemotherapy amongst breast cancer patients at a tertiary hospital in the Western Cape* [Conference session]. BIGOSA [Breast Interest Group of Southern Africa] 2021 Virtual Scientific Meeting, Virtual Conference.

CHAPTER 1

INTRODUCTION

Cancer is one of the leading causes of mortality worldwide with its incidence expected to increase, especially in low- and middle-income countries (LMIC) (Bloom et al., 2011; Lince-Deroche et al., 2017). According to the Global Cancer Incidence, Mortality and Prevalence (GLOBOCAN) 2020, breast cancer has surpassed lung cancer as the most commonly diagnosed cancer worldwide accounting for 11.7% of total cases (Sung et al., 2021). More women are affected by this non-communicable disease than men (World Health Organisation [WHO], 2014). Globally amongst women, breast cancer is the most commonly diagnosed cancer as well as the leading cause of cancer-related death (Sung et al., 2021).

In South Africa, the national Department of Health (DoH) (2017) has identified breast cancer as a national priority as it is the most prevalent cancer as well as the leading cause of death among women. Approximately 115 000 South Africans receive a cancer diagnosis each year, with a cancer survival rate of six out of 10 people (National Institute for Communicable Diseases [NICD], 2014). South Africa's National Cancer Registry (NCR) states that South African women have a 1 in 7 lifetime risk of developing breast, cervical, colorectal, uterus or lung cancer (NICD, 2016). Breast cancer is the most commonly diagnosed cancer amongst South African women with an incidence rate of 35.35 per 100 000 population, and a mortality rate of 8.2 per 100 000 population (NICD, 2017; Sung et al., 2021). The lifetime risk of developing breast cancer among women in South Africa according to the NCR is 1 in 25 (NICD, 2017). The GLOBOCAN 2020 estimates that 108 168 new cancer cases were diagnosed in 2020 of which breast cancer accounted for 14.3% of cases for both sexes, making it the most commonly diagnosed form of cancer in South Africa. Amongst women, breast cancer was also estimated to be the most commonly diagnosed cancer accounting for 27.1% of new cases (Sung et al., 2021).

Adherence to cancer treatment in LMIC such as South Africa remains a challenge (WHO, 2013). Geographic and socio-economic disparities, as well as a focus on communicable diseases has limited access to proper healthcare for many individuals with breast cancer (Cumber et al., 2017; Lince-Deroche et al., 2017). Other factors such as cultural (e.g. traditional healing as an alternative to the prescribed treatment regimen) and economic factors (e.g. low socio-economic level) also affect access to proper healthcare as well as adherence to cancer treatment (Lince-Deroche et al., 2017). Disease factors (e.g. disease severity), patient factors (e.g. beliefs regarding breast cancer), family factors (e.g. support), treatment factors (e.g. adverse effects) and system factors (e.g. relationship with healthcare professionals) all contribute to poor adherence among breast cancer patients (DiMatteo, 2004; Ingwu et al., 2019; Jacobs et al., 2017; Puts et al., 2014; Sabaté, 2003). Chemotherapy, one of three treatment modalities available to cancer patients within South Africa, is used to treat appropriate breast cancer patients. Anthracycline and Taxane-based medication regimens are some of those prescribed, with these and other drugs used to inhibit tumour progression (Breastcancer.org, 2018; DoH, 2017). Knowledge regarding the factors that affect adherence to chemotherapy within the South African context is limited (WHO, 2013) and this study will focus on the factors affecting adherence to intravenous chemotherapy.

In this study I will attempt to identify the barriers and facilitators to adherence to intravenous chemotherapy among breast cancer patients from the perspective of patients, their family members and healthcare professionals. This multi-stakeholder perspective is important as patient medication adherence is strongly influenced by family as well as healthcare provider attitudes (DiMatteo, 2004; Timmers et al., 2017). My study is framed in Bronfenbrenner's Ecological Systems Theory (EST) as it recognizes the individual as embedded within a social system and describes the bidirectional influence of individual,

social, and environmental factors on health behaviours at multiple levels (Bronfenbrenner, 1975; Golden & Earp, 2012; Stokols, 1992).

1.1 Rationale

Within South Africa, breast cancer is the most commonly diagnosed cancer amongst women with its incidence expected to rise (NICD, 2017; Bloom et al., 2011; Lince-Deroche et al., 2017). Adherence to cancer treatment is essential for patients as it allows for optimal benefits and treatment efficacy (Wells et al., 2015). Furthermore, adherence results in several outcomes for breast cancer patients, including increased quality and preservation of life and decreased recurrence of cancer (Kane & Shaya, 2008; Sokol, et al., 2005; Wells et al., 2015). The breast clinic at the tertiary hospital, which is affiliated with Stellenbosch University, serve many patients who are adherent to and complete their cancer treatment. However, healthcare workers at the tertiary hospital have also found that patients come for cancer treatment but then stop due to psychosocial factors and are not treated for two to three years (J. Edge, personal communication, May 3, 2019). When these patients return, often it is because of complication due to the spread of their cancer, and they present with incurable advanced stage cancer (Clegg-Lamprey et al., 2009b; Adisa et al., 2011; J. Edge, personal communication, May 3, 2019). Adherence to chemotherapy amongst breast cancer patients is not a well understood phenomenon in LMIC and therefore knowledge is limited regarding the barriers to and facilitators of adherence to intravenous chemotherapy. The results of this study may also contribute to intervention development, focusing on the improvement of adherence to treatment rates.

I selected a qualitative research design to gain an understanding of the phenomenological perspectives regarding chemotherapy adherence behaviours. I used the EST as it spoke to factors at different systems levels and aided in the purpose of diversity for including the different stakeholders by providing a holistic account of the phenomenon.

Therefore, the results of this study added to knowledge in the field of psychology regarding the factors influencing adherence to intravenous chemotherapy amongst breast cancer patients. Furthermore, the qualitative research design allowed for a rich and detailed narrative to be produced as information was not limited by predetermined questions.

1.2 Aims and objectives

In this study I identified the barriers to and facilitators of adherence to intravenous chemotherapy amongst breast cancer patients at a tertiary hospital in the Western Cape, in South Africa. I used semi-structured interviews to elicit patients', family members' and healthcare workers' perspectives of factors influencing intravenous chemotherapy amongst breast cancer patients.

1.3 Objectives

The objectives of the study were:

- (1) to explore breast cancer patients' perspectives on the barriers to adherence to intravenous chemotherapy,
- (2) to explore breast cancer patients' perspectives on the facilitators of adherence to intravenous chemotherapy,
- (3) to explore family members of breast cancer patients' perspectives on the barriers to intravenous adherence to chemotherapy,
- (4) to explore family members of breast cancer patients' perspectives on the facilitators of adherence to intravenous chemotherapy,
- (5) to explore healthcare workers' perspectives on the barriers to adherence to intravenous chemotherapy, and
- (6) to explore healthcare workers' perspectives on the facilitators of adherence to intravenous chemotherapy.

1.4 Overview of chapters

In Chapter 2, I provide an overview of the cancer burden nationally and globally, breast cancer, its risk factors, treatment, chemotherapy, adherence to medication and chemotherapy and barriers and facilitators that influence adherence to chemotherapy. In Chapter 3, I describe the theoretical framework within which the study is conceptualized. In Chapter 4, I describe the study's methodology including the research design, study setting, recruitment strategy, research participants, data collection methods, data analysis methods, trustworthiness and reflexivity and ethical considerations. In Chapter 5, I report the findings of the study as mapped onto the EST and in Chapter 6 I evaluate and interpret the results of the study including the implications of the results as well as limitations and suggestions for future research.

CHAPTER 2

LITERATURE REVIEW

In this chapter, I provide an overview of the literature regarding the cancer burden worldwide as well as adherence to chemotherapy. I begin by presenting the cancer burden globally, in sub-Saharan Africa and in South Africa. I then present an overview of breast cancer, its risk factors, screening and diagnosis, its treatment and various treatment modalities. I then provide a definition for adherence followed by a discussion of the general factors influencing adherence. I then discuss adherence to oral and intravenous chemotherapy followed by evidence on the existing barriers to and facilitators of adherence to chemotherapy identified in the literature.

2.1 Cancer burden globally

Worldwide, cancer is one of the leading causes of mortality, with its incidence expected to increase, especially in LMIC (Bloom et al., 2011; Lince-Deroche et al., 2017). The GLOBOCAN 2020 estimated 19.3 million new cancer cases and 10 million cancer-related deaths in 2020 (Sung et al., 2021). The number of new cases shows an increase of more than 4 million cancer cases and almost 2 million cancer-related deaths compared to the World Cancer Report in 2014 (WHO, 2014). According to the GLOBOCAN 2020, breast cancer is the most commonly diagnosed cancer having surpassed lung cancer however, lung cancer is still the leading cause of cancer-related deaths accounting for 18% of total deaths compared to breast cancer which is ranked fifth accounting for 6.9% of cancer-related deaths (Sung et al., 2021). Breast cancer is the most commonly diagnosed cancer as well as the leading cause of cancer-related death among women worldwide (Sung et al., 2021). In 2020, 2.3 million new breast cancer cases were reported (Sung et al., 2021), compared to the 2.1 million new cases reported in GLOBOCAN 2018 (Bray et al., 2018), and a dramatic increase from the 1.7 million new cases reported in 2012 (Ferlay et al., 2015). Also, in 2020, other

cancer incidences reported were lung cancer (2.2 million cases), prostate cancer (1.4 million cases), nonmelanoma of skin cancer (1.2 million cases) and colon cancer (1.1 million cases) (Sung et al., 2021).

In both developed and developing countries, breast cancer is one of the top six cancers that explains more than half of the incidence burden (Ferlay et al., 2015; Sung et al., 2021). In 2021, the WHO (2021) stated that approximately 70% of cancer-related deaths occurred in LMIC. The WHO (2013) estimates that by 2025, more than 19.3 million women will be affected by breast cancer, with the majority of women living in sub-Saharan Africa (SSA). Further, globally, breast cancer is the most commonly diagnosed form of cancer in 159 out of 184 countries (Sung et al., 2021), especially among women, as is cervical cancer (Bloom et al., 2011; Lince-Deroche et al., 2017; WHO, 2014; Sung et al., 2021).

2.2 Cancer burden in sub-Saharan Africa

In SSA, breast cancer is the second leading cause of death and the most commonly diagnosed cancer among women (Sung et al., 2021). The highest incidence rates of breast cancer in Africa are found among women in SSA. The prevalence of breast cancer risk factors in SSA have been impacted by considerable changes in sociocultural factors, lifestyle and built environments as a result of growing economies and more women participating in the industrial workforce (Jemal et al., 2012; Sung et al., 2021). Risk factors such as increased levels of excess body weight and physical inactivity, having fewer children as well as the postponement of childbearing have also resulted in a risk factor profile that largely resembles that of western countries (Jemal et al., 2012; Sung et al., 2021). Breast cancer mortality rates in SSA are among the highest in the world which is reflective of poor survival outcomes as a result of weak health infrastructure (Sung et al., 2021). Despite the high incidence rate of breast cancer among women in SSA, the issue is not prioritized as a public health issue. As a result, there are limited data on breast cancer owing to the fact that there is a lack of

screening services, an absence of population-specific cancer registries and competing health demands such as tuberculosis and HIV/AIDs (Jemal et al., 2012). A lack of national cancer registries in most SSA countries means that the true burden and incidence of cancer is not well understood and likely under-reported (Black & Richmond, 2019). Healthcare delivery in many low-income countries in SSA is also impeded by socioeconomic factors such as poor literacy, nutrition, transport and sanitation which is worsened by poor infrastructure and health policies as well as the lack of medical staff (Shulman et al., 2010; Edge et al., 2014; Nelson et al., 2016; Vanderpuye et al., 2019; Lubuzo et al., 2021). Specialist knowledge is required in the management of cancer, a scarce resource in SSA along with a scarcity of essential medications and support services (Edge et al., 2014; Nelson et al., 2016; Vanderpuye et al., 2019).

Cancer treatment as well as other chronic conditions are not covered by national health insurance programs in most countries in Africa and therefore women are obliged to pay for breast cancer screening and treatment (Anyanwu et al., 2011). Younger age at diagnosis is a risk factor among women with breast cancer in SSA compared to high-income countries, with age at diagnosis being on average 10 years younger essentially making it a premenopausal disease (Anwanyu et al. 2011; Clegg-Lamptey & Hodasi, 2007; Black & Richmond, 2019). Late stage-presentation is a common barrier in SSA and is the largest attributer of low survival rates. Approximately 77% of staged cases in 17 SSA countries were either stage III/IV at diagnosis (Sung et al., 2021). Social beliefs regarding women's bodies also play a role in the management of breast cancer as they influence knowledge and understanding of cancer (Mdondolo et al., 2003; Wright, 1997). Most women are treated with mastectomy in SSA partly because treatment options are limited for presentation with late-stage disease but also because surgery costs are lower compared to other forms of treatment such as chemotherapy (Clegg-Lamptey & Hodasi, 2007; Clegg-Lamptey et al., 2009a; Tetteh

& Faulkner, 2016). Vanderpuye et al. (2019) found that common barriers to oncology care in Africa reported by oncologists associated with the African Organisation for Research and Training in Cancer (AORTIC) from 18 African countries included unavailability or limited access to new cancer treatments, chemotherapy and radiotherapy, high clinical volumes and patients' inability to pay for treatment. The loss of a breast has discouraged many patients from accepting surgical treatment for breast cancer despite presentation with locally advanced disease (Anwanyu et al., 2011). Many women seek alternative treatment such as the use of herbs, prayer camps and traditional healers (Clegg-Lampsey et al., 2009a). Treatment- and travel-related costs also deter women from seeking treatment (Tetteh & Faulkner, 2016).

2.3 Cancer burden in South Africa

Breast cancer has been identified as a national priority in South Africa as it is the most prevalent cancer as well as the leading cause of death among women (DoH, 2017). The 2017 NCR identified breast cancer as the most commonly diagnosed cancer among women in South Africa (NICD, 2017). The five-year survival rate after a breast cancer diagnosis in South Africa is 40% compared to 90% in high-income countries (WHO, 2021a). Ferlay et al. (2015) found South Africa's cancer incidence and mortality rates to be of low validity as information was only based on national data, with cancer incidence being largely under-reported owing to a lack of a national population-based registry. The data had incomplete population coverage resulting in low mortality rates. Edge et al. (2014) state that the information available in the national data registry are compiled from individual units in state healthcare facilities. Furthermore, the national data registry is a pathology-based registry and not currently up-to-date (DoH, 2017). The DoH's (2017) Breast Cancer Control Policy identified several factors affecting access to healthcare including living in rural areas, limited knowledge regarding breast cancer, lack of infrastructure and equipment as well as disparities and inequitable distribution of services. Further factors included, problems with transport and

poor referral systems, inadequately trained healthcare workers, and literacy barriers as information was mostly given through written material and in English which excluded women living in rural areas were also identified (DoH, 2017). Duvenage (2019) attribute advanced stage presentation and inefficiency of patient transport and health care system logistics to late-stage diagnosis of breast cancer among South African patients. They state that it can take approximately six or more clinic visits or up to two months for a breast cancer diagnosis to be established (Duvenage, 2019).

2.4 Breast cancer

Cancer is caused by the uncontrollable multiplication of abnormal cells which then break off and spread locally within the affected area such as the breast (WHO, 2021b). These cells are invasive and may metastasize to other areas of the body as well, with metastases being the primary cause of death from cancer (WHO, 2021a). In the breast, cancer presents as a mammographic abnormality or physical changes such as asymmetrical thickening or a mass, skin or nipple changes or nipple discharge (Davidson, 2020). Often, cancer that starts in the breast is classified as a primary cancer as it has not metastasized to other parts of the body. The spread of breast cancer occurs via the blood system to distant organs or may become trapped where narrower blood vessels occur or may follow the lymphatic system to local lymph nodes, usually originating under the arm (Edge & Woods, 2014).

Breast cancer occurs in the lining cells of the ducts, which accounts for 85% of all cancers seen, and may also occur in the lobules (15%) and very rarely in the tissue in between the breast (Edge & Woods, 2014; WHO, 2021a). Carcinoma in situ or non-invasive breast cancer occurs when malignant cells develop and are confined to the ducts or lobules and do not cause symptoms. In the ducts, it is called ductal carcinoma in situ and will progress to invasive breast cancer over time as malignant cells break through the wall of the duct and invade the surrounding fatty tissue. The cells then spread to nearby lymph nodes or other

organs in the body resulting in regional or distant metastasis (Akram et al., 2017; Edge & Woods, 2014; WHO, 2021a). A less common carcinoma is lobular carcinoma in situ and if this carcinoma is found anywhere in the breast, the woman has a higher chance of developing breast cancer. This type of cancer may be difficult to diagnose as it may look like normal breast tissue on cytology and is difficult to see on mammograms (Edge & Woods, 2014). Triple negative breast cancers, commonly seen in premenopausal women, display an expression deficiency of the receptors commonly found in breast cancer namely the oestrogen, progesterone or the human epidermal growth factor (HER2) receptors (Akram et al., 2017; Davidson, 2020). Other types of breast cancer include two rare forms of breast cancer. These are inflammatory breast cancer in which the skin of the breast is red, warm, thick and pitted and a lump is usually not present; and Paget's disease which is characterised by red, inflamed patches on the skin of the nipple and surrounding areola and originates in the ducts (Akram et al., 2017; Davidson, 2020; Edge & Woods, 2014).

The most common characteristics of breast cancer are a change in the appearance, shape or size of the breast, a painless lump or an abnormal thickening in the breast (DoH, 2018; WHO, 2021a). Not all lumps are malignant, so it is important for the individual to have the lump checked out to determine the cause (Western Cape Government, 2020). Besides the presence of a lump, there are several other signs and symptoms to watch for namely breast pain, nipple pain or nipple inversion or retraction, dimpling, puckering or irritation of the breast skin, swelling, warmth or redness that persists in the breast, sudden nipple discharge besides breast milk occurring in only one breast, one breast lying lower than the other, swelling, thickening or a lump in the underarm area and scaliness, thickening or redness of the breast or nipple skin (Edge & Woods, 2014; DoH, 2018; Western Cape Government, 2020; WHO, 2021a).

2.4.1 Risk factors for breast cancer

Breast cancer is not an infectious or transmissible disease such as human papillomavirus (HPV) and cervical cancer (WHO, 2021a). The WHO (2021a) states that approximately half of breast cancer cases in women have no identifiable breast cancer risk factors other than being female (gender) and age (over 40 years). According to Davidson (2020), the three critical risk factors for breast cancer are being female, having a family history of breast cancer and age as older women are more likely to be diagnosed with breast cancer, although this is contrary to the younger age at diagnosis seen in SSA (Anwanyu et al. 2011; Clegg-Lamprey & Hodasi, 2007; Black & Richmond, 2019). Women with a family history of breast cancer account for 20% of breast cancer cases which is linked to mutations in the breast cancer susceptibility genes, BRCA1 and BRCA2 and relates to a 50-85% increased lifetime breast cancer development risk (Davidson, 2020; Edge & Woods, 2014; WHO, 2021a). Established risk factors for breast cancer are similar to those affecting women in high-income countries and include genetics (BRCA1 mutation – 72% (95% CI, [65%, 79%]), BRCA2 mutation – 69% (95% CI, [61%, 79%]) (Kuchenbaecker et al., 2017); alcohol consumption (OR, 1.25; 95% CI [0.99, 1.58]) (Baglia et al., 2017); being overweight (41% risk increase of all-cause mortality (95% CI [29-53%]) (Chan & Norat, 2015); a lack of physical exercise (increased physical activity is a protective factor (RR, 0.86; 95% CI [0.78, 0.95]) (McTiernan et al., 2003); smoking (HR, 1.16; 95% CI [1.00, 1.34]) (Luo et al., 2011); low socioeconomic status (OR, 2.05, 95% CI [1.34, 3.13]) (Orsini et al., 2016) and hormonal and reproductive factors such as early onset of menarche (OR, 2.83; 95% CI [1.02, 7.86]) (Thakur et al., 2017); late onset of menopause (OR, 2.43; 95% CI [1.2, 4.9]) (Thakur et al., 2017); older age at first childbirth (OR, 6.34; 95% CI [2.04, 27]) (Thakur et al., 2017) and nulliparity (OR, 1.98; 95% CI [1.12, 3.49]) (Balekouzou et al., 2017).

2.4.2 Screening and diagnosis

Breast screening includes breast self-examination, screening mammography and a clinical breast examination by a healthcare professional in an otherwise healthy individual (Davidson, 2020) with the aim of early cancer detection in order to reduce mortality (De Villiers, 2019b). In South Africa, there are several methods of screening namely via imaging which consists of the mammogram scan, ultrasound scan and MRI scan, via a clinical examination, and via cytology (diagnosis as a result of examining single or clusters of cells) and histology (microscopic examination of suspected tissue). A triple test in which imaging, cytology and a clinical examination is carried out is used to make an accurate diagnosis (Edge & Woods, 2014; De Villiers, 2019b). Mammograms use x-rays to view underlying breast tissue and can identify abnormalities before they may be felt. Mammograms are more reliable when breast tissue is less dense such as in women older than 50 years or who are postmenopausal, therefore younger and premenopausal women are encouraged to go for an ultrasound of the breast as their breast tissue is denser (De Villiers, 2019b; Western Cape Government, 2020). The ultrasound scan makes use of sound waves to image the breast tissue and a picture is produced based on the absorption and reflection of sound by the different types of breast tissue. This method can also distinguish between a solid and cystic mass and a cancerous and non-cancerous lump (Edge & Woods, 2014; DoH, 2018). The MRI scan also produces pictures of the breast using magnets and radio waves and are used in conjunction with mammograms to screen women with a high risk for developing breast cancer (De Villiers, 2019b). If an abnormality is detected on the mammogram or ultrasound scan, a fine needle aspiration or core biopsy is done for further cytology and histology investigation (Edge & Woods, 2014; DoH, 2017). Another important method for detection is the breast self-examination, to check the breast for lumps or other irregularities and should be done 2 days after the last day of a woman's period. The early detection of breast cancer is essential

as it is linked to effective and efficient treatment, with the assumption that the smaller the cancer detected, the better the survival outcome thus resulting in reduced breast cancer mortality (DoH, 2017; Western Cape Government, 2020). A triple assessment is conducted following the detection of a palpable breast abnormality or when suspicious findings on a screening mammogram usually result in a diagnostic evaluation for breast cancer (Davidson, 2020; DoH, 2017). The triple assessment consists of a clinical assessment (general medical history and breast examination), imaging (mammogram, ultrasound scan or MRI scan), and cytology (Edge & Woods, 2014). If a mass is found, cytology with a fine needle aspiration is performed. A needle is inserted in the lump or cyst and fluid or cells is extracted (DoH, 2018). To confirm a diagnosis, histology needs to be done in which a solid tissue sample is examined under a microscope. The tissue sample is obtained by means of a core biopsy in which a core biopsy needle is inserted to remove a core of the tissue and is performed under local anaesthetic (Edge & Woods, 2014).

2.4.3 Treatment

There are various treatment modalities used to treat breast cancer. The aim of treatment is to preserve quality of life and prolong life expectancy as well as provide temporary relief from symptoms. In some cases, treatment may be used with curative intent (Akram et al., 2017). Two types of management are available for treating breast cancer namely local management (breast and armpit) and systemic management (the whole body). Local management treatment available in South Africa are surgery and radiation whereas systemic treatment available are targeted therapy, hormone therapy and chemotherapy (Edge & Woods, 2014; Nietz, 2019; Western Cape Government, 2020). Resource constraints, high patient volumes and provider shortages however limit access to treatment modalities within South Africa's public health care system (O'Neil et al., 2019). Surgery and radiation are used for control of the disease in the lymph nodes, breast and surrounding areas whereas systemic

therapy is given orally or intravenously and treats or reduces the risk of metastasis (WHO, 2021a). For healthcare providers to decide on the appropriate treatment, the type of cancer, stage of the cancer, and the patient's general health and fitness are established. The stage at which the patient is diagnosed is also important as it describes whether the cancer has spread to the lymph nodes (the nodal status) as well as other parts of the body (metastatic status) and indicates the size of the primary tumour. Breast cancer patients who have stage I, II and some stage III cancer are classified as being in the early-stage of the disease and are often treated with surgery followed by radiation therapy, with some receiving drug therapy, such as chemotherapy, hormone therapy, HER2 targeted drugs or a combination of these drug therapies as well (American Cancer Society, 2016b; Breastcancer.org, 2015; Davidson, 2020). Individuals with some stage III and stage IV cancer are classified as having advanced-stage or metastatic cancer and receive chemotherapy for control and palliative care of their cancer (Breastcancer.org, 2015, 2018; Davidson, 2020).

Other characteristics of the cancer such as the grade and hormone-receptor status are assessed to determine the most appropriate treatment, although the local availability of treatment options also impacts which treatment options are available to the patient (Edge & Woods, 2014). The grade of cancer conveys the aggressiveness of the cancer as well as the cohesiveness of the cells. Grading occurs on a scale of 1 – 3 with indicating 1 the least aggressive to 3 indicating the most aggressive. A higher grade indicates less cohesion of the cells as well as increased cell multiplication meaning that the cancer is more likely to metastasize unless treatment is administered. The hormone-receptor status of the cancer refers to the hormone receptors that are present on most cells in the body to which specific hormones attach to. Breast cells usually have receptors for the female hormones, progesterone (PR) and estrogen (ER), which affects the behaviour of breast cells. These receptors may also be present on cancer cells resulting in cancers that may be PR or ER

positive and therefore be treated with endocrine (hormone) therapies such as aromatase inhibitors or tamoxifen. Hormone receptor negative (PR/ER) cancers are usually treated using chemotherapy (Edge & Woods, 2014; WHO, 2021a). Cancer cells may also overexpress the epidermal growth factor receptor type 2 (HER2) which results in a metastatic breast cancer and is treated with a targeted therapy such as Herceptin (inhibits the proliferation of cancer cells that overexpress HER2) used in conjunction with chemotherapy (Davidson, 2020; WHO, 2021a).

2.4.4 Treatment modalities

Breast cancer patients who receive surgery, do so in order to remove a tumour, and all other visible cancer cells that may be present in the breast or axilla (armpit) (Cancer.net, 2019). The surgery on the breast consists of either a wide local excision or breast conserving surgery in which the tumour as well as a small cancer-free region of tissue is removed or a mastectomy in which the entire breast is surgically removed (Akram et al., 2017; Edge & Woods, 2014). A lumpectomy or partial mastectomy is commonly used today for the majority of breast cancers instead of a mastectomy and only the breast tumour is removed (WHO, 2021a). Until the mid-1980s axillary surgery consisted of an axillary lymph node clearance in which the lymph nodes under the arm were completely removed as it was thought a necessity to the prevention of the spread of cancer. Since the 1990s however, a smaller procedure called the sentinel lymph node biopsy, in which the first lymph nodes to which cancer spreads in the breast are checked for cancer cells using dye and/or a radioactive tracer (Edge & Woods, 2014; DoH, 2018; Magnoni et al., 2018; WHO, 2021a).

Large tumours (≥ 2 cm) (Thompson & Moulder-Thompson, 2012), or those that grow quickly, may first require chemotherapy, Herceptin or hormone therapy before surgery, called neoadjuvant therapy, in order to shrink the tumour (Cancer.net, 2019). Chemotherapy, radiation therapy, targeted therapy with Herceptin or hormone therapy given after surgery is

called adjuvant therapy and helps to lower the risk of the cancer recurring and destroys any remaining cancer cells (Cancer.net, 2019; Davidson, 2020). Radiation therapy used for cancer treatment consists of high-energy x-rays or other types of radiation that are used to destroy cancer cells and can be administered using a machine or through the placement of radioactive substances via needles, wires or catheters into the tumour (Cancer.net, 2019; National Cancer Institute, 2021). Hormone therapy is targeted at breast cancer with estrogen receptors on their cancer cells which use hormones in order to grow. Hormone therapy therefore reduces production of these hormones or blocks their action, thus prohibiting the growth of cancer cells (Gudgeon, 2019). Targeted therapy such as Herceptin identifies and targets the tumour's specific proteins, genes and tissue environment which aids in its growth and survival in order to prevent its growth and spreading, while reducing damage to healthy cells (Cancer.net, 2019). Target therapy results in less damage to normal cells compared to chemotherapy or radiotherapy as well as fewer side effects as it only acts on cells with a select receptor/pathway (Gudgeon, 2019; National Cancer Institute, 2021). Finally, chemotherapy is any drug used to kill cancer cells by eliminating the cancer cells' ability to proliferate and metastasize (American Cancer Society, 2016a; Cancer.net, 2019; DoH, 2018).

2.5 Chemotherapy

Chemotherapy is prescribed as a treatment regimen to cancer patients by a multidisciplinary team made up of surgeons, radiologists, and oncologists with one of three goals in mind, namely cancer treatment with curative intent, control of cancer or for palliative care of the cancer (Edge & Woods, 2014; Gudgeon, 2019). The length of treatment regimens is variable and dependent on many factors including patient factors (age and tolerance of the treatment), regimen used, biology and stage of the disease (J. Edge, personal communication, May 3, 2019). When chemotherapy is used with a curative intent, the intention is for complete remission of the cancer, but this is not always the case for many patients and

chemotherapy is therefore used to attempt control of cancer's progression (American Cancer Society, 2016a). Chemotherapy is administered in cycles and may be a single drug or a combination of drugs (Chemocare, 2015; Mayo Clinic, 2018). For early-stage cancer patients, chemotherapy is used to shrink the tumour before surgery (neoadjuvant) or to eliminate any cancer cells remaining where there is a high risk of recurrence after surgery (adjuvant) and reduces the risk of cancer recurrence (Breastcancer.org, 2018; Cancer.net, 2019; Gudgeon, 2019). Chemotherapy given as adjuvant therapy with curative intent may have strong side effects and results in hair loss. For neoadjuvant as well as adjuvant therapy the patient may receive more than one drug which may result in the tumour shrinking faster but may also have more side effects (Edge & Woods, 2014). For advanced-stage or metastatic cancer patients, chemotherapy is used as palliative care to destroy or slow the spread of cancer cells to ease the symptoms of individuals for control rather than with a curative intent (American Cancer Society, 2016a; Breastcancer.org, 2018; Gudgeon, 2019).

Chemotherapy may be administered intravenously, orally or on the skin but is commonly administered intravenously or orally. Chemotherapy that is administered intravenously is injected via a vein into the patient's blood stream that allows for rapid circulation and absorption. Chemotherapy that is administered orally takes the form of tablets, capsules, pills or liquid and is ingested by the patient (Chemocare, 2015). In South Africa, the most common chemotherapy regimens for breast cancer include cyclophosphamide, and 5-fluorouracil with either methotrexate (CMF), epirubicin (CEF), or doxorubicin (Adriamycin) (CAF) and can be used in conjunction with taxanes (blocks cancer cell growth by stopping mitosis) as well (Edge & Woods, 2014; Gudgeon, 2019). Several contraindications to chemotherapy have been identified by Gudgeon (2019) which include other comorbidities in which women may experience more problems than benefits in the presence of multiple comorbidities. Finally, a large infrastructure is required in the

administration of chemotherapy as well as careful monitoring. In the absence of this due to a lack of resources, chemotherapy should not be given (Gudgeon, 2019).

2.5.1 Side effects and life changes

Side effects of chemotherapy are dependent on the regimen given, the individual's response to drugs and the route of administration (Gudgeon, 2019). Liu et al. (2021) conducted a systematic review of qualitative research regarding the experiences of women undergoing chemotherapy. In one of their synthesized findings regarding the impact of side effects of chemotherapy and subsequent life changes, Liu et al. (2021) identified four categories namely physical changes, cognitive changes, emotional distress and life changes. Physical changes due to the long duration of the chemotherapy process included vomiting, insomnia, hair loss, cognitive changes and chemotherapy-related fatigue with the latter three identified as predominant physical symptoms. Hair loss, although an impermanent symptom, was detrimental to women's image of themselves and fatigue was described as lethargy or weakness that was not alleviated by rest or sleep. Cognitive changes were linked to "chemo brain" (Mann, 1999) in which patients feel unable to think clearly (Edge & Woods, 2014) and manifested as memory problems, difficulty finding words, concentrating and paying attention as well as organizing and prioritizing problems and sensory problems (Liu et al., 2021). The emotional distress experienced by patients during the chemotherapy period included uncertainty (Cowley et al., 2000; Lai et al., 2017), anger (Banning et al., 2009), worry (Anarado et al., 2017; Banning et al., 2009; Browall et al., 2006), anxiety (Anarado et al., 2017), fear (Banning et al., 2009), depression and sadness (Anarado et al., 2017; Nizamli et al., 2011), with the latter four symptoms being the most predominant symptoms identified in the study (Liu et al., 2021). Anxiety was associated with body changes, loss of independence and possible future cancer recurrence (Chen et al., 2016). Fear related to the disease being incurable, the adverse effects of chemotherapy or permanent separation from family

(Anarado et al., 2017; Browall et al., 2006; Banning et al., 2009; Chen et al., 2016).

Depression and sadness were indicated when patients blamed themselves for unfulfilled maternal responsibilities as a result of adverse chemotherapy effects (Anarado et al., 2017; Banning et al., 2009). The consequences of this strong psychological strain resulted in women feeling desperate and powerless, with some women having attempted suicide or having suicidal ideation (Chen et al., 2016; Liu et al. 2021). Finally, the life changes identified by Liu et al. (2021) related to the roles that women played as mothers, wives and daughters and the role failure they experienced when dealing with the emotional and physical burdens of treatment (Banning et al., 2009; Beaver et al., 2016; Browall, 2006; Chen et al., 2016; Nizamli et al., 2011). Beaver et al. (2016) found that many women struggled with a rapid transition from being healthy and fit with various family, work and household responsibilities to being ill and retaining those same responsibilities, while coping with diagnosis and treatment. Women also experienced sensitivity and isolation with regards to changes in their physical appearance and self-image (Nizamli et al., 2011). Furthermore, life changes encompassed the impact that side effects had on women's activity levels and resulting reduced ability to perform daily activities (Banning et al, 2009; Boehmke & Dickerson et al., 2005; Browall et al., 2006; Chen et al., 2016; Liu et al. 2021). Banning et al. (2009) found that women who experienced physical weakness and subsequently experienced an inability to work efficiently saw their weakness as a reminder of breast cancer. Other non-specific side effects identified include psychosocial issues, and infertility (Edge & Woods, 2014; Gudgeon, 2019).

2.6 Adherence to Medication

Adherence may be defined as “the extent to which a person's behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (Haynes, 1979, pp. 1-2). Rapoff (2010) states that the above definition as

defined by Haynes (1979) is a commonly cited definition and qualifies three reasons as to why it is commonly used. Firstly, the definition specifies behaviours required to satisfy a prescribed treatment regimen. Secondly, the use of the word “extent” indicates that adherence is influenced by a variety of factors. Thirdly, the definition calls to attention whether patient behaviour coincides with the healthcare provider’s treatment recommendations (Rapoff, 2010).

The WHO also developed a definition for adherence based in part on Haynes’ definition as “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider” (Sabaté, 2003, p. 3). Healthcare workers prefer the term adherence as it emphasizes patient autonomy compared to compliance which indicates healthcare advice is passively being followed by the patient instead of the treatment plan being based on an established agreement between the patient and healthcare worker (Adisa et al., 2008a). Based on the above definitions, treatment adherence is essential in order for individuals to achieve optimal health outcomes as non-adherence has been shown to result in decreased survival and an increased chance of the cancer recurring or treatment failure occurring as well as increased treatment costs (Puts et al., 2014).

2.6.1 Factors affecting adherence to medication

According to the WHO, adherence is a multidimensional phenomenon which is determined by the interplay of five dimensions namely patient-related factors, condition-related factors, social/economic factors, therapy-related factors, and health system/healthcare team (HCT) factors (Sabaté, 2003).

2.6.1.1 Patient-related factors. Patient-related factors encompass the attitudes, beliefs, expectations, knowledge, perceptions, and resources of the patient (Lin et al. 2017; Sabaté, 2003). The interaction between the patient’s self-efficacy and motivation to engage in

illness-management behaviours, their knowledge and beliefs of their illness as well as their expectations regarding treatment outcomes and perceived barriers to adherence influence adherence behaviour. Some of the patient-related factors identified include psychosocial stress, feeling stigmatized by the disease and anxieties about possible adverse effects (Lin et al., 2017; Sabaté, 2003). Patients' beliefs regarding their disease and treatment and actual disease severity are influential to adherence as greater disease severity threat is associated with better adherence. However, for more serious conditions such as cancer, patients who experience worse health are less likely to be adherent to treatment (DiMatteo et al., 2007). Furthermore, patients' decisions regarding treatment may also be influenced by their evaluation of the risks and benefits associated with medication, with misunderstandings of these risks or benefits negatively influencing adherence (Banning, 2012; Marshall & Given, 2018).

Patient-specific barriers identified include lack of knowledge or information to understand their medication regimen as well as erroneous or incorrect beliefs regarding medication (Axelsson et al., 2015; Tranulis et al., 2011), a lack of motivation as well as poor health literacy, especially with regards to understanding written language or if instructions are not in the patient's native language (Ågård et al., 2016; Huang et al., 2020; Schatz et al., 2019). Facilitators of adherence identified included a good understanding of the patient's illness and the treatment thereof as well as experiencing mild adverse effects. Social support and realistic and achievable treatment goals are also facilitators of adherence with patient motivation identified as an essential facilitator of adherence (Kvarnström et al., 2021). Furthermore, positive views and beliefs about medication has also been identified as a facilitator of adherence (Lin et al., 2017). The context in which adherence occurs is also of importance as the individual's relationships with healthcare workers, family and friends as

well as social factors influences the individual's behaviour in a simultaneous and reciprocal manner (Berben et al., 2012; Sabaté, 2003).

2.6.1.2 Condition-related factors. Condition-related factors which influence adherence to medication encompass specific illness-related demands that the patient may face including rate of disease progression, treatment availability and symptom severity (Sabaté, 2003). Koh et al. (2018) stated that adherence to medication could depend on how seriously the patient assessed their condition as sometimes patients had not accepted their illness or blamed the occurrence of the illness on someone else (Kvarnström et al., 2021). The experience of cancer symptoms may also enable patients' perceptions that medication is needed to treat their illness whereas side effects experienced after treatment commencement may negatively influence patients' medication perceptions (Marshall & Given, 2018). Lin et al. (2017) however state that condition-related characteristics are likely non-modifiable and investigating their impact is less advantageous when looking at interventions to improve adherence.

2.6.1.3 Social/economic factors. Various social/economic factors have been identified as being significant influencers of adherence to medication including poverty, cultural beliefs and social networks (Sabaté, 2003). A poor socioeconomic status, which was prevalent in developing countries, resulted in patients prioritising available funds and resources to meet their families' competing needs which influenced adherence (Sabaté, 2003; Shriver et al., 2000). Furthermore, a lack of social support, preference for alternative treatment(s) and spiritual/religious beliefs (such as relying on prayer to cure cancer) may pose as barriers to adherence (Kvarnström et al., 2021). Economic factors relating to poor adherence include the financial cost and burden of medication, unemployment and lack of money to buy necessities such as food which make medication less of a priority. Other factors include difficulties travelling to a clinic which occurs especially in developing countries,

medication shortages and issues regarding availability of medication which is also prevalent in developing countries (Kvarnström et al., 2021).

2.6.1.4 Therapy-related factors. Some of the most notable therapy-related factors according to WHO include side effects of the treatment regimen, the complexity of the treatment regimen and the rapidness of beneficial side effects (Sabaté, 2003). Saratsiotou et al. (2011) identified beliefs about medication as the most important factor associated with medication adherence as beliefs that treatment would not be effective was associated with lower adherence and greater beliefs in treatment efficacy was associated with greater adherence. Patients who have a more positive view of treatment are therefore more likely to initiate and adhere to treatment compared to those with less positive views (Banning, 2012). Furthermore, Marshall & Given (2018) state that symptoms and side effects may be an influential factor in how patients think about their illness and perceive treatment.

Kvarnström et al. (2021) state that medication-specific barriers include lack of information among patients regarding their condition as well as medication needed for treatment. Treatment may sometimes seem complex and time-consuming and patients may struggle with side effects (Jarab et al., 2018; Hogan et al, 2014). Patients may seek alternative information sources such as the internet if they feel that the information provided is inadequate and media may also influence patients' opinions of drug quality (Hayden et al., 2015; McKillop & Joy, 2013).

2.6.1.5 Health-system/Health Care Team (HCT) factors. HCT and system-related factors include lack of knowledge and training for healthcare workers on managing chronic diseases, underdeveloped health services and decreased system capacity to educate patients and provide follow-up (Sabaté,2003). Poor medication adherence may result from long waiting times as well as poor access to healthcare (Ho et al., 2017). Further barriers to adherence include a lack of support from healthcare workers as well as poor patient-provider

relationships (Kvarnström et al., 2021). Conversely, patient-provider relationships that are trust-based and collaborative in nature were found to be essential to adherence as well as access to quality healthcare and ongoing communication with healthcare workers. Fearing healthcare workers or having a desire to please them serve as a facilitator of adherence as well as support from healthcare workers (Kvarnström et al., 2021).

2.7 Adherence to chemotherapy

Adherence to chemotherapy, one of three treatment options available to breast cancer patients, has not been well-documented within South African literature. Literature searches on Sabinet, Taylor and Francis Online Journals, SAGE Journals, Stellenbosch University library search, Google Scholar and Elsevier using the keywords (Psychological OR Psychosocial) AND (Breast Cancer OR Cancer) AND (South Africa OR Africa OR Low-income country OR sub-Saharan Africa OR SSA) AND (intravenous OR oral) AND (chemotherapy) AND (adherence OR “nonadherence” OR compliance OR adherence behaviours) AND (discontinuation) AND (treatment), reveals limited to no results regarding breast cancer therapies as well as adherence to chemotherapy within South Africa.

According to Wells et al. (2015), adherence to chemotherapy regimens in women with breast cancer is important as it is an essential component of optimum clinical benefit as well as treatment efficacy. Furthermore, adherence results in several outcomes for breast cancer patients, including increased quality and preservation of life and decreased relapse or recurrence of cancer (Kane & Shaya, 2008; Sokol, et al., 2005; Wells et al., 2015).

2.7.1 Oral Chemotherapy

Oral chemotherapy entails taking prescribed medication in pill form (Chemocare, 2015). As such, with this method of chemotherapy, the responsibility of acquiring and administering the chemotherapy drugs rests on the patient instead of a healthcare worker which may lead to notable adherence issues (Krikorian et al., 2019; Lin et al., 2017).

Krikorian et al. (2019) identified several reasons for medication non-adherence including patient-related factors such as forgetfulness, lack of information, poor relationships with healthcare workers, and high out-of-pocket costs. Medication-related factors such as complexity of dosing regimens, other potential interacting drugs and dosing schedules also result in medication non-adherence. Adherence to oral chemotherapy is measured as the percentage of doses of chemotherapy a patient reports taking (pill count) in comparison with the recommended dose of chemotherapy that was originally prescribed (Jacobs et al., 2017). Greer et al. (2016) and Krikorian et al. (2019) both state that there is no consensus regarding what constitutes satisfactory compared to poor adherence in terms of cancer treatment, however an adherence rate where patients took 80% of their prescribed chemotherapy (adherence threshold) has often been viewed as satisfactory in clinical studies (Greer et al., 2016; Krikorian et al., 2019). In Krikorian et al.'s (2019) study, adherence to medication was calculated as a percentage by counting the number of pills removed from the prescription bottle, dividing it by the number of pills prescribed and multiplying it with 100 - with an adherence rate between 90-100% considered to be satisfactory. Jacobs et al. (2017) measured adherence with the use of a self-report survey and an electronic pill cap and bottle which electronically recorded the date and time of bottle openings. The adherence rate was then operationalized as a ratio of the percentage of prescribed pills taken to number of cap openings in comparison with the expected number of openings during the study (Jacobs et al., 2017). In their study, Jacobs et al. (2017) found adherence rates for oral chemotherapy to be 67.8% (90% adherence threshold) and reported a non-adherence rate of 25.6%.

2.7.2 Intravenous Chemotherapy

Intravenous chemotherapy entails the injection of chemotherapy drugs via a vein into the patient's blood stream (Chemocare, 2015). Intravenous chemotherapy is administered in a controlled environment, with observation occurring directly by a healthcare worker (Weingart

et al., 2008). This form of chemotherapy therefore requires the patient to be present in person at the healthcare facility for all cycles and be well enough to tolerate the side effects (J. Edge, personal communication, May 3, 2019). High rates of cancer relapse and death are associated with premature discontinuation of intravenous chemotherapy (Dhotre et al., 2016). Wells et al. (2015) state that previous studies found poorer clinical outcomes for patients who received less than 85% of total intravenous chemotherapy compared to those who completed treatment. Intravenous chemotherapy is based on the patient attending a chemotherapy session, and therefore adherence is measured according to a patient's medical chart or by the number of appointments the patient attended out of their prescribed number of chemotherapy sessions (Wells et al., 2015; Yee et al., 2017). Wells et al. (2015) state that adherence with this method is dichotomous, with those individuals who attend 100% of their chemotherapy appointments determined to be adherent, and those who attend <100% (i.e., miss even a single chemotherapy session) determined as non-adherent. In their study conducted among African-American and Caucasian women with early stage breast cancer in America, Wells et al. (2015) found that 90% of the participants were 100% adherent to their chemotherapy treatment regimen. Yee et al. (2017) reported adherence rates based on information from patients' medical records and also viewed adherence as dichotomous (yes/no) with an ability to receive $\geq 85\%$ of prescribed chemotherapy doses being considered adherent. They found the adherence rate in their sample of African American and white women with breast cancer to be 60.3% (85% adherence threshold) and reported non-adherence rates of 33.3%. Another study carried out in Nigeria by Adisa et al. (2008a) among breast cancer patients considered non-adherence to intravenous chemotherapy as missing two consecutive doses of chemotherapy and reported a non-adherence rate of 80.9%. Furthermore, studies conducted by Männle et al. (2021) in Germany and Neuget et al. (2016) in America defined premature termination or early discontinuation of intravenous chemotherapy as the receipt of <80% of

the number of chemotherapy cycles for the treatment regimen initiated. Neuget et al. (2016) stated that if a regimen was four cycles, early discontinuation was defined as missing one or more cycles. For the purposes of this study, I utilised Wells et al.'s (2015) definition of adherence to intravenous chemotherapy to identify adherent and non-adherent patients. Therefore, patients who attended 100% of their intravenous chemotherapy sessions were considered adherent and patients who attended <100% of their appointments were considered to be non-adherent.

2.8 Barriers and facilitators to adherence to chemotherapy

Multiple factors contribute to non-adherence in patients, specifically those that are related to the healthcare system, the healthcare worker and the patient (Brown & Bussell, 2011). Non-adherence to medication directly impacts an individual's health and wellbeing and is therefore an important aspect to assess (Rapoff, 2010). Patients who fail to take their medication, cease to benefit from them and therefore experience increased morbidity and mortality, and increased expenditure (Brito et al., 2014; Brown & Bussell, 2011).

Discontinuation of intravenous chemotherapy has been associated with depression, older age and lack of social support (Hu et al., 2011; Irwin, 2013; Kissane, 2009; Kubicek et al., 2011; Navari, Brenner, & Wilson, 2008). When non-adherent patients return for treatment, they often present with advanced disease which is mostly incurable (Clegg-Lamptey et al., 2009b). It is therefore important to identify the factors influencing adherence to chemotherapy in order to understand and address challenges to medication adherence.

2.8.1 Barriers to adherence to chemotherapy

2.8.1.1 Patient-related factors. In a study by Mdongolo et al. (2003) conducted in South Africa which assessed reasons for delay in seeking medical treatment for breast lumps, it was found that Xhosa women were reluctant to share a breast lump diagnosis with family and others and tended to keep it secret. Women chose to keep their diagnosis secret as in their

culture, the breast is significant in terms of love and intimacy, femininity and breast-feeding. In their opinion, the female body image is represented by the breast and a loss of their breast would impact their intimate relationships, appearance, and femininity. Women in Mdondolo's study also stated that the "possibility of losing a breast is a devastating idea to a Xhosa woman" (Mdondolo et al. 2003, p. 92).

In Nigeria, a developing country with a context similar to South Africa, treatment non-adherence is also common among patients and further exacerbates high numbers of women with breast cancer progressing to metastatic disease (Adisa et al., 2011). An earlier study by Adisa et al. (2008a) found that a common reason for non-adherence was that the patients felt well enough to discontinue chemotherapy which was explained by spiritual and religious beliefs. Other factors such as the cultural influence of the spouse as well as family members also influences treatment acceptance and adherence (Adisa et al., 2011). Another study carried out in Nigeria by Egwuonwu and colleagues (2012) investigating the reasons for defaulting on neoadjuvant chemotherapy in premenopausal women reported that 17 (38.6%) of the 44 study participants defaulted on treatment. Three patients indicated that they preferred to undergo a mastectomy instead of initiating chemotherapy whereas four other patients chose not to receive a mastectomy after completing neoadjuvant chemotherapy which the authors state could likely be attributed to fear of mastectomy which was common among women in their environment (Egwuonwu et al., 2012). A recent study, also conducted in Nigeria by Ingwu et al. (2019) examining the factors influencing non-adherence to chemotherapy among breast cancer survivors found patient-related factors related to concerns regarding treatment outcomes, fear of long-term dependence on medication, and a lack of emotional support.

A study in Ghana, conducted by Clegg-Lampsey et al. (2009b) investigating reasons for late reporting or absconding during treatment also found fear of mastectomy to be the

leading cause for defaulting on treatment. In contrast, a German study by Männle et al. (2021) found that patients who discontinued or refused adjuvant chemotherapy were likely to be significantly older (8-10 years older than patients completing treatment) or had undergone a mastectomy. Further reasons identified by Clegg-Lampsey et al. (2009b) for absconding treatment included the use of herbal and alternative treatment such as acupuncture, prayers and prayer camps, pressure from family members to refuse a mastectomy, financial incapability and reduction in physical symptoms. Diminished quality of life, the inconvenience of weekly clinic appointments and severity of the chemotherapy side effects were identified by oncology nurses as reasons for premature discontinuation of chemotherapy in an American study by Dhotre et al. (2016).

A Kenyan study by Sayed et al., (2019) which assessed the knowledge, perceptions and practice of breast cancer among women, male heads of households, opinion leaders and healthcare workers within a rural community identified fear of stigma regarding diagnosis as well as limited decision-making autonomy as barriers to accessing cancer care. Participants stated that women's fear of a breast cancer diagnosis stemmed from the possibility of being labelled undesirable by their husbands and subsequently being cast off and replaced. Women faced divorce, rejection, stigma or disownment as a result of a cancer diagnosis or mastectomy. Healthcare workers in the study stated that limited decision-making autonomy impeded women's ability to seek care as permission first needed to be sought from husbands or in-laws in order to access health facilities, which was especially true among less educated women (Sayed et al. 2019).

A study conducted in Indonesia by Iskandarsyah et al. (2013) assessing the psychosocial and cultural reasons for delay in seeking help and nonadherence to treatment among breast cancer patients found cancer beliefs, lack of awareness and knowledge and treatment beliefs to be patient-related factors of non-adherence. Patients who described

cancer as a shameful, dangerous, deadly and incurable disease, were unintentional in their delay in seeking medical help owing to limited knowledge regarding breast cancer risks and perceived treatment, particularly surgery, as a frightening and painful procedure (Iskandarsyah et al., 2013). Patients in the study referred to the emotional burden of cancer treatment citing fear of death and concerns regarding the treatment's ability to cure their cancer. Patients expressed concern regarding distress as a result of treatment side effects if treatment was not curative. Further, patients expressed guilt toward their children and husbands as treatment was energy and time-consuming and impeded their ability to function as a mother and wife (Iskandarsyah et al., 2013).

2.8.1.1.1 Alternative Treatment. Traditional healers were found to be the most appropriate healthcare source according to Xhosa women in studies by Mdongolo et al. (2003) and Wright (1997). Breast lumps or cancer was conceptualised as ancestral complaints, witchcraft and/or other people's anger or jealousy, with medical treatment being sought if traditional medicine proved ineffective or if further complications arose from traditional remedies prescribed (Mdongolo et al, 2003; Wright, 1997). Women also tended to prefer non-invasive, traditional treatment options as they believed that the cancer would spread if biopsies or surgery was done as blades and needles are used which could hinder the efficacy of traditional remedies (Mdongolo et al., 2003, Wright, 1997). Furthermore, a loss of privacy and independence was also a reason provided for absconding from treatment as visiting traditional healers did not reveal the patient's diagnosis to others (Wright, 1997).

In Nigeria, belief in non-orthodox healing practices is commonplace and influences late presentation of breast cancer patients at hospitals (Adisa et al., 2011). A similar occurrence was seen in rural Kenya in families who thought that breast cancer was caused by curses or witchcraft and therefore visited traditional healers first. The authors found that women engaged in self-medication or went to traditional healers when symptoms were not

considered serious enough to go to a healthcare facility. Healthcare workers stated that limited breast cancer knowledge resulted in women accessing traditional healers instead of healthcare facilities and further stated that ease of access as well as affordability of traditional healers made them the preferred choice as well (Sayed et al., 2019). Similarly in Indonesia, alternative treatment delayed medical treatment as a strong belief in traditional healers was identified. Patients perceived traditional healers as an alternative or complementary source of treatment. Patients consulted traditional healers on recommendation from relatives or spouses and traditional healers were also stated as being affordable with regards to fees and transportation costs, provided treatment without surgery and focussed on patients' feelings as well as their physical symptoms providing a holistic care approach (Iskandarsyah et al., 2013).

2.8.1.2 Social/economic-related factors. In Wright's (1997) study, the participants spoke about the social and economic expense of "adopting the sick role" (p. 1543). For these women, adopting this role meant that they would have fewer working hours, would have to pay for public transport as well as carers for their children and may experience social stigmatization due to possibly being labelled an invalid. Women in the study were consequently reluctant to adopt this role and preferred hiding their cancer diagnosis than experiencing these difficulties.

In Nigeria, Adisa et al. (2008a) found that the most noted reason for non-adherence was financial difficulties. In a later study by Adisa et al. (2011), they found late presentation of breast cancer was influenced by poverty as patients bear the costs for cancer treatment which they often cannot afford. Another study from Nigeria conducted over a 5-year period by Anyanwu et al. (2011) was used to identify patient adherence and acceptance to medical recommendations as well as the identification of system and patient barriers to adherence. Patients were offered various treatment modalities with most patients presenting with an

advanced stage of breast cancer (i.e., stage III or IV). Of the 275 patients who participated in the study, 53 patients were offered neo-adjuvant chemotherapy and 44 patients were offered adjuvant chemotherapy. Only 28% of the neo-adjuvant patients were able to complete their treatment course while 38.6% of adjuvant patients were able to complete their treatment course. The most common reason cited for non-completion was the cost of treatment as patients were required to pay for laboratory expenses, drugs and transportation to the hospital. In contrast, another study from Nigeria by Ayoade et al. (2019) which assessed response to neoadjuvant chemotherapy among breast cancer patients found majority adherent individuals with minimal non-adherent patients. One of the main reasons for non-adherence cited was financial difficulty (Ayoade et al., 2019). Similar findings were seen in Indonesia by Iskandarsyah et al. (2013). Egwuonwu and colleagues' (2012) study found that the main reasons for defaulting treatment were related to finance as some women were unable to afford the procurement of chemotherapy or defaulted after their first and second treatment courses due to lack of adequate funding.

A study by Lambert et al. (2020) conducted at the largest public hospital in South Africa investigated the experiences of 50 Black women who sought breast cancer treatment. Barriers to care included transportation costs, overcrowding, distance to local clinics and hospitals and long wait times. Similarly, Ingwu et al. (2019) also found distance from the healthcare facility and long clinic waiting times to be factors influencing non-adherence. Lambert et al (2020) found that many women found attending treatment appointments to be stressful as overcrowding and long lines at the clinic as well as money spent on public transport costs and waking up early to attend clinic took a toll on them. Loss of independence and self-sufficiency as a result of undergoing treatment was also reported by many women in Lambert et al.'s (2020) study, especially among women who were previously employed. An inability to retain clients, lack of understanding regarding treatment and missed work time at

work and cycles of sickness unemployment were all reported. Many women also reported that they were unable to care for themselves independently and relied on others for instrumental care such as bathing (Lambert et al. 2020). Dhotre et al. (2016) stated that oncology nurses also identified a lack of social support and family problems as reasons for stopping chemotherapy. Further explanations were fear of patients' families finding out about their cancer diagnosis, strain on marriages and dealing with divorce.

In a study by Reddy et al. (2020) investigating the disparities in perceptions of barriers to breast cancer treatment among Hispanic women and their healthcare workers, the social factors identified included limited emotional/social support, cultural views toward cancer and treatment such as viewing a cancer diagnosis as something that God wanted for her and (dis)trust in health systems. Hispanic women struggled with accessibility constraints when attending treatment such lack of childcare accessibility, employment conflicts and subsequent resignation and transportation as patients struggled to find an accessible or affordable means of transport to hospital appointments. Financial constraints identified by Hispanic women as a barrier to treatment included cost of care which encompassed high out-of-pocket costs of treatment coupled by an inability to work, transportation issues and a lack of insurance coverage (Reddy et al., 2020).

2.8.1.3 Condition- and treatment-related factors. Adisa et al.'s (2008a) study cited fears regarding subsequent surgery and the experience of severe side effects as a reason for non-adherence among many of its participants. Similarly, Iskandarsyah et al., (2013) also found that severe side effects resulted in missed treatment schedules with patients reporting that chemotherapy side effects were burdensome. Side effects of breast cancer treatment was also stated as a reason for non-adherence in two other studies from Nigeria (Ayoade et al., 2019; Ingwu et al., 2019), however in one study, some individuals who experienced side effects later returned to complete treatment (Ayoade et al., 2019). Ingwu et al. (2019) also

cited the duration of the treatment period and a preference for taking oral medication as factors influencing non-adherence to chemotherapy. Egwuonwu and colleagues' (2012) also reported treatment deferment in 20 (45.5%) of the 44 participants in their study. The reasons given related to hematologic toxicity such as anemia, finance, feeling unwell, needing to attend a funeral and one participant gave no reason. Fourteen of the 20 deferring participants deferred one treatment course, while 12 deferred two courses (Egwuonwu et al., 2012). Another study by Clegg-Lampsey & Hodasi (2007) found that the majority of patients who defaulted on treatment did so because their health improved or they were due for a mastectomy. The authors stated that misconceptions or fear surrounding mastectomies could be reasons for defaulting. Furthermore, the authors found that patients defaulted on treatment and returned with metastatic or incurable disease, as is seen at many institutions, including the tertiary hospital, and then requested a mastectomy due to various breast cancer complications such as ulcerated breasts (Clegg-Lampsey & Hodasi, 2007).

In Neuget and colleagues' (2016) prospective cohort study carried out at three healthcare organizations in America, they assessed the rate and reasons for early discontinuation of adjuvant chemotherapy and found early discontinuation to be associated with longer treatment regimens, especially regimens with more than four cycles, potential toxicity of chemotherapy as well as psychological side effects. They did not however find an association between the experience of treatment side effects and discontinuation (Neuget et al., 2016).

Lambert et al. (2020) found that chemotherapy resulted in considerable distress, fear and pain among participants with most women stating that chemotherapy instead of cancer was the cause for their sickness. Furthermore, patients seemed to view chemotherapy as a separate disease from breast cancer which the authors state may likely be owed to the association of their conditions with side-effect symptoms. Chemotherapy was therefore

viewed as an illness associated with symptoms such as diarrhoea, nausea, loss of appetite, vomiting and hair loss instead of as a cure to breast cancer. The longer lasting effects on women's physical appearance such as skin discolouration and weight loss also brought distress to many women (Lambert et al., 2020). Similar symptoms such as nausea and hair loss were also reported by oncology nurses as reasons for stopping treatment with nurses also stating that some patients found dying preferable to dealing with the side effects of chemotherapy as the symptoms sometimes outweighed the benefit (Dhotre et al., 2016).

2.8.1.4 Healthcare system, health education, and healthcare worker factors. In Anyanwu et al.'s (2011) study, for patients who discontinued treatment including other treatment modalities, the most common reasons cited were lack of bed space in hospital, the cost of treatment and a lack of a family member to care for them. Poor health education was also found to influence late presentation of breast cancer among patients at hospitals which may influence adherence (Adisa et al., 2011). Patients also stated that inadequate health literacy posed a significant barrier to treatment as patients stated that there was a need for information regarding treatment options as well as expectations throughout the treatment process (Reddy et al., 2020).

Patient's relationship with their healthcare worker is very important during treatment as Wright (1997) found that some patients absconded from treatment due to unpleasant experiences with hospital staff members or experiences within areas of the hospital. Some individuals also reported that staff members were condescending and abrupt with patients when they failed to comprehend instructions or questions. Iskandarsyah et al. (2013) found that patients perceived doctors as having a higher status and therefore assumed a non-assertive communication style during consultations to avoid conflict and show respect. Some patients were also reported as feeling inferior to doctors owing to low education and coming from a rural area. Furthermore, patients felt that information provided by doctors was

insufficient because it was scant or unclear and the gap between needed and provided information may have impacted patients' understanding and treatment adherence (Iskandarsyah et al., 2013).

Language barriers also presented misunderstandings between patients and hospital staff (Wright, 1997). A similar barrier was identified in Reddy et al.'s (2020) study with patients indicating that language limitations were often present between the patient and healthcare worker owing to a shortage of interpreters on staff.

A Canadian study by Fitch et al. (2020) identified aspects that patients perceived as important qualities in cancer care. The study found that patients wanted to be treated with dignity and respect and care provided should take their needs into account. Access to relevant and timely information as well as clear communication were also important aspects identified, with positive experiences of care being associated with consistency, communication and ongoing interactions with staff (Fitch et al., 2020). Results from a South African study assessing adjuvant breast cancer care compliance with quality measures indicated that patients who lived less than 20 kilometres from their hospital and were primarily English speakers were found to be more likely to receive measure-concordant care (O'Neil, 2019).

2.8.2 Facilitators of adherence to chemotherapy

2.8.2.1 Patient-related factors. Neuget and colleagues (2016) found that completion of chemotherapy treatment was associated with gaining personal strength. Further factors included patients anticipating total benefits from chemotherapy, having a new appreciation of life and seeing new possibilities (Neuget et al., 2016).

2.8.2.2 Social support. Social support has been shown to have a positive influence on adherence among patients (DiMatteo, 2004; Larizza, Dooley, Stewart, & Kong, 2006; Lebovits et al., 1990; Xu et al., 2012), while the opposite may also be true where low social support has a negative influence on adherence (Greer et al., 2016). Furthermore, family conflict, cohesiveness and marital status were all identified as having significant influence on adherence by DiMatteo (2004).

Wright (1997), in her study examining reasons for absconding from breast cancer treatment in black African women, found that the decision-making process for breast cancer treatment was not only up to the breast cancer patient, but was rather a collaborative process involving various family members who were usually the elders. Other members who made up these support groups were church members and leaders who advised prayer and medical treatment instead of traditional treatment options. This support group provided mutual emotional as well as economic support to members and was especially prevalent in Black African communities. These groups were especially important to participants as they might later be unable to support their family as they progressed to the terminal stages of the disease (Wright, 1997). A similar theme was identified by Lambert et al. (2020) who found that women's social support comprised of their family members and close friends as well as church groups and counselling groups with peers who were also diagnosed with breast cancer. The social support that women received enabled them to openly share their struggles and reinforced their will to live and also provided physical and instrumental support in the form of finances. Furthermore, the ability to speak to other breast cancer patients had a positive impact on women who described the experience as allaying their fears regarding chemotherapy and cancer as a death sentence, enabling acceptance of treatment and providing advice for managing their condition (Lambert et al., 2020).

2.8.2.2.1 Support from healthcare workers. Lambert et al. (2020) rarely found interactions with healthcare workers to be a barrier to receiving care. According to the authors, participants consistently felt supported by healthcare workers and stated that their faith as well as following healthcare advice was essential factors to their survival (Lambert et al., 2020).

2.8.2.2.2 Faith-based support. Faith and faith communities emerged as a fundamental aspect to healing for women enrolled in Lambert et al.'s (2020) study. As previously stated, their faith coupled with adherence to healthcare advice was essential to their survival and many women stated that their faith and faith communities gave them hope that they would survive cancer and encouraged their will to live (Lambert et al., 2020).

2.8.2.3 Treatment acceptance. In Wright's (1997) study, the author found that chemotherapy was an acceptable treatment option as it was believed to "cool down the poison and made it smaller" (p.1542) after which traditional treatments were used to draw the cancer from the body. Other factors that have been identified in contrast to some of the barriers to adherence identified above include belief in the necessity of medication, higher income, belief that medication may stop cancer development, treatment in an academic hospital and longer prescription refill intervals (Grunfeld et al., 2005; Hershman et al., 2010; Lebovits et al., 1990; Marques & Pierin, 2008; Sedjo & Devine, 2011). As many of these factors were identified in developed countries, their applicability within the South African context remains to be investigated.

2.9 Conclusion

In this chapter I described the global cancer burden as well as the cancer burden in SSA as well as South Africa. I gave a brief overview of breast cancer, its risk factors, screening and diagnosis and treatment was given. I described adherence to medication as well as the factors relating to adherence. I then addressed the importance of treatment and

adherence to treatment, as non-adherence to treatment results in decreased survival and an increased chance of the cancer recurring or treatment failure occurring as well as increased treatment costs. Finally, I presented previously identified barriers to and facilitators of adherence, with a dominance of barriers identified. In the next chapter, I will be outlining the theoretical framework through which the study is conceptualised, interpreted and understood.

CHAPTER 3

THEORETICAL FRAMEWORK

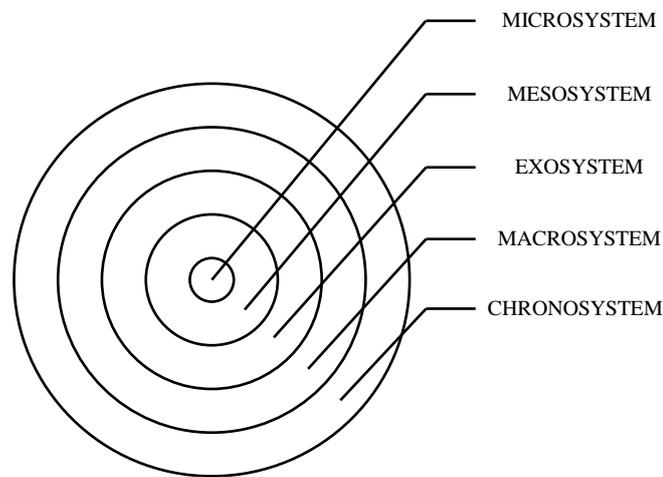
In this chapter, I provide an overview of the theoretical framework used in this study. The conceptualization, interpretation and understanding of this study is based on the EST as outlined by Urie Bronfenbrenner (1979). I chose the EST because it recognizes the individual as embedded within a social system and describes the bidirectional influence of individual, social, and environmental factors on health behaviours at multiple levels (Bronfenbrenner, 1975; Golden & Earp, 2012; Stokols, 1992). Furthermore, Stokols (1992, 1996) stated that health is influenced by a cumulation of cultural, social, and physical aspects and the EST, a multi-levelled framework, may therefore illustrate how multiple levels of influence may act as barriers to or facilitators of individual adherence behaviours. As such, I will use the EST to identify, organize and discuss the barriers to and facilitators of adherence to chemotherapy among breast cancer patients.

3.1 Bronfenbrenner's Ecological Systems Theory

The EST was originally developed as a theory of human development (Bronfenbrenner, 1979) but was later applied to many other fields including health research (e.g., McClaren & Hawe, 2005; Richard et al., 2011; Tanhan, 2019). In his theory, Bronfenbrenner posits that the socio-ecological environment, consisting of nested structures, influenced the psychological and social aspects of human development (Bronfenbrenner, 1979). According to Bronfenbrenner, the ecological environment consists of five interdependent systems that facilitate proximal processes of interaction (Bronfenbrenner, 1979; 1994). These systems are the micro-, meso-, exo-, macro- and chronosystems. These systems are contextualized as five levels and arranged in a model, with the individual situated at the centre.

Figure 1

The five systems of the Ecological Systems Theory



At the centre of the EST model is the microsystem, in which the individual is nested, and consists of proximal interactions with his or her immediate environment (Bronfenbrenner, 1979; Johnson, 2008). It comprises the activities, roles and interpersonal relationships the individual has with family members, the greater community and healthcare workers (Bronfenbrenner, 1979, 1994). The microsystem in the context of this research study for breast cancer patients included patients' interactions with their family and healthcare workers. For example, the breast cancer patient may be unable to cope with the severity of side effects as a result of chemotherapy and may decide to default on treatment. The microsystem is embedded in the mesosystem.

The mesosystem consists of the interactions between the participants of the microsystem, namely the patients, their religion, their family members and greater community as well as the healthcare workers involved in their treatment. It is essentially a system of microsystems with interactions occurring in a bidirectional manner. Therefore issues that arise in one of the individual's microsystems could negatively impact other microsystems in the individual's life (Bronfenbrenner, 1979, 1994). For example, social support from family may influence the breast cancer patient positively, which in turn has a

positive influence on adherence to treatment. Therefore, if a breast cancer patient is not supported, they may become nonadherent to treatment as they are unable to cope with the burden of disease alone. The interactions that took place in the mesosystem in this study's context included social and community support and the relationship with healthcare workers. The mesosystem is embedded in the exosystem.

The exosystem comprises the interactions between two or more settings, one of which the individual is not an active participant, but which indirectly influences them (Bronfenbrenner, 1979; 1994; Johnson, 2008). The exosystem in this research study's context included the patients' workplace policies as well as the institution-related factors influencing treatment. An example of this is the hospital transport provided to patients free-of-charge which allows them to attend their hospital visits. The exosystem is embedded in the macrosystem.

The macrosystem is the largest system and its effects can be seen in the functionality of the micro-meso- and exosystem. It is the overarching pattern of the previous systems' characteristics and consists of the belief systems, values, lifestyles, customs, attitudes, ideologies and laws of a particular subculture or culture (Bronfenbrenner, 1994; Johnson, 2008). The macrosystem in this research study's context included governmental healthcare policies and the individual's cultural, religious and/or spiritual beliefs.

The chronosystem encompasses change to both personal and environmental characteristics that occur throughout the individual's life. These include changes in the individual's socioeconomic status, family structure and home environment (Bronfenbrenner, 1994).

Bronfenbrenner's EST has however been criticised for neglecting the individual's ability to influence their own success. It has been argued that greater emphasis should be placed on individual agency before analysing the other systems' interaction and influence on

the individual (Christensen, 2010; 2016). Christensen (2010; 2016) also highlighted a lack of an ‘international level’ which takes into account the effects of globalisation on the individual beyond the macro-level. Christensen (2010; 2016) argues that in order to rectify this, the concept of resilience should have been integrated to the theory as stated by Engler (2007) as it enables our understanding of an individual’s capacity to deal with and overcome adversity.

3.2 EST and medication adherence

The EST has been utilised as a framework for understanding and organising factors influencing adherence to antiretroviral therapy used for the treatment of the non-communicable disease, HIV (Coetzee et al., 2011). Coetzee et al. (2011) used EST to examine and understand the structural barriers to antiretroviral treatment (ART) adherence amongst patients living with HIV and AIDS at a peri-urban hospital in South Africa from the perspective of healthcare providers. Through the lens of the EST, the authors stated that individuals who disclose their status to members of their microsystem such as their family, experienced ease of access to social support which facilitated their adherence to treatment. Stigma and non-disclosure however hindered patients’ ability to adhere to treatment at the mesosystem as patients preferred to receive treatment at clinics away from home which in turn impeded their ability to access healthcare. Coetzee et al. (2011) further argued that social intercourse in the microsystem would have knock-on effect throughout the rest of the systems of the EST.

Accordingly, using Bronfenbrenner's EST to contextualise the factors that influence adherence, one can recognize that the barriers and facilitators to adherence exist at multiple levels and influences the individual both directly and indirectly. Therefore, the EST is an appropriate lens through which to organise the factors affecting adherence to chemotherapy in breast cancer patients as it considers adherence behaviours of the individual as embedded within a system of environments that are in interaction with each other.

3.3 Conclusion

In this chapter, I described the conceptualization, interpretation and understanding of this study through the lens of the EST. I described the development of the EST along with some of its criticisms and described its suitability to contextualize adherence factors. In the next chapter I will report on the methodology of the study.

CHAPTER 4

METHODS

In this study I aimed to examine the barriers to and facilitators of adherence to intravenous chemotherapy amongst breast cancer patients at a tertiary hospital in the Western Cape, South Africa. In this chapter, I will provide an overview of the research design, sampling, and recruitment processes. I will then discuss the data collection and analysis procedure, followed by a description of the steps undertaken to ensure trustworthiness and rigour in the present study. Finally, I will describe my reflexivity and the ethical considerations related to the study.

4.1 Research Design

In this study, I utilized an exploratory, qualitative research design. I chose this design as I explored the lived experiences of individuals regarding adherence to breast cancer treatment (Cresswell, 2013). Semi-structured interviews as the method of data collection were appropriate as it allowed participants to provide flexible, open-ended responses about their experiences (Willig, 2013). Qualitative research is described as an exploration of the texture and quality of experience as opposed to the identification of cause-effect relationships. The focus of this type of research was to gain a better understanding of the adherence behaviours of patients as well as possible issues surrounding adherence, and studied these individuals within their natural environments (Cresswell, 2013; Willig, 2013).

4.2 Study setting

This study was conducted at the breast clinic and chemotherapy unit at a tertiary-level public hospital, which is both a teaching hospital and a clinical facility situated in the Western Cape. The hospital serves approximately 70% of individuals without access to private healthcare facilities which includes half of the rural population in the Western Cape (Schoeman et al., 2013). At this hospital, a multidisciplinary approach is used to diagnose

patients as it results in improved outcomes for breast cancer patients (Nietz, 2019). This approach is carried out by a multidisciplinary team (MDT) which is comprised of specialists from various medical fields and allied health services including a radiotherapist, oncologist, pathologist, and doctors working in the breast clinic and chemotherapy unit. MDT meetings take place weekly on a Friday morning and all aspects of care are discussed including systemic therapy, radiation, surgical therapy, and diagnosis. Comprehensive treatment plans for patients are also decided upon in this meeting (Nietz, 2019). Treatment is paid for based on the patient's income.

4.3 Recruitment strategy

4.3.1 pre-COVID-19 recruitment strategy

I used a purposive sampling strategy to recruit participants for this study. This strategy was suitable as individuals were included in the study based on criteria that were relevant to the research question (Bryman, 2016; Silverman, 2014). My study population therefore consisted of breast cancer patients who were currently receiving or had previously received chemotherapy at the breast clinic and chemotherapy unit, their family members and healthcare workers involved in the administration of intravenous chemotherapy. The key population in this study was breast cancer patients who had defaulted on their treatment, meaning that they had attended <100% of their chemotherapy appointments (Wells et al., 2015).

In compliance with the research proposal approved by Stellenbosch University's Health Research Ethics Committee (HREC) (Reference number: S19/07/130) (see Appendices A and B), I did not directly approach potential participants for recruitment. Healthcare workers identified participants for me to approach from the list of patients present on the day in the chemotherapy unit. In the breast clinic, the head of the clinic asked patients that she had attended to if they would be willing to speak to me about a research study. If

patients expressed interest in the study, the doctor introduced me to the patients and I explained the purpose of the study. If patients then expressed willingness to participate, I obtained their consent and commenced with the interview. After the combined clinic meetings on a Friday, the head of the breast clinic, notified me if a defaulting patient had an appointment for the following week Thursday. The healthcare workers were also usually present with me when I contacted potential participants as they introduced me to the patients. In November 2019, I amended my ethics application to include the chemotherapy unit (see Appendix C) as an additional study site as I had discovered that patients only attend the breast clinic when they first came for tests and again once they have completed their chemotherapy. Without this additional study site, I would have been unable to recruit patients who were currently receiving chemotherapy.

4.3.2 COVID-19 recruitment strategy

On the 16th of March 2020, I received a departmental email indicating that face-to-face data collection had been suspended until the 30th of March 2020. On the 20th of March, 2020, I received formal notification from the Research Ethics Committee (REC): Social, Behavioural and Education Research that research involving physical contact or close proximity with human participants had been suspended until further notice. In May 2020, I included a second ethics amendment to conduct telephonic interviews with patients, family members and healthcare workers due to the COVID-19 pandemic. I included an amendment to access non-adherent patients' files on a referral from the head of the breast clinic who is also a collaborator on this study. Based on her referral I would contact patients regarding possible study participation. The amendment for access to non-adherent patients was included as only one participant was recruited for my key population of patients who had defaulted on their treatment.

In June 2020, I received approval for the ethics amendment (see Appendix E). Due to concerns regarding privacy issues relating to contacting patients and their family members over the phone, I only conducted one interview with a healthcare worker using a Voice Over internet Protocol (VoIP). In August 2020, the country moved down to Level 2 lockdown and the suggestion was made by the head of radiation oncology for me to resume recruiting patients. Due to the continued embargo on face-to-face research imposed by the HREC/REC, I was unable to recruit patients and had to apply for an extension of my study period. I received approval in October 2020 valid until October 2021 (see Appendix F).

On the 5th of October 2020, the HREC in their communique on research during the COVID-pandemic stated that the country's move to level 1 lockdown allowed for the continuation of data collection provided all health protocols were followed. I also applied for an extension to conduct research at the tertiary hospital which was granted in February 2021 (see Appendix G). Despite approval, it was difficult to recruit patients as there was a delay in approval from the tertiary hospital and there were still concerns regarding face-to-face interviews with patients.

4.3.3 Breast cancer patients

I placed recruitment posters (with permission from the relevant staff at each facility) (see Appendix H) in the waiting area of the breast clinic as well as the chemotherapy unit. I approached 15 patients who were referred to me by healthcare workers of whom nine participated. None of the participants were recruited using the recruitment poster, as most were identified by a nursing sister or doctor in the chemotherapy unit or in the breast clinic using the inclusion criteria.

I took note of patients who were adherent and nonadherent based on information from healthcare workers as well as self-disclosure, to ensure I recruited participants for my key population. Adherent breast cancer patients were participants who were currently receiving

chemotherapy and had attended 100% of their chemotherapy sessions (Wells et al., 2015). Nonadherent breast cancer patients were participants who had received <100% of their chemotherapy sessions (Wells et al., 2015) or were previous patients at the breast clinic and chemotherapy unit but had defaulted on treatment and then returned for treatment. I explained the purpose of the research study to the patients after which they either agreed or declined to participate in the research study. Nine breast cancer patients were recruited in the breast cancer patient group and remuneration of R100 was offered as compensation.

In addition to the criteria already described, for participants to be included in the study, they needed to:

- be a female between the ages of 18 and 60 years of age. This age range was chosen and suggested by Dr Jenny Edge (a medical doctor and head of the breast clinic) as age may affect tolerance of treatment (J. Edge, personal communication, May 3, 2019); an amendment was made to decrease the lower age limit of participants from 30 to 18 years of age (see Appendix D)
- speak either English or Afrikaans. I had purposed to include Xhosa, but due to financial implications, I was unable to do so;
- have time to meet for an interview of approximately 30 to 45 minutes within the breast clinic or the chemotherapy unit or be willing to participate in a telephonic interview at a time convenient for the participant;
- have a formal clinical diagnosis of breast cancer from stage I to IV (see glossary of terms);
- be attending the breast clinic and chemotherapy unit at the tertiary hospital and;
- currently be receiving intravenous chemotherapy (have had one or more chemotherapy appointments or were finishing therapy), or have missed one or

more of their chemotherapy appointments or have received intravenous chemotherapy in the past and defaulted for psychosocial and not physical reasons but have now returned for therapy again.

I asked breast cancer patients to describe their cancer journey thus far, how the diagnosis and subsequent treatment had impacted their lives as well as to identify the factors that enabled or did not enable them to attend treatment (see Appendix K for interview schedule)

4.3.4 Family members

I placed a recruitment poster (see Appendix I), in the reception/waiting area of the breast clinic and the chemotherapy unit. None of the participants in this subgroup were recruited using the recruitment poster. These participants were family members of breast cancer patients who attended the breast clinic and the chemotherapy unit. It was not required that these individuals should be related to a breast cancer patient already in the study. However, all of the family member participants were recruited by asking the breast cancer patient participant if they had brought a family member with them. Family members had to be available to meet for an interview of 30 to 45 minutes within the breast clinic or chemotherapy unit. I approached the identified family members and explained the purpose of the study to them after which they either agreed or declined to participate. Three participants were recruited for this group. I asked family members to describe how the cancer journey had affected the breast cancer patient, themselves, as well as the rest of the family (see Appendix L) and to identify factors that they think might influence patients' adherence behaviours (Willig, 2013). I offered family members a remuneration amount of R100 as compensation.

4.3.5 Healthcare workers

I invited participants in this subgroup to participate using a recruitment poster (see Appendix J) as they were healthcare workers at the breast clinic or at the chemotherapy unit.

The telephonic interview conducted was conducted with a healthcare worker whose contact details had previously been personally shared with me. I sent the healthcare worker an SMS to explain the study and asked if they were willing to participate. Once the healthcare worker indicated willingness to participate, I arranged an interview at a time that was convenient to them. The inclusion criteria for this group were individuals who were either nurses or doctors in the breast clinic or chemotherapy unit and who were in regular contact with breast cancer patients. Oncology nurses are likely to yield important insights into patients' decisions as they spend more time with patients than doctors do, therefore their relationship with patients could provide considerable understanding of patients' treatment decisions (Peter & Liaschenko, 2004; Dhotre et al., 2016). In addition, these healthcare workers were involved in the treatment regimen or administration of chemotherapy to breast cancer patients and had worked at the clinic or chemotherapy unit for at least one year. None of the participants in this group were recruited using the recruitment poster. Instead, participants were recruited with the help of the head of the breast clinic, the head of the chemotherapy unit and a nursing sister in the chemotherapy unit with a total of eight individuals participating. The head of the chemotherapy unit introduced me to the nursing sister in charge of the chemotherapy room who suggested I introduce my study to the nurses at the end of one of their weekly Friday morning meetings and asked if anyone was willing to participate. I made appointments with the nurses and doctors to interview them at a time that was suitable to them and interviews lasted between 15 and 20 minutes. One healthcare worker was interviewed telephonically using WhatsApp (VoIP) during the lockdown, with the rest of the healthcare workers being interviewed via face-to-face interviews. The interviews with healthcare workers were guided by an interview schedule (see Appendix M) and they were asked to describe their interactions with patients and the factors that they thought influenced patients' adherence behaviours.

Light refreshments including a bottle of water, a wrap and chocolate were offered as compensation.

4.4 Research participants

This study was conducted at a tertiary hospital in the Western Cape and I presented at the chemotherapy unit on a Monday, Tuesday, and Thursday morning and at the breast clinic on a Thursday morning. Participants were included in the study if they met the inclusion criteria and expressed interest in participating in the study. Twenty-nine participants were invited to participate of whom 20 agreed to be interviewed across all the participant groups. I approached 15 breast cancer patients of whom nine participated. The reasons for declined participation were the arrival of chemotherapy medication for two patients who then went into the treatment room and the unavailability of a private room in which to conduct the interview for two other patients. One patient was referred by an oncologist but she was already receiving treatment in the chemotherapy room and had just started a 4-hour chemotherapy treatment session. The final patient contacted me to be interviewed but did not respond to follow-up requests for the interview to take place. Six family members were approached of whom three declined. Their reasons for declining included being a family friend and therefore not having sufficient knowledge about the patient's treatment experience. The unavailability of a private room in which to conduct the interview and the final family member approached declined participation with no reason given. Eight healthcare workers were approached and agreed to participate in the study. I struggled to recruit participants for my key population of non-adherent patients as these patients failed to attend treatment and efforts by healthcare workers to contact these patients were futile as they stated that they found that patients' contact details changed and were not updated, they lost their phones, or they no longer resided at the address on file when the police were sent out to look for these patients. Five non-adherent patients were referred to me, of which three failed to arrive for

treatment, one had an informal interview as she did not want to take part in the study but wanted to explain her reason for defaulting treatment and the other non-adherent patient declined participation in the study.

4.4.1 Impact of COVID-19 on research strategy and recruitment

The COVID-19 pandemic as well as the subsequent embargo on face-to-face research imposed by the HREC/REC resulted in a disruption in data collection for my research study. As a result, I was forced to amend my research and recruitment strategy. I was only able to interview one healthcare worker during the level 5 lockdown the country experienced as I had had previous contact with them before the pandemic began. I was unable to interview breast cancer patients and family members during hard lockdown, and this was also partially due to the fact that I did not want to burden healthcare workers with referring patients via word of mouth as they were already experiencing strenuous working conditions. When I was able to return to the hospital, several considerations such as health concerns and the transmission of the virus made me hesitant and cautious about engaging with potential participants. I was however able to interview two healthcare workers as well as a family member.

4.5 Data Collection

Data collection was conducted from 1 October 2019 to 31 May 2021 following the research procedure described as follows. Due to the COVID-19 pandemic, telephonic interviews were added as a method of data collection. Face-to-face as well as telephonic interviews were conducted with participants in a private room at the participants convenience, or via VoIP. For the telephonic interview, I sent a word document of the consent form (see Appendix N), which they completed and returned to me via email before the interview was conducted. Before the interview commenced, I informed participants who met the inclusion criteria of the purpose of the study and indicated that their participation was entirely voluntary and that they could withdraw from the study at any time without

consequence. Participants then received a consent form (see Appendices O; P; Q) and a demographic questionnaire (see Appendix R). I gave participants the option of reading the forms alone or going through the form together. Most participants in the patient and family member groups opted for the form to be read to them. Participants were informed that their responses would be kept confidential and that all data obtained would be anonymous. Furthermore, permission was obtained from participants for an audio-recorder to be used during the interview to allow for verbatim transcription to occur. Once I had read through the form, the participant was able to ask me any questions regarding information that was unclear to them.

Malterud et al. (2016) suggested that sample sizes in qualitative research should be guided by information power. They identified several considerations to assess the information power of the study which include the quality of dialogue, theoretical background, study aim, sample specificity, and strategy for analysis. As I am a novice researcher, I required more participants as my personal shyness affects my ability to establish good dialogue. My study is however theoretically grounded and I have an understanding of previously identified factors influencing adherence. The aim of my study was neither broad nor narrow and I was assisted by healthcare workers to recruit patients therefore participants had characteristics specific to my study. Finally, as my study was exploratory in nature, I endeavoured to present selected patterns relevant to the study aims (Malterud et al., 2016). Data collection ceased as the interviews conducted had a high relevance for the research aim therefore the sample held sufficient information power (Malterud et al., 2016). It should also be noted that I was not contacted by healthcare workers in the chemotherapy unit despite distributing individual recruitment posters. I struggled to recruit participants for the family members' group as family members were not allowed to accompany patients to the chemotherapy unit and had to

instead wait at the entrance of the building. I was also not being contacted regarding referrals for non-adherent patients anymore.

4.5.1 Demographic questionnaire

The demographic information (see Appendix R) I collected from participants included age, marital status, postal code (as a proxy for SES), and religious belief for the breast cancer patient group. I asked family members to record their relation to the breast cancer patients as well as their marital status and religious belief. I asked healthcare workers to provide their occupation (e. g. doctor or nurse) and the number of years they had worked in their occupation. The demographic information allowed me to get to know the participants and informed some of the research results.

4.5.2 Semi-structured interview

Interviews were conducted with breast cancer patients for 20 minutes on average, with family members for 26 minutes on average and with healthcare workers for 20 minutes on average. Interviews were conducted in English or Afrikaans as Xhosa-speaking patients understood English, using a semi-structured interview schedule (see Appendices K, L, M). Semi-structured interviews are a loose, flexible means for gaining insight into participant perspectives, experiences, beliefs, feelings, and thoughts regarding a particular phenomenon (DeJonkheere & Vaughn, 2019).

Patients and family members were interviewed on days when they had appointments at the breast clinic or the chemotherapy unit which were Mondays, Tuesdays, or Thursdays. Most patients who were still receiving chemotherapy or were completing chemotherapy attended the chemotherapy unit on a Monday and Tuesday. Defaulting patients and some completing patients attended the breast clinic on a Thursday. Interviews with nurses and doctors were conducted at a time that was convenient to them which was usually on a Friday morning or afternoon. Breast cancer patients (see Appendix K for interview schedule) were

interviewed regarding their experience of chemotherapy as well as any factors that affect their adherence to chemotherapy. Family members were asked to share their opinions regarding their family members' experience of chemotherapy as well as the effect that the cancer journey had had on themselves as well as the family unit (see Appendix L for interview schedule). Healthcare workers were asked their opinion regarding factors that affect patients' adherence to chemotherapy (see Appendix M for interview schedule).

Participants were encouraged to share freely during the interview however, several factors influenced the duration of the interviews, especially amongst breast cancer patients. Language barriers were a hindrance for four patients who did not speak English or Afrikaans as a first language, but indicated that they were comfortable with the interview being conducted in English. Despite probes used to encourage engagement such as 'can you tell me *how* your family supports you during the chemotherapy process', language barriers resulted in some frustration and discomfort on my part. I struggled to get participants to elaborate on their closed-ended answers and I instead ended up asking more closed-ended questions relating to previous interview answers that I had received to see if there were any similarities in participants' experiences.

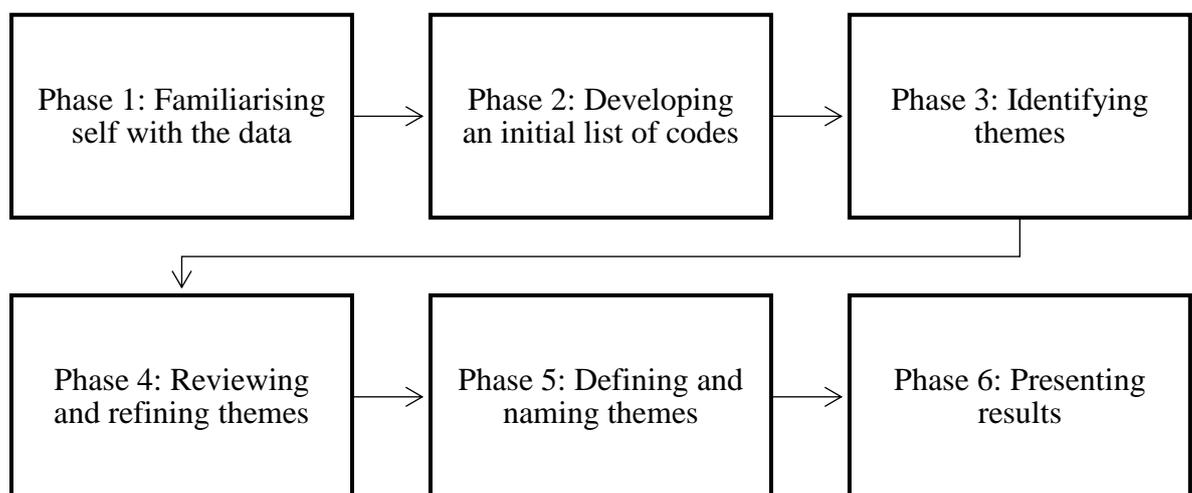
4.6 Data Analysis

Following data collection, I transcribed the digitally recorded interviews verbatim. I analysed the interviews using ATLAS.ti v8 and v9. ATLAS.ti is a computer programme used to analyse large amounts of audio, graphical, video and textual data in order to gain a rich understanding of the narratives (ATLAS.ti, 2019). I then used the steps outlined by Braun & Clarke (2013) to thematically analyse the data collected from the interviews. According to Braun & Clark (2013), thematic analysis is an adaptable qualitative method as it does not subscribe to a particular epistemological or theoretical position. In this method, patterns within the data were identified, analysed and reported which allowed me to create a rich and

detailed as well as complex narrative of the data. The different stakeholders in this research study were first analysed separately, after which overlapping themes between the different stakeholders were grouped together. I followed this process as I wanted to identify the most salient factors identified by the various stakeholders and created a global description of the most salient factors of adherence in the study. The purpose for the diversity of the stakeholders was to find out from the individuals themselves what factors affect adherence at different levels of the ecological system. It was essential for me to indicate clearly and concisely what was being researched, why it was researched and how the data analysis was carried out. By adhering to the recommendations of Braun & Clarke (2013), I purposed to maintain scientific rigour and transparency.

Figure 2

The six phases of thematic analysis adapted from Braun and Clarke (2013)



4.6.1 Phase 1: Familiarising self with the data

I transcribed, translated, and repeatedly read through the interview transcripts in this phase. Prior to transcribing the interviews, I listened to the recording and then transcribed the interview verbatim. I encountered some difficulty in transcribing interviews that were conducted in Afrikaans as participants sometimes spoke too fast or used a mixture of English and Afrikaans to convey their ideas. I also encountered some difficulty with Xhosa-speaking

participants as they could not always express themselves in English and struggled to understand the question at times. I did however make notes after each interview, so I referred to them and relistened to the recording several times to make sense of what was being said. I found that participants got distracted when I took notes during the interview so I seldomly did so during the interview. Any language use errors were not corrected during the transcription and translation process to ensure that the written text remained true to what participants said and that its meaning remained unaltered. Once the interviews were all transcribed, I read through the transcriptions and made notes of any reflections, thoughts, or patterns I found in the data. The interviews were then imported into ATLAS.ti v8 and v9 and I used the memo function to record the notes I made after interviews as well as to note any points of interest and initial codes I generated in re-reading the transcripts. The three participant groups were initially analysed separately, after which the themes identified across all three groups were collated and compared. The comparison of themes across the various participant groups was to create a global understanding of the participants' perspectives on barriers to and facilitators of adherence to chemotherapy.

4.6.2 Phase 2: Developing an initial list of codes

I created a list of initial codes and then coded all relevant quotations in the first round of coding. Each code was named according to the participant group it fell under e. g. Breast Patient (BP), the main idea it described and its relation to the main idea e. g. BP_barriers_transport. In the second round of coding, the initial codes were reviewed for redundancy and codes with similar or related ideas were merged into one for each participant group.

4.6.3 Phase 3: Identifying themes

According to Braun and Clarke (2013), a theme describes an important aspect of the data in relation to the research question that is repeated throughout the responses in the data

set (Braun & Clarke, 2013). In this phase, I analysed the list of codes generated and combined those which shared a relationship to form potential overarching themes and sub-themes for each participant group. Codes were colour-coded according to the main idea described e. g. barriers to indicate the broad theme which they formed part of.

4.6.4 Phase 4: Reviewing and refining themes

In this phase, I reviewed and refined the themes by eliminating themes that did not have enough data to support it, or where the data was too diverse, I collapsed themes into each other as separate themes. Once this process was completed, I checked that the themes followed a coherent pattern and that they reflected an accurate representation of the data set.

4.6.5 Phase 5: Defining and naming themes

In phase five of thematic analysis, I defined and further refined the themes identified to reflect the essence of the contents of the theme, which included identifying sub-themes (Braun & Clarke, 2013). I noted any thoughts and reflections I had regarding the content and meaning of each of the themes and sub-themes identified. A table of themes and sub-themes was constructed for each participant group after which the themes identified across the various participant groups were collated and compared for similarities and differences. The EST was used to further refine the themes and sub-themes identified and a global table was then constructed to indicate the most salient themes identified across all the participant groups.

4.6.6 Phase 6: Presenting results

In this phase I presented the results of the data analysis. I aimed to synthesize a rich description of the identified themes, including my interpretation of the themes' relevant to my research question. Furthermore, I included excerpts from the data in order to provide evidence of the themes.

4.7 Trustworthiness and rigour

In this research study, I employed the trustworthiness criteria of Lincoln & Guba (1985) to ensure the trustworthiness and rigour of this qualitative research study. Lincoln & Guba (1985) introduced criteria for trustworthiness in qualitative research namely dependability, credibility, and confirmability.

Dependability of qualitative research is concerned with the reliability of the findings attained from the data and ensures that the research process is well-documented over time (Bitsch, 2005; Nowell, 2017). I made use of an audit trail to account for all the research activities and decisions I made, and also to indicate how data was collected, recorded and analysed (Bitsch, 2014). I also provided detailed descriptions of the research design, study setting, recruitment strategy, research participants, data collection methods and data analysis I did.

Credibility assesses whether the information presented is a correct interpretation of the participants' original opinions. Lincoln and Guba suggest that credibility be addressed using peer debriefing, which provides an external view of the research process, and reflexivity in which I created an account of the research process (Lincoln & Guba, 1985; Nowell et al., 2017).

Transferability refers to the degree to which the study can be transferred or generalized to other settings or contexts. I therefore used purposive sampling to recruit participants based on inclusion criteria relevant to the research question. I also endeavoured to provide rich descriptions in order to ensure transferability (Lincoln & Guba, 1985).

Finally, confirmability is established when credibility, dependability and transferability are achieved. Furthermore, confirmability is related to the degree to which the research study findings can be confirmed by other researchers. It establishes that the data and interpretations of the findings are clearly derived from the data and not the researcher's

imagination. I did this by means of reflexivity and an audit trail (Lincoln & Guba, 1985; Nowell et al., 2017).

4.8 Reflexivity

Dodgson (2019) states that it is important for the researcher to articulate all the elements of the research space in order for better understanding of the research context. Furthermore, who the researcher is influences the findings of their study as objectivity is not present (Dodgson, 2019). The researcher needs to be aware of their self-knowledge and sensitivity, understand the role of self in knowledge creation and be mindful of the impact of their beliefs, biases and personal experiences on their research (Berger, 2015; Cresswell, 2013). The researcher also needs to take into consideration their position as an insider or outsider as well as similarities and differences between themselves and the participants (Berger, 2015).

When I began this research project, I had just completed my honours degree in Psychology. I was inexperienced in the field of my research study, but had previously completed a qualitative research project as part of my honours degree. I was considered an ‘outsider’ as I did not have personal experience with breast cancer or the treatment thereof (Berger, 2015). However, prior to data collection, I familiarised myself with the procedures at the hospital with regards to the daily operations of the breast clinic and the chemotherapy unit and I attended a few multidisciplinary meetings in order to gain an understanding of the diagnostic and treatment procedures of the hospital. I also engaged with the head of the breast clinic, the head of the chemotherapy unit as well as various doctors working in the respective hospital areas in order to gain insight as to when patients come in for treatment and when the most appropriate time would be to present at hospital for data collection and interviews. I engaged in persistent observation of my study’s target sample as I presented to hospital several days a week, for a few hours at a time (Whittemore et al., 2001).

During data collection I kept field notes of my experiences at the sites and after interviews conducted with participants, in order to reflect thereon, especially in terms of how I assumed participants may have perceived me and how I perceived participants and my interactions with them (Mulhall, 2003). I am an introverted and shy person by nature and was initially timid with regards to participant recruitment. It was easier for me to recruit healthcare workers for my study as I was introduced by either the head oncology nurse, the head of the breast clinic or the head of the chemotherapy unit and because of previous engagement, they were friendly and receptive. Patient recruitment was sometimes challenging when I approached patients alone after a referral from a healthcare worker because I assumed I was an unfamiliar face and patients would be hesitant to speak to me. However, I found that they assumed I was a healthcare worker, especially when I was introduced to the patient by a doctor. I was cognisant of the fact that most participants were older than me and tried to ensure that I came across as respectful and empathetic. While walking to the interview room, I made some small talk with patient and family participants in order to build rapport. I tried to remain approachable and understanding throughout the interview and throughout most interviews, patients seemed comfortable and genuine.

I did however encounter some language barriers both on my own part as well as that of some participants. Although I am able to speak Afrikaans, I tend to speak faster and stumble over my words more, especially because I am more self-conscious. During some interviews I would switch between English and Afrikaans when I found that I was not able to articulate myself, although I did apologise to the participant and made every effort to conduct the interview in one language. If participants indicated that I could ask questions in English, I did so only when I could not properly articulate the question in Afrikaans. The language barriers I encountered on the part of patients resulted in some frustration and discomfort on my part as I could see their struggle and wanted to assist them in order to minimise

discomfort during the interview. This could result in researcher bias as I tried to guide patients' answers by asking more closed-ended questions relating to previous interview themes identified in order to assess for similarities or differences (Knox & Burkard, 2009; Cresswell, 2013).

4.9 Ethical Considerations

Preceding the interview with each participant, I obtained their written informed consent when I conducted face-to-face interviews and verbal consent when I conducted the telephonic interview (see Appendix N, O, P, Q) from all participants. I asked participants whether they understood what I had explained to them and what was expected of them. I also explained that their participation in the study was entirely voluntary. I told participants that they were free to decline participation and could withdraw from the study at any given time without any penalization or consequences. I also informed participants that they would not directly benefit from the study. I obtained permission from participants to record the interview using an audio tape recorder and explained the intentional use of the audio tape recorder for transcription and translation of data to the participants. I ensured participants that any information shared would be kept confidential and that their identity would be kept confidential and protected. After I conducted an interview, I transferred the audio recording to a password-protected computer. To ensure confidentiality, I assigned each participant subgroup a name (e. g. Breast Cancer Patient: BCP) and each individual participant in the subgroup an identity letter (e. g. BCP_A). For the purpose of reporting findings, each participant in the breast cancer group was assigned a pseudonym according to their identity letter. Family members were reported using their subgroup and identity letter e. g. Family member A as well as their relation to the breast cancer patient and healthcare workers were reported according to their occupation and identity letter e. g. Doctor A. All data collected were entered into an Excel spreadsheet and stored on a password-protected private computer.

These data were also backed up on Microsoft OneDrive. Informed consent documents and demographic questionnaires are kept in a locked cupboard in my supervisor's office in the Department of Psychology at Stellenbosch University. I recorded informed consent for the telephonic interview at the beginning of the interview and the recording was stored on a password-protected private computer.

4.9.1 Beneficence

Before the interview began, all participants were informed that should they feel discomfort during or after the interview, the Welgevallen Clinic had agreed to provide psychological support should any of the participants need it (see Appendix S). Transport costs were covered by my supervisor's research funds for those participants who needed to travel to receive face-to-face therapy. Telephonic support was also available to participants if needed as face-to-face therapy was not possible during the national lockdown. None of the participants indicated the need to make use of this service and many found the interviews therapeutic and a positive experience.

4.10 Conclusion

In this chapter I presented the methodology used in the study. I collected qualitative data and used thematic analysis as outlined by Braun and Clarke (2013) to examine the factors influencing adherence to intravenous chemotherapy amongst breast cancer patients as identified by the patients themselves, their family members and healthcare workers. I described my study participants as well as the data collection and analysis process. Trustworthiness, rigour and the ethical considerations of the study were also described. In the following chapter, I will report the results of the data analysis.

CHAPTER 5

RESULTS

In this chapter, I will report on the findings of the interviews conducted with healthcare workers (n=8), breast cancer patients (n=9) and family members (n=3). In total, I conducted 19 interviews with 20 individuals, as one interview was conducted with two healthcare workers together, who were aged 18 years and older. I will first give a summary of the participants' characteristics, followed by a table collating the themes and sub-themes identified across all three participant groups. Thereafter I will report the themes and sub-themes that emerged across all three participant groups and finally I will give a summary of the chapter. The themes and sub-themes were arranged to reflect the barriers to, and facilitators of adherence identified in each system across all the participant groups. Nine themes and 14 sub-themes were identified (Table 1.2). The themes and sub-themes are structured, in this chapter, according to three of the five system levels of the EST. The EST was an appropriate lens through which to organise and interpret the factors at various system levels as it allowed for the factors affecting adherence behaviours to be contextualised according to the system level they were found in. The following section details each identified theme, its associated sub-theme(s) as well as supporting quotations.

Table 1*Demographics table for breast cancer patients, family members and healthcare workers*

Characteristics	BP, n = 9 Adherent (67%)	Non-adherent (33%)	FM, n= 3
<i>Breast cancer patients and family members</i>			
Age (Mean, (Standard Deviation) in years)	(M=45,11, SD =12,78)		
Marital status			
Single	3		
Married/Partner	5		3
Divorced	1		
Religious belief			
Christian	9		3
Current work situation			
Employed full-time	1	1	1
Employed part-time			1
Self-employed	1		
Student	1		
Unemployed	3	2	1
Relation to patient			
Daughter			1
Sister			2
<i>Healthcare workers</i>			
Characteristics	n = 8	%	
Occupation			
Professional nurse	5	63	
Medical Doctor	3	37	
Years in occupation			
≤ 5 years	2		
≤ 10 years	3		
≤ 20 years	3		

Note. Breast cancer patients (BP) and Family members (FM)

Table 2*Themes and sub-themes across all participant groups*

Systems	Themes	Sub-themes
Microsystem	Factors influencing decision to start treatment	Beliefs and assumptions regarding treatment Impact of chemotherapy on fertility and body image
	Individual barriers to adherence to chemotherapy	Side effects Forgetfulness
	Poverty-related structural barriers to adherence to chemotherapy	Migration Transport & Finances
	Individual facilitators of adherence to chemotherapy	Self-motivation Symptom improvements Religious/spiritual beliefs
Mesosystem	Interpersonal and familial barriers to adherence to chemotherapy	Lack of social support Family responsibility
	Interpersonal facilitators of adherence to chemotherapy	Physical support Work-related support Instrumental support Emotional support Support from healthcare workers Communication with healthcare workers
Exosystem	Impact of work on treatment adherence	
	Institution-related barriers to adherence to chemotherapy	Lack of oncology-trained staff
	Institution-related facilitators of adherence to chemotherapy	Multidisciplinary care Fee subsidy Hospital transport and disability grant

5.1 Microsystem

As described in the EST, the individual, namely the breast cancer patient (and henceforth known as the patient), is at the centre of the microsystem. The microsystem is the innermost system of the EST and describes the individual level factors that directly relate to the patient in their immediate environment that impacts on their adherence to chemotherapy. The immediate environment of the patient consists of their interactions with their family, and healthcare workers. It also consists of their religious beliefs, their perceptions regarding treatment and the physical side effects of chemotherapy.

I identified three underlying themes in this system namely the (1) factors influencing decision to start treatment, (2) individual barriers to adherence to chemotherapy and (3) individual facilitators of adherence to chemotherapy.

5.1.1 Factors influencing decision to start treatment.

5.1.1.1 Beliefs and assumptions regarding treatment. Negative preconceptions regarding treatment, side effects and medication was identified by healthcare workers and patients as a significant theme as it described patients' (mis)beliefs as well as the social influences on their decision to start treatment. Several patients and healthcare workers mentioned that family and community preconceptions regarding cancer and treatment often played a role in patients' decision to begin treatment. For example, healthcare workers stated that patients thought that a mastectomy would influence the way in which the patient's spouse, family and community would think of them, so they therefore declined treatment. They also stated that patients from these communities also often declined undergoing mastectomies because culturally, they would be deemed as less of a woman without breasts.

We have actually encountered that maybe... the patients they don't want to go through a mastectomy and chemo because that will sort of... culturally... she's almost deemed as less of a woman cause now she doesn't have her breasts anymore... (Doctor C, P17)

Doctor B (P6) and Doctor C (P9) stated that some patients made decisions regarding treatment in conjunction with and based on advice from family members. For example, Gloria (P11), a patient, said that members of her community told her, "Cancer is a dangerous thing... they don't say [it] a- affects them... they say the cancer is dangerous maybe you gonna die." Doctor B (P6) stated "the family's not supportive of chemotherapy [for] lots of patients... we'll tell them about the need for the chemotherapy and they feel they cannot... make that decision on their own... they need to go back and discuss it at home... if at home everybody is thrashing the chemo idea... then they don't take the chemotherapy". Other negative preconceptions related to negative treatment side effects, infertility and hair loss. Further, these negative preconceptions also related to the negative portrayal of cancer in the media as referenced by Doctor C who stated that patients expressed fear regarding treatment or declined treatment as a result of their association with treatment and death.

Most people when they think of cancer and if they have been diagnosed and they think of what they see on TV in the movies. Typically, what you see in a movie is a person that has gotten chemotherapy, the hair is off... so I think most of them associate that- that picture or that image of a bald chemo patient as they associate that- that with- with dying and that is also maybe- maybe that is what scares them off as well and just puts them off going through the whole process. (P17)

Furthermore, several healthcare workers reported that some patients expressed concern and anxiety regarding treatment side effects based on second-hand accounts from other chemotherapy patients. For example, Doctor A stated:

Because sometimes they hear stories from other people that had chemo... not specifically the same chemo... uhm... then they worried are they going to you know... are the side effects going to be very bad or not uhm but it is normally you know uhm... not related to the same chemo that this patient will have. (P5)

As seen from the quote above, Doctor A explained that patients were hesitant to start treatment as they assumed or believed that they would experience the same or worse side effects. Doctor A went on to explain that treatment was individualised and the side effects experienced were different for each patient, and this information was communicated to patients who were deciding to undergo chemotherapy treatment.

5.1.1.2 Impact of chemotherapy on fertility and body image. Participants stated that the impact of chemotherapy on fertility was an initial concern for some patients who were deciding to receive treatment. For example, healthcare workers indicated that concerns about fertility were more common amongst their younger patients as older patients were more likely to have completed their families and therefore fertility was not a concern for them. Doctor B stated that interactions with younger patients were difficult as they were more emotional and less accepting of their diagnosis.

Interacting with the- the young ones it's difficult because most of the time... there isn't much insight in the actual disease so they're not as accepting as the older ones... but the younger ones are more uhm... I would say they're more the- more the emotional ones. (Doctor B, P6)

Nurse C attributed this lack of acceptance to the fact that younger patients saw their diagnosis as a punishment.

The younger people it's like it takes longer to accept it yeah... because they ask them... they question... they're still questioning themselves why uhm... had that happened to them or it's almost like a punishment. (Nurse C, P12)

Doctor C mentioned that younger patients who had estrogen-positive breast cancer were recommended surgical removal/radiation of their ovaries to shrink hormone-receptor-positive breast cancer and reduce the risk of recurrence. Doctor C continued that the inability to have biological children also had a psychological impact on patients as well as their partners and played a significant role in the patient's decision to continue with treatment. A similar occurrence was seen amongst pregnant women according to Doctor C who indicated that many pregnant women were reluctant to undergo treatment as the administration of chemotherapy during the first trimester could lead to major birth defects. Doctor C said that chemotherapy is only safe to administer during the second term of pregnancy and mentioned a case where a pregnant patient carried her baby to term before treatment commencement.

So, the pregnant cancer patient also a scenario where we potentially find the mother reluctant to have chemotherapy due to the potential effects on the baby, even though going through a 9-month pregnancy without any treatment is more harmful to the mother. So, I have personally encountered cases where a mother will opt to follow through with her pregnancy first, and only after delivery of baby seek medical assistance for herself. (Doctor C, P17)

Faith (P10), a student who shared that she was the first in her family to be diagnosed with breast cancer stated, “I’m worried because they said uhm... it could be... not having children because the hormones would be... tired... the chemo would affect that.”

Hair loss was also identified as a factor influencing patients’ decision to start chemotherapy treatment. Doctor B mentioned that hair loss was one of the first concerns that patients mentioned and was more concerning for younger patients than older patients who were more accepting of hair loss, as some already wore head coverings. For younger patients, Doctor B said “they’re thinking they’re gonna lose it and it- it’s over they’re going to be bald for the rest of their life” (P6). Doctor B also stated:

But the young ones... the 20-something-year-old and early 30s... it’s a big... image... changing thing (Doctor B, P6)

Although healthcare workers stated that hair loss was an unfortunate side effect of chemotherapy, they explained that they constantly reassured patients that hair loss was not a permanent side effect, and that once treatment was completed their hair would grow back again. Several patients indicated that they wore a wig, weave or head covering. Asanda (P3) stated that she wore a wig because she wanted to look good for herself and people were often shocked to find out that she had cancer because she always made the effort to look good.

Then they said to me... “Hayi [no] you don’t look like you... like someone who got cancer...” I say I do have it... I do have cancer. (Asanda, P3)

Some patients indicated that they had accepted that their hair would fall out as a result of treatment, with two patients, Ellie and Hannah having shaved their heads before hair loss occurred. Other patients reported neutrality regarding their hair loss as they found their hair was now easier to manage or had no influence on their body image. Both Ellie and Hannah

experienced positive reactions which helped them to maintain a positive attitude. For example, Ellie said:

I forget that I'm bald because people like... look at you [laughter] and then you think about 'whaa... oh yeah I've got no hair' But it- other than that it's been quite fun because everyone goes "Yoh you look so good..." "Like you lost weight you- your hair you're looking..." [laughter] "No one's supposed to look this good while-" [laughter]... "Did you have to die to look good Ellie" [laughter]. (Ellie, P9)

One patient however indicated that she struggled with the idea that she would experience hair loss as a result of chemotherapy.

But the problem is that... that hair that you lose your hair...[sigh] I'm stressing about it... it's [hair loss and regrowth] gonna take- take long... it's six months or seven months I don't know. (Faith, P10).

Patients, family members and healthcare workers reported that patients had to consider whether their health or their hair was more important. Nurse C (P12) said, "the doctor will also tell them they must choose what is important... like if it's your hair... your hair can grow back again... but your life... you can't get your life back again".

5.1.2 Individual barriers to adherence to chemotherapy

Once patients have overcome their hesitancy to start treatment, there are additional factors that may influence their adherence to treatment once it commences. In this section, I identify several factors relating to barriers to adherence behaviours for both adherent and non-adherent breast cancer patients. These factors have been divided into two sub-themes namely (1) side effects, and (2) forgetfulness.

5.1.2.1 Side Effects. Participants indicated that the physical side effects associated with chemotherapy posed a barrier for both adherent and non-adherent patients. Adherent patients described side effects related to pain, headaches, dizziness, nausea, fatigue, weakness, weight loss and loss of appetite as influencing their decision to remain adherent to treatment. For example, Hannah described the side effects she experienced after chemotherapy:

It's just after getting chemotherapy then I feel nauseas... I don't have an appetite it makes me miserable and... my sense of taste isn't the same... since I started chemotherapy and... yes and I lost weight... I- I don't have the same appetite that I used to have so I will feel one way today and tomorrow I will feel different. (Hannah, P13, adherent participant).

Several patients stated that fatigue rendered them unable to complete simple tasks. One patient, Faith (P10), indicated that she was a student and said that treatment negatively impacted her studies. She stated that she had almost failed a subject because she was unable to attend classes due to hospital visits as well as side effects such as fatigue and nausea.

Sho, it affects them very bad, but I almost fail a subject so- because I don't attend [classes] if I can be here for chemo. Then I would five days I won't attend the school if I- if I had nausea and vomiting. (Faith, P10)

For some patients, the side effects of chemotherapy were severe and their bodies simply could not cope with the demands of chemotherapy as was the case for Deborah (P8). Deborah explained that the severity of her side effects caused her to “pray to God to take me away... that is how bad the chemo made me” (Deborah, P8, non-adherent due to medical advice). Treatment termination for Deborah occurred due to a medical decision following hospitalization for a blood transfusion as a result of becoming severely ill after a chemotherapy session.

Another patient, Ellie, reported that she missed a treatment cycle as a result of a lung infection which she was hospitalised for prior to her scheduled chemotherapy session. As a result, Ellie's treatment cycle was delayed for two weeks.

So, I arrived for my second chemo and saw Doctor and he said uhm, "Get back on the scale." So, he said, "Why have you lost all this weight?" so I said "I'm really sick... my lung is like screwed I can't breathe like there's foam coming out of my mouth." He said, "Sit." [He] tapped my lung... he said, "Come". [He] took me for an X-ray. He said, "Come." [He] took fluid. He said, "Sorry sister... hospital... two weeks". (Ellie, P9, non-adherent due to medical advice).

Nurse D (P18) stated that patients becoming sick as a result of chemotherapy was a barrier to adherence as many patients decided to cease treatment due to the anxiety they experienced as a result of needing oxygen or further hospitalisation. Healthcare workers however reported that some patients chose not to disclose the severity of their side effects which later resulted in treatment nonadherence when they could not cope with the severity anymore.

So maybe a patient has now come once or twice for chemotherapy and now they suddenly- the develop really bad side effects so... I've had that patients- I've had that... after maybe the second session of chemo they just completely they decide against it they just don't wanna go any further because the side-effects were just too bad. (Doctor C, P17)

Furthermore, healthcare workers stated that patients sometimes became nonadherent as a result of a lack of understanding regarding treatment mechanisms and duration as well as the consequences of missing a chemotherapy cycle.

They don't realise initially that the treatment will be over a period of months... because if their cycle is about every three weeks then they don't realise that they have to stay here for... a long time then they... they go back [home] and they default. (Doctor B, P6)

This misunderstanding regarding treatment oftentimes occurred amongst patients who were recommended neoadjuvant chemotherapy as they believed that the lack of physical symptoms such as pain and/or a mass or lump meant that they were now cured and no longer needed treatment. Doctor B stated that for these patients:

When the mass disappears, they feel okay this has worked... I don't need anything anymore then they carry on with their life... not realising that it's actually the start of the treatment and the fact that they can't palpate it, it means that it's working but they still need to complete their treatment and eventually get to surgery so it's just that miscommunication. (P6)

Non-adherent patients were also identified by healthcare workers as often being the family breadwinner. Attending treatment meant that these patients would lose out on a day or more worth of wages depending on the side effects they experienced after chemotherapy.

You as a mother, you left with your family... you maybe... now you must also be the sole bread winner because [the man]- the husband is gone. (Nurse B, P2)

Healthcare workers also mentioned non-adherence amongst palliative care patients. For these patients, the uncontrollable spread of the cancer and subsequent deterioration of their condition lead to treatment nonadherence and later treatment termination as they no longer experienced relief from their physical symptoms such as pain as a result of the treatment.

When they come in at the later stage... they... don't make it maybe half dur- through the treatment because our intent is palliative to make them comfortable and to control the

disease... but sometimes the disease is so... gets spreading out of order and the treatments... they don't complete because they... go uhm deteriorate. (Nurse A, P1)

5.1.2.2 Forgetfulness. Healthcare workers indicated that some non-adherent patients were found to be non-compliant to other prescribed medication or stated that they had simply forgotten the appointment date. Healthcare workers mentioned that when non-adherent patients were asked about their reasons for defaulting treatment on their return to hospital, the patients stated that they had been waiting for communication from the hospital regarding an appointment.

And also, they don't also have that uh insight to actually say let me phone Hospital and check... some of the patients will phone... and say "I've been waiting for a phone call and no one has phoned me" they take the initiative... but most patients don't do that... they just sit there waiting for a call... (Doctor B, P6).

Doctor B continued that, in her experience, non-adherent patients neglected to contact the hospital because it was common for patients to experience long intervals before receiving treatment. Conversely, other healthcare workers stated that they experienced difficulty contacting nonadherent patients due to a lack of contact information as a result of patients' failure to report a changed contact number or missing cell phone. In some instances, healthcare workers provided the police with non-adherent patients' addresses to request assistance to bring these patients to hospital for treatment.

Uhm sometimes uhm even at other clinics if pa- patients have not been coming we even sometimes get the police to go and look for them. (Doctor B, P6)

5.1.3 Poverty-related structural barriers to adherence to chemotherapy

Patients may experience structural barriers as a function of poverty (Shriver et al., 2000). In this section, I identify poverty-related structural barriers to adherence behaviours. These

factors have been divided into two sub-themes namely (1) migration, and (2) transport and finances.

5.1.3.1 Migration. Most non-adherent patients were identified by several healthcare workers as individuals from the Eastern Cape. Healthcare workers explained that these patients' non-adherence resulted from their need to return home due to family responsibility despite being sick and in need of treatment themselves. When these patients returned, it was oftentimes with other complications such as fungal infections due to the deterioration of their condition. For some non-adherent patients, especially those from the Eastern Cape, treatment non-adherence occurred due to a misunderstanding regarding treatment frequency which occurred every few weeks over a period of a few months.

Because we are close to the Eastern Cape, the major defaulters are people living uhm having family in the Eastern Cape. For example, there are a couple of patients here that disappear, they go to the Eastern Cape especially over the Christmas period, or they came here for their health reasons, but actually their parents or the rest of the family is in the Eastern Cape. (Doctor A, P5)

5.1.3.2 Transport and finances. Transport and finance issues relating to transport was a consistent barrier to adherence identified across all participant groups. Doctor C (P17) said that due to the low socio-economic level of most of the patients, access to private transportation was often unaffordable. Many patients reported that they relied on public transportation to travel to hospital or utilised the hospital transport provided. For example, Gloria (P11, adherent patient) reported that she sold cleaning items such as detergents in her community which allowed her to pay for her food and travelling expenses. Busi (P4, adherent patient) stated that she and her

husband were both unemployed and therefore she did not always have travelling fare. She would sometimes have to leave home and ask others for money despite feeling unwell.

Yes, there's a little challenge for money... my husband is not working... [and] myself... [Even] when I'm not feeling well, I must get up... to struggle to go to walk around and look for money see. (Busi, P4)

Faith (P10, adherent patient) mentioned that she sometimes had to borrow money for transport from a fellow classmate to attend her hospital appointments, something that she said was very difficult for her to do. She would also arrive late for her appointments sometimes as a result of using public transport. Carol (P7, non-adherent patient), who had missed a chemotherapy cycle but was now able to afford private transport, indicated that at the time she did not have money for transport to attend her appointment. She travelled with her sister who worked on the hospital premises which was especially beneficial as she was wheelchair-bound due to the cancer metastasizing to her bones.

I struggled with transport money... I was unable and then I didn't have money for taxi. (Carol, P7)

For other patients like Inga and her sister who could arrange private transport, both stated that travelling was expensive, especially because Inga was unemployed, and they depended on assistance from community members. Inga's sister (P16) stated that financial assistance had been promised but had not been made available and that community members had provided financial assistance thus far as there was usually someone willing to bring them to hospital appointments. Inga however stated that it was expensive because she sometimes had to pay for the private transport herself. Inga's sister further mentioned that Inga's boyfriend was unemployed and there were times when she had to assist the family financially.

There's many times there's no income and her boyfriend's not working... then she ask me... we must eat together. (Family B, P16)

In some instances, patients reported being accompanied by relatives to their hospital appointments. Hannah's daughter, Ellie's father and Deborah's husband all accompanied them to their hospital appointments and stayed for the duration of the day which healthcare workers also identified as a facilitator of adherence.

Similar to Faith, Nurse B (P2) and Nurse E (P19) reported that some patients borrowed money to be able to attend treatment which showed their determination to adhere to treatment.

The biggest thing I think yes there is a lot of our patients who're poor... but that is not because they come, they still come and make a way to get here even if they have to borrow money they still come. (Nurse B, P2)

Nurse B (P2) stated that some patients who made use of private transport later could not afford transportation costs and eventually decided to stop coming for treatment. Doctor C reported that this was especially true for patients who lived far outside the town in which the hospital was situated. In contrast, Nurse E (P19) stated that patients who lived locally and did not qualify for hospital transport because of their proximity to the hospital, also struggled to travel to and from appointments. Nurse E relayed that they had been approached by patients asking for money to travel home because they could not afford to do so otherwise. These patients also struggled to receive grant money, despite applying for assistance.

You'll find out most of the people who are sick who needs our help here are staying around even though they are staying around it's not a walking distance still they are struggling uhm the doctors they do refer them to the social worker in order for them to get the grant but not all of them are getting so that is the challenge. (Nurse E, P19)

Doctor C also reported that the demographic of the population which the hospital catered to experienced significant financial and transport challenges. These challenges were especially exacerbated by the length of an average chemotherapy regimen which consisted of six cycles, administered every three weeks over a period of three to four months. The costly nature of multiple hospital visits discouraged patients from attending treatment.

5.1.4 Individual facilitators of adherence to chemotherapy

In this theme, I identified factors that were considered facilitators of adherent behaviour identified across the participant groups. I identified three sub-themes namely (1) self-motivation and (2) symptom improvement and (3) religious/spiritual beliefs.

5.1.4.1 Self-motivation. One of the most salient facilitators of adherence identified by participants was self-motivation. Participants across all three groups stated that many patients were adherent to treatment because they wanted to get better, they had a reason to live, and they recognised the benefit of adhering to and completing treatment. For example, Asanda (P3) stated ‘it’s me... I motivated myself... because I want to be happy... and then I want to be fine’. She continued that she wanted to complete treatment and nothing would prevent her from adhering to treatment as she felt the chemotherapy was working for her. Another patient, Ellie (P9) stated that when she received her initial cancer diagnosis, she only had two choices, either she would fight and live or she would give up and die.

Well, I have two choices here... there aren't six choices... [laugh] there's not three choices there's two choices... I... fight and I live or I give up and I die... or I die anyway but... I'm not going to live if I don't fight to live or chang-" [hesitant sounds] you live or you die... there's no... there's no road in the middle no. (Ellie, P9)

Hannah shared that she motivated herself at every hospital visit stating “I said to myself you must... you must do it you’ve been here before you know what is so... just persevere again... But I just think... I just lifted my head... I made up my mind that I wasn’t going to be upset” (P13). Deborah (P8) described recalling the treatment explanation the doctor gave her that would mean she didn’t have to undergo a mastectomy:

I knew I had to come and have that chemo... because as the... the- the- the professor explained to me it will take it [cancer] away... and then maybe I don’t have to have surgery. (P8)

Furthermore, patients stated that lifestyle changes such as eating fruit, vegetables, and hormone-free foods for cancers that were hormone-receptor-positive, also helped to stay adherent to treatment. Ellie stated, “I knew that if I didn’t only nourish my body and *just* nourish my body that there was no chance” (P9). Asanda (P3) said that since being diagnosed, her fruit and vegetable intake had increased and she ensured that she ate at least one fruit every day. She also stated that she no longer consumed coffee and drank green tea instead.

Hannah’s daughter stated that her mother sometimes struggled to eat because of the loss of appetite she experienced. To combat this, the family would sometimes force Hannah to eat to ensure that she was able to receive chemotherapy at hospital visits. Hannah’s daughter also mentioned that she researched foods that were beneficial to her mother and the family had changed their eating habits as a result to help Hannah eat healthier.

Several healthcare workers also echoed the sentiment that patients’ self-motivation was important. Nurse A stated “I think... most of them do come... and they want to come for their treatment and they know that they want to get better and it’s for the good for them... that they have to come... and finish their treatment... and on time” (P1). Nurse C mentioned that the

patients' self-motivation to complete chemotherapy in turn uplifted the other patients around them stating "if they say no today they want to receive chemo, the more they receive the chemo, the better it is because they're just in a hurry to finish. Maybe for example six months... I'm there... I'm almost there... then it's almost like the one uplifts the other one also" (P12).

5.1.4.2 Symptom improvement. Participants indicated that an improvement in their physical symptoms as well as a reduction in the size of the patients' breast lump motivated them to complete treatment. The most commonly reported symptom prior to treatment was pain with several patients describing it as excruciating and debilitating despite pain medication. Ellie (P9) reported experiencing debilitating pain after her initial biopsy and said it felt as if her tumour had come alive because of the throbbing and burning sensations she experienced. Ellie's pain disrupted her sleep and was at one point so severe that she over-medicated on pain tablets and nearly had to be rushed to hospital.

When the anaesthetic of the biopsy had gone away the pain was chronic, and it was almost as if the tumour had come alive okay. I- there was no amount of pain killers that I could take for the next two months that got rid of that pain. This thing just grew and throbbed and burnt and grew and throbbed and burnt. It did not stop. It was right out here [indicated swelling]. My arm was lame, the spasm was up my neck [and] I could not move my neck. The swelling was here and right up my neck... that [indicates arm] it was swollen... like really swollen to the touch... hot... painful... on fire... burning. (Ellie, P10)

Ellie said that after her first chemotherapy cycle however, the pain and swelling disappeared, and her breast reduced in size. She described the relief saying "it was like heaven". This was the experience for most of the patients who said that their symptoms gradually improved with each chemotherapy cycle. This sentiment was also echoed by the family members

and healthcare workers. Participants also indicated that a reduction in the size of the breast lump was a facilitator for adherence. Deborah (P8) said that her lump decreased from 7.4 centimetres to 1 centimetre after only four chemotherapy cycles and continued that it would have most likely disappeared if she had been able to complete her treatment regimen. Both Hannah and her daughter also mentioned a reduction in lump size with Hannah's daughter stating:

So far, the treatment is helping. It [the lump] was 9 by 10 centimetres. The last time we were here it was 5 by 6 centimetres, so the treatment helps so that is also good because it helps my mother. (Family A, P14)

Hannah (P13) stated that if she had not started chemotherapy, her cancer would have metastasized and welcomed news that her lump had shrunk at every hospital visit. Healthcare workers also indicated that patients whose breast lump had shrunk, and whose breast pain had subsided tended to be more adherent to treatment and finished their chemotherapy cycle. Inga's sister (P16) reported that Inga had been prescribed various pain tablets as well as three antibiotic courses, but the pain persisted. Inga was later unable to do anything for herself and Inga's sister said that she felt helpless regarding Inga. She continued that she wished she had been the one diagnosed with cancer so that Inga did not have to suffer. Once Inga started treatment, she experienced symptom improvement which continued with each cycle.

Conversely, healthcare workers found that some patients became non-adherent once the lump had shrunk or disappeared because they thought they had been cured and therefore failed to receive subsequent treatment such as surgery or radiation which removed further cancer cells, decreasing the risk of recurrence. Many non-adherent patients had also been found to believe that they were now cured in this state as they no longer experienced any pain or felt a lump and as

Doctor B said, “[Patients] believe they do not need to come back for treatment and can continue with their lives” (P6).

5.1.4.3 Religious/spiritual beliefs. Several participants identified the influence of religious/spiritual beliefs as an important facilitator of adherence. Patients and family members described the support received as house visits from spiritual leaders and church members as well as personal prayers and prayers by fellow church members, family, and friends. Several patients stated that they had begun to pray more often since their diagnosis with many praying prior to coming for their hospital appointment. Deborah (P8) described the upliftment she received from the prayers and singing of her church members when they visited. She inferred that it was only through faith and her husband’s support that she was able to endure treatment. Religious beliefs encouraged patients to remain positive, and Hannah included that the messages of hope she received from people also enabled her to adhere to treatment.

I think it is- it’s sort of what motivated me... all the- all the positive that I get from people and the message. Some mornings then you feel ‘oh no’ you don’t want to then you get a message uhm from someone that- that says uhm, just remember the Lord is there, and then for you it’s just ‘you know what it’s true... He- He is there’. (Hannah, P13)

Inga’s sister (P16) stated that she often encountered people who told her to tell her sister not to worry and that many people were praying for her. She continued that she had also accompanied Inga to church where she had renewed her faith.

5.2 Mesosystem

The mesosystem consists of the interactions between the participants of the microsystem, namely the patients, their religion, their family members and greater community as well as the healthcare workers involved in their treatment. Interactions within the mesosystem include the

extent of social and community support patients receive as well as their relationship with healthcare workers.

In the mesosystem, interpersonal and familial barriers to adherence emerged as one of two significant themes, with (1) lack of social support, and (2) family responsibility as sub-themes. Interpersonal facilitators of adherence emerged as the second significant theme with (1) physical support, (2) work-related support, (3) instrumental support, (4) emotional support (5) support from healthcare workers and (6) communication with healthcare workers as sub-themes.

5.2.1 Interpersonal and familial barriers to adherence to chemotherapy

5.2.1.1 Lack of social support. The negative perceptions and beliefs of relatives and community members regarding cancer and chemotherapy were identified as barriers to treatment adherence. Only one patient, Gloria (P11), mentioned the fear and negative perceptions that community members had regarding cancer with members saying that it was harmful and that she would succumb to it. Healthcare workers reported that patients who did not receive social support from family or community members were more likely to be non-adherent. Doctor B (P6) mentioned that patients experienced demoralisation at home if they experienced side effects as a result of chemotherapy as they had gone against their family's advice.

Once they get side effects and go home... the same people who said "don't take the chemo" are going to say "you see now you are ill" so then they get demoralised then they don't come back. (Doctor B, P6)

Oftentimes as a result these patients did not return for treatment. Similarly, Doctor C recalled encounters where patients' adherence was determined by their families' opinion of treatment.

I have also encountered as well where it is family members and the rest of the family actually influencing the patient's decision as well and they are the ones, they've googled a lot of other things and all the bad side effects and they have influenced the patient to not to continue with the chemo and things like that we have also encountered as well.

(P17)

5.2.1.2 Family responsibility. Healthcare workers stated that family responsibility sometimes posed a barrier to adherence amongst patients, especially when young children were in consideration. At times, patients were unable to attend treatment appointments as there was no one to care for their children in their absence. In contrast however, many of the patients stated that their children and grandchildren motivated them to adhere to treatment because they wanted to be there for them in the future.

My kids... (laugh)... I look at them then I say I must... be strong... yeah for them. (Busi, P4)

One healthcare worker, Nurse B (P2) shared her experience of a patient who had a son with a substance dependence stating that the patient had been scared to attend treatment because she was concerned about returning home to an empty house with no food after her chemotherapy cycle. Nurse B (P2) stated that patients not only dealt with the burden of disease, but also social issues such as drug addiction.

5.2.2 Interpersonal facilitators of adherence to chemotherapy

The support that patients received from social networks, including their family, friends, community members as well as healthcare workers was identified as salient facilitators of adherence. Six sub-themes were identified namely (1) physical support, (2) work-related support

(3) instrumental support, (4) emotional support, (5) support from healthcare workers and (6) communication with healthcare workers.

5.2.2.1 Physical support. The importance of having social support whilst undergoing chemotherapy was emphasized by two patients. Carol stated that it was challenging to cope with treatment alone and that a support system as well as physical support were needed. Similarly, Deborah (P8) stated that she received a lot of support from people around her and that patients who were undergoing chemotherapy needed support from whoever was around them. Physical support from the patients' family, friends and community members included collection of prescribed medication and ensuring that the patient was comfortable after chemotherapy cycles. Some participants also reported that patients were often accompanied by a relative or significant other, with Nurse D (P18) indicating that this was commonplace amongst patients who made use of private transportation as patients utilising hospital transport came alone. The relative or significant other would stay with the patient for the duration of their hospital visit which was often for hours at a time as patients had to report to hospital at 7am. Inga's sister indicated that she accompanied her sister to every hospital visit oftentimes after working night shift. She stated, "I am tired but I must push through because there's no one that can support her understand I'm her only sister" (Family B, P16). Hannah's daughter also accompanied her to hospital and said that she assisted her mother by driving her to hospital and ensuring that all the necessities for their trip was packed the night before as they lived an hour away from the hospital and travelled early in the morning. She added that she ensured that her mother was comfortable after her chemotherapy treatment and usually experienced nausea, so she drove slowly and stopped whenever her mother became unwell.

5.2.2.2 Work-related support. Support from employers was mentioned by two patients, Deborah (P8) and Hannah (P13). They mentioned still being employed whilst undergoing treatment and stated that their workplace management had been accommodating of their circumstances. Both women were able to negotiate leave and time away from work whenever the side effects of chemotherapy rendered them incapable of performing work-related tasks. Deborah (P8) indicated that she was able to get leave from work for hospital visits because her husband was part of the management team at work. He would also take her home if she became fatigued at work. Hannah mentioned telling her employer's son "listen here this is how it works... uhm I can't always tell you I'm coming to work tomorrow or after chemo because it takes time to exhaust me. He told me that it was next year's worry... but so far they've been very supportive" (Hannah, P13).

5.2.2.3 Instrumental support. Several patients indicated that they received instrumental support, which is tangible assistance, from family members. Assistance included help with housework such as cooking and cleaning, hygiene activities and providing care for children. Carol and Ellie indicated that they were living with family as they were unable to care for themselves. Carol stated that she had relocated from a different province to live with her mother and sister because she did not have anyone to support her or care for her in the city that she was living in. Carol's cancer had metastasized to other parts of her body including her bones, lungs, and liver.

I couldn't walk... by myself anymore... I couldn't look after myself. (Carol, P7)

As a result, she was wheelchair-bound and said that she could do nothing for herself. Carol reported that her mother bathed her and constantly checked to see if she was still

breathing. Carol found it difficult to be cared for by her mother because she felt that she should be looking after her parent and not the other way around.

Ellie received a cancer diagnosis following a devastating accident which left her unemployed and in excruciating pain. At the time of her diagnosis, she was a private patient but could not afford to start treatment as she was unemployed. The oncologist who diagnosed her assisted her to the tertiary hospital where the study took place where she later found that her cancer had metastasized. Due to her financial situation, Ellie moved in with her father so that her basic needs could be met.

I gave up everything and moved home to my dad so that I have at least got a roof over my head and uhm electricity and water and Wi-Fi. (Ellie, P9)

5.2.2.4 Emotional support. Participants reported that the initial reaction to diagnosis for most patients was an acute sense of fear, anxiety and disbelief. Many patients indicated that the diagnosis came as a shock. Patients however stated that they found solace in the emotional support provided by family, friends, fellow patients, and healthcare workers. This emotional support was also referred to when participants spoke about support during chemotherapy. Hannah's daughter described chemotherapy as being emotionally difficult and draining on her mother and felt that she had to be strong for her mother "so that her mother did not have to stand strong because it's actually a lot... [for someone] to go through" (Hannah's daughter, family A, P14). Other patients described their family as well as the healthcare workers as being a source of positivity and happiness. Children and grandchildren were also said to be enablers of adherence as patients wanted to share in their developmental and personal milestones.

Every time I must go to my treatments... for my children... because [they're] too small so I- so I can't leave [them] like you know... I know everyone must going to die but I must

die... and then I must first... like I must be strong for my children... so that's why every time- and then I- I don't want to miss anything. (Asanda, P3)

Patients and healthcare workers described the effect that fellow chemotherapy patients had on their ability to adhere to treatment. Asanda (P3) stated that she no longer felt alone when she saw other patients in the waiting area. Similarly, Ellie described seeing familiar faces and befriending fellow patients as helping her adhere to treatment. Furthermore, healthcare workers reported that patients felt encouraged and motivated when they could relate to someone who was undergoing a similar experience and had heard of patients using social media to keep in contact with and encourage one another.

When they talk to other patients- sometimes it is very nice when we have new patients. If we have got other patients on treatment already, some patients need to hear first from someone who is on the chemotherapy so at some situation, we will call someone who is about to finish who goes around to speak to them to encourage them and motivate them. Suddenly when they look at someone who has got the exact same cancer and they are encouraging them, then it becomes more uhm... it is more realistic. (Doctor B, P6)

5.2.2.5 Support from healthcare workers. The support and care provided by healthcare workers was identified as an enabler of adherence across all participant groups. Patients reported that healthcare workers were friendly, empathetic, kind, and made them feel comfortable. Several patients also iterated that healthcare workers were knowledgeable regarding treatment administration and information dissemination which set patients at ease. Patients were appreciative of the care that they received, especially from the nurses in the chemotherapy room as several nurses indicated that patients would later share personal details of their lives with them. Nurse B (P2) and Nurse D (P18) indicated that nurses in the chemotherapy room were

always mindful of the patients' emotional wellbeing and that meeting the patients' needs was their priority. She continued that the nurses tried to ensure that the hospital environment was one of positivity and friendliness to minimize any fear, anxiety or stress that patients might be experiencing.

They really do appreciate what we are doing and how we approach them they feel comfortable here, they are happy here at X Block. (Nurse A, P1)

5.2.2.6 Communication with healthcare workers. Healthcare workers stated that they were aware that some of the patients who attended the chemotherapy clinic had a low level of literacy. To assist these patients, simplified explanations of treatment and care were disseminated.

I said it just depends on... uhm... where you come from and what your knowledge is but I said- but as I said most of our people are poor... and they... not so... educated so yeah, we just have to explain it in simple terms and make it simple as possible for them to understand yeah. (Nurse A, P1)

Healthcare workers stated that understanding treatment mechanisms and having knowledge regarding breast cancer was essential to adherence to treatment and patients were therefore encouraged to ask questions. Nurses indicated receiving most questions as patients claimed they felt more comfortable communicating with them compared to doctors, and they were usually the point of contact at hospital visits. Healthcare workers also stated that patients who were well-informed were more likely to be adherent.

Nurse D (P18) stated that healthcare workers usually assumed which language a patient spoke but they stated that difficulties in communication arose when communicating with Xhosa-speaking patients, especially those who were elderly or patients who could not speak English,

Afrikaans or Xhosa. Doctor B stated that to navigate this, healthcare workers would ask for assistance from a fellow colleague or relative who spoke the patient's language to communicate with the patient. She stated, 'because even if it- a language uhm barriers we always try to find someone who understands their language just to try find someone who understands their language just to try and uhm... emphasize what we are meaning by the different things'(P6).

Nurse D (P18) also indicated that staff would make use of body language if there was no one to assist the patient in their native language, as was the case with foreign nationals.

5.3 Exosystem

The exosystem consists of one or more settings in which the patient is not an active participant, but which indirectly influences them. The factors identified in this system relate to the patients' school or workplace policies as well as the institution-related factors with regards to treatment. Three underlying themes were identified in this system which described the impact chemotherapy had on work and school as well as the institution-related barriers to and facilitators of adherence to treatment. The themes identified were (1) impact of work and school on treatment attendance, (2) institution-related barriers to adherence and (3) institution-related facilitators of adherence. Institution-related facilitators were further divided into three sub-themes were namely (1) multidisciplinary care and (2) fee subsidy and (3) hospital transport and disability grant.

5.3.1 Impact of work on treatment attendance

Several participants stated that treatment and scheduled hospital visits negatively impacted patients' income and occupational circumstances. Patients would have to negotiate leave with their employers if they wished to attend treatment and it was likely that many patients who could not negotiate leave were unable to adhere to treatment. Several patients indicated that

they became unemployed following treatment commencement. Carol reported that her workplace had told her, “Ah it’s better you resign now” (Carol, P7). Doctor B in contrast stated that although work was seldom a reason for nonadherence, it did occur as some patients reported that it was difficult to organize leave in order to attend hospital visits.

Cause some patients... if they are too scared their bosses are not giving them days off... that- they would rather go to work than come for treatment cause they still need to feed their family some of them are ah- ah- breadwinners at home... everyone is depending on them. (Doctor B, P6)

5.3.2 Institution-related barriers to intravenous chemotherapy

5.3.2.1 Lack of oncology-trained staff. Several healthcare workers reported that a lack of after-care support as well as a lack of oncology-trained staff served as a potential barrier to adherence. Nurse B (P2) stated that there was a need for more oncology-trained staff, especially at primary and secondary healthcare facilities because she felt that patients lacked support once they completed their chemotherapy treatment. She also indicated that referral and diagnostic procedures relating to cancer were inadequate as patients were often misdiagnosed.

Once they finish with the treatments and they ha- need follow-up and even those starting out, they need to really be followed up properly and assessed properly and referred properly, so that their- their chances or the times that they start is not thrown out by misdiagnosis you know. And- and telling the patients you got TB or you got this and that and the other thing when actually- in actual fact it’s cancer. (Nurse B, P2)

Similarly, Nurse A mentioned that many patients experienced misdiagnosis which delayed treatment, an issue that was mentioned across participant groups.

And uhm like the correct referrals... like the day hospitals the comp- the staff should be competent and know when to refer... in time and not wait. (Nurse A, P1)

A lack of oncology-trained staff was also stated by Doctor B who said that most of the trained staff worked in tertiary hospitals. As a result of this, many tertiary hospitals served a large population and therefore waiting periods between screening, diagnosis and treatment commencement could be very long for patients.

In terms of the healthcare system, I think unfortunately the situation is we have a large drainage area [and] unfortunately the health system can't bridge that gap because we don't have enough staff to see them again there [primary/secondary healthcare facility] because it's also patients that are coming from Other Areas. (Doctor B, P5)

5.3.3 Institution-related facilitators of adherence to chemotherapy

5.3.3.1 Multidisciplinary care. Healthcare workers stated that a multidisciplinary approach is utilised in the care of breast cancer patients which includes doctors and nursing staff as well as allied healthcare workers such as social workers and dieticians. Healthcare workers ensured that consistent information was provided to patients with queries, concerns or referrals being addressed by the relevant health discipline. Doctor C indicated that breast cancer patients were also offered psychological support services in the breast clinic by a volunteer psychologist but it was unfortunately a limited service as it was offered on a voluntary basis and was not a fully optimized service. The psychologist was available 2 days per week and also per request from patients. Doctor C also indicated that this was a result of limitations within the government sector owing to a lack of staff, but it was an issue that should be improved on. Carol (P7), who had previous experience at a chemotherapy clinic in a different province, indicated 'I don't see counsellors here... [in] City there're good counsellors... they gave me counselling immediately

when they diagnosed me... I don't see counsellors here', and mentioned that a counsellor would be beneficial at the tertiary hospital where the study took place. Nurse D (P18) indicated that a counselling nurse had seen newly diagnosed patients in the past which patients had found beneficial but the service was unfortunately no longer running.

5.3.3.2 Fee subsidy. Healthcare workers stated that patients pay hospital fees according to their income category. Depending on the category, patients pay a percentage of the hospital fees, with the rest being subsidised by the government. The subsidised fees enabled patients to adhere to treatment as many could otherwise not afford treatment.

They get categorized like uhm the patients- the elderly patients, the ones that gets grants... they just have to bring their pension card and they're treated as free patients... but the others who work they must bring proof of income and they get categorized according to H1 H2. (Nurse B, P2)

Several patients stated that their fees were waived and for those who did pay, the amount was minimal. Healthcare workers stated that there were cases where patients did not pay their hospital fees, but they were not refused treatment.

5.3.3.3 Hospital transport and disability grant. Healthcare workers indicated that patients with financial and transport issues were referred to social workers who assisted patients in applying for a disability grant. Many patients were dependent on disability grants as their primary source of income and it also enabled adherence to treatment.

The social worker will then also play a role in those patients if they are working... applying to at least get them temporary grants while they are out of action with work and it is usually for [a] nine- six-to-nine-month period that they will offer them that temporary disability grant. (Doctor C, P17)

To assist patients for whom the tertiary hospital was not considered to be in their immediate surroundings, the hospital provided the HealthNET (Health Non-Emergency Transport) service. This service transports patients from their homes to the hospital and back free-of-charge. The transport is booked for every scheduled hospital visit dependent on the amount of chemotherapy cycles the patient must undergo. Healthcare workers identified this service as a facilitator of adherence and several patients indicated that utilising the hospital transport allowed them to attend their hospital appointments as they struggled financially and lived far from the hospital. Nurse D (P18) however indicated that hospital transport sometimes posed problems for patients who travelled from far as:

Many patients come from the Platteland and maybe the hospital transport does not pitch... and especially look here when there are major public holidays and then they have to come on their own... and then they don't have the means to do so so they don't come for treatment. (P18)

Unfortunately, this service was not available to patients for whom the hospital was considered within their immediate surroundings.

5.4 Conclusion

In this chapter I presented the range of barriers to and facilitators of intravenous chemotherapy adherence identified through the semi-structured interviews conducted with breast cancer patients, family members and healthcare workers. I presented the main themes and sub-themes that emerged across the three participant groups through the lens of the EST and provided quotations to further describe the essence of the themes and sub-themes. The main barriers and facilitators related to individual factors, interpersonal factors and institution-related factors. In the microsystem, the main barriers and facilitators related to individual factors such as beliefs and assumptions regarding treatment, physical side effects and self-motivation. In the mesosystem,

barriers and facilitators identified related to interpersonal factors such as a lack or presence of social support from family and healthcare workers. In the exosystem, barriers and facilitators included institution-related factors such as the fee subsidy provided and the lack of oncology-trained staff. The varying perspectives provided insight into the perceived barriers and facilitators to treatment adherence. A discussion of these results which follows in Chapter 6 will consider the results of the study within the EST.

CHAPTER 6

DISCUSSION AND CONCLUSION

In this study, I aimed to examine the barriers to and facilitators of adherence to intravenous chemotherapy amongst breast cancer patients at a tertiary hospital in the Western Cape. I conducted semi-structured interviews with breast cancer patients, family members of breast cancer patients and healthcare workers to elicit their perspectives on the barriers to and facilitators of adherence to chemotherapy. The findings of the study suggest that there are various factors which influence adherence to intravenous chemotherapy and that these factors exist at multiple systems levels. In this chapter, I discuss and interpret these findings through the lens of the EST (Bronfenbrenner, 1979; 1994).

6.1 Microsystem

The microsystem consists of proximal interactions between the individual and their immediate environment. The interpersonal relationships in this system included those with family and healthcare workers. The results of the study showed that there were factors that influenced patients' decision to start treatment. Factors influencing decision to start treatment was therefore identified as a significant theme which consisted of beliefs and assumptions regarding treatment and the impact of chemotherapy on fertility and body image as significant factors. Furthermore, the results of the study indicate that the most salient barriers to adherence identified at the microsystem level were physical side effects of treatment and transport and finances. The most salient facilitator of adherence was patients' self-motivation to complete treatment as well as symptoms improvement as a result of chemotherapy.

6.1.1 Factors influencing decision to start treatment

6.1.1.1 Beliefs and assumptions regarding treatment. The microsystem described the influence that beliefs and assumptions by both patients and individuals in their immediate environment had on their decision to commence treatment. Similar to findings by Wright (1997) and Clegg-Lamprey et al. (2009b), the present study found that patients often made decisions regarding treatment in conjunction with and based on advice from family members. For example, in the study by Clegg-Lamprey (2009b), patients experiencing pressure from family members to refuse a mastectomy absconded from treatment. Similarly, healthcare providers in Sayed et al.'s (2019) study stated that women had limited decision-making autonomy which impeded their ability to seek care as permission first needed to be sought from husbands or in-laws. In the present study, patients who valued their family's opinion were therefore more likely to be hesitant to start treatment when negative preconceptions were held about cancer and its treatment (Kvarnström et al., 2021).

Similar to previous studies, hesitancy regarding a mastectomy was also mentioned as a factor influencing treatment commencement, with patients being reluctant to get one as they felt that their family and community members would think differently of them. Studies by Mdonolo et al. (2003) and Clegg-Lamprey & Hodasi (2007) attributed hesitancy regarding mastectomies to the cultural significance of breasts in relation to female body image and femininity. Hesitancy was also attributed to fear regarding mastectomies as well as pressure from family members to refuse mastectomies, and being labelled undesirable by patients' husbands (Clegg-Lamprey et al., 2009b; Egwuonwu et al, 2012; Sayed et al., 2019). Additionally, Sayed et al. (2019) found that women also faced divorce, rejection, stigma or disownment as a result of a cancer diagnosis or mastectomy. Furthermore, the present study found that negative preconceptions predominantly

related to treatment side effects influenced decision to start treatment (Browall et al., 2006), however patients were reassured that all treatment was individualized and side effects would be different amongst patients.

6.1.1.2 Impact of chemotherapy on fertility and body image. This sub-theme was situated within the microsystem as it concerned patients' evaluation of the impact of chemotherapy on fertility and body image as a barrier to adherence. In the present study, concerns regarding chemotherapy's impact on fertility and hair loss was most commonly reported amongst younger women by healthcare workers who were said to be more emotional regarding a cancer diagnosis and saw it as a punishment. Chemotherapy is associated with emotional distress, physical changes such as hair loss and psychological strain which leaves women feeling desperate and powerless (Liu et al., 2021) and may therefore impede on women's ability to adhere to treatment. Chen et al. (2016) reported hair loss as the most common adverse effect in their study with women reporting being fearful of going out and being seen as a result. These negative associations to chemotherapy influence patients' motivation to adhere to treatment as chemotherapy results in outcome expectancies such as hair loss and possible infertility which affect adherence to treatment. In the present study however, healthcare workers stated that patients' lives were more important than their hair when faced with choice. This occurrence could be explained by a greater benefit-to-risk analysis in which patients in the study perceived that there were more benefits to undergoing chemotherapy than there were risks (Banning, 2012; Marshall & Given, 2018).

6.1.2 Individual barriers to adherence to chemotherapy

6.1.2.1 Side Effects. The WHO has identified side effects as one of the most notable therapy-related factors affecting adherence (Sabaté, 2003). Patients need to be strong enough to

tolerate side effects (J. Edge, personal communication, May 3, 2019) in order to be adherent as nurses in Dhotre et al.'s (2016) study state "the [treatment] process is mental" (p.621). Physical side effects of chemotherapy therefore influence patients' beliefs about treatment which in turn impedes their ability to adhere to chemotherapy as the experience of negative side effects could result in a negative evaluation of treatment. In the present study, patients reported a range of side effects however, in contrast to previous studies (e. g. Ayoade et al., 2019) and in agreement with Neuget et al. (2016), none stated that the experience of side effects influenced their ability to be adherent to treatment. Only one patient indicated the influence of side effects on their treatment which resulted in treatment termination as a result of hematologic toxicity which is similar to findings by Egwuonwu et al. (2012). In contrast to the findings of Lambert et al. (2020) in which patients viewed chemotherapy as a separate disease to breast cancer, patients in the present study attributed their breast cancer symptom improvement to chemotherapy. This positive evaluation of treatment facilitated adherence amongst patients (Banning, 2012).

Furthermore, in agreement with Dhotre et al. (2016), the present study found that healthcare workers reported physical side effects as a barrier to adherence amongst patients, citing severity of side effects as a determining factor. According to healthcare workers in the present study, patients who became sick as a result of chemotherapy decided to cease treatment due to the anxiety they experienced as a result of needing oxygen or further hospitalisation. Patients therefore had negative views of treatment which resulted in negative illness representations and decreased perceived benefit of treatment which led to nonadherence (Saratsiotou et al., 2011; Banning, 2012; Marshall & Given, 2018). Nurses in Dhotre et al.'s (2016) study also stated that patients found dying preferable to dealing with side effects as symptoms sometimes outweighed the benefits of chemotherapy.

6.1.3 Poverty-related structural barriers to adherence to chemotherapy

6.1.3.1 Transport and finances. The present study found issues relating to transport and finances to be a function of poverty and it was therefore identified as a poverty-related structural barrier to adherence (Shriver et al., 2000). The tertiary hospital where the data in this study were collected serves approximately 70% of individuals without access to private healthcare facilities which includes half of the rural population in the Western Cape (Schoeman et al., 2013). As such, many patients presenting at the hospital come from a low socio-economic background as stated by several healthcare workers. Previous studies including the present study, found that transport expenditure was an issue for patients, with one patient and several healthcare workers in the present study identifying it as a barrier to adherence (Anyanwu et al., 2011; Lambert et al., 2020; Reddy et al., 2020). The present study however found that patients would borrow money from relatives and friends in order to come for treatment, something which was not always easy to do, but healthcare workers felt it showed patients determination to adhere to treatment.

Patients who were able to afford private transportation referred to the high cost associated with it, which healthcare workers stated could later become a barrier to adherence when patients could no longer afford the costs. Transport and financial costs therefore served as a barrier to adherence for some patients as it impeded patients' physical ability to attend appointments and be adherent to treatment.

6.1.4 Individual facilitators of adherence to chemotherapy

6.1.4.1 Self-motivation. Patient motivation was identified as an essential facilitator of adherence in a systematic review on factors associated with medication adherence conducted by Kvarnström et al. (2021). Patients who understood the necessity of treatment and its contribution

to positive health benefits had improved motivation (Kvarnström et al., 2021). The present study found that patients were adherent to treatment because they wanted to get better, had a reason to live and recognized the benefits of adhering to and completing treatment which reflected positive beliefs regarding treatment as well as outcome expectancies (Chen et al., 2016; Kvarnström et al., 2021). Healthcare workers echoed that patients' self-motivation was an important facilitator of adherence and also stated that patients' self-motivation to complete treatment in turn uplifted other patients around them.

6.1.4.2 Symptom improvement. The most commonly reported symptom prior to treatment was pain with several patients describing their pain as excruciating and debilitating in spite of the use of pain medication. Patients, family members and healthcare workers reported that patients experienced an improvement and reduction in physical symptoms from the first chemotherapy cycle. Patients' beliefs regarding their disease and its treatment are essential to adherence, with greater disease severity threat being associated with better adherence (DiMatteo et al., 2007). Patients in the study adhered to treatment as they saw the benefits of chemotherapy in reducing cancer-associated symptoms (Banning, 2012; Grunfeld et al., 2005; Marshall & Given, 2018). A reduction in breast mass or lump size as well as improvements in physical symptoms was therefore identified as facilitators of adherence. Some healthcare workers however found that symptom improvement could also pose as a barrier to adherence amongst patients who thought they had been cured once the breast mass had shrunk or disappeared (Sabaté, 2003). These patients also believed they were cured as they no longer experienced any pain which is similar to findings by Clegg-Lampthey & Hodasi (2007) and Clegg-Lampthey et al. (2009b). Patients may have perceived that their medication was unimportant due to their assumption that their cancer had been cured in the absence of physical symptoms which may

have resulted in non-adherence (Grunfeld et al., 2005). Similarly, patients in Adisa et al.'s (2008a) study felt well enough to discontinue treatment which the author's explained was due to spiritual and religious beliefs.

6.2 Mesosystem

The mesosystem consists of bidirectional interactions between participants of the microsystem. The interactions in this system included social support that patients received. The results of the study identified interpersonal and familial barriers to adherence to chemotherapy as a significant theme with lack of social support as the most salient sub-theme and interpersonal facilitators of adherence to chemotherapy as a second significant theme. The most salient facilitators of adherence to chemotherapy were physical, instrumental, emotional and work-related support which will be discussed as social support, and support from healthcare workers and communication with healthcare workers.

6.2.1 Interpersonal and familial barriers to adherence to chemotherapy

6.2.1.1 Lack of social support. Little or a lack of social support has been identified as having a negative influence on adherence (Greer et al., 2016; Kvarnström et al., 2021). In accordance with findings by Dhotre et al. (2016) and Reddy et al. (2020), the present study identified lack of social support as a barrier to adherence. Healthcare workers stated that patients who did not experience social support were more likely to become non-adherent to treatment. A meta-analysis found that patients who lacked practical support, emotional support and social support were on average more likely to be nonadherent to treatment (DiMatteo, 2004). Doctor B mentioned that patients experienced demoralization at home if they experienced side effects as a result of chemotherapy as they had gone against their family's advice.

6.2.2 Interpersonal facilitators of adherence to chemotherapy

6.2.2.1 Social support. Several studies have identified social support as an essential facilitator of adherence (DiMatteo, 2004; Larizza, Dooley, Stewart, & Kong, 2006; Lebovits et al., 1990; Xu et al., 2012; Kvarnström et al., 2021). In the present study, social support was found to be a facilitator of adherence and included instrumental support, physical support and emotional support. Similar to findings by Chen et al. (2016) and Lambert et al. (2020), the present study found that patients' social support comprised their family members, close friends, other breast cancer patients and church members/groups. The social support that women received enabled them to openly share their struggles, reinforced their will to live and provided physical and instrumental support in the form of finances (Lambert et al., 2020). Additionally, the present study found that instrumental support included assistance with housework such as cooking and cleaning, hygienic activities and providing care for children. Physical support provided to patients in the present study included collection of prescribed medication and accompanying patients to hospital appointments which were done by family members or significant others. These support definitions were similar to findings by Scheurer et al. (2012) who reported a significant positive association between practical (instrumental and physical) support and adherence with regards to both satisfaction with support and amount of support. In the present study, two patients also indicated that they were living with family as they were unable to care for themselves, which also provided financial support to them.

Undergoing chemotherapy can be an emotionally distressing process (Liu et al., 2021) and the present study found that emotional support during chemotherapy was an important facilitator of adherence to treatment. Scheurer et al. (2012) identified significant positive associations between emotional support and adherence and found it correlated best when patients

had close friends and in the meeting of unmet needs. In the present study, patients and healthcare workers reported emotional support as being able to engage with and learn from other breast cancer patients (Beaver et al., 2016), which in turn motivated them through shared experience similar to findings by Anarado et al., (2017) and Lambert et al. (2020). However, Anarado et al. (2017) also found that patients who saw a fellow patient in a worse state than their own or heard of the death of a fellow patient found the experience discouraging. Similar to findings by Beaver et al. (2016), the present study found that some patients received support from their employers who were understanding of their condition. Some participants in Beaver et al.'s (2016) study however said that employers mistakenly assumed a swift return to a pre-diagnosis state of health. Social support identified in the present study therefore enhanced patients' access to other resources through financial assistance as well as emotional and tangible support. These resources were identified as having a facilitating effect on adherence to chemotherapy.

6.2.2.2 Support from healthcare workers. Similar to findings by Lambert et al. (2020), the present study found that interactions with healthcare workers served as a facilitator of adherence. Kvarnström et al. (2021) identified patient-provider relationships that were trust-based and collaborative in nature as essential to adherence. Patients in the present study felt supported by healthcare workers and included that they were essential factors to patients' survival (Lambert et al., 2020; Fitch et al., 2020). In the present study, healthcare workers were described as friendly, empathetic and kind, in contrast to findings by Wright (1997) and Iskandarsyah et al. (2013) in which they were described as condescending and abrupt and where patients felt inferior and assumed a non-assertive communication style. In the present study, healthcare workers were also a primary source of information to many patients and were described as knowledgeable regarding treatment administration and information dissemination

which set patients at ease. This is contrary to previous findings in which patients sought alternative information sources when they felt that the information provided was inadequate owing to scant or unclear information provided by healthcare workers (Anarado et al., 2017; Hayden et al., 2015; Iskandarsyah et al., 2013; McKillop & Joy, 2013). Greater adherence prevalent in this study may therefore be due to the fact that patients were provided adequate information regarding breast cancer and treatment which provided the necessary knowledge for adherence to occur (Kvarnström et al., 2021). Healthcare workers in the present study also indicated that they were always mindful of patients' wellbeing and tried to ensure that the hospital environment was one of positivity and friendliness (Lambert et al., 2020).

6.2.2.3 Communication with healthcare workers. In the present study, healthcare workers indicated the presence of low literacy levels as well as language barriers amongst patients at the tertiary hospital. Language barriers and low literacy levels have previously been identified as a barrier to treatment and adherence as it presented misunderstandings between patients and healthcare workers and limited access to information for patients who could not read as well as those for whom instructions were not in their native language (Ågård et al., 2016; Huang et al., 2020; Reddy et al., 2020; Schatz et al., 2019; Wright, 1997). To assist patients, healthcare workers made use of simplified explanations of treatment and care as understanding treatment mechanisms and having knowledge regarding breast cancer was essential to adherence to treatment (Lin et al., 2017; Sabaté, 2003). Healthcare workers also stated that patients who were well-informed were more likely to be adherent to treatment (Fitch et al., 2020; Kvarnström et al., 2021). Language barriers were navigated through the assistance of a language-speaking staff member or a relative accompanying the patient. Body language was also used in instances where no language speaker was present. Communication with healthcare workers therefore

assisted patients to adhere to treatment as they were provided with information regarding breast cancer and its treatment as well as the benefits of adherence. Ongoing communication between healthcare workers and patients at hospital appointments ensured that the patient-provider relationship was collaborative and facilitated adherence.

6.3 Exosystem

The exosystem comprises the interactions in two or more settings of which the patient is not an active participant in one of them, but which indirectly influences them. The results of the present study identified institution-related barriers to and facilitators of adherence to chemotherapy as significant themes. The most salient barrier to adherence at the exosystem level was lack of oncology-trained staff and the most salient facilitators of adherence identified were the fee subsidy, hospital transport and disability grant.

6.3.1 Institution-related barriers to adherence to chemotherapy

6.3.1.1 Lack of oncology-trained staff. Healthcare workers in the present study identified a lack of oncology-trained staff as a potential barrier to adherence. Two nurses indicated that patients were misdiagnosed which delayed treatment. Most oncology-trained staff are found in tertiary hospitals who serve a large population and therefore waiting times are long. Duvenage (2019) states that several challenges impede the referral pathways in South Africa. These challenges include long waiting times for appointments as breast clinics at regional (tertiary) hospitals are overbooked, the requirement for imaging requests to be made by a regional hospital and not a district hospital resulting in a hospital visit solely to access imaging. The incorrect performance of fine needle aspirations (FNA) or biopsies before imaging or FNAs performed by untrained staff result in delayed diagnosis. Finally, hospital transport may have

limited space in rural areas as transport is arranged according to transport availability instead of medical service appointment availability (Duvenage, 2019).

A recent global survey describing the infrastructure, delivery of care and clinical workload of clinical oncologists in Africa found them to be older in age compared to oncologists in upper-middle and high-income countries which may worsen an already high workload in years to come (Vanderpuye et al., 2019). In the study, the scarcity of oncologists in Africa was highlighted as well as the complexity of cancer care delivery in Africa as most oncologists treat patients with all cancer sites and prescribe chemotherapy and radiotherapy, despite the European Union recognizing medical oncology and radiation oncology as separate entities (Vanderpuye et al., 2019). The potential for oncology burnout in Africa was also highlighted in the study as job satisfaction was reportedly lower for African oncologists which the authors suggest may be due to poor compensation, the high clinical workload, and the complexity of delivering care in low resource settings (Vanderpuye et al., 2019). Patients' physical ability to adhere to treatment through access to trained oncology staff may therefore be compromised and may pose as a barrier to adherence in years to come due to the expected increase in cancer incidence and burden of disease (Vanderpuye et al., 2019).

6.3.2 Institution-related facilitators of adherence to chemotherapy

6.3.2.1 Fee subsidy. The present study identified the fee subsidy provided to patients at the tertiary hospital as a facilitator of adherence. Patients paid a percentage of their hospital fees depending on their income category, with the remaining fees being subsidized by the government. In contrast, Anwanyu et al. (2011) states that cancer treatment in most countries in Africa are not covered by national health insurance programs and women are therefore obligated to pay for breast cancer screening and treatment. High out-of-pocket treatment costs as well as a

lack of insurance coverage was also identified by Reddy et al. (2020). Healthcare workers in the present study stated that patients were also not refused treatment if their hospital fees were not paid in time. Patients were therefore afforded able to adhere to treatment as access to treatment and cost of treatment was made affordable to them.

6.3.2.2 Hospital transport and the disability grant. Patients in the present study who experienced financial issues were assisted by social workers in applying for a disability grant. Healthcare workers indicated that many patients were dependent on disability grants as their primary income source and that it enabled adherence to treatment as it covered transport and treatment costs. The HealthNET (Health Non-Emergency Transport) service was provided to patients for whom the hospital is not considered to be in their immediate surroundings. The present study identified this as a facilitator of adherence as the service was provided free-of-charge to patients for the scheduled hospital appointments. The transport service transported patients from their homes to the hospital and back.

6.4 Strengths of the study

The present study identified several barriers to and facilitators of adherence to chemotherapy through the triangulation of perspectives of breast cancer patients, family members and healthcare workers. Through the use of the EST, the study was able to consider the factors at various systems' levels which impacted individual's ability to be adherent to intravenous chemotherapy.

Participants who took part in the study spoke about how they enjoyed the interview process as they had not previously had an opportunity to share their experiences. Furthermore, most of the patients were adherent to treatment and therefore more facilitators of adherence were

identified compared to barriers to adherence which is in contrast to previous studies in which more barriers were identified.

6.5 Limitations and Recommendations

The present study has several limitations. First, participants for the breast cancer patient group were recruited with the help of healthcare workers and not the recruitment poster. Participants may therefore have felt obligated to participate in the study in order to please the referring healthcare worker or may have agreed to participate because the healthcare worker suggested they do so.

Second, the COVID pandemic and subsequent lockdown and embargo on face-to-face research impacted my ability to present to hospital and recruit participants. This may have been one of the reasons why I struggled with participant recruitment towards the end of my study as patients and family members may have been hesitant to speak to me owing to health concerns.

Third, I encountered language barriers with some participants who indicated willingness to participate in the study. These patients struggled to express themselves in English or did not understand the questions posed and therefore gave mostly closed-ended answers. The study's inclusion criteria allowed for patients who were able to speak Afrikaans, English or Xhosa to be study participants. However, due to limitations in funding of the study, hiring an interpreter/translator was not possible. Future research should aim to include interpreters or interviewers who speak the participants' language in order to mitigate language barriers and for patients to be able to express themselves.

Fourth, only two participants in the patient group were identified as being non-adherent to treatment therefore barriers to adherence were mostly identified from the perspectives of healthcare workers. Future research should aim to employ pre-identification of nonadherent

patients with the assistance of healthcare workers and incentivize participation for non-adherent patients.

Fifth, interviews with breast cancer patients were shorter than interviews with the other participant groups, which provided little opportunity for rapport building between the interviewer and the interviewee. Factors which influenced the length of interviews included awareness of time constraints as some patients were interviewed before their chemotherapy appointment and anxiousness on the part of some participants. Future research should aim to build rapport with patients before interviews commence as may help to establish trust and make patients feel comfortable. This in turn may give better access to information and data for the researcher as well.

Finally, further research should aim to include social workers and counsellors who work with breast cancer patients in order to gain an understanding of further psychosocial issues influencing adherence to intravenous chemotherapy.

6.6 Conclusion

The findings of this study give us insight into the barriers and facilitators that influenced breast cancer patients' adherence to chemotherapy from the perspectives of breast cancer patients, family members and healthcare workers. The use of the EST allowed for the exploration of contextual and health systems factors within the South African context which influence patients' adherence. The findings showed that breast cancer patients' adherence to treatment was shaped and influenced by their interactions with family, friends, healthcare workers as well as poverty-related and institution-related factors. Patients' understanding, knowledge and access to information regarding breast cancer and its treatment mechanisms also served as important determinants of adherence.

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APPENDICES

Appendix A: HREC Ethical Approval



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Notice

New Application

29/08/2019

Project ID :10199

HREC Reference No: S19/07/130

Project Title: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients

Dear Miss Brigitta Kepkey,

The **Response to Modifications** received on 28/08/2019 15:25 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 29/08/2019 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: This project has approval for 12 months from the date of this letter.

Please remember to use your Project ID **[10199]** and Ethics Reference Number **[S19/07/130]** 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 you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC 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.

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. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. 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 instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/10199>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mr. Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

REC-130408-012 (HREC1)-REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)-IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects](#); the South African [Department of Health \(2006\). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the Department of Health (2015). [Ethics in Health Research: Principles, Processes and Structures \(2nd edition\)](#).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix B: Approval to Conduct Research at the Tertiary Hospital



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG**
Marinus
TELEPHONE: **021 938 5752**

Project ID: 10199

Ethics Reference: S19/07/130

TITLE: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients.

Dear Miss Brigitta Kepkey

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

A handwritten signature in black ink, appearing to be "GG Marinus", written over a horizontal line.

DR GG MARINUS
MANAGER: MEDICAL SERVICES

A handwritten signature in black ink, appearing to be "D Erasmus", written over a horizontal line.

DR D ERASMUS
CHIEF EXECUTIVE OFFICER

Date: 9 September 2019

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

Project ID: 10199

Ethics Reference: S19/07/130

TITLE: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients.

BY  _____
An authorized representative of Tygerberg Hospital

NAME Dr DS Erasmus

TITLE CEO

DATE 19 September 2019

Appendix C: Approval of Additional Study Site



13/11/2019

Project ID: 10199

Ethics Reference No: S19/07/130

Project Title: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients

Dear Miss Brigitta Kepkey,

Your amendment request dated 05/11/2019 19:06 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendments were reviewed and approved:

1. Amended protocol_breast cancer version 2.0 dated 31 October 2019
2. Addition of the Chemotherapy Unit in X Block at Tygerberg Hospital as an additional study site.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID **[10199]** and ethics reference number **[S19/07/130]** on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mr. Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:

IRB0005240 (HREC1)·IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix D: Ethical Approval to Lower Age Limit of Participants



12/03/2021

Project ID: 10199

Ethics Reference No: S19/07/130

Project Title: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape

Dear Miss Brigitta Kepkey

Your amendment request dated 25/02/2021 12:38 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved:

Protocol Amendment #3 dated, 25 February 2021

- I. Decreasing the lower limit of the age criteria for this study from 30 years of age to 18 years of age.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Inforetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID 10199 and ethics reference number S19/07/130 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee (HREC 2)

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

*Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)*

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix E: Approval for Ethics Amendment



18/06/2020

Project ID: 10199

Ethics Reference No: S19/07/130

Project Title: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients

Dear Miss Brigitta Kepkey

We refer to your response to modifications dated 12/06/2020 12:24 refers.

Thank you for attending to the requested modifications. your amendment is now finally approved.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved:

Protocol version 2, dated 14 May 2020.

1. Addition of telephonic interviews as a method of data collection.
2. Request to access files of breast cancer patients who are undergoing intravenous chemotherapy, those who have either missed one or more chemotherapy appointments but who have continued with treatment and those who have defaulted on their treatment and have returned to the hospital in order to get their contact details to ask if they would be willing to participate in the study in the hopes of maximizing recruitment.
3. Request to contact the family members of the patients who respond by asking the responding patient whether there is a family member the researcher can speak to.
4. Request to contact the healthcare professionals, including social workers, who work with breast cancer patients to ask if they would be willing to participate in telephonic or VoIP interviews.
5. access to the patient files as well as the healthcare professionals would be through the supervision of Dr. Jenny Edge

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID 10199 and ethics reference number S19/07/130 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee 2

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:

IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the

World Medical Association (2013), Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix F: Approval for Extension of Study Period



02/10/2020

Project ID: 10199

Ethics Reference No: S19/07/130

Project Title: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients

Dear Miss Brigitta Kepkey

We refer to your request for an extension/annual renewal of ethics approval dated 15/09/2020 10:02.

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

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

Approval date: 02 October 2020

Expiry date: 01 October 2021

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

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your Project Id 10199 and ethics reference number S19/07/130 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee 2

National Health Research Ethics Council (NHREC) Registration Number:
REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects](#); the South African Department of Health (2006). [Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the Department of Health (2015). [Ethics in Health Research: Principles, Processes and Structures \(2nd edition\)](#).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix G: Approval for Extension to Conduct Research at the Tertiary Hospital



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG**
Marinus
TELEPHONE: **021 938 5752**

Project ID: 10199

Ethics Reference: S19/07/130 - RENEWAL

TITLE: Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients

Dear Miss Brigitta Kepkey

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Tygerberg Hospital Health Research Policy and Protocol of **April 2018**, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).


DR GG MARINUS
MANAGER: MEDICAL SERVICES

Date:

10/2/2021

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

Appendix H: Breast Cancer Patients' Recruitment Poster



LIVING WITH BREAST CANCER?

Have you been diagnosed with breast cancer and are currently receiving intravenous chemotherapy?

If so, please consider participating in a study examining the factors that influence adherence to chemotherapy.

Adherence to treatment in low and middle-income countries such as South Africa is a challenge with patients having to be strong enough to deal with their diagnosis, come to appointments and endure the side effects of chemotherapy. It is important for individuals to take the full course of medication in order to receive optimal treatment benefits as missing even a single dose may have negative consequences. This study aims to examine the positive and negative influences on adherence to chemotherapy that may make it easy or difficult to stick to the treatment regimen.

I am looking for individuals:

- ❖ Between 30 to 60 years of age
- ❖ have a formal clinical diagnosis of breast cancer from stage I to IV
- ❖ be attending the breast clinic at Tygerberg Hospital
- ❖ currently be receiving intravenous chemotherapy or have received in the past

If you are interested in participating, please contact me to schedule a short screening questionnaire which will assess your eligibility.

PRIMARY RESEARCHER: BRIGITTA KEPKEY

EMAIL: 19151039@sun.ac.za

I am a masters student in the Psychology Department at Stellenbosch University. I am doing this research study in pursuit of my MA (Psychology) degree with my supervisor Dr. Bronwyne Coetzee and co-supervisor Prof. S. A. Kagee.

Appendix I: Family Members' Recruitment Post



HAS YOUR FAMILY MEMBER BEEN DIAGNOSED WITH BREAST CANCER?

Has your loved one been diagnosed with breast cancer and are currently receiving intravenous chemotherapy?

If so, please consider participating in a study examining the factors that influence adherence to chemotherapy.

Adherence to treatment in low and middle-income countries such as South Africa is a challenge with patients having to be strong enough to deal with their diagnosis, come to appointments and endure the side effects of chemotherapy. It is important for individuals to take the full course of medication in order to receive optimal treatment benefits as missing even a single dose may have negative consequences. This study aims to examine the positive and negative influences on adherence to chemotherapy that may make it easy or difficult to stick to the treatment regimen.

I am looking for individuals who

- ❖ Have a family member who has been diagnosed with breast cancer
- ❖ The family member should be over the age of 18 years old
- ❖ The family member should be receiving intravenous chemotherapy or have received intravenous chemotherapy in the past and has returned for treatment

If you are interested in participating, please contact me to schedule a short screening questionnaire which will assess your eligibility.

PRIMARY RESEARCHER: BRIGITTA KEPKEY

EMAIL: 19151039@sun.ac.za

I am a masters student in the Psychology Department at Stellenbosch University. I am doing this research study in pursuit of my MA (Psychology) degree with my supervisor Dr. Bronwyne Coetzee and co-supervisor Prof. S. A. Kagee.

Appendix J: Healthcare Workers' Recruitment Poster



BARRIERS TO AND FACILITATORS OF ADHERENCE TO INTRAVENOUS CHEMOTHERAPY

Do you provide healthcare to patients who receive intravenous chemotherapy?

If so, please consider participating in a study examining the factors that influence adherence to chemotherapy

Adherence to treatment in low and middle-income countries such as South Africa is a challenge with patients having to be strong enough to deal with their diagnosis, come to appointments and endure the side effects of chemotherapy. It is important for individuals to take the full course of medication in order to receive optimal treatment benefits as missing even a single dose may have negative consequences. This study aims to examine the positive and negative influences on adherence to chemotherapy that may make it easy or difficult to stick to the treatment regimen.

I am looking for individuals who

- ❖ Work with or administer intravenous chemotherapy on a regular basis

If you are interested in participating, please contact me to schedule a short screening questionnaire which will assess your eligibility.

PRIMARY RESEARCHER: BRIGITTA KEPKEY

EMAIL: 19151039@sun.ac.za

I am a masters student in the Psychology Department at Stellenbosch University. I am doing this research study in pursuit of my MA (Psychology) degree with my supervisor Dr. Bronwyne Coetzee and co-supervisor Prof. S. A. Kagee.

Appendix K: Breast Cancer Patients' Interview Schedule

Thank you for accepting the invitation to participate in my research study. I really appreciate this time that you are allowing me. Demographic information e.g., age and post code

- Could you tell me in your own words what the study is about?
 - So, can you tell me what made you decide to participate in the study?
1. Can you tell me about how you felt after your diagnosis?
 2. Can you tell me about how your chemotherapy treatment has been?
 3. What are some of the things that has helped you cope with your chemotherapy treatment? OR DIAGNOSIS?
 - E.g., people or church group: how has your church group helped you cope?
 - How have these things (or people) helped you cope with your diagnosis?
 4. What are some of the challenges that you have faced attending chemotherapy?
 - Can you tell me why it has been difficult to attend?
 - You said it has been easy, what are the things that make it easy for you to attend?
 5. Have you ever been unable to attend a chemotherapy session?
 - If so, can you recall how many you have missed?
 - **What were the reasons (or circumstances) surrounding you missing your appointment?**
 6. What has your interactions with the hospital staff been like?
 - Which hospital staff do you regularly interact with?
 - Can you tell me whether these interactions have influenced your attendance of chemotherapy sessions?
 - E.g., Have these relationships made it more difficult or less difficult for you to attend?
 7. How do you feel that you have benefitted from your chemotherapy treatment?
 - Are you concerned about cancer recurrence?
 8. Have you experienced any financial challenges with regards to your treatment?
 - How do you cover additional costs of treatment?
 9. Is there anything that you would like to mention that has not been covered?

Appendix L: Family Members' Interview Schedule

Thank you for accepting the invitation to participate in my research study. I really appreciate this time that you are allowing me.

- Could you tell me in your own words what the study is about?
 - So, can you tell me what made you decide to participate in the study?
 - Which family member has been given a cancer diagnosis (so as not to keep saying family member – no names)
1. Can you tell me how your family member's cancer diagnosis impacted yourself personally as well as the family?
 - How has the chemotherapy treatments impacted the family life?
 2. What are some of the challenges that your family member experiences as a result of undergoing chemotherapy?
 - What are your interactions like before and after a chemo session? How different is it to their usual behaviour?
 - 3. What are the factors that make it difficult for your family member to attend their chemotherapy sessions?**
 - 4. Chemotherapy is a difficult treatment to undergo and patients need a lot of support throughout, what type of support does your family member receive?**
 - In your opinion, who or what are these support structures and how have they helped your family member and your family?
 5. The hospital staff and environment play a big role in your family member's care, can you share your opinion of the hospital environment and staff?
 6. What are some of the financial challenges that you/FM face with regards to treatment?
 - How does your family cover any extra costs of treatment?
 7. Is there anything you would like to mention that has not been covered?

Appendix M: Healthcare Workers' Interview Schedule

Thank you for accepting the invitation to participate in my research study. I really appreciate this time that you are allowing me.

GENERAL e.g.: how long have you been a nurse, healthcare professional ...

- So, can you tell me what made you decide to participate in the study?
 - Could you tell me in your own words what the study is about?
 - How long have you worked with chemo patients or breast cancer patients etc.
1. What have your interactions with breast cancer patients who receive chemotherapy been like?
 - Experience/relationships
 2. Do you think that patients are provided with the necessary support from the healthcare system?
 - financially or otherwise for chemotherapy treatment? What do you think are the existing support structures e.g., individual, psychosocial, family, church, social groups, online etc.
 3. **Do you find that patients understand the treatment process?**
 - Can you explain the diagnosis and Rx process?
 - What do you think patients find difficult to understand? Do they ask questions or do they just accept what they are told? (active/passive)
 4. Some patients come for treatment and finish the course whereas others don't finish the treatment and drop out. **Can you share your opinion on what makes it difficult for breast cancer patients to attend chemotherapy sessions?**
 - What makes it easier for some patients to finish their treatment?
 5. **What things make it easy for breast cancer patients to come for chemotherapy sessions?**
 - What helps patients cope with their diagnosis and treatment regimen? (examples)
 6. Is there anything you would like to mention that has not been covered?

Appendix N: Healthcare Workers' Informed Consent Form (VoIP)

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM HEALTH CARE WORKERS - VoIP

TITLE OF RESEARCH PROJECT:	
Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Miss Brigitta Kepkey	Ethics reference number: S19/07/130
Full postal address:	PI Contact number:

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely 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. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

In South Africa, breast cancer is the most diagnosed form of cancer among women across all ages, with the number of women being diagnosed with breast cancer expected to rise. This study aims to explore the reasons why breast cancer patients may or may not attend all their cancer treatment sessions. In order to receive the maximum benefits of treatment, patients need to attend all the intravenous chemotherapy appointments. However, there are many reasons which may cause patients to attend less than 100% of their chemotherapy sessions such as the side effects they experience, the level of support they receive and their financial circumstances. Within South Africa, the reasons for chemotherapy non-attendance are not well understood, and this study therefore aims to identify some of the reasons.

The interview will take place via a Voice over Internet Protocol (VoIP) platform. VoIP is the technology that converts your voice into a digital signal which allows you to make a call directly to an electronic device such as a phone or computer. The interview will be recorded using the VoIP platform. The platforms used in this study will be WhatsApp or Microsoft Teams. The number of participants who will be asked to participate will be approximately 35, with 15-20 breast cancer patients, 2-5 family members and 5-10 healthcare workers. The interview will take place at a time that is suitable to the participant.

Why have I invited you to participate?

You have been invited to participate in this study to share your opinion of how patients experience their chemotherapy treatment including factors that make it difficult or easy for them to cope with the treatment as well as ways in which the healthcare system and HCPs provide support for patients.

You have furthermore been invited to take part in this study as you are older than 18 years of age, speak either English, Afrikaans or Xhosa, are involved in the treatment process or administration of intravenous chemotherapy to patients or should have worked with patients in a social work capacity and regularly interact with breast cancer patients at the clinic who are undergoing intravenous chemotherapy.

What will your responsibilities be?

If you agree to take part in this study, you will be asked to answer questions relating to your opinion of the experience of chemotherapy for breast cancer patients, including factors that you have identified that have helped them cope with treatment or have discouraged them from attending treatment. The interview will take place on a VoIP platform at a time suitable for you and should take approximately 15-30 minutes.

Will you benefit from taking part in this research?

I hope that by participating in this study you will understand and be more aware of patient chemotherapy adherence behaviours. Your participation in this study will help to understand the challenges that breast cancer patients experience while undergoing chemotherapy treatment regimen in a South African context. Your participation will benefit future patients as the results of the study may also contribute to intervention development, focusing on the improvement of adherence to treatment rates.

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

Some of the questions asked may result in negative feelings that may cause you to feel uncomfortable. Please note that you are able to withdraw from this study and stop the interview at any time without any consequences should you wish to do so.

If you do experience any discomfort and would like to speak to someone, the Welgevallen Clinic has agreed to provide telephonic psychological support should you wish to make use of it.

The VoIP platforms used in this study encrypts all data that is collected which encodes the data using substitute numbers, letters and symbols and renders it unintelligible to unauthorised access. Despite this encryption, privacy may be an issue as VoIP platforms require users to provide certain personal identifiers which may lead to data potentially being re-identifiable. To mitigate this risk, re-identifiable data that has been collected will not be used in the transcription of audio and video text and the data will be stored on the principal investigator's password-protected computer. Only myself and my supervisor will have access to the data. Furthermore, pseudonyms will be used during the transcription and analysis of the data.

Finally, by consenting to the interview, you understand that despite the employment of security measures, online communications may be at greater risk for third party (hacking, intrusions, and other) violations.

If you do not agree to take part, what alternatives do you have?

If you do not agree to partake in this study, there will be no consequences and the interview will come to an end.

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

You will not have to pay for anything if you do take part.

Is there anything else that you should know or do?

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that the principal investigator has not explained to you, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*“Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape”*).

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been 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 nothing bad will come of it – I 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 that we have agreed on.

Signed at (*place*) on (*date*) 2021.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

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

Signed at (*place*) on (*date*) 2021.

.....
Signature of investigator

.....
Signature of witness

Appendix O: Breast Cancer Patients' Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM BREAST CANCER PATIENTS

TITLE OF RESEARCH PROJECT:	
Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape.	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Miss Brigitta Kepkey	Ethics reference number: S19/07/130
Full postal address:	PI Contact number:

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely 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. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

In South Africa, breast cancer is the most diagnosed form of cancer among women across all ages, with the number of women being diagnosed with breast cancer expected to rise. This study aims to explore the reasons why breast cancer patients may or may not attend all their cancer treatment sessions. In order to receive the maximum benefits of treatment, patients need to attend all the intravenous chemotherapy appointments. However, there are many reasons which may cause patients to attend less than 100% of their chemotherapy sessions such as the side effects they experience, the level of support they receive and their financial circumstances. Within South Africa, the reasons for chemotherapy non-attendance are not well understood, and this study therefore aims to identify some of the reasons.

The interview will take place via a Voice over Internet Protocol (VoIP) platform. VoIP is the technology that converts your voice into a digital signal which allows you to make a call directly to an electronic device such as a phone or computer. The interview will be recorded using the VoIP platform. The platforms used in this study will be WhatsApp or Microsoft Teams. The number of participants who will be asked to participate will be approximately 35, with 15-20 breast cancer patients, 2-5 family members and 5-10 healthcare workers. The interview will take place at a time that is suitable to the participant.

Why have I invited you to participate?

I have invited you to participate as you are currently receiving intravenous chemotherapy, or have received intravenous chemotherapy in the past, have defaulted for reasons other than a physical reason and have returned for treatment. In South Africa, the information regarding reasons for continuing with or stopping treatment is limited and this study therefore aims to understand the reasons why some individuals are able to complete their full chemotherapy treatment plan, while others are unable to do so.

You have therefore been invited to take part in this study as you are older than 18 years of age, speak either English, Afrikaans or Xhosa, have a formal clinical diagnosis of breast cancer from stage I to IV, attend the breast clinic at Tertiary Hospital and are currently receiving intravenous chemotherapy or have received intravenous chemotherapy in the past and have returned to finish your treatment.

What will your responsibilities be?

If you agree to take part in this study, you will be asked to answer questions relating to your experience of your chemotherapy treatment, including factors that helped you cope with your diagnosis and treatment, as well as why you may have been unable to complete your treatment plan is that was the case. The interview will take place on a VoIP platform at a time suitable for you and should take approximately 15-30 minutes. should take approximately 30 minutes.

Will you benefit from taking part in this research?

I hope that by participating in this study you will understand and be more aware of the factors that have affected your experience of your chemotherapy treatment. Your participation in this study will help to understand on the challenges that breast cancer patients experience while undergoing chemotherapy treatment regimen in a South African context. Your participation will benefit future patients as the results of the study may also contribute to intervention development, focusing on the improvement of adherence to treatment rates.

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

Some of the questions asked may result in negative feelings that may cause you to feel uncomfortable. Please note that you are able to withdraw from this study and stop the interview at any time without any consequences should you wish to do so.

If you do experience any discomfort and would like to speak to someone, the Welgevallen Clinic has agreed to provide psychological support should you wish to make use of it. Your transport costs will be covered if you need to travel to receive face-to-face therapy at the clinic.

The VoIP platforms used in this study encrypts all data that is collected which encodes the data using substitute numbers, letters and symbols and renders it unintelligible to unauthorised access. Despite this encryption, privacy may be an issue as VoIP platforms require users to provide certain personal identifiers which may lead to data potentially being re-identifiable. To mitigate this risk, re-identifiable data that has been collected will not be used in the transcription of audio and video text and the data will be stored on the principal investigator's password-protected computer. Only myself and my supervisor will have access to the data. Furthermore, pseudonyms will be used during the transcription and analysis of the data.

Finally, by consenting to the interview, you understand that despite the employment of security measures, online communications may be at greater risk for third party (hacking, intrusions, and other) violations.

If you do not agree to take part, what alternatives do you have?

If you do not agree to partake in this study, there will be no consequences and the interview will come to an end.

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

For your participation in this study, you will be given an airtime voucher to the value of R100. You will not have to pay for anything if you do take part.

Is there anything else that you should know or do?

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that the principal investigator has not explained to you, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*“Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape”*).

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been 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 nothing bad will come of it – I 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 that we have agreed on.

Signed at (*place*) on (*date*) 2021.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

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

Signed at (*place*) on (*date*) 2021.

.....
Signature of investigator

.....
Signature of witness

Appendix P: Family Members' Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FAMILY

TITLE OF RESEARCH PROJECT:	
Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape.	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Miss Brigitta Kepkey	Ethics reference number: S19/07/130
Full postal address:	PI Contact number:

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely 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. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

In South Africa, breast cancer is the most diagnosed form of cancer among women across all ages, with the number of women being diagnosed with breast cancer expected to rise. This study aims to explore the reasons why breast cancer patients may or may not attend all their cancer treatment sessions. In order to receive the maximum benefits of treatment, patients need to attend all the intravenous chemotherapy appointments. However, there are many reasons which may cause patients to attend less than 100% of their chemotherapy sessions such as the side effects they experience, the level of support they receive and their financial circumstances. Within South Africa, the reasons for chemotherapy non-attendance are not well understood, and this study therefore aims to identify some of the reasons.

The study will take place in a room at the breast clinic at Tertiary Hospital during clinic hours. The number of participants who will be asked to participate will be approximately 35, with 15-20 breast cancer patients, 5-10 family members and 4-5 healthcare professionals. The interview will take place at a time that is suitable to the participant and on a day when they come with their family member, who is a breast cancer patient, for an appointment at the clinic. Therefore, they will not need to come in for a follow-up appointment.

Why have I invited you to participate?

I have invited you to take part in this study because you are a family member of someone who is receiving intravenous chemotherapy at the breast clinic at Tertiary Hospital. In this study, I aim to explore the impact that the breast cancer diagnosis has had on the family and how the family has supported the breast cancer patient. I also seek to explore the family's opinion on the impact the diagnosis and chemotherapy has had on the patient. Understanding factors that affect adherence from the perspectives of family members may offer additional insight not identified by the patients themselves.

You have therefore been invited to take part in the study as you are older than 18 years of age, speak either English, Afrikaans or Xhosa, have a family member who has a formal clinical diagnosis of breast cancer from stage I to IV and who attends the breast clinic at Tertiary Hospital and who is currently or has in the past received intravenous chemotherapy.

What will your responsibilities be?

If you agree to take part in this study, you will be asked to answer questions relating to how breast cancer diagnosis has impacted on your family and how you think your family member has coped with attending chemotherapy sessions. The interview will take place in a room at the breast clinic at Tertiary Hospital at a suitable time for you and should take approximately 30 minutes.

Will you benefit from taking part in this research?

I hope that by participating in this study you will understand and be more aware of your family member's experience of their chemotherapy. Your participation in this study will help to understand the challenges that breast cancer patients experience while undergoing their chemotherapy treatment regimen in a South African context. Your participation will benefit future patients as the results of the study may also contribute to intervention development, focusing on the improvement of adherence to treatment rates.

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

Some of the questions asked may result in negative feelings that may cause you to feel uncomfortable. Please note that you are able to withdraw from this study and stop the interview at any time without any consequences should you wish to do so.

If you do experience any discomfort and would like to speak to someone, the Welgevallen Clinic has agreed to provide psychological support should you wish to make use of it. Your transport costs will be covered if you need to travel to receive face-to-face therapy at the clinic.

If you do not agree to take part, what alternatives do you have?

If you do not agree to partake in this study, there will be no consequences and the interview will come to an end.

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

For your participation in this study, you will be paid R100. You will not have to pay for anything, if you do take part.

Is there anything else that you should know or do?

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that the principal investigator has not explained to you, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*“Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape”*).

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been 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 nothing bad will come of it – I 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 that we have agreed on.

Signed at (*place*) on (*date*) 2021.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

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

Signed at (*place*) on (*date*) 2021.

.....
Signature of investigator

.....
Signature of witness

Appendix Q: Healthcare Workers' Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM HEALTH CARE PROVIDERS

TITLE OF RESEARCH PROJECT:	
Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Miss Brigitta Kepkey	Ethics reference number: S19/07/130
Full postal address:	PI Contact number:

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely 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. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

In South Africa, breast cancer is the most diagnosed form of cancer among women across all ages, with the number of women being diagnosed with breast cancer expected to rise. This study aims to explore the reasons why breast cancer patients may or may not attend all their cancer treatment sessions. In order to receive the maximum benefits of treatment, patients need to attend all the intravenous chemotherapy appointments. However, there are many reasons which may cause patients to attend less than 100% of their chemotherapy sessions such as the side effects they experience, the level of support they receive and their financial circumstances. Within South Africa, the reasons for chemotherapy non-attendance are not well understood, and this study therefore aims to identify some of the reasons.

The study will take place in a room at the breast clinic at Tygerberg Hospital during clinic hours. The number of participants who will be asked to participate will be approximately 35, with 15-20 breast cancer patients, 5-10 family members and 4-5 healthcare professionals. The interview will take place at a time that is suitable to the participant at X-block.

Why have I invited you to participate?

You have been invited to participate in this study to share your opinion of how patients experience their chemotherapy treatment including factors that make it difficult or easy for them to cope with the treatment as well as ways in which the healthcare system and HCPs provide support for patients.

You have furthermore been invited to take part in this study as you are older than 18 years of age, speak either English, Afrikaans or Xhosa, are involved in the administration of intravenous chemotherapy to patients or in the treatment process of intravenous chemotherapy to breast cancer patients and regularly interact with breast cancer patients at the clinic who are undergoing intravenous chemotherapy.

What will your responsibilities be?

If you agree to take part in this study, you will be asked to answer questions relating to your opinion of the experience of chemotherapy for breast cancer patients, including factors that you have identified that have helped them cope with treatment or have discouraged them from attending treatment. The interview will take place in a room at X-block at Tygerberg Hospital at a time suitable for you and should take approximately 15 minutes.

Will you benefit from taking part in this research?

I hope that by participating in this study you will understand and be more aware of patient chemotherapy adherence behaviours. Your participation in this study will help to understand the challenges that breast cancer patients experience while undergoing chemotherapy treatment regimen in a South African context. Your participation will benefit future patients as the results of the study may also contribute to intervention development, focusing on the improvement of adherence to treatment rates.

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

Some of the questions asked may result in negative feelings that may cause you to feel uncomfortable. Please note that you are able to withdraw from this study and stop the interview at any time without any consequences should you wish to do so.

If you do experience any discomfort and would like to speak to someone, the Welgevallen Clinic has agreed to provide psychological support should you wish to make use of it. Your transport costs will be covered if you need to travel to receive face-to-face therapy at the clinic.

If you do not agree to take part, what alternatives do you have?

If you do not agree to partake in this study, there will be no consequences and the interview will come to an end.

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

Light refreshments will be offered at the conclusion of the interview. You will not have to pay for anything, if you do take part.

Is there anything else that you should know or do?

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that the principal investigator has not explained to you, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*“Barriers to and facilitators of adherence to intravenous chemotherapy among breast cancer patients at a tertiary hospital in the Western Cape”*).

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been 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 nothing bad will come of it – I 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 that we have agreed on.

Signed at (*place*) on (*date*) 2021.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

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

Signed at (*place*) on (*date*) 2021.

.....
Signature of investigator

.....
Signature of witness

Appendix R: Demographic information

Demographic Information

Breast cancer patient

Age of participant: _____

Marital status: _____

Religious belief: _____

Gender: _____

Postal code: _____

Demographic Information

Healthcare Workers

Gender: _____

Occupation: _____

Years spent in occupation: _____

Demographic Information

Family member

Marital status: _____

Religious belief: _____

Gender: _____

Postal code: _____

Appendix S: Permission from Welgevallen for Psychological Support



WELGEVALLEN COMMUNITY PSYCHOLOGY CLINIC

Department of Psychology, Stellenbosch University

Tel: 021 808 2696 Email: wcpcc@sun.ac.za Web: www.sun.ac.za/wcpcc

05/07/2019

RE: Free Psychological Services

The Welgevallen Community Psychology Clinic is a clinic offering free psychological services to people in need within the greater Stellenbosch area.

This letter serves as confirmation that the clinic services are available to provide support to any research participants who may experience psychological distress during or due to participation in the research being conducted by Brigitta Kepkey. The clinic services will also be available to the researcher, Brigitta Kepkey, should the need arise for support or debriefing during or after the research process.

The abovementioned research student is conducting her Masters research under the supervision of Dr Bronwyné Coetzee from the Department of Psychology at Stellenbosch University

Her research title is: Barriers to and facilitators of adherence to intravenous chemotherapy amongst South African breast cancer patients.

The aforementioned researcher agrees to provide the clinic details to all research participants to ensure that they are aware of the support available, and are thus able to access the necessary support should the need arise.

Please do contact me for further information

Megan Snow

Clinical Psychologist

Clinic Manager

Welgevallen Community Psychology Clinic

Stellenbosch University

Web: www.sun.ac.za/wcpcc

Tel: 021 808 2696

Email: wcpcc@sun.ac.za