

SOUTH AFRICAN MALE PARTNERS' PERCEPTIONS  
OF BREAST CANCER

“I MUST LOVE HER MORE”: BLACK SOUTH AFRICAN MALE PARTNERS’  
PERCEPTIONS OF BREAST CANCER AND THEIR ROLE IN THEIR PARTNER’S  
ACCESS TO HEALTH CARE IN DIEPSLOOT, JOHANNESBURG

By: RAQUEL C. BURGESS, B.Sc.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the  
Requirements for the Degree Master of Science (Global Health)

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Author Note

This thesis was made possible thanks to generous funding by the Canadian

Institute for Health Research

(Frederick Banting & Charles Best Canada Graduate Scholarship).

Author Contact Details: [burgess.raq@gmail.com](mailto:burgess.raq@gmail.com).

McMaster University MASTER OF SCIENCE (2017) Hamilton, Ontario (Global Health)

TITLE: “I must love her more”: Black South African male partners’ perceptions of breast cancer and their role in their partner’s access to health care in Diepsloot, Johannesburg

AUTHOR: Raquel C. Burgess, B.Sc.

SUPERVISORS: Dr. John Eyles (McMaster) & Dr. Ruari McBride (University of the Witwatersrand)

NUMBER OF PAGES: xiii, 148

## **LAY ABSTRACT**

In South Africa, women with breast cancer often do not reach the conventional healthcare system until the disease has progressed significantly and chances of survival are poor. This occurs because of a lack of knowledge about the disease and large distances to health care centers. Furthermore, in the male-dominated society of South Africa, women have limited independence. Therefore, this study sought to determine what men in South African know about breast cancer and how they are involved in their partner's access to health care. Interviews were conducted with 20 men living in a resource-poor setting. The men portrayed little knowledge and specific misconceptions about breast cancer and cancer in general. They appear to be playing an active and mostly positive role in their partner's access to health care. Public health efforts should increase awareness of the disease and recognize the significant role of the male partner in women's health issues.

## ABSTRACT

**Background:** In South Africa (SA), women with breast cancer (BC) present to the health care system at advanced stages of the disease, resulting in poor prognosis. Limited awareness of the disease, large distances to health care centers, and lack of affordable transportation have all been implicated as factors delaying presentation. In addition, women in SA have limited social and financial independence, which may make it difficult for them to resolve their own health care needs. Despite this, little is known about what South African male partners know about breast cancer and what role they play in their partner's access to health care.

**Methods:** This interpretive qualitative case study, guided by the theoretical framework of hegemonic masculinity(ies), used semi-structured interviews to investigate perceptions and knowledge of BC and gender norms in regards to health care access in a group of black South African males (n=20) in long-term heterosexual relationships living in a resource-poor setting. Interview data was analyzed using thematic analysis and compared to insights gained through interactions with local BC organizations.

**Results:** Participants demonstrated very little knowledge of breast cancer and cancer in general. Some specific misconceptions about cancer are reported, including confusion between cancer and HIV. Participants were positive about receiving health care for cancer but are burdened by barriers to reaching care and a lack of access to information about the disease. The men describe themselves as playing an active, mostly positive role in their partner's access to health care. They demonstrate perspectives about gender relations that defy hegemonic forms of masculinity.

**Conclusions:** Major public health efforts are required to increase awareness of BC in order to encourage earlier presentation to the healthcare system. These efforts should recognize the importance of the male partner in women's health issues.

## ACKNOWLEDGEMENTS

I would like to sincerely thank both of my supervisors, Dr. John Eyles of McMaster University, and Dr. Ruari McBride of the University of the Witwatersrand. Dr. Eyles provided the guiding support for the completion of my thesis from both a methodological and practical view. He was encouraging of any endeavor I undertook, and guided me with patience and positivity. Dr. McBride provided invaluable support in the development of the interview guide and also acted as the point person in the field for which to resolve all practical considerations. In addition, the members of my supervisory committee, Dr. Dorothy Pawluch and Dr. Robert Wilton, are very much appreciated for their encouraging support throughout this process. I would also like to thank Dr. Nicola Christofides and Shehnaz Munshi for their assistance in the initial development of the project, ethics application and site considerations.

I would like to extend my sincere appreciation to Brown Lekekela and the other members of Sonke Gender Justice in Diepsloot for their unwavering and generous assistance in the recruitment of participants and completion of the interviews.

Furthermore, I would like to thank Dr. Jim Lyons for giving me the opportunity to dive head first into research and develop a passion for it during my undergraduate degree. I would not be where I am now if it was not for your mentorship. Furthermore, thank you to Jessica Skultety and Heather Plyley for their advice throughout the writing process.

I would be remiss if I did not acknowledge the Canadian Institute for Health Research for funding this research and making it possible. The opportunities this organization gives to graduate students and their focus on knowledge translation is important for the advancement of health research both in Canada and abroad.

I would like to thank my Mom, Kim Devine, for providing unconditional support throughout my life, and also for providing inspiration for this thesis. Without you, I am not sure where I would be today. I can only hope that the results of this thesis will be useful in improving breast cancer care in South Africa, so that South African woman may be given the chance to survive breast cancer as you did.

Finally, to everyone who was involved in the research process, both in Hamilton and in South Africa, your efforts are very much appreciated.

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## **LIST OF ABBREVIATIONS**

BC	Breast Cancer
BSE	Breast self-examination
CAT(s)	Community Action Team member(s)
CBE	Clinical breast examination
CIHR	Canadian Institute for Health Research
HIM	Husbands Initiated Movement
KT	Knowledge translation
LMIC(s)	Low- and middle-income country(ies)
NHI	National Health Insurance
SA	South Africa
SSA	Sub-Saharan Africa
TH(s)	Traditional healer(s)

## **DECLARATION OF ACADEMIC ACHIEVEMENT**

The following is a declaration that the content of the research in this document has been completed by Raquel C. Burgess and recognizes the contributions of Dr. John Eyles, Dr. Ruari McBride, Dr. Robert Wilton, and Dr. Dorothy Pawluch in both the research process and the completion of this thesis.

## CHAPTER 1: LITERATURE REVIEW

*Luke: Ahh, this one [cancer], I don't like.*

*RB: Okay. You don't like it?*

*Luke: Yeah, I don't like this.*

*RB: Why's that?*

*Luke: This is sick, I can't like sick (laughs).*

### 1.1 INTRODUCTION

As illustrated by the above quote, cancer is a globally disliked phenomenon and unfortunate aspect of the human experience. However, the experience of cancer changes quite drastically depending on the social and cultural context in which the individual exists. The initial inspiration for this thesis came from an article by Asobayire & Barley (2015) that explores the understanding of breast cancer (BC) in the Kassena-Nankana District in Ghana. The article describes how women are presenting at advanced stages of the disease due to lack of awareness as well as their constrained position in society based on the gendered hierarchy. Women in Ghana experience structural inequities related to health (e.g. illiteracy), as well as factors that constrain their agency, such as the requirement for permission from male compound heads before accessing health care (Asobayire & Barley, 2015). The researcher's interest in the topic is derived from a history of BC in the family, a concern for how gender inequality affects women's health, and a belief that this inequality is a significant but overlooked aspect of women's experience of BC in sub-Saharan Africa (SSA). The researcher specifically desired to investigate how gender inequality may influence access to BC care in South Africa (SA),

a country with a very different social context than Ghana but one in which the agency of women is also highly constrained (Jewkes, Sikweyiya, Morrell, & Dunkle, 2009).

To begin, a focused literature review was conducted to explore the areas that are most relevant to the understanding of BC in SA. An overview of the review is presented below, beginning with the state of BC in low- and middle-income countries (LMICs) and continuing with factors specific to the South African context: knowledge and awareness of BC, traditional and faith-based healing practices, relevant political and historical influences, social and structural barriers to health care, gender norms in relation to health outcomes, current policy and public health initiatives, and the role of BC civil society. This culminates in the objectives of the current study, as informed by the literature review.

## **1.2. BREAST CANCER IN LMICs**

Although BC is often perceived as a disease that primarily affects high-income countries, 53% of BC cases in 2012 occurred in developing countries (Ferlay et al. 2015; Torre et al. 2015). In addition, the incidence of BC in these countries is rapidly increasing (Ferlay et al. 2015); this trend is expected to continue as life expectancy and the prevalence of risk factors related to urbanization increase, such as smoking, obesity, and physical inactivity (Akarolo-Anthony, Ogundiran, and Adebamowo 2010; Jemal et al. 2012). This is a critical problem given that there are massive disparities in age-standardized survival rates between low- and high-income countries for BC; ranging from 12% in The Gambia (Sankaranarayanan et al. 2010) to around 80% in high-income countries such as Canada (Coleman et al. 2008). These inequalities reflect the lack of



available resources for BC care in low and middle-income regions. Specifically, LMICs are challenged with the unavailability of early detection programs, functional diagnostic equipment, treatment facilities, health care professionals, population cancer data, as well as poor accessibility to care (World Health Organization, n.d.). These factors contribute to a high proportion of patients presenting at an advanced stage (Stage III or IV) of the disease, when treatment is more expensive and less effective than treatment at earlier stages (Groot et al. 2006; Nair et al. 1993; Zelle et al. 2012). In middle-income countries such as SA, non-communicable diseases are quickly altering the nature of the disease burden (Mayosi et al., 2009), and both research and strategic planning are required in order to mitigate their effect on the population.

### **1.3 BREAST CANCER IN SOUTH AFRICA**

In South Africa, BC is the most common form of cancer in women, with an age-standardized incidence rate of 32.60 per 100,000 women (National Cancer Registry, 2012). In 2013, BC accounted for 22% of female cancers in South Africa (National Cancer Registry 2013). Like many other LMICs, SA does not have a national mammography screening program, and relies on the ability of women to recognize symptoms and self-present to the health care system (Moodley et al. 2016). The lifetime risk of BC for white individuals is 1:11, whereas it is only 1:51 for black individuals (National Cancer Registry, 2013). Factors including late menarche, early age at first birth, multi-parity, universal and prolonged lactation, low use of hormone replacement therapy and a low fat/high fiber diet may contribute to lower incidence rates in the black

population (Vorobiof, Sitas, & Vorobiof, 2001; Walker, Adam, & Walker, 2004). Lifestyle changes in response to urbanization in SA are likely to reduce these protective factors (Walker et al., 2004), placing black individuals at greater risk in the future. Despite the apparent lower risk for black individuals, the South African National Department of Health recognizes that cancer incidence is largely underreported due to an inadequate National Cancer Registry (National Department of Health, 2017, p. 15). It is highly likely that greater underreporting occurs amongst black individuals as they are less likely to have access to basic services such as health care (Coovadia et al. 2009).

In addition, it is thought that black South African women in particular are presenting to the health care system at an advanced stage (Stage III or IV) of the disease (Maree & Wright, 2010; Vorobiof et al., 2001; Walker et al., 2004), although a lack of available data constrains this statement from being made with certainty. Two relatively large-scale studies (n=1092 and 1051, respectively) (Cubasch et al. 2013; Dickens et al. 2014) found that over 50% of samples of predominantly black women presented at advanced stages; Walker et al., 2004 report rates over 80% (n=57). Moodley et al. (2016) found that the average delay from women noticing change in their bodies to presenting to the health care system for BC was 5.3 months (n=20), though this study failed to delineate the race of the participants. Again, underestimations of advanced presentation are likely as these studies exclude individuals who did not present to the health care system at all. Advanced presentation contributes to higher BC age-standardized mortality rates in SA compared to the world standard (16.5 compared to 12.9 per 100,000 women, respectively) (International Agency for Research on Cancer 2012). This is particularly

devastating given the high survival rate for early diagnosed BC: five-year survival rates for localized (early-diagnosed) BC averages almost 99% whereas distant (advanced) breast cancer averages only 27% [American data] (Howlader et al., 2017). Given the social, financial and structural barriers that black individuals face in accessing care, it is reasonable to assume that this population is presenting at more advanced stages of the disease when compared to other population groups.

Other demographic determinants of advanced presentation in SA have been identified as a low education level, not having health insurance, having no family history of BC, and living in a rural area (Hoffman et al. 2000). As reported by Dickens et al. (2014), it is important to identify context-specific barriers to presentation in SA in order to employ interventions that achieve earlier diagnosis.

### *1.3.1. Awareness, Attitudes & Knowledge of Breast Cancer*

A lack of knowledge of BC signs and symptoms, and misconceptions about causes and treatments are frequently reported as significant barriers to presentation in many SSA populations (Asobayire and Barley 2015; Brinton et al. 2014; Saghir et al. 2011).

The most recently conducted study in South Africa on BC awareness evaluated knowledge and attitudes towards symptoms and treatments among 243 black African women in a rural area in Limpopo (Trupe et al. 2017). Roughly half of the women were able to identify a lump as a symptom of BC. About 40% of women had no knowledge of treatment options, with the most commonly identified treatments being medicine (31.3%) and mastectomy (25.9%); only 1.7% of women were able to identify chemotherapy. The

women were extremely positive about receiving health care for BC, with almost all (>97%) indicating it is important to check your breasts for cancer and to go to a health professional if you notice any changes. Almost 70% indicated that BC is likely survivable with early detection, and half considered it likely that they would get BC in the future. Reasons for not seeking care included not having enough money, long wait times and the perceived poor quality of care at public clinics, a belief that breast pain was not a symptom of BC, and fear of death or having a breast removed, though these reasons were only reported by a small minority of the participants. Only a quarter of the women had previously received a clinical breast examination (CBE), and only a third had previously performed a breast self-examination (BSE). Notably, increased knowledge of BC did not predict whether or not they engaged in BSE. About one third of the women reported knowing someone who had been diagnosed with BC, indicating prevalence rates approaching high-income countries (American Cancer Society 2015). The authors concluded that structural barriers, rather than the cultural influences that are typically reported in SSA populations, are more likely to influence care seeking for BC in SA. They indicated that an early detection program would be likely to gain acceptability in the region (Trupe et al., 2017).

Another recently conducted study with 20 newly diagnosed BC patients in Cape Town (Moodley et al., 2016) found that many women reported no prior knowledge of BC, with a few receiving information from pamphlets, the radio and relatives who had been previously diagnosed. Many of the women did not perceive themselves as being at risk for BC and little was known about BSE; most had noticed the lump accidentally or had

gone to the clinic for an unrelated reason. They reported being uncomfortable feeling their own breasts, a factor that may lead to difficulty promoting BSE. Most mentioned that BC is not something that is openly discussed in the community (Moodley et al., 2016).

Furthermore, a survey conducted in a low SES area in the Western Cape province (n=100), found that stigma, secrecy and misconceptions surround BC, including that it is thought to be induced by trauma and more likely to occur in younger women (Krombein and De Villiers 2006). In contrast to the findings from Moodley et al. (2016), the women were not embarrassed to have their breasts examined by a doctor or to examine their own breasts. The biggest barrier to screening was fear of diagnosis, as diagnosis is seen as a “death sentence” (Krombein and De Villiers, 2006, p.14c), although 82% also indicated that they perceived most cases could be cured. Furthermore, Maree & Wright (2010) report that BC is an issue perceived as being only experienced by the white population.

Despite the conflicting results from these studies, in general it appears that South African women are aware of the importance of early detection of BC and are somewhat positive about seeking health care for BC. Their low level of knowledge of BC symptoms and treatments and their limited use of SBE and CBE provide an immense opportunity for improvement. The contrasting results observed in knowledge and awareness are likely reflective of differences in the sample population, including sampling from different geographical regions, differences in socioeconomic status, or educational attainment.

### *1.3.2. Traditional Healing & Faith-Based Practices*

Utilization of traditional healing (TH) services is another factor commonly implicated in delays in accessing the conventional health care system in other African populations (Asobayire and Barley 2015; Brinton et al. 2014). Decisions about where to seek care are often influenced by cultural factors, past experiences with THs and the healthcare system, as well as patients' social networks (Golooba-Mutebi and Tollman 2007; Stekelenburg et al. 2005).

In SA, traditional healing is based on the belief that the supernatural, spiritual and physical entities are interconnected, and that ancestral spirits protect the living; THs are used to call upon these spirits (Kale, 1995). Since conflict between the spirits is believed to cause human suffering, most THs in SA use divination, purification rituals and various herbal remedies to re-establish balance and peace for the patient (Kale, 1995).

Estimates of the rates of utilization of THs vary quite considerably depending on the source, and there does not appear to be reliable scientific data available. There is a substantial body of literature, however, on the use of THs for HIV/AIDS care. Peltzer & Phaswana-Mafuya (2014) found that roughly half of the 618 Black African Zulu (majority female) patients attending three public hospitals in the KwaZulu-Natal province had used traditional, complementary and alternative remedies in the last six months. Babb et al. (2007) similarly reported rates of 84% and 32% for past and current use of traditional medicine for HIV amongst male clinic attendees, respectively. However, a recent survey of 4,762 households (Nxumalo et al. 2011) found that only 1.2% of South Africans accessed a TH in the last month for all health issues. Importantly, however, there were

slightly higher utilization rates among the populations that appear to be at higher risk for late presentation (Maree & Wright, 2010; Vorobiof et al., 2001; Walker et al., 2004): black South African's were two times more likely to have used a TH, and those of lower socioeconomic status were also more likely to access. Men and women were found to have similar utilization rates (Nxumalo et al. 2011). Furthermore, negative portrayal of THs in SA society may mean that utilization rates are underreported. It is also difficult to determine how usage differs based on specific health issues; the utilization for cancer might be very different than it is for HIV/AIDS, for instance. As indicated by the current study results, the decision to use traditional or conventional medicine for a specific health issue appears to be a complex personal and belief-based decision. In general, the reasons for using a TH include their perceived effectiveness, they provide continuity of care, they offer respectful and non-invasive treatments, they are in close proximity, and they provide greater availability of medicines than the conventional healthcare system (Nxumalo et al. 2011).

In regards to cancer specifically, a qualitative study by Steyn & Muller (2000) (n=30) found that THs believe the causes of cancer to be the result of witchcraft, the ancestors, germs, medication, lack of self-care and having too many sexual partners, as well as smoking, alcohol, and diet. Some felt that nothing could be done to prevent cancer (because survival is based on the ancestors' will), whereas some called for the use of preventative herbal medicines, and many spoke of the importance of health education. In regards to BC, most were aware of it, and could identify a lump as a sign. Traditional treatments for BC included leaves placed on the lump, washing the breast with hot

medicine, and using medicine to clean the blood and reduce pain. The THs had positive attitudes towards conventional surgical treatments for cancer, but felt that chemotherapy did not cure cancer and should only be used alongside traditional medicine. They wished to receive more information and training about cancer in order to refer their patients to the conventional system effectively. The specifically addressed the need for greater collaboration between the two healthcare systems (Steyn & Muller, 2000).

Of additional note is the apparent prominent role of religion in black South Africans' lives. Although religion does not seem to be recorded in any of the statistical releases of the 2011 census, the 2001 census data indicates that almost 80% of black South Africans are affiliated with Christian churches, 1.3% belong to other religions, and 18.8% have no religious affiliation or did not specify (Statistics South Africa, 2004, p. 28). Some South Africans appear to be using faith-healing to resolve their health issues (Peltzer, 1999), although the literature on faith-healing is scant and little appears to be known about the population's utilization rates (Peltzer, 2009). This type of healing diagnoses individuals through divination with the Holy Spirit using techniques involving prayer, holy water, physical restraint, the use of ashes, and confession (Peltzer, 2009). These methods are most commonly used to treat witchcraft/sorcery related conditions, substance abuse, 'lifestyle' diseases such as high blood pressure and diabetes, children's diseases and mental disorders (Peltzer, 1999). Most faith-based healers do not appear to refer individuals to other health professionals, except for chronic illnesses such as cancer (Peltzer, 1999), however it is possible that their practices have changed in the last 20



years. The results of the current study indicate that churches may also play a role in health care by facilitating access through the provision of funds to individuals in need.

### *1.3.3. Political & Historical Factors*

Any analysis of health issues in South Africa would be remiss if it did not include a discussion of the past and present political factors that continue to affect levels of awareness and access to care. Apartheid, the period of time (1948-1994) in which segregation of white and non-white individuals was legalized and institutionalized in SA, denied black individuals their basic human rights in an effort to maintain ‘racial purity’ and secure the privileged position of the white population (Seekings, 2008, p. 3-4). Policies such as the Natives Land Act of 1913 and the Group Areas Act of 1950 forced individuals that were characterized as ‘black’ to relocate to specified areas on the outskirts of cities which were devoid of basic services such as clean water and sewerage treatment/removal (Mahajan, 2014). Furthermore, the Bantu Education Act of 1953 provided black individuals with separate and inferior education, designed ‘in accordance with their opportunities in life’ [Hendrik F. Verwoerd] (Clark and Worger, 2016). In general, the control of information was integral to the apartheid regime, resulting in the need to pass the Promotion of Access to Information Act in 2000, as recommended by civil society and the Truth and Reconciliation Commission (McKinley, 2003). As evidenced even by this literature review, access to information continues to be a problem in South African society, and Pillay (2002) argues that restrictions on access to

information during apartheid could have contributed to the low levels of BC awareness seen today.

In addition, Coovadia et al. (2009) postulate that former apartheid policies have influenced the current gender dynamics and rural health disparities seen in SA. When black South Africans were forced to relocate to specified areas on the periphery of cities, the men would often have to stay apart from their partners and children for work, creating a culture of male labour migration (Coovadia et al., 2009). This is thought to influence current norms regarding relationships and fatherhood in South Africa (Coovadia et al. 2009; Richter, Chikovore, and Makusha 2010). Furthermore, the authors argue that the lack of funding and development that occurred in the ‘black’ areas during this time continues to affect access to health care and contribute to health inequities for this population (Coovadia et al. 2009).

Although SA officially dismantled apartheid and became a democracy in 1994, extreme divides continue to persist between the haves and the have-nots (Morrell, Jewkes, & Lindegger, 2012), divides that are still largely demarcated by race (Mbewe & Woolard, 2016). Wealth inequalities within South Africa are extreme, and have increased in the ten years following the end of apartheid (Coovadia et al. 2009; Lehohla 2008) in part due to macroeconomic policies that attempted to increase growth and reduce governmental debt (Coovadia et al. 2009). Although South Africa is a middle-income country, it is basically both a low- and a high- income country due to the severe inequities that exist (Edge et al. 2014). These inequalities are perhaps one of the most pressing issues that South Africa currently faces, and necessarily contribute to inequalities in health outcomes.

#### *1.3.4. Social & Structural Factors*

The poverty that millions of South Africans experience provides structural barriers to accessing the health care system, which can include health insurance status, socioeconomic status, competing work commitments, and inaccessibility of transportation (Dickens et al., 2014; Hoffman et al., 2000; Maree & Wright, 2010; Moodley et al., 2016). A recent study (Rayne et al., 2016) concluded that fear of treatment was a larger barrier to access than demographics or socioeconomic status, however this study analyzed an urban population in which the costs of transportation may be less likely to pose an issue than in rural populations that live farther away from specialist health centers (Dickens et al. 2014). Additionally, the study found that black women were more likely to be affected by structural barriers such as transportation issues, competing family and work commitments, and being able to afford care (Rayne et al., 2016). Although the authors admit that racial disparities to BC care access exist, they proposed that these race differences were moderated by socioeconomic and educational factors (Rayne et al., 2016).

Dickens et al. (2014) found that those who lived farther away from a hospital were more likely to present at an advanced stage of BC, with a 1.25 increase in risk per 30 km from a health center. Importantly, transportation costs for the poorest quintile represented 10% of their household expenditure, which poses a significant financial barrier to receiving care. Travel to health care centers usually occurred by walking or by public transport in the form of fee-charging mini-buses (Dickens et al., 2014).

A study by Harris et al. (2011) on general health inequities in South Africa found that 20% of the poorest wealth quintiles required health care compared to just 5.6% of the richest. Need for health care, defined as self-reported health status as well as recent injury/illness among household members, was higher among those with a lower level of education. A greater number of black Africans self-reported poor health compared to other groups. Utilization of private health care was highest in the richest quintile, and those without insurance were found to have much lower levels of in-patient care utilization. On average, it took 30.7 minutes to travel to a health facility; travel time was significantly higher for poor residents than wealthy ones (38.2 min and 20.2 min, respectively), and for black South Africans compared to whites (32.5 min and 17.5 min, respectively) (Harris et al., 2014).

In line with this research, the national Breast Cancer Prevention and Control Policy (National Department of Health 2017) in South Africa recognizes that the lack of health infrastructure in rural areas, transportation issues, poor referral systems, inadequately trained health care professionals, and the provision of health material in written English are challenges that specifically affect marginalized populations in South Africa (p. 15).

#### *1.3.5. Gender in South Africa: Norms, Roles & Relations*

Another pertinent factor in reference to health outcomes and health seeking behavior in SA is the influence of gender roles and gender inequality (e.g. Coovadia et al.,

2009; Jewkes, Dunkle, Nduna, & Shai, 2010; Pronyk, Makhubele, Hargreaves, Tollman, & Hausler, 2001).

Within the cultural context of SA, the concept of hegemonic masculinity has been explored particularly with reference to the high levels of normative physical and sexual violence towards women (e.g. Dworkin, Colvin, Hatcher, & Peacock, 2012; Morrell, Jewkes, & Lindegger, 2012). The incidence of violence towards women is distressingly high: in a recent questionnaire study, half of the sample (n=4440) reported being physically violent towards a partner and one third reported raping a woman in their lifetime (Jewkes, Sikweyiya, Morrell, & Dunkle, 2009). Many studies have attempted to define the cultural factors promoting this and use the term ‘hegemonic masculinity’ to refer to idealized versions of masculinity in South Africa that emphasize “control, (un)emotionality, physicality, toughness, competition, success, heterosexuality, and responsibility” (Luyt, 2005, p. 213). The emphasis on male responsibility could have implications for health-seeking behavior regarding BC as males may be perceived as having responsibility over their partner’s care. Mba (2005) argues that authority is tilted heavily towards men in South Africa, and that women are expected to be accepting and submissive; the dominant form of femininity emphasizes compliance and tolerance (Jewkes & Morrell, 2010). Furthermore, Coovadia et al., (2009) point to evidence that indicates “the control of women is a central part of present day constructions of South African masculinity” (p. 821) and that these ideals have been influenced by South Africa’s history of violent racial and gendered discrimination and historical factors influencing the socialization of young boys (Morrell, 1998). Due to extremely high levels

of unemployment, it is suggested that South African males feel particularly frustrated, perceiving that they have lost economic, social and political power in society (Dworkin et al., 2012). This may result in annoyance or anger towards advances in South African women's rights (Dworkin et al., 2012).

It is argued that this culture of masculinity poses health risks to both men and women (Dworkin et al., 2012) and gender-specific barriers are thought to influence health seeking behaviour. There is a relatively large body of evidence looking at rates of HIV, intimate partner violence and masculinities (Dunkle et al., 2006; Dworkin et al., 2012; Jewkes, Dunkle, Nduna, & Shai, 2010). Pronyk et al. (2001) report another example of the health risks of gender inequality in SA, finding that South African women were less likely than men to present to the healthcare system for tuberculosis. The authors postulated that this occurred because of socioeconomic status and cultural factors that constrain women from dealing with their own health needs (Pronyk et al., 2001). Maree & Wright (2010) point to evidence that women's health seeking behavior is influenced by their perception of their worthiness (Chamberlain et al. 2007; Schooley et al. 2009), and argue that this may be influencing their health seeking behavior in regards to BC. They report that the limited social and financial independence of South African women that has resulted from historical patriarchy and religious factors may contribute to this perception of 'unworthiness of care' (Maree & Wright, 2010). The results of their survey with 565 women found that 44.9% believed that they shouldn't be spending money on their own health. Additionally, 20.7% reported needing permission from their husbands or parents before seeking care (Maree & Wright, 2010). Vorobiof et al. (2001) similarly report that

decisions surrounding women's health are made alongside other family members and respected members of the community and that women are not necessarily responsible for making the final decisions regarding their own health.

For these reasons, many studies within the BC literature in SSA argue that male partners and authority figures need to be involved in BC awareness programs (e.g. Ameade, Amalba, Kudjo, Kumah, & Mohammed, 2014; Asobayire & Barley, 2015; Opoku, Benwell, & Yarney, 2012). This argument is supported by the recognition of the importance of male participation in other health issues in SSA; for example, male participation in interventions promoting the prevention of mother-to-child HIV transmission is strongly, negatively correlated to mother-to-child transmission rates (Aluisio et al. 2011). Similarly, Ditekemena et al., (2012) argue for the introduction of interventions specifically targeted at males to increase their participation in maternal and child health services. Male-targeted campaigns for BC may be effective in promoting awareness of the symptoms and severity of the disease, allowing for the facilitation of earlier presentation of women to the healthcare system. In addition, it is necessary to determine the dimensions of influence that male partners and gender dynamics have in women's health seeking behaviour in regards to BC, as this will inform efforts to promote earlier diagnosis.

#### *1.3.6. Current Policy & Public Health Initiatives*

Health care in SA is provided through a mix of public and private health providers. The private sector expanded rapidly in the late 1980s and early 90s in response

to government policies of privatization, which were influenced by international trends and the perceived quality of care of the public system (Coovadia et al. 2009). Patients accessing public facilities for BC are more likely to be black, single and living with others, less likely to be employed, and have a lower educational level than those accessing private facilities (Rayne et al., 2016). In 2016, only 10.4% of black South Africans were covered by medical aid (private health insurance) compared to 71.3% of white South Africans (Statistics South Africa, 2017, p. 25). Although this equates to only 17.4% of the total population having coverage (Statistics South Africa, 2017, p. 24), the private sector accounts for just over half of the total health expenditure (The World Bank, 2014).

In an effort to reduce the divide between the public and private health system, SA is in the process of implementing a new National Health Insurance (NHI) plan that seeks to reduce the number of private medical schemes; private health insurance will only be used to cover services that are not covered by the NHI (National Department of Health, 2015; National Health Insurance South Africa [NHI SA], n.d.). The NHI has been put in place specifically to address the racial inequities in access to high quality health care and to unify the previously fragmented healthcare system (Naidoo 2012). The principles guiding the plan are: right to access, financial risk protection, effectiveness, equity, affordability, and efficiency (Naidoo 2012). The government is implementing the NHI in stages, with full implementation scheduled for 2025 (NHI SA, n.d.)

Alongside the implementation of the NHI, the National Department of Health has



recently released a revised policy on BC prevention and control (National Department of Health, 2017). This was done in response to local advocacy efforts and the identification of breast and cervical cancer as ‘National Priorities’ in South Africa due to their increasing incidence (p. 4). The specific objectives of the new policy are to improve early detection, promote awareness, improve referral pathways, set standards of care, and evaluate the outcomes of breast health interventions (p. 17). The standards of care that have been set include that all women over 40 years of age who are attending a primary health clinic will undergo a CBE twice a year. In addition, printed breast health education materials will be provided at all clinics, and all female clinic attendees will be taught BSE techniques. Health workers will be advising any women who experience a change in their breast to report to a health facility immediately (p. 25). In order to facilitate these standards, the policy stipulates that primary health care professionals will need training and education on breast health (p. 45). Transport will also need to be available to patients to reach the referral facility (p. 45). Mammography was deemed to be too resource-intensive as a BC strategy in SA, and will only be performed on high-risk patients (p. 28). Referred patients will be diagnosed at a specialist breast unit, and receive counselling and management options; these patients will access provincial oncology units to receive chemotherapy and radiation services. Those with a confirmed BC diagnosis should receive treatment within 31 days, and a nurse or patient navigator will be assigned to assist the patient throughout the process (p. 61). Statistics about the number and characteristics of cases, including stage at diagnosis, will be recorded to improve the available data on the national burden of BC (National Department of Health, 2017, p. 92).

The policy could be further developed in terms of strategies for public health messaging and awareness efforts. Although this is addressed as a ‘Key Area’, and the policy recognizes that educational campaigns are a “crucial initial step” and “can be implemented at low or minimal cost” (National Department of Health, 2017, p. 93), the community engagement strategy appears to be almost ‘tossed in’ at the end of the policy document, and the majority of the responsibility is placed on civil society organizations to develop and disseminate information about BC to communities. There is a lack of a clear approach in public health messaging, demonstrated by vague action items such as “awareness can be promoted by education via videos, posters and pamphlets” (p. 94) and “when there is a similar environment, social fabric and belief system, cancer education has been more effective” (p. 95). There is recognition that qualitative research is required in order to identify community information sources and beliefs, and to appropriately educate communities about the disease (National Department of Health, 2017, p. 94).

#### *1.3.7. The Role of Civil Society in Breast Cancer Care*

As evidenced by the reliance on civil society for community engagement on BC in SA (National Department of Health, 2017, p. 93), civil society is integral to the BC prevention and control strategy in countries of all income levels, specifically in regards to increasing public awareness, advocating and shaping public policy, and providing services that the government does not address (Azenha et al. 2011). As argued by Azenha et al. (2011), civil society also “politicizes the personal breast cancer experience to drive system change” (p. 86), creating the political will to improve BC detection and treatment.

In SA, there is a relatively well-established civil society for cancer control and advocacy. The Cancer Alliance forms the umbrella for cancer civil society; their ‘National Call to Action’ argues for the need for cancer to be a national priority, to develop a national cancer control plan, and to improve cancer registries (Cancer Alliance South Africa n.d.). Launched in 2014, Advocates for Breast Cancer (ABC) represents the collective of BC organizations that have been lobbying the government for the development of a sustainable BC policy (Advocates For Breast Cancer (ABC), n.d.), which eventually led to the release of the aforementioned policy. The policy was also highly informed by the input from the Breast Interest Group of Southern Africa (BIGOSA), a group of clinicians that formulated the BC policy for the KwaZulu-Natal province (National Department of Health, 2017, p. 5). ABC is now turning its attention to lobbying for what it perceives are the gaps in the current policy: community awareness, access to CBEs and essential medicines, supportive and palliative care, and lymphedema and prosthetic services (Advocates For Breast Cancer n.d.).

As described by Azenha et al. (2011), BC civil society in low- and lower-middle income countries tends to focus on the provision of essential services, raising awareness of the disease, and utilization of a peer-support model in which survivors provide emotional support to those recently diagnosed. Higher-middle income countries address structural barriers to care and emphasize early detection coupled with the provision of breast examination and mammography services (Azenha et al. 2011). South African civil society appears to represent a mixture of these services, and will continue to play an important role in making BC a priority health issue in SA in the future.

## **1.4 SUMMARY & STUDY OBJECTIVES**

### *1.4.1. Summary of the Literature*

There are a number of interacting factors that influence the experience of BC in SA. Black women in SA appear to be presenting at more advanced stages of the disease, likely because of the social, structural and historical factors influencing their ability to access and receive care. These barriers include a lack of knowledge and awareness of the disease, inaccessibility to clinics due to financial and transportation issues, and possible cultural beliefs in traditional healing. Yet, SA is in the process of changing the national health care system in an attempt to remove some of these barriers. The release of the recent BC control strategy demonstrates a recognition of BC as a priority health issue in SA (National Department of Health, 2017, p. 4). There is a demonstrated need to study the perceptions and knowledge of BC that currently exist within SA, in order to develop strategies to provide education and promote earlier diagnosis. Given the apparent lack of agency that women possess in the patriarchal society of SA, there is a specific need to identify the perceptions and knowledge that black South African male partners have towards BC and how conceptualizations of gender norms and relations may influence their partner's health seeking behaviours.

### *1.4.2. Study Objectives*

Therefore, the objectives of this study are:

- 1) To determine the perceptions and knowledge that black South African male

partners hold towards BC symptoms, risk factors, causes, treatments, and self-examination, and

- 2) explore the role that men have in their partner's access to health care in a resource-deprived community.

Moodley et al. (2016) have identified that there is a gap in research knowledge about the process that South African women follow to reach a BC diagnosis, calling for a need for research that informs interventions attempting to promote earlier presentation. Since most research in in this area focuses on the perceptions that women hold of BC, this study may offer valuable insight into the perceptions of men and the role of household dynamics in the understanding of BC. This approach follows a line of research and interventions in SA that seek to examine and involve men in gendered issues (Morrell et al., 2012). In line with this, the study also holds value in applying a gendered lens to both health seeking behaviour and chronic illness in SA, which could be useful in analyzing inequities in health outcomes for other illnesses in South Africa.

## **CHAPTER 2: METHODOLOGY**

### **2.1 INTRODUCTION**

This interpretive qualitative study, guided by the theoretical framework of hegemonic masculinity(ies), provides a case-study of the perceptions and knowledge of BC and conceptualizations of gender relations in regards to health care that are exhibited by a specific population: black men in long-term heterosexual relationships living in Diepsloot, northern Johannesburg. Data was obtained through face-to-face, in-depth, semi-structured interviews with the men. Thematic analysis was conducted on the interview data using NVivo 11 qualitative data analysis software (QSR International, 2015) and the resulting themes were informed by interactions with local breast cancer organizations. Although some limitations to the study are noted, measures were taken to mitigate the effects of these limitations whenever possible.

### **2.2 THEORETICAL FRAMEWORK**

As described by Merriam (2009), a theoretical framework is the “concepts, terms, definitions, models and theories of a particular literature base and disciplinary orientation” (p. 67) that forms the “structure, the scaffolding, the frame of your study” (p. 66). Those that are proponents of the use of theoretical frameworks in qualitative research argue that it is impossible to conduct a study without prior beliefs, propositions and theoretical conceptions (Anfara & Mertz, 2006, p. xxv). Theoretical frameworks provide different ways to ‘see’ the phenomenon being studied, illuminating some aspects while necessarily concealing others (p. xxviii). It is important to acknowledge and explicitly

make clear the theory and assumptions that guide the research to maintain transparency for the reader (Bordage, 2009).

The theoretical framework guiding this study is the concept of hegemonic masculinity(ies) described in Section 1.3.7. Originally proposed by Connell (1995; 1987), the concept argues that multiple forms of masculinity exist in a society, one of which is hegemonic. This hegemonic masculinity is dominant not due to the sheer number of individuals who embody it but because it serves to oppress other forms of masculinity; it represents how a ‘real man’ should behave according to the cultural ideal (Connell & Messerschmidt, 2005). This particular form of masculinity is produced and fortified by the state, schools, churches, and is thought to be reinforced through the threat of violence (Morrell, 1998). However, it is also fluid and is continuously being contested by other forms of masculinity; therefore, it has the capacity to change over time (Connell & Messerschmidt, 2005). The concept is useful because it encapsulates the idea that not all men receive the same benefits from a patriarchal society, as groups of men can also be “victims of the gendered order of society on, for example, grounds of race, sexual orientation, and poverty” (Morrell, 1998, p. 3). In the South African context, it has been proposed that three forms of hegemonic masculinity exist: white masculinity, African masculinity, and black masculinity (Morrell et al., 2012). White masculinity is said to have been produced by the dominant social position of the white population, African masculinity is thought to originate from customary hierarchies and black masculinity through the creation of urban African townships (1994, 1998, 2001; Morrell et al., 2012). Scholars postulate that black masculinity, which is of importance to this study, is based on

the control of women as an indicator of success in the context of poverty (Boonzaier, 2005; Coovadia et al., 2009; Jewkes et al., 2010). It is argued that black men's inability to fulfill gender roles that are based on the accumulation of wealth and provision for the family predicates harmful activities including alcohol use, risky sexual behaviours, and violence against women, which are used to assert control (Boonzaier, 2005; Coovadia et al., 2009; Jewkes et al., 2010).

The body of work on hegemonic masculinities in SA, although much more extensive than this summary allows, informed the current research questions regarding the role of the male partner in women's access to health care, and served to guide the analysis of themes specific to gender. A discussion of how the study findings align to this theoretical concept is presented in Section 4.2.

## **2.3 STUDY DESIGN**

As indicated, this is an interpretive qualitative case study. As one of the most common types of qualitative studies, interpretive studies seek to uncover the meanings that are constructed by individuals interacting in their worlds (Merriam 2009). As described by Merriam (2009), the “the overall purpose [of an interpretive study] is to *understand* how people make sense of their lives and their experiences [emphasis is the author's]” (p. 23). Furthermore, if the unit of analysis of an interpretive study is considered a ‘bounded system’, then the study constitutes a case study (Merriam, 2009). A bounded system refers to an entity or population that has clear boundaries defining it, and is usually studied because it is intrinsically interesting or can lead to a better understanding of a particular issue (Merriam, 2009).



The current study studies a specific population of black South African men in long-term heterosexual relationships. This was done in order to examine how gender relations influence access to health care in a population in which these gender relations and household dynamics have already been firmly established. However, these men represent a unique population because over 40% of South African households are female-headed (Statistics South Africa, 2016, p. 58), almost 67% of black South African children do not live with their biological fathers (Statistics South Africa, 2012, p. 27), and rates of marriage are low (Hosegood, McGrath, and Moultrie 2009); therefore, it is relatively uncommon for cohabitation between male and female married or unmarried partners to occur for extended periods of time (Hosegood, McGrath, and Moultrie 2009). Furthermore, the results that are described in Section 3.2 reflect differing views towards gender relations than would have been expected given the aforementioned work on hegemonic forms of masculinity in SA, which may be reflective of the characteristics of men in these committed relationships. However, studying this specific population helps foster alternative conceptualizations of black South African males that defy literature and media representations that focus on these men as absent fathers, dominating men, and perpetrators of violence (e.g. Britton, 2006; eNEWS Channel Africa, 2013; Harding, 2013; Jewkes et al., 2010). Therefore, this case study can be considered ‘instrumental’, in that it affords the “redraw[ing of] a generalization... [and] facilitates our understanding of something else” (Stake, 2005, p. 437). In a similar fashion, Sideris (2004) interviewed a group of South African men who openly reject violence against women and children in

order to learn how and why they reject the harmful gender norms that have such a strong presence in their community.

To explore the understandings of the population group in the current study, in-depth, face-to-face, semi-structured interviews were conducted with men (n=20) living in the township of Diepsloot. Since little appears to be known about this population's understanding of BC, quantitative research in the form of a survey or questionnaire was deemed implausible due to the lack of a 'starting point' in which to assess knowledge and perceptions, and the difficulty it posed to examining gender relations. A survey or questionnaire would also exclude the emergence of unidentified factors that could only be determined through the elaboration of responses. Semi-structured interviews were deemed the most effective qualitative method, as it allowed specific research questions to be targeted while simultaneously affording the emergence of new themes. These were conducted on an individual basis due to the high likelihood of a group setting significantly affecting the responses received. An iterative approach to the interviews was used, such that the interview guide was adapted as new questions and themes arose throughout the data collection process. An important example of the benefits of this iterative approach occurred as it became clear that some of the participants had little knowledge of cancer in general, and therefore the interviews were also used to explore their thoughts on cancer, while maintaining a focus on BC.

An important aspect of case studies is the use of multiple sources of information to develop an understanding of the issue (Creswell, 2007, p. 73). In the current study, the results were informed by volunteer opportunities that the investigator engaged in with

local BC organizations. This was done in order to provide a more comprehensive perspective on BC care in SA, to validate the themes that emerged from the interview data, and to engage in knowledge translation efforts after the completion of the study.

Throughout the development of the study, prior to and during data collection, the researcher reflected on her own biases regarding the experience of breast cancer, health care, and gender norms, roles and relations. This reflects the concept of reflexivity, in which the researcher “is conscious of the biases, values, and experiences that he or she brings to a qualitative research study” (Creswell, 2007, p. 243) and recognizes that the resulting interpretation is the product of his or her own cultural, social, gender, class and personal politics (p. 179). Of particular note is the researcher’s experiences with BC in her family, as both her mother and aunt are survivors of BC. Their experiences with BC are characterized by having the knowledge to recognize the symptoms in their own bodies, receiving high-quality treatment and care in Canada, and living in a country where BC receives significantly more attention and less stigmatization than it does in SA. In terms of their relationships, differing roles were played by the male partners in regards to the experience of BC. In one case, her partner advocated for her to receive earlier treatment, whereas in the other, her partner left her after the diagnosis. In addition to this, the researcher’s own perceptions of gender roles, norms and relations are the product of living in Canada, a very different cultural context than SA. The researcher attempted to recognize these biases and suspend them as much as possible during data collection and analysis.

## **2.4 STUDY SITE**

Describing the setting of a case study is important in order to contextualize the findings (Creswell, 2007, p. 76); therefore, Section 2.4 and 2.5 provide detailed descriptions of the study site and participants, respectively.

The study site is Diepsloot, a peri-urban township located 50 km north of Johannesburg city center (Gauteng province). The word ‘township’ refers to urban areas of SA that were created during apartheid in order to segregate ‘non-white’ individuals (Mahajan, 2014). Post-apartheid, townships are inhabited predominantly by black individuals, reflect varying levels of poverty, and often do not have adequate access to services such as sewage, water and electricity (Mahajan, 2014). Although exact population data do not exist, estimates indicate that between 250,000 – 500,000 individuals live in Diepsloot, in 13 ‘extensions’ (Figure 1) (Sonke Gender Justice, personal communication, February 10, 2017). The township is located near a wealthy, predominantly white-inhabited area known as Fourways; this is representative of the extreme inequality seen throughout South Africa. Most residents of Diepsloot live in government-subsidized housing and informal shacks. Protests over the lack of services in Diepsloot are common, one of which briefly interrupted data collection for this study. The residents include a mixture of South Africans and migrants from other countries (commonly Zimbabwe), and it is estimated that around 50% of the population is unemployed. The township is known for high levels of crime, rape, and violence (Bearak 2009; Malan 2016). There are two public health clinics servicing the entire area, and these exist in Extension 2 and Extension 7. The nearest public hospitals are Tembisa Hospital

and the Helen Joseph Hospital, which are located 30 and 35 kilometers away, respectively. The nearest private hospital, Life Fourways Hospital, is 14 kilometers away. Transportation occurs mainly through walking and a system of fee-paying mini buses which is common in SA.

Diepsloot was selected as the study site due to its accessibility from Johannesburg as well as the partnership with a local organization that has an established presence in the community (see Section 2.6). In addition, the residents of Diepsloot experience significant structural and financial barriers to accessing health care, which may cause them to present later to the health care system than other individuals. Finally, there has been a clearly identified problem of gender-based violence in Diepsloot (Malan 2016), indicating the presence of traditional gender norms regarding the control of women. Therefore, it seems pertinent to explore how gender roles and norms affect access to health care in this community.

## **2.5 PARTICIPANTS**

The study population consists of black men between the ages of 25-55 years old. The selection of specifically black individuals occurred because of literature indicating that black women in SA are more likely to present late to the health care system for BC than white women (Maree & Wright, 2010; Vorobiof et al., 2001; Walker et al., 2004). The criteria for inclusion in the case study stipulated that men must have been living with their current female partner for a period of at least two years and were sufficiently proficient and comfortable in speaking English to complete the interview. The exclusion

criteria disallowed participation from men whose partners had previously been diagnosed with BC, as this likely will have affected their level of knowledge and perceptions regarding BC.

In the current study, the median age of participants was 41 years old. The study sample represented a mixture of individuals from 9 different African cultural/linguistic groups in Southern Africa: Sotho, Tswana, Sepedi, Venda, Tsonga, Xhosa, Shona, Zulu, and Ndebele. The majority of the participants considered themselves to be religious, and represented a mixture of Christian, Zion, Apostolic, Lutheran, and traditional cultural belief systems. Less than half had completed ‘matric’ (graduated from secondary school) or pursued higher education. Only four of the participants were formally employed, and thirteen of their partners were. Most received income through a mixture of piece work, selling small items, social grants, or assistance from family members. The median combined monthly income of the participant and their partner was 4500 Rand, the equivalent of about \$335 USD. All except one participant were married or engaged, and had been with their partner for nearly thirteen years. About half of the participants used the public clinics in Diepsloot; participants could walk or use a minibus depending on their physical condition and which extension they live in. Transportation to the public clinic cost an average of 14 Rand (\$1 USD) round trip. The other half either used private clinics or a mixture of public and private services. The private clinics attended were in Witkoppen and Randburg, 10 km and 30 km away from Diepsloot, respectively. Transportation to private clinics cost an average of 30 rand (\$2.2 USD), or was sometimes provided by the clinic. The consultation fee at the private clinics ranged from

30-280 Rand (\$2.2-20.7 USD). The total costs of transportation and consultation fees at private clinics represent roughly 1-7% of the median combined monthly income of the participant and his partner per visit. Only four participants indicated that they currently or have recently used a TH. THs were deemed to be very accessible, with participants indicating they are located on almost every street in Diepsloot. The participants reported that prices for TH services can vary quite considerably, from free to 10,000 Rand (\$739 USD) depending on the healer and health condition. Only two participants had medical aid (health insurance), and two did not but indicated that their partner did. Four of the participants were affiliated with the organization Sonke Gender Justice, which was used to recruit individuals to the study. Two had participated in Sonke events before, and fourteen had no experience with Sonke. Appendix A provides a summary of this demographic information.

## **2.6 RECRUITMENT**

Participants (n=20) were recruited through a partnership with Sonke Gender Justice, a non-profit organization in Southern Africa. Sonke focuses on issues of gender equality, preventing domestic and sexual violence, and HIV/AIDS, and specifically believes in the importance of including men in efforts to improve gender equality (Sonke Gender Justice n.d.). In Diepsloot, the organization is currently conducting the CHANGE trial, which seeks to refine the ‘One Man Can’ gender-transformative program through the inclusion of community mobilization (Sonke Gender Justice and Wits Department of Health, 2015). This involves the addition of Community Action Teams (CAT), which are comprised of residents of Diepsloot who engage in various community mobilization and

advocacy activities related to reducing gender-based violence through addressing harmful forms of masculinity. Due to the similarities between the principles of the organization and the current study, as well as the organization's prior engagement with the community, a partnership with Sonke was formed in order to recruit and interview participants. An initial convenience sample of the CAT members was recruited and snowball sampling was used to recruit the rest of the participants. The CATs were asked to refer on other men in their community that might be interested in participating, who then referred on others, and so forth. In this way, it was possible to recruit a diverse demographic of men within the specific population group being studied.

## **2.7 DATA COLLECTION**

### *2.7.1. Semi-Structured Interviews*

Data collection occurred during the period of June – July 2017. Interviews were conducted in English; other languages were not used due to the significant costs and impracticalities of hiring a translator to assist with the interviews.

The interviews took between 20-60 minutes and were conducted at the Sonke office. The interviews were conducted in a private room with only the researcher and the participant present. This maintained the confidentiality of the participants as much as possible and reduced the chances of their answers being influenced by other individuals in the room. The room was located in the office near many of Sonke's staff members, ensuring the safety of the researcher and the participant.

Due to the differences that existed between the researcher's own culture, skin colour, gender and age, and those of the participants, special consideration was taken to



ensure that the interview environment was one in which the participant felt they could express themselves as comfortably and as accurately as possible. Measures to build rapport included spending time to chat with the participant before the interview, thoroughly reading through the Information Form (Appendix B) with them, providing them with refreshments, reminding them that not knowing the answer to a question is okay, and asking sensitive questions in a respectful manner. If a participant did not understand a question, the question was rephrased in several ways. If they still did not understand, the question was dropped. The researcher altered the questions slightly depending on the participant's proficiency in English.

Prior to the start of the interview, the participants completed an Oral Demographic Form (Appendix E), which asked them relevant questions about their age, religion, employment, income, and access to health care. Questions were also asked regarding their partner in these domains. The demographic form was delivered orally in case some of the participants were not literate. The oral format also allowed participants to expand on more complex questions such as their ability to afford health care. The answers they gave contributed to the themes that are presented in Section 3.2.

The interview guide (Appendix F) that was used was developed from the focused literature review and was structured in three parts in order to address the aforementioned research questions. The first part was introductory and asked the participants questions about themselves, their family, their hobbies, and their relationship with their partner. The second part focused on their thoughts on cancer and more specifically, BC. The final part focused on their role in their partner's health care. The interview was primarily directed

by the researcher, however space and opportunity were given to participants to delve into new topic areas and probes were used to encourage elaboration of their responses, which the participants typically did. This process allowed for new themes to emerge and adaptations to the interview guide to be made throughout the interview process. After 20 interviews had been collected, it was believed that saturation, the point at which ‘no new or pertinent information emerg[es]’, had been reached (Aurini, Heath, & Howells, 2016, p. 152).

The researcher kept a research journal throughout the data collection process in order to reflect on the experience, what was learned, and to continuously review her own biases, a strategy recommended by Gale, Heath, Cameron, Rashid, & Redwood (2013).

#### *2.7.2. Volunteer Opportunities*

As mentioned, the results of this study were also informally shaped by the investigator’s interactions with local breast cancer organizations, which took place through various volunteering opportunities. Broadly, these opportunities included a breast cancer awareness outreach in four different townships, as well as time spent at a local breast clinic. The specifics of these interactions have been removed from the thesis (edited in September 2019) in order to protect the confidentiality of the individuals involved. A summary of the edits made to this thesis in September 2019 are provided in Appendix M.

## **2.8 DATA ANALYSIS**

The oral demographic information and interviews were recorded on an audio-recording device with the express written permission of participants. The audio was then transcribed verbatim by the investigator. To analyze, the researcher conducted three cycles of coding, as per the strategy outlined by Aurini et al. (2016). The first cycle of coding, ‘pre-coding’, included the highlighting of key passages, adding of memos, and the development and assignment of preliminary codes. These preliminary codes were guided by the study’s research questions as well as information that had emerged throughout the interviews, reflecting both a deductive and inductive approach to coding (Harding, 2013, p. 129). Before the next cycles of coding took place, the researcher read through the transcripts fully two times in order to obtain an overall impression of the data.

The next cycles of coding (‘First Cycle’ and ‘Second Cycle’) were conducted in NVivo for Mac, Version 11.4.1 (QSR International, 2015). The researcher went through the data again and assigned codes to chunks of the data, looking for data that fit the preliminary codes as well as assessing for the emergence of new codes. The coding process involved some ‘frequency coding’ (Aurini et al., 2016), which refers to counting how many times an event, word, or phrase is expressed, and was useful for coding items such as the identification of smoking as a risk factor for cancer. In addition to coding the relevant phrases, this process was enhanced through the use of ‘Text Search’ and ‘Word Frequency’ queries in NVivo. As the coding process continued, the codes were refined, condensed and integrated into ‘Categories’ through hierarchical structuring. These were

then arranged into six different ‘Themes’, which are ‘big ideas’ that are generated from the data (Aurini, Heath, and Howells, 2016).

After the completion of coding, the interview transcripts were read fully through one more time in order to ensure that the themes, categories, and codes that had been established reflected the participants’ own views, a strategy recommended by Harding (2013, p. 171) to improve the validity of the data. Triangulation of data sources, which involves using multiple sources of information to enhance the credibility of the data (Aurini et al., 2016, p. 52) was also used through comparing the emerging themes to insights gained while volunteering with the breast cancer organizations.

## **2.9 ETHICAL CONSIDERATIONS**

The study was approved by the Hamilton Integrated Research Ethics Board (HIREB) and the Human Research Ethics Committee (Medical) at the University of the Witwatersrand in Johannesburg.

### *Recruitment & Consent*

During recruitment, the primary investigator was given the phone numbers of the participants who had expressed interest in the study to their referring community member. The primary investigator called the potential participant and explained the nature of the study, the risks, rewards and practicalities using a pre-approved telephone recruitment script. If the individual expressed interest in participating, a mutually-beneficial date and time was set up for the interview to take place at the Sonke Gender Justice Office in Diepsloot. At this time, the study was reviewed in full with the participants by explaining

the Information Form (Appendix B) orally to them. If they indicated consent to participate, they then signed the general Consent Form (Appendix C) as well as the Consent to Audio Recording (Appendix D), and the interview commenced.

### *Debrief*

After the interview was complete, participants were provided with information about BC by the researcher. The researcher delivered an overview of the symptoms, causes, treatments and risk factors for BC and responded to the participant's questions. The participants were then provided with informational material on BC and BSE (Appendix H) as well as prostate and testicular cancer. The information also included the telephone support number of a local breast cancer organization, which participants were encouraged to use if they had further questions or concerns about cancer. This material had been given to the researcher by local BC organizations.

### *Risks*

The risks to participants in this study included the potential to experience psychological distress when talking about a serious health issue such as BC and the health of their partner. To minimize these risks, the participant was informed about their rights to not answer questions they do not wish to answer and to withdraw from the study at any point during the interview. The participants were also provided with the contact information for Lifeline Johannesburg, a free telephone counselling service that operates 24/7 (LifeLine Johannesburg n.d.). Other risks include the possibility of stigmatization

due to the fact that BC is stigmatized in some areas of SA (Moodley et al., 2016; Krombein et al., 2006). This was mitigated by maintaining the participant's confidentiality in participating in the study as much as possible.

### *Confidentiality*

In an effort to ensure confidentiality as much as possible, the participants' data was de-identified and they were assigned a pseudonym. The de-identified and identifiable information were kept in separate encrypted folders on the researcher's computer, password-protected hard drive and iCloud account. The recordings were permanently deleted off of the recording device.

The data will be kept for a period of two years (or six years if no publication ensues), after which it will be permanently deleted. The hard copies of the consent forms will be shredded and discarded.

### *Access to Study Results*

Participants were given the option to receive a summary of the study results (Appendix I) either by email or by mail delivery to their residence. They were encouraged to contact the researcher with further questions by telephone until the end of the data collection period, and by email thereafter. In total, fifteen participants requested access to the study results, however it was not clear if the participants realized that they did not have to provide contact information if they did not wish to receive the results.

## **2.10 LIMITATIONS OF METHODOLOGY**

### *2.10.1. Potential for bias*

As with all interviews, there is the potential for response bias to influence the results. In the current study, the potential role of social desirability bias should be recognized; this type of bias refers to participants giving responses that are deemed as socially acceptable even if it does not represent their true beliefs (Krumpal 2013). This bias may be present due to the sensitivity of the research topics (BC and gender relations) as well as the differences in gender, age, skin colour, and culture of the researcher and the participants. Furthermore, the interviews were conducted at the Sonke Gender Justice office, which may have influenced the participants to provide more ‘gender-equitable’ responses. In order to mitigate this, participants were asked to be honest and assured that no judgement would be taken on anything they expressed. They were also explicitly explained the measures taken to maintain their confidentiality. As previously noted, the researcher also took multiple measures to ensure that a comfortable atmosphere was created and to reduce any potential power dynamic between the participant and the researcher.

Sampling or selection bias, which refers to certain subgroups in the target population being unrepresented (Krumpal 2013), also has the potential to influence the results of the current study. Since the interviews were conducted in English, this excluded those who do not speak English and may have biased the sample towards a more highly educated demographic. Furthermore, a relatively high reimbursement rate relative to the participants income level was offered (150 Rand, or \$11 USD), which may have

influenced their participation. The fact that the interviews were conducted primarily during weekdays may have also influenced the sample to include men who were unemployed and looking for extra income. More importantly, the inclusion of Sonke members could have biased the results in that men associated with Sonke are more likely to embody the gender-equitable forms of masculinity that are advocated by the organization, and are also more likely to demonstrate a sense of responsibility to their community. Efforts were taken to ensure that the sample contained a relatively small amount Sonke-affiliated participants and reflected a diverse group of men in terms of ethnicity, education level, employment status, religion, and age.

This latter point speaks to one of the major concerns of case study research: the issue of generalizability (Merriam 2009). Can the findings of this study be applied when thinking about black South African males in other communities, those that are not in long-term relationships, or in the context of a different health issue? Proponents of case study research argue that much can be gained from analyzing a specific case (Merriam 2009). As universals do not exist in human issues (Flyvbjerg 2006) and general truths can be found in specific situations (Erickson 1986), findings from a specific case can be applied to similar situations or used to guide further research. Case studies are further criticized for their lack of representativeness and inclusion of bias based on the subjectivity of the researcher; case study researchers argue that the purpose of case studies is to account for difference rather than eliminate it, and therefore issues of rigour that are applied to quantitative studies do not necessarily apply to case studies (Merriam 2009).



Finally, the analysis and presentation of the data has the potential to be influenced by the researcher's own personal biases. The researcher attempted to mitigate this as much as possible by being reflexive in her own recording of the data.

#### *2.10.2. Validity & reliability of qualitative data*

There is much debate in the literature regarding the terms and criteria for establishing validity and reliability in qualitative research (Morse et al. 2002). Validity in general refers to whether or not the findings accurately reflect reality, although it should be noted that reality is constructed and thus qualitative research should attempt to accurately reflect how participants view the world (Merriam 2009). If there were no practical and financial constraints on the study, the validity of the results could have been enhanced through 'member checking', which involves reviewing the results of the analysis with participants so that they can judge their accuracy (Creswell, 2007, p. 208). In this study, validity was established through triangulation, negative case analysis (reporting cases that do not fit with the established codes), and clarifying researcher bias (p. 251-52).

Reliability generally refers to the consistency or replicability of the results (Merriam 2009). Reliability would have been enhanced in this study by employing multiple independent coders and determining if there is intercoder agreement (Creswell, 2007, p. 210). Despite these limitations, it is suggested that the study design is sound enough to offer useful insights into the understanding of breast cancer in South Africa.

## **CHAPTER 3: RESULTS**

### **3.1 INTRODUCTION**

In this section, the six major themes that emerged from the semi-structured interviews will be discussed. Following this, a summary of the insights gained through volunteering opportunities with local breast cancer organizations is provided.

### **3.2 FINDINGS**

#### *3.2.1. Interview Data*

The six major themes that have been established are: Knowledge of (Breast) Cancer, Perceptions of Cancer, Cancer Education, Access to Health Care, Gender Roles & Relations, and Responsibility to Community. Please see Appendix G for a summary of these themes and their related categories and codes.

#### *Knowledge of (Breast) Cancer*

The theme Knowledge of (Breast) Cancer explores the participant's knowledge and understanding of the different types of cancer, as well as the causes, risk factors, symptoms, and treatments of cancer. There is a specific focus on breast cancer and BSE.

In general, participants often admitted that they knew very little about cancer, and even less about BC. When asked about cancer, many participants would answer "...I don't know what, what kind of that sick of cancer." [Kyle] or offer non-specific descriptions such as:

...to me it will be a little bit, difficult, difficult question to answer...cancer just like any other disease can affect, a person can just find themselves have that cancer, just like another disease [Bonani].

Overall, the spectrum of knowledge of cancer ranged from very little knowledge to a moderate understanding of BC and cancer in general.

The most commonly identified types of cancer were lung cancer (mentioned by six participants) and blood cancer (3). The majority of participants identified smoking (13) and drinking too much alcohol (10) as risk factors for cancer. Participants also identified a history of cancer in the family (9), and eating unhealthy foods (7) such as sugar, fatty foods, and meat. Being overweight (3), a lack of exercise (3), and stress (2) were mentioned to a lesser extent. In terms of gender, two participants thought men could also acquire BC, five thought it occurred mainly in women but that men could potentially experience it, three indicated men could not get BC, and ten were not sure or did not specify.

Many participants indicated that they either did not know the cause of (breast) cancer, or believed that it is “...something that can just grow...on you.” (it does not have a specific cause) [Nick]. Two participants reported that putting money, coins, cell phones, and lip balm containers in your bra could cause BC to develop; one mentioned that he learned this from television. The concern about a lip balm container was due to the perception that putting steel (container) close to your skin could cause cancer. One participant indicated that using bath soaps or deodorant that your body was not familiar with could give you cancer, and another participant thought that cancer was caused by “a shortage of some...enzymes or something inside the blood.” and that it is “generate[d] deep in your blood plasmas.” [Bonani]. One participant reported that cancer can be caused by not receiving treatment for multiple diseases: “Because if you don’t take it off

[receive treatment]...maybe four or three diseases in the same place, they can cause cancer” [Thuso].

A lump was identified by nine participants as a sign or symptom of BC. Two of the participants further described this as a phenomenon where “some blood can’t flow so maybe some of the blood stay[s] at certain place[s] until they make something like a clot” [Matsimela], and another as “sometimes you can feel like a bruise under your breast” [Rapula]. Participants (4) also mentioned pain in the breast as a symptom, as well as the breast feeling itchy. As described by Jacob: “could be a pain or the itching... of something from the inside, where you can’t feel it with your hands. That thing is inside. Yeah, that’s how, how I think it’s come.”

Participants had very little knowledge of any of the treatments used for cancer, with eleven participants indicating that they did not know any treatment options. Seven participants reported that the breast (or other affected body part) could be removed, and that this is usually the last option available:

...cuz they say when it’s badly infected now, there’s no option of curing that breast, now it will be cut off. That’s the only option they have to use to save your life. [Sicelo]

Three participants were able to identify chemotherapy as a treatment option, but did not describe it in detail.

When asked if they knew if their partner ever checked herself for BC (completed BSE), four indicated that she had, four reported that she did not, and twelve were unsure or did not specify. One reported encouraging her to do so: “I always tell her to examine her breasts to see if there’s a lump or something that’s different... she says ‘Ah, I

normally do that every morning.” [Sicelo]. The others indicated their partner completed BSE monthly (2) or twice every 3 months (1). Two reported that she learned how to complete BSE from television programs, and one had learned from attending a workshop in the community about cancer. A few participants thought it was important that she does complete BSE, indicating “but I think it’s important to go and check it.” [Bonani]. Finally, two participants thought their partners were checked for all diseases when they attended the clinic for pregnancy check-ups:

... I do think, if she’s pregnant, when going to the hospital they must try to check whether she’s HIV positive or negative, or, TB, and even those cancers. They must check them, and tell them answer. [Thuso]

### *Perceptions of Cancer*

In addition to the information described above, several common perceptions about cancer emerged during the interviews.

One of these perceptions involved whether or not cancer could be spread to others. Half (10) of the participants thought cancer could not be spread to others, and two were unsure or did not specify. Importantly, three participants believed “...if you got a breast cancer and if you got a baby, I think you have to bottle feed.” [Nick], indicating that they thought BC could be spread to a baby through breastfeeding. An additional two participants believed cancer could be spread through sex, one thought it could be passed to others through eating off the same plate, and another participant believed it could be spread by using the same deodorant or toothpaste as the affected person. This led to perspectives such as “She mustn’t do or touch anything...she have to...stay on their own

room.” [Kyle] and “If like me, I’m living with my girlfriend, I think she must get treatment cuz I don’t know what’s the risk of me getting it.” [Rapula]. When asked if someone could be ‘sent’ BC, which may occur if someone was jealous of them, the overwhelming majority indicated that “No, there’s no such thing as that.” [Sicelo] (including two current users of THs). One participant indicated that it could be sent to you (current TH user), one thought it maybe could (non-TH user), and two were unsure or did not specify (non-TH users). One participant said that, according to cultural beliefs, “they believe you have been cursed... some of the people they believe in those things.”; he also used to believe this but now “...from my Christian background, no, there’s no such thing.” [Akhumzi]. In line with this, most participants believed that cancer is “...something that happens naturally, there’s nothing that caused it. It doesn’t choose, it just goes to wherever it wants to go to.” [Sicelo] This ran parallel to beliefs that these things “...they are meant to be.” [Akhumzi]. Getting cancer was not seen as someone’s fault, rather: “...this thing just happen... not on his, or her will... I think if it’s just that person...is just uhh, bad luck to be attacked by the disease.” [Bonani]. In contrast, one participant reported that his partner might be scared to tell her family if she had cancer because they “might blame her for that” [Nick]; they may think she acquired it because she was cursed or from drinking or smoking too much.

Some participants demonstrated confusion between cancer and characteristics of HIV/AIDS. This is illustrated by discourse such as “So the other people don’t want to go there, so you know, your status is good. To know your status. Once you know your status, you can’t spread [to] someone.” [Luke]. It is also illustrated by perceptions about how BC

can be spread, such as to a baby through breastfeeding, and to others through sexual activity or interaction with an open wound.

This association between cancer and HIV/AIDS may have also contributed to the very prominent category of the importance of seeking health care. Participants were adamant about the need to visit the clinic if themselves or their partner thought they might have cancer: “You must first go to clinic. If you have something... you can’t find it, you can’t know about it, you must go to clinic and they can tell you what’s that.” [Rapula]. Many (11) made an unprompted indication of the importance of visiting the clinic for cancer early, “before it grows” [Nick].

If you can, you find out so early, they can go to the clinic or hospital, can go for a check-up. And they check it, if they find it still early when it’s still developing, yeah it can be cured. [Jacob]

As Jacob describes, most participants (11) believed that as long as the person with cancer receives treatment, they will survive. This is further illustrated by Lesebo: “...once they get to the clinic and then they get some check-up, and then he [they] will survive. They know how to treat that cancer.” The connection between surviving HIV/AIDS and cancer is made by Mark:

You can get cancer and survive and be okay, as long as you are following the prescriptions. Taking the medication, uhhhh can keep you, it’s not like having a can-, cancer you have been sentenced to die, no, it’s not like that, still going to live. It’s the... same thing as having HIV and AIDS and diabetes. Those are not... life threatening issues. Okay, they are life-threatening issues if you are not taking care of yourself. But if you stand up for yourself and say okay, I’m not going to let [knocks on table] this thing, destroy me, and then it won’t destroy you. But if you just sit back and go ah,...you see?

In contrast, one participant thought that people who have cancer “always die” [Nick], likely because his boss had been diagnosed with cancer and passed away even though his “boss has got money to pay, to do everything, but he end up dying with it” [Nick].

Another prominent category was the belief that “cancer doesn’t discriminate.” [Mark] (12), it “...affects everyone who’s alive, living, in the world. Yeah, doesn’t go with your race or colour or what.” [Sicelo]. Despite this belief, some participants (6) indicated that although cancer affects all people, it can be specifically dangerous to black people. This is because black people are thought to have less awareness of breast cancer:

... the only that we are, that’s talked about, it’s HIV, HIV, HIV. I think they know about HIV, but not cancer. They just take for granted, you know. [Bonani].

This lack of awareness was seen as contributing to an advanced stage of presentation:

“...so the time you see that you got cancer, there will be no time for you to live.” [Nick].

Cancer is also an issue for black people because “we are not financially stable, mostly to go to have some checks ups and stuff like that.” [Nick]. Being financially unstable was perceived as a problem for survival rates as well:

I think they can survive from it. But...if you have the means. The money to get the medical health care you need. Cuz, I think, a lot of people like they just give up cuz like apparently cancer medication is very expensive. [Khuselwa].

### Cancer Education

In general, sources of cancer information were reported as television (specifically health programs, the news, and ‘soapies’) (11), and famous figures (5) who had been diagnosed with cancer. Participants reported learning about cancer through books (5), magazines and newspapers, from people talking about it (4), the radio (4), receiving



pamphlets at clinics (2), and learning about it at school when they were younger (2). Eleven participants reported knowing someone in the past that had been diagnosed with cancer, which also appeared to be a source of information about cancer.

In regards to advertisements about BC specifically, half of the participants reported that they have never seen any advertisements about BC testing or prevention, and two were unsure or did not specify. Nine participants reported having seen BC advertisements from a mixture of radio (3), television (2), at clinics or hospitals (2), and on poles on the street (1).

A prominent category pertaining to cancer education that emerged from the interviews is that people in Diepsloot are “just in the dark” [Akhmuzi] about cancer. Although eleven participants had known someone in the past with cancer, usually this person was not from Diepsloot. As stated by Jacob:

In Diepsloot, eh, ehh...I've never heard of somebody having cancer... But I know, maybe somebody there, somebody got it. Maybe [they] don't know. Because some other people they don't even know the signs.

Never having known someone with cancer in Diepsloot was a common answer when asking participants whether they thought cancer was a ‘big problem’ in Diepsloot.

Interestingly, Mark states:

I can't say it's a big problem, though it is. Just that people are like keeping, they are turning a blind eye on that. You see people not accepting the reality, so if you[re] diagnos[ed], with cancer, you gonna hide it, so maybe you don't tell your partner about it. You start, you keeping it to yourself, you stressing yourself. And the minute you start stressing yourself it's getting power, and then it's, it's going to overpower you one day. And then once it overpowers you, cuz you going to tell us the truth and the last minutes like you know, I'm suffering from this, and at that moment there's nothing you can do, you see.

In line with this, the majority (15) of participants indicated that cancer is not something discussed in Diepsloot: “No people talking about cancer in Diepsloot. I never met someone talking about cancer.” [Simon]; however, some indicated that “it needs to be discussed about” [Boipelo]. As Rapula describes, “Some are afraid to talk about. But others they can tell you. So, I can say they don’t talk about it. And you must talk about it.” Matsimela describes it as only being discussed at certain times of the year:

I think that’s we need...more posts talking about, because the only time that we can see or hear about cancer is when we have that breast cancer month [October] that’s where people start talking and making sure that people are aware of cancer but after that month, there’s no talks, there’s nothing.

Another idea discussed by three participants was “the only that we are, that’s talked about, it’s HIV, HIV, HIV. I think they know about HIV, but not cancer.” [Khuselwa]. HIV/AIDS is more of a worry in Diepsloot than cancer is:

Like AIDS, if you had sex with somebody you go up to the hospital and get a check-up, I think they worry much about it, but cancer, I don’t think, doesn’t worry that much. [Nick]

This is further described by Khuselwa:

I think it [cancer] is a problem in Diepsloot but a lot of people are not aware of it. They don’t know much about cancer... a lot of people around Diepsloot, they know about HIV. They know more about HIV than cancer. Because like you, you come across someone who’s sick, the first thing that comes to mind is, “She’s got AIDS, she’s got HIV and stuff”, and then you find out maybe that person has cancer and something but just as long as you’re sick, around here, you’ve got AIDS. So I don’t think they know about cancer. But I think... a lot of people might have it, but they already died but they didn’t know it was cancer. Because I don’t think they know much about it. Including me, I don’t know, I didn’t know much about cancer, but I’m trying to.

In congruence with Khuselwa’s last line in the above quote, participants expressed the need for more education about cancer in Diepsloot, stating “Education can be...an

*answer* to it [italics reflect participant's emphasis] [Bonani], in terms of the lack of knowledge and discussion of cancer in Diepsloot. A lack of knowledge was also a reason that a BC diagnosis would be feared. As described by Matsimela:

Because of lack of knowledge, some people might be shocked [if she was diagnosed with BC], thinking that 'oh she's already going to die'...if she follow the procedures and everything that the doctor has prescribed for her she is going to survive, but...if you don't have information you are already thinking of death.

Half of the participants specifically expressed the desire to learn more about cancer: "I also want to learn. I know nothing about this. I want to know more." [Rapula]. Participants requested specific information from the researcher throughout the interviews; for example, "I'd like to know where they do this treatment stuff, around Johannesburg." [Akhumzi], "...can breast cancer, can it be transmitted to a child? Like... through breast feeding or?" [Nick] and "...my mother of my wife she got a cancer, for 25 years now, so how can I help her for that?" [Bhekimuza]. The researcher answered these questions after the interview was finished. Despite the desire to learn, some participants indicated that they did not know where to start learning about cancer: "what must I do in order to know these things [?]" [Thuso]. This problem is further expressed by Khuselwa:

Like since, like around here, in Diepsloot, we don't know much about cancer... sometimes I think, what if I can be affected with cancer... what steps can I take, where can I get help, like where maybe, since I'm not working, where I can get help, maybe they can give me treatment for free and stuff, like those kinds of questions. Like I often ask, like, if I were to be diagnosed with cancer right now, where would I go... that's what I would like to know... I don't what step, what first step I can take. Maybe I might just, end up like accepting it, like let me just sit and let the cancer eat me up because, I don't know where, where I will go.

Finally, some participants also expressed their desire to spread knowledge of cancer to others in their community:

I just want to know about those things. Until, I reach the point where I'm, because if, by doing that, there's so many people I would help about all those things, after I learned a lot about all those things. [Thuso].

### Access to Health Care

Another prominent theme that was explored was how participants and their partners accessed health care, and the relevant barriers and/or facilitators to their access. In general, participants expressed dissatisfaction about the public clinics. The main issues reported were:

You have to wake up at half past four in the morning [to go to the public clinic], half past five you need to be in the queue, hopefully the clinic opens, I think it opens at seven. So, you have to queue next to the gate, when they open then they give you numbers, if you fall under there, they say they take maybe say 200 a day, if you fall beyond that number then it means you have to come another day. [Akhumzi]

The difficulties in being seen at a public clinic stem from the small number of clinics compared to the population needs: "Because it's only two clinics with what, a population of what, 750 000, close to a million. And then we using only two clinics, you see." [Mark]. The clinics also have inconvenient hours:

But around Diepsloot there is something that I don't understand. Sometimes, around, during weekend, around by five or six, you can go there no one. I don't know what is happening. And according to my idea, clinic was supposed to open 24 hours. [Thuso]

Furthermore, by walking to the clinic early in the morning in order to be assisted, residents of Diepsloot put themselves in danger: "Just walking there and going there, you can get robbed, get shot or get killed, something, or get raped if you're a woman. Eish, it's not safe here." [Sicelo]. One participant also reported: "see me I don't trust much the clinic. The clinic, these ladies working there sometimes don't treat people nicely." [Luke].

These issues generally led participants to prefer the services at private clinics: “So it forces, it forces you to go and seek help from the private facilities...” [Mark].

The private clinics were used because their convenience, despite the cost of the consultation:

So I must be, the private way, pay, treating people nice. Like eh, I enjoy too much [a private clinic]. [At the private clinic] you pay there. So, there is no problem. For all thing you want there, they give you. They give it to all treatment you want there, can give. I can go there you see, here is not right, my stomach is not right, headache, they can give you all this medication, for one pay. [Luke]

The private clinics were also seen as more convenient because “you don’t have to sit for a long time before you get attended. Maybe twenty minutes, fifteen minutes is enough. [Sicelo]” and “that one is convenient. The opening times, they open from eight in the morning, and they close eight pm.” [Akhumzi]. There was a perception that the private clinics are of higher quality than the public clinics: “...we go to the private doctor because they say it’s better than the public centers.” [Matsimela].

In addition to dangers on the way to the clinic, other barriers to accessing both the public and private clinics was the cost of the taxi fare and/or the consultation fee, respectively. Not having enough money could cause the participant to delay scheduled appointments:

Yeah, as I should have gone a long time before... and the problem was I didn’t have money, to take a taxi to go there. And also the hospital, I must pay. So I was just waiting for the right time to come, so I could find something, so I could go there. [Jacob]

Notably, two participants also reported that their partner currently had pain in their breast but they had not had the chance to get it checked at the clinic yet; the pain had started

roughly two and a half months ago for one partner and four to five months ago for the other.

Furthermore, one participant described the issues with calling a public ambulance if you needed one:

Because sometimes if you need a, if you need help, you can try calling an ambulance, and sometimes it comes, sometimes it doesn't come, sometimes it doesn't come where exactly you are, and then they say you can come and meet us this side, at a pick-up point. [Nick]

Since some of the private clinics offered transportation as part of the consultation fee, this was another reason they were preferred over public clinics.

As previously stated, the majority of participants (16) indicated that they are not current users of traditional healers. Those that did use these services did so for 'life' problems: "Okay, when I go to the clinic, it is when eh, my body does not feel well. And also, when I go to the traditional healing... I'm going to check my life." [Anthony], or issues related to culture:

Like, cultural things, like, like as it is Africans, like there's a thing that we communicate with our ancestors and... So I'd go to a TH for those kinds of things, and I'd go to a clinic, health care, for things like, go to check up, to check uh high blood pressure and stuff, things like that. [Khuselwa]

When asked for examples of issues they would use a TH for, participants reported: "...for instance if my partner suffered a miscarriage, then we would have to go and consult so that she could be cleansed." [Mark] and "The reason I went to a traditional healer is because, like, when I was sleeping at home, there was like, I could hear some strange noise or something, so someone advised me to go and see a TH." [Khuselwa]. One participant reported that, though he uses THs, he would not go to a TH for BC "because

traditional healer, doesn't know about breast cancer.” [Anthony]. Among those that did not use traditional healing services, a prominent reason for not using them was “now I go to Church. And I guess eh I don't trust in those things [THs], actually I believe in my Church because that's where I go.” [Sicelo]. Two participants also indicated that THs are not used as much as they used to be: “When I was young my grandfather used to use one but as for me, no, this generation is now different.” [Dave].

### *Gender Norms, Roles and Relations*

This theme explores gender norms, roles and relations, particularly in reference to how it influences health experiences.

In terms of gender roles, the men expressed the need to find a job in order to provide for their family: “...I've got families...So that's why I need a job. Straight job you know, you can. To sustain my families, nothing I have.” [Luke]. Not being able to find a job was a source of discomfort: “Myself, I like to work hard, to support [my family], cuz each and every day I think about I'm not working, how can I improve myself...” [Bhekimuzi]. One participant specifically expressed his frustration that his wife was employed but he was not: “So like, it frustrates me, seeing like, a lot of things, she's the one who's doing a lot of things for our daughter, so it kinda frustrates me...I feel like I should be the one providing for my daughter, and providing for her.” [Khuselwa].

Within their relationship with their partner, participants expressed the openness they had with one another, an openness shared because “We are friends. We talk about

everything” [Rapula]. As described by Thuso: “...that means this one is going to be my friend, forever. We can share everything. Don’t afraid to share with her. Don’t afraid to share with him. No, everything we must talk.” When asked if they thought their partner would talk to them about an issue with her breast, eighteen participants answered “Yes, I think she would. I know it. I know she would tell me.” [Rapula], and two did not specify.

As explained by Jacob:

... because it’s part, pain is part of the life. Yeah. There is pain, there is death. So I don’t think she could hide that from me. Like myself, in fact, pain goes together with the death. I could die anytime. So she must know. Can’t hide something away from me.

In their partner’s access to health care, the men played various roles. Differing views were expressed regarding finances. One of these is that the man should provide the funds for his partner to access health care:

... I’m the one who’s supposed give her money. No matter she got her money around, I don’t, I don’t care about that one... I’m the owner of the house (laughs)... there must be a money for those things like bread, tea, something, meat, something like those things. I’m the one who’s supposed to do it because that is my house. [Thuso]

Some expressed that money was shared equally between themselves: “Uh, you know, it’s another thing is, it’s not my money, her money, it’s our money. It’s all our money.” [Mark]. Others, whose partners were employed but they were not, stated that she used her own money to access health care. Finally, some indicated they would need to borrow money from someone else to get health care: “... otherwise I must make a plan. Sometimes we must lend, if it’s urgently required, we must lend it somewhere, someone from, the people, those that can help, so she can go to the hospital.” [Jacob]. When asked if she would go to the clinic alone or with someone else, many of the men (11) expressed



that “If I’ve got a chance, I have to go with her, and then if no chance she can go alone.” or that she would go with other family members if he was not available. However, “if it’s serious, I go with her” [Nick]. One of the participants mentioned that she must go alone because they cannot afford transport for both of them to go there. Seven of the participants indicated they will always go with her: “I must make sure that I accompany her.” [Jacob]. When asked if their partner should ask him permission before accessing health care, nine participants answered that she should and one did not specify. In contrast, ten indicated that she does not need to: “She just go, she must go. She’s a woman, she’s my wife. Yeah, her health comes first...There’s no need to ask permission from me.” [Jacob].

Finally, evidence of changes in gender roles occurred when their partner was sick, with participants stating: “Okay, all I can say, for me, what I’m telling is true, whatever she used to do at the house, if she getting sick, I’m the one who supposed to do it...Even to cook, I’m doing that.” [Thuso]. Participants also expressed some change in gender roles that occurred if she was employed and he was not: “Because she’s the one who’s working, I sometimes try like, when she’s back from work and then I’ve been home the whole day, I cook sometimes and wash the dishes.” [Khuselwa]. One participant described what happened when their daughter was young and his partner was working but he was not:

I’m a responsible father. I stayed with my, my child. I didn’t know that this child, she must eat. After she ate, there is a time for bath. After she bath, I know must also sleep. For how long, she must sleep. When she wake up, I must make sure I’m here. I must bath her, yeah, feed her. When the mother comes, she was used to me. Even she couldn’t give, realize the mother is not here because I’m there, I was there for her. [Jacob]

Finally, it emerged that participants felt strongly that they would stay with their partner no matter what, “[b]ecause, we’ve been through a lot together.” [Khuselwa]. For example, Boipelo describes: “...and she is not employed too. But we stay together.” Many participants also described how, if their partner was diagnosed with BC, they would stay together: “We come from very far, many years so how can I just leave her like that.” [Sicelo] As Anthony affirms:

Because of, I love it [her]. Yeah, when somebody is not feeling well, you mustn’t say ‘No, my wife is not healthy, I’ll have to leave it alone.’ No. Which is wrong. Yeah we must be together. Same like before eh, it is still good. We’ll have to stick with it.

Some argued that a BC diagnosis would “bring us closer cuz, I’ll support her as my partner.” [Matsimela]. The idea that she will need more support during this time was expressed by several participants. For example, Jacob states:

Breast cancer? I think, I must love her more. I must love her more. Because breast cancer, I know, many women, when they’ve got breast cancer, they think maybe it’s the end of their life. So I must support her more... That she don’t have to think of many things. Because some people, some women, they feel about breast cancer, they think it’s the end of the world. Maybe they could end their life before that time comes. So she will need more than support.

Thuso describes how: “While I must try by all means, in order to, to give her a power to show that I’m still in love with her.” Finally, participants described what their reaction might be if she had to have part of her breast removed due to cancer:

... according to my experience, I know my wife... she had everything in her. And, if one part goes away, it doesn’t mean, she’s not dead to me. She’s still there, she needs my support. Yeah. And if I reject her, that means I will be putting her in danger, I will be endangering her life... I must protect more. [Jacob]

A similar perspective is described by Matsimela:

I don't think, I know she might have issues, she might start doubting herself, but in terms of me, I don't think I'll have a problem cuz, after all, I love her not her body. So I know that her body is part of us, but, what is important is our, is her health more than my, my needs or yeah.... it's not about me, in this... it's about her getting the treatment.

Two of the participants also specifically mentioned that, after learning about BC through participation in the study, they would “start talking about it” [Rapula] with their partner, and if she had BC they would “push her to get treatment, so she get better” [Rapula].

### *Responsibility to Community*

Finally, a minor theme that emerged from the interviews (mostly with members of Sonke, but also with others), was the sense of responsibility to improve their community. When asked what he likes to do in his free time, one participant replied: “What I need most to do is...to work with the community, and my area, and uh, stop crime in my area.” Another expresses: “Because I have the experience of violence within the community, so I want to bring difference.”

Participants who were affiliated with Sonke specifically expressed their gratitude that they had the opportunity to make a difference in their community through their work: for e.g., “You see here actually, for me, at this moment, I am say thank God, to meet Sonke.” They expressed the passion they had for their work: “So every day, day in, day out when I wake up, I feel pumped to go there, I just want to go there and make difference.” They also reflected on how much they had personally learned through Sonke:

Eish you know, here I, I learned a lot. I, I was afraid to be with some people. But for now, I just, I feel to be with with some other people, in order for share, what kind of life we can live. From a, from Sonke... I learnt lot about those things. And I've been smoking! I was a drunk. But for now, I used to drink in responsibility.

I'm no longer smoking. I'm no longer fighting with some other people. Actually, if I see someone fight I give against to each other, I know how can I help those people. It's what I learnt about from Sonke this moment.

### 3.2.2. *Summary of Interview Data*

In general, participants had little knowledge about cancer and knowledge of BC was even more minimal. The most commonly identified type of cancer was lung cancer, and the most frequently identified risk factors were smoking, alcohol use, and family history. There were some misconceptions about the causes of BC, specifically that it can be caused by putting objects in your bra. A lump was a relatively well-identified sign of BC, but very little was known about treatments, except for removing the breast. Most of the participants thought their partner did not or were unsure if they completed BSE.

Some participants believed cancer was contagious, and could be spread to a baby through breastfeeding, or to others through sexual activity or an open wound. This reflects the confusion participants portrayed between cancer and HIV/AIDS. Breast cancer is seen as something that cannot be 'sent' to you in a spiritual manner, rather it is natural and simply bad luck to acquire it. Participants perceived it very important to access health care for cancer, specifically before the cancer progressed. They believed that if treatment was received, the individual would survive BC. Cancer is seen as something that affects all races equally, although it is a greater threat to black individuals because of their social and financial positions.

The most commonly reported sources of information about cancer was television, famous people that have been diagnosed, books, magazines, and newspapers. However, most participants had never seen advertisements specifically about BC. In general, participants indicated that they have never seen anyone with cancer in Diepsloot, it is not

discussed, and there is a need for more education about cancer in their community. People in Diepsloot mostly know and worry about HIV/AIDS, but not cancer. Participants indicated a desire to know more about cancer and spread this knowledge to others, but they were not sure where or how to start learning about it.

In terms of access to health care, participants disliked public clinics because they have to wake up early in the morning to access them and wait all day in the queue with the potential of not being seen. They indicated that the operating hours of the clinics were inconvenient, the people working there may not treat them respectfully, and that they put themselves in danger by walking there early in the morning. These factors led some to pursue private health care options, which were seen as convenient and of high quality despite the cost of accessing them. Barriers to health care included not having enough money for the taxi and/or consultation fee (for a private clinic), and issues with the public ambulances. Participants who used traditional healing services did so for ‘life’ or cultural issues, and those that did not use them indicated it was because of their current religious affiliation. It was also expressed that South Africans do not use THs as much as previous generations.

Regarding gender norms, roles, and relations, participants expressed the desire to acquire a job in order to provide for their family. Not having a job to fulfill this role was discomforting to them, and one participant expressed frustration that their partner was the provider in the family instead of himself. Within their relationship, participants described the openness they had with their partner, because they are friends. They thought their partner would tell them if she had an issue with her breast. In terms of their role in their

partner's access to health care, some indicated that they should give her money to go to the clinic, whereas others indicated that their money was shared equally, she would use her own, or they would borrow from someone. Most participants reported that they would go with her to the clinic, or that she would go alone if he was not available; some asserted that he would always go with her. About half of the participants thought she should ask him for permission before accessing health care. When she is sick, participants described some transfer of gender roles in which he would be required to perform household or child caring duties. Overall, participants expressed that they would stick together no matter what because they have already been through a lot together. If she was diagnosed with BC, they thought they would stay together and that he must support her more. It was reported that, if she had to have part of her breast removed, it would not affect their relationship because they could not reject her for that.

A minor theme that emerged, mostly with Sonke members but also among other participants, was the feeling of responsibility participants had to improve their community through reducing crime and violence. Sonke members specifically expressed gratitude that they could do this through their work. They displayed the passion they had for their work and described some of the personal improvements they had experienced through Sonke.

### *3.2.3. Volunteer Opportunities*

As previously mentioned, the researcher spent time volunteering with two local BC organizations. The specific details of these interactions have been removed to protect

the confidentiality of those involved; instead broad summaries of the relevant insights are presented below.

The researcher participated in an awareness and screening outreach campaign in local townships. In this campaign, the importance of including local healers was empathized in order to respect the local culture. Many of the older women in the communities in which the activities were undertaken were illiterate and/or did not speak English. In cases where the woman was illiterate, another woman would step in to help translate her personal information, which raised some concerns regarding privacy and confidentiality. Almost all of the women indicated there was no history of BC in their family. In general, the demand for screening was high and the women seemed eager to be tested. They also received material incentives to participate in the screening. In some townships, turnout from the community was much lower, which was attributed to the municipal leaders not doing as good of a job at mobilizing individuals to attend the screening. The researcher was informed that some women refuse treatment when they screen positive for BC, which may have to do with the requisite travel to a larger treatment facility. Moreover, many women receive screening at a point when the cancer is already significantly advanced. As relayed by members of the organization, many newly diagnosed women are concerned that their partners will leave them. Unfortunately, public cancer oncologists in South Africa are resigning in protest of the lack of functional equipment they have available to diagnose and treat cancer (“Last cancer doctor quits in Durban,” 2017), rendering it difficult for women who screen positive to receive treatment.

The researcher also participated in a similar outreach campaign at a local university. University students appeared to be much more aware of BC than the individuals in the townships, and seemed more likely to indicate a history of BC in the family.

In addition, the researcher volunteered to help with some activities at a local breast cancer clinic. The clinic indicated that their awareness campaigns sometimes include the role of the male partner. Most of the women at the clinic did not appear to be accompanied by a male family member or partner.

According to the organization, beliefs in traditional healing are thought to significantly contribute to the delays they see in women presenting to the breast clinic. Often, women will not tell them they have been to see a TH but they will see evidence of the use of herbs and other traditional healing practices in the breast wound. BC is thought to be the result of a curse from a jealous family member.

### *3.2.3. Summary of Insights Gained from Volunteer Experiences*

In summary, the opportunities to volunteer with local BC organizations offered useful insights into the role of civil society in breast cancer prevention and care in SA. As well as serving to ground or validate the interview data, the volunteer experiences provided additional information regarding BC in SA, particularly the processes surrounding screening, diagnosis and treatment for public healthcare system patients from low-income communities. Through conversations with some of the organizations' members, insight was also gained about the perspectives of women who have been



diagnosed with BC. The insights obtained from these experiences is compared and contrasted to both the interview data and the previous literature in the following section.

## **CHAPTER 4: DISCUSSION**

### **4.1 INTRODUCTION**

Firstly, an interpretation of the major findings and their relevance to previous literature is presented. The discussion of knowledge and perceptions of (breast) cancer is done with reference to the Health Belief Model, which is used to explain preventative health behavior based on culturally-influenced attitudes about health (Becker, 1974; Johnson et al., 2008). The primary constructs of the Health Belief Model include the *perceived susceptibility* an individual has about acquiring a disease, the *perceived severity* in terms of the difficulties the individual believes the disease will create, and the *perceived benefits* of one's actions towards preventing the disease. The other constructs are the *perceived barriers*, which refers to the degree to which the treatment is considered unpleasant, *cues to action* that motivate an individual to complete a specific action and *self-efficacy*, the individual's belief that they can successfully complete the required action (Becker, 1974; Johnson et al., 2008).

Following this, the relevance of the findings related to gender norms, roles and relations and contributions to the concept of hegemonic masculinity(ies) is discussed. A specific set of recommendations to improve the understanding and experience of BC in SA is offered based on the study's findings. Finally, an outline of the major limitations of the study is offered in order to contextualize the results.

### **4.2 FINDINGS**

It is clear that most participants exhibited little knowledge regarding both breast cancer and cancer in general. In SA, the most common types of cancer for women are

breast cancer, basal cell carcinoma (a type of skin cancer), and cervical cancer; for men, it is basal cell carcinoma, prostate and squamous cell carcinoma (another type of skin cancer) (National Cancer Registry, 2013). As of 2013, lung cancer is the 5<sup>th</sup> most common cancer for men and the 8<sup>th</sup> for women (National Cancer Registry, 2013). Among participants, lung cancer and smoking were the most commonly identified type and risk factor for cancer, respectively. The high awareness of the dangers of smoking is likely due to significant efforts towards tobacco control by the South African government, which now boasts “one of the most comprehensive tobacco control policies in the world” (Malan & Leaver, 2003, p. 149).

Among participants, the risk factors of smoking, alcohol consumption, and family history were relatively well-identified, and eating unhealthy foods, being overweight, a lack of exercise and stress were identified by some. It is not clear whether participants knew that these risk factors were specific to cancer or rather were listing the tenets of basic healthy habits for the general prevention of disease. Other risk factors, such as the use of oral contraceptives and reproductive history (Nelson et al. 2012), were not mentioned, although it is encouraging that many identified family history as a risk factor. Many participants also portrayed the belief that “there’s nothing that caused it” [Sicelo], it “just happen[s]” [Bonani], it is just “bad luck to be attacked by the disease” [Bonani] and “only God knows [if she will die]” [Thuso]. The lack of control that this discourse portrays reflects fatalistic beliefs that are commonly reported in regards to health seeking behavior in marginalized populations (e.g. Mayo & Hunter, 2003; Peek, Sayad, & Markwardt, 2008; Schwab, Meyer, & Merrell, 1994). Fatalism refers to beliefs that health

is “largely determined by forces outside of the control of the individual” (Davison, Frankel, & Smithy, 1992, p. 676). For disadvantaged populations, these fatalistic beliefs are likely to simply reflect the actual material barriers these individuals experience in resolving their health needs (Espinosa de los Monteros and Gallo 2010), and could be further influenced by a similar lack of control in other areas of their lives. This feeling of a lack of control may be even stronger for women in SA, who have even more limited social and financial independence and barriers to seeking care than men (Maree & Wright, 2010; Pronyk et al., 2001).

Some of the participant’s perceptions about BC being caused by putting things in your bra or using different bath soaps could be based on alternative conceptions of how the human body operates that are formulated due to their lack of access to conventional biomedical information. Notably, the belief about putting items in your bra was also found by Moodley et al., (2016). It could be the result of recent attention in SA surrounding the possibility of cell phones causing cancer when placed close to the body for extended periods of time (“Cellphone radiation: only the facts,” 2012; “Do Cell Phones Cause Cancer?,” 2017), although this does not explain the concern with placing a wallet or lip balm container there.

In regard to signs and symptoms, a lump was relatively well-identified as a sign, although many could not identify other signs such as changes to the shape of the breast or the nipple (Canadian Cancer Society n.d.). Furthermore, very little was known about treatments for (breast) cancer, besides removing the affected body part through surgery. Although most participants were very positive about an individual’s chances of survival if

they received treatment, their lack of knowledge of BC treatments creates mystery surrounding BC care that may cause some to delay seeking treatment due to fear of the unknown. This is supported by numerous studies indicating fear of diagnosis is a barrier to seeking BC care for South African women (Krombein & De Villiers, 2006; Moodley et al., 2016; Rayne et al., 2016). Fear and its relation to a lack of information was also something brought up by participants in the current study. Mastectomy, the removal of all or part of the breast, was likely the most commonly identified treatment because it is so visible. However, since cutting off the breast is essentially the only recognized treatment, this may also elicit fear and hesitation among individuals to seek care. These arguments are in line with the perceived barriers descriptor of the Health Belief Model, which describes how a major factor influencing health-seeking behavior is whether the treatment is considered unpleasant, painful, upsetting, or expensive (Becker, 1974; Johnson et al., 2008).

Most of the men were unaware if their partner completed BSE or not. This could be because she does complete BSE and does not discuss it with him; more likely it is because BC is not something that is discussed or worried about in general in Diepsloot. According to the perceived benefits factor in the Health Belief Model, an individual must perceive the benefits of particular actions for preventing disease in order to be motivated to engage in them (Becker, 1974; Johnson et al., 2008). Some of the participants believed that their partner was checked for cancers when attending the clinic for pregnancy check-ups. Whether this truly occurs or not is unknown, however the new BC control policy indicates that information regarding BC and BSE will be available in all public clinics in

the future (National Department of Health, 2017, p. 25), and health care professionals will be trained on BC screening and care (p. 45).

Some participants reported beliefs that cancer is contagious, and could be spread to others through sex, eating off the same plate or using the same hygiene products. This led to perspectives that the individual would have to “stay on [in] their own room” [Kyle], wear a mouth mask, and not touch anything. These misconceptions are not surprising given that communicable diseases such as HIV and tuberculosis are such prevalent health issues in SA (Mayosi et al. 2009). However, these beliefs can be very harmful in terms of stigmatizing and ostracizing the individual with cancer and preventing their engagement in activities of daily living or work.

Furthermore, some of the participants associated cancer with characteristics of HIV/AIDS, such as knowing your status, and the perceptions that cancer can be spread through sex, an open wound or transmitted to a baby during breastfeeding. This is likely due to the high prevalence rates of HIV (Statistics South Africa 2017b), significant attention and efforts made by the media and civil society, and aggressive public health action taken in the form of the government’s HIV Counselling and Testing Campaign (National Department of Health 2010); objectives of the campaign include increasing HIV discussion, reducing stigma, and promoting testing (Motsoaledi 2010). This is supported by participants’ comments that individuals in Diepsloot are aware of HIV and the importance of being tested. The association between cancer and HIV that participants portrayed may prove harmful as individuals may associate similar stigma or attribute an individual’s acquirement of cancer to inaccurate reasons. In contrast, HIV awareness

seems to also positively influence cancer awareness as participants stressed the importance of being tested early for cancer, before it develops, which may have resulted from public health efforts promoting the importance of HIV testing. Furthermore, since HIV is now a manageable chronic illness in SA due to the availability of anti-retroviral therapy (Deeks, Lewin, and Havlir 2013; Levitt et al. 2011), this could have elicited their belief that an individual will survive cancer as long as they receive treatment.

The vast majority of participants believed that “cancer doesn’t discriminate.” [Mark] and affects individuals of all racial groups equally. This belief may have been influenced by efforts to improve racial equality in SA since the end of apartheid. However, participants also demonstrated awareness of their own vulnerable social and financial positions due to their race, specifically their lack of access to health care, inability to afford treatment, and lack of knowledge and awareness of cancer. This is consistent with the literature arguing for the increased risk of black individuals to present with advanced cancer (Maree & Wright, 2010; Vorobiof et al., 2001; Walker et al., 2004). As described by Khuselwa: “Maybe I might just...let the cancer eat me up because I don’t know...where I will go.” The lack of knowledge about where to access cancer diagnosis and treatment services may contribute to advanced presentation to the healthcare system. The self-awareness of the extreme social and financial barriers that black individuals face in accessing health care may also reduce their self-efficacy towards receiving and finishing treatment.

In relation to the studies on knowledge of BC among South African women, the men in this study report similar or slightly lower levels of knowledge of BC. In the

recently conducted study by Trupe et al. (2017) (n=243), about half of the women were able to identify a lump as a symptom, most reported knowing very little about treatments, all were positive about receiving health care for BC, and 70% thought it was survivable with early detection; this is similar to the perceptions of the men in this study. Other findings that are supported by previous literature include: the lack of discussion about BC in the community (Moodley et al., 2016), some women require permission from men to access health care (Maree & Wright, 2010), and participants are keen to increase their knowledge about BC and spread this knowledge to others (Krombein et al., 2006). In contrast to previous literature, this study found that men perceive BC as a disease that affects all races equally, as opposed to previous perceptions that BC is a white person's disease (Maree & Wright, 2010).

In terms of cancer education, the data indicates that television (specifically health programs and 'soaps'), endorsement by popular figures, and magazines and newspapers are important sources of information about cancer. Promoting cancer awareness through these channels is supported by the Health Belief Model, which argues that cues to action, such as media attention, are required for individuals to engage in health seeking behavior (Becker, 1974; Johnson et al., 2008). The researcher's volunteer activities indicated that the provision of information about cancer in written English may be a barrier to some individuals who do not speak English or are illiterate; this is also recognized in the current BC prevention policy (National Department of Health, 2017, p. 15).

In addition, health information in schools appears to be lacking, however most participants received their education during the apartheid era and therefore were subjected



to the Bantu Education system, which limited black individual's education to what was deemed necessary to become a physical labourer (Clark and Worger 2016). In 2012, SA addressed the importance of health education in South African primary and secondary schools through the introduction of the Integrated School Health Policy (National Department of Health and National Department of Basic Education 2012). Currently, health education focuses on HIV, child abuse, oral health, high risk behaviours, and malaria prevention, among others. Notably, the strategy does not appear to address cancer education, despite cancer's significant health burden in SA (Mayosi et al. 2009). Including cancer awareness in the current school health education strategy may encourage earlier presentation of future cases. Providing cancer education and reducing inequalities in access to information is in accordance with South Africa's attempts to redress educational inequalities, especially in regards to those "to whom a quality education has previously been denied" (Lomofsky and Lazarus 2001; Support Services 1992).

Furthermore, since cancer does not appear to be widely discussed in Diepsloot, many individuals do not know anyone that has been diagnosed, which could be contributing to a failure to perceive risk as well as produce stigma surrounding cancer. This is line with another of the primary constructs of the Health Belief Model: perceived susceptibility, which refers to the individual's perception of their personal risk of acquiring a specific health issue (Becker, 1974; Johnson et al., 2008). As participants indicated, a lack of awareness and access to information about cancer also produces fear of diagnosis because of the tendency to automatically think of the worst-case scenario (death). It also may create anxiety surrounding how to be a supportive caregiver. This is

implied by Bhekimuza when he asked for information on how to properly take care of his mother-in-law, who had previously been diagnosed with cancer. Participants expressed a seemingly genuine desire to learn more about cancer and educate others in their community about it.

In general, access to health care was an issue for participants since there are not enough clinics serving the population of Diepsloot. This means that participants must wake up early in the morning to go to the clinic (potentially putting themselves in danger), stand in long queues to be seen, and possibly experience a loss of income due to missed time at work. The public clinics were also perceived as having inconvenient hours, being of lower quality than private clinics, and having disrespectful staff. These comments about the public health system are supported by other studies (Bogart et al. 2013; Goudge et al. 2009; Trupe et al. 2017), and the high expenditure of the private system compared to the public system (The World Bank 2014). This leaves individuals feeling “force[d]...to go and seek help from the private facilities” [Mark], which becomes problematic because of the high cost of the clinic’s consultation fees relative to income level (consultation fees reflect between 0.7-6.2% of the average combined monthly income of the participant and their partner in the current study). Transportation is also a major barrier to accessing health care, in terms of affording transportation as well as inadequacies with the public ambulances; these issues caused some of the participants to delay or miss their scheduled appointments. Importantly, two participants expressed that their partner has been experiencing pain in her breast for several months but they had not

yet had the chance to get it checked, although the reasons for not having it checked yet were not explicitly specified.

In terms of traditional healing, participants reported that they did not think BC could be sent from another individual as a ‘curse’, and most reported not seeking care from traditional healers. Although this could be the result of social desirability bias and may not represent their actual beliefs, reductions in the use of traditional healing services in SA is supported in the literature (Peltzer, 2009). In contrast, insights from the researcher’s volunteer activities indicates that individuals do use traditional healing services for BC fairly often, causing them to delay accessing the conventional healthcare system. The results of the current study indicate that religion appears to be playing a significant role in the reduction of traditional African beliefs and the use of traditional healing systems, a theme that should be explored with further research.

In regards to gender norms, roles and relations, men expressed a feeling of responsibility to provide for their family which is consistent with traditional gender roles. In this sample, only four of the participants were formally employed compared to thirteen of their partners, indicating that the female is the sole provider in the household for many of participants in this study. The lack of employment for men seemed to be a source of discomfort, and one participant specifically expressed frustration that his wife was the provider for their child when he felt it was his duty to fulfill this role. This is in line with other literature that suggests that frustration over not being able to fill traditional gender roles leads to feelings of irrelevance and can perpetuate gender-based violence (Dworkin et al., 2012).

In the context of access to health care, the men portrayed varied responses in terms of decisions regarding finances, accompanying their partner to the clinic, and whether or not she needs his permission to seek health care. Although many men indicated that they prefer to accompany their partners to the clinic, observation at a breast clinic indicates that women appear to be attending the clinic alone for breast health issues. Despite exhibiting beliefs in some traditional gender norms that can be considered controlling of women, such as half of the men reporting that their partners require permission from them to access health care, the men describe themselves as playing a prominent and mostly positive role in their partner's access to care. The discourse used indicates that the men feel a sense of responsibility over their partner's health care, much in the same way they expressed a sense of responsibility to provide for their families and improve their communities.

The participants also described the openness shared between themselves and their partner, which led them to believe that she would tell him if she had an issue with her breast, although Maree & Wright's (2010) study indicates that only one in four women would tell their husbands of their suspected BC. Participants also described how they would need to support her more during this time which indicates that men may be an important source of practical and emotional support during the experience of BC, an idea supported by Moodley et al.'s (2016) findings. The study by Maree & Wright (2010) also indicates that male partners can play an important role in encouraging a woman to seek care for BC, which is supported by the current participants' descriptions of the importance of seeking care, providing support to their partner and specific comments so as "...And I

will [would] push her to get treatment, so she get better.” [Rapula]. Yet experiences with the breast cancer organizations indicates that women fear a BC diagnosis because they are worried that their husbands will leave them. The current study indicates that, from the male perspective, this may not be the case, with the majority of participants believing that they would stay together, and that the possible removal of the breast would not affect their relationship. The influence of social desirability bias in these findings should be recognized, however it provides evidence that women’s concerns regarding this may not be grounded in reality.

As previously discussed, this study was guided and analyzed through the lens of the concept of hegemonic masculinity, with particular reference to recent work in SA (Dworkin et al., 2012; Jewkes & Morrell, 2010; Morrell et al., 2012; Morrell & Jewkes, 2013). In SA, the hegemonic forms of masculinity are characterized as white masculinity, black masculinity, and rural African masculinity (Morrell, 1994, 1998, 2001; Morrell et al., 2012). This study adds to this body of work by providing insight into how masculinities and gender norms and roles are negotiated in the context of health and health seeking behaviours, outside of the literature’s specific focus on HIV, gender violence and sexual behaviours. Particular attention is paid to the embodiment of black masculinity, which is thought to focus on physical strength and the control of women (Dworkin et al., 2012; Jewkes & Morrell, 2010; Luyt, 2012). The findings provide evidence supporting the complexity of masculinity at the individual level, as many of the men expressed views that were in congruence with hegemonic masculinity and views that reflected a more gender-equitable, contemporary form of masculinity within the same

conversation. For example, Thuso indicates that he is supposed to provide his wife with money to go to the clinic because “I’m the owner of the house...I’m the one who is supposed to do it because that is my house” and that she used to ask permission from him to go the clinic (although does not anymore); these perspectives conform to traditional gender norms and roles and imply beliefs in men’s control of women. However, he then goes on to describe how, if she is sick, he must complete tasks such as cooking and cleaning that are usually designated to the woman. He also describes how he must support her emotionally during this time, and if she had BC, he “must try by all means...to show that I’m [he’s] still in love with her”; these perspectives are more in line with contemporary, gender-equitable perspectives towards relationships. Similar dichotomies are also demonstrated by other participants. For instance, Khuselwa portrays beliefs in traditional gender norms when he describes his frustration that his wife is the financial provider for their daughter; he feels that “I [he] should be the one providing for my daughter, and providing for her [his wife]”. However, he defies traditional norms when he reports that “I don’t think she’s supposed to ask for permission from me to go to the clinic”. As this study is specifically focused on the context of health and illness, it is difficult to say how these gender roles and relations are negotiated in other circumstances. However, there is some evidence of the fluidity of these roles in different situations, such as when Jacob describes how he took care of their child when his partner was employed and he was not, even though this was a new experience for him. It is suggested that men are responding to a complex barrage of competing conceptions of masculinity encouraged in South African society. For instance, the current president of SA (Jacob Zuma) and the

leader of the Economic Freedom Fighters political party (Julius Malema) are prominent figures promoting masculinities based on male superiority (Morrell et al., 2012), although Malema may have recently changed his perspective on women's rights (Pillay, 2013). On the other hand, Nelson Mandela, who is still a highly respected figure in SA, promoted egalitarian masculinity and encouraged men to defy traditional gender roles by cooking, cleaning, and looking after children (Morrell et al., 2012). Furthermore, Sideris (2004) points to the influence of improved rights for women, concern over having multiple sexual partners due to the threat of HIV, and significant outrage towards violence against women and children as catalyzing the contestation of hegemonic forms of masculinity in SA. Organizations such as Sonke Gender Justice also continue to play a prominent role in challenging traditional gender norms and facilitating the rise of new masculinities. This regional contestation of masculinities appears to be influencing how gender relations are described at an individual level, resulting in internal contradiction. Walker (2005) supports this idea through her examination of black men involved in a gender advocacy group in the Alexandra township, north of Johannesburg. She suggests that men are negotiating how to be a 'real man' in the "context of competing masculinities both old and new", and that "situating a man as for or against (or even in-between) [forms of masculinities] is too rigid and clear-cut" (p. 236). As argued by Connell & Messerschmidt (2005), this contestation has the potential to eventually lead to the establishment of a hegemonic masculinity that is gender-equitable and 'positive'; embodiment of this more positive form can be encouraged through further efforts by civil society and changes to societal structure.

Finally, as previously indicated, this thesis constitutes a case study in that it describes a unique population group's knowledge of BC, and conceptions of gender relations in regards to health care. This population is non-typical in that it consists of black South African men who are in long-term relationships with their female partners, which is a relatively uncommon family structure in SA (Hosegood, McGrath, and Moultrie 2009). Furthermore, and perhaps because of this, the men appear to describe gender relations in ways that differ from previous literature on black South African males, demonstrated by discourse describing their openness and commitment to their partner, as well as specific examples of their engagement in 'female' tasks such as cooking and cleaning, sharing of familial income, and questioning the biological differences between males and females. The latter behaviours were also found by Sideris (2004) in her examination of men who reject gender violence in the Nkomazi, Mpumalanga. In a similar manner to Sideris (2004), this case study provides alternative conceptualizations of black South African men that differ from previous portrayals of this population as inadequate and absent fathers, dominating men, and perpetrators of crime; in direct opposition to this, some of the men in this study could be described as responsible fathers, preventers of crime, and exhibitors of a complex range of traditional and gender-equitable masculinities. The utility of providing alternative conceptualizations of black South African men becomes clear when one considers the potential for harmful stereotypes towards black men to prevent the eventual achievement of racial equality in SA. Furthermore, as Morrell (2012) describes, stigmatizations of young black men through discussions of harmful forms of masculinity provides opportunities for prominent figures



like Zuma and Malema to demonize gender equality discourse, reducing the opportunity for the encouragement of gender-equitable norms. Thus, in addition to investigating perceptions and knowledge of BC among South African males, this study serves an instrumental purpose in providing a re-conceptualization of South African males and insight into how hegemonic masculinities can be both embodied and rejected in complex ways at the individual level.

#### **4.3 RECOMMENDATIONS**

This study provided support for several actionable recommendations that have the potential to improve the prevention and control of breast cancer in South Africa. These are further delineated and described below.

1. Strategic public health messaging to encourage earlier presentation of cancer to the healthcare system

There is a pressing need to employ significant efforts towards increasing awareness and knowledge of cancer throughout SA, particularly among marginalized and low-income groups. This is a relatively easy and inexpensive way to promote earlier presentation of cancer to the healthcare system, improve mortality rates, and reduce the overall burden on the health system. A study that examined the cost-effectiveness of BC treatment in Africa, North America, and Asia found that the most cost-effective interventions were treating individuals at Stage I and employing an extensive BC program that combined awareness campaigns and screening to promote earlier presentation; advanced BC treatment was found to be very cost-ineffective (Groot et al. 2006). Cancer is likely to be one of the most significant health issues in South Africa's future, due to

increases in risk factors related to development and urbanization (Akarolo-Anthony, Ogundiran, and Adebamowo 2010; Jemal et al. 2012). A clear and evidence-based approach to increasing awareness and promoting earlier presentation to the health system has the potential to ‘nip the problem in the bud’ before it becomes an unmanageable health crisis. There is clear support for the effectiveness of public health measures regarding tobacco use (Peltzer, 2008) and HIV/AIDS risk factors (Jewkes et al., 2008) in SA, and cancer needs to be attacked with the same vigor. These efforts should focus on clearly distinguishing cancer from HIV/AIDS and targeting specific misconceptions (such as the belief that cancer is contagious) that can be harmful or promote stigma towards individuals with cancer. Although specific social and financial barriers exist for black individuals in SA in regards to health issues, access to information is an inequity that can be relatively easily improved compared to other inequities. Doing so has the potential to empower individuals and reduce fatalistic beliefs towards health issues.

Furthermore, it is recommended that public health messaging strategies use the identified mediums of television, magazines, and radio, as well as endorsement by famous figures in SA; this strategy was also recommended in the current BC policy (National Department of Health, 2017, p. 95). Endorsement by a popular soccer player may be particularly engaging as this appears to be a common and beloved past-time for many individuals. Collaboration with local religious bodies may also prove to be a fruitful way to reach individuals as religion appears to be a prominent feature of many individuals’ lives. Public health messaging and cancer education needs to be provided in

African languages and in visual as well as written form in order to reach those who do not speak English and/or are illiterate.

Finally, awareness and knowledge efforts will play a pivotal role in the management of the cancer burden in SA, and should not be simply left to civil society as indicated by the current BC policy (National Department of Health, 2017, p. 93). Efforts to improve awareness and knowledge should be clearly established and delineated, and the government needs to play an active role in the coordination and implementation of efforts in order for them to be successful.

## 2. The inclusion of cancer education in schools

Furthermore, it is recommended that information about cancer, specifically the signs and symptoms, treatment options, and the importance of early detection for South Africa's major cancers (especially skin, cervical, and breast) should be included in the current health education program in primary and secondary schools. This has the potential to reduce the future cancer burden in the country by demystifying cancer, increasing awareness, and educating the future generation about their screening options. The information about cancer delivered in schools also has the potential to be brought back to parents through pamphlets or word of mouth, which could increase awareness of cancer among older generations.

### 3. Recognition of the role of the male partner in women's health issues

Within these efforts to increase awareness and promote earlier presentation, the prominent role of the male partner in women's health issues should be recognized and incorporated into public health efforts. The Breast Health Global Initiative is a collaborative organization of breast health experts that aim to develop realistic guidelines for BC care in low- and middle-income countries (Saghir et al., 2011). The group specifically addresses the need for campaigns that target husbands, parents, and community leaders as women's health decisions are often dictated or influenced by these individuals in low-resource settings (Saghir et al. 2011). Research from other countries and other health issues in SA also point to the importance of including the male partner (e.g. Asobayire & Barley, 2015; J.E. Maree, Wright, & Makua, 2011; Mullany, Becker, & Hindin, 2007).

The current BC control policy refers to the Multilevel Context of Care (Figure 2) as adapted from Taplin et al. (2012) to illustrate the levels of influence on a patient's care, including the family, health care provider, health system and government, although it does not specifically refer to the male partner. The particular influence that the male partner may have on health decisions from a financial, emotional and decision-making capacity should be considered. Furthermore, the policy states that "women identify more easily with their peers" (p. 95), and therefore should be provided with cancer education in this format. Although peer education may be one format in which BC education is delivered, the indication that women fear their husband will leave them after a BC diagnosis argues for the need to address this barrier to screening through the inclusion of men in the

discussion. As illustrated by the current study, hearing men's perspectives on this may serve to ease some of the anxiety that women experience.

Furthermore, men can be utilized as an influential presence to encourage women to complete BSE and receive check-ups as necessary. The Husbands Initiated Movement (HIM) (<http://www.himinitiative.com/>) is an example of an Indian initiative to include men in the fight against BC through encouraging their wives to complete BSE and CBEs (Husbands Initiated Movement Against Breast Cancer, 2016). A similar initiative, tailored to the specific cultural context of South Africa, may prove useful in promoting earlier presentation. It may also circumvent some of the documented barriers to women receiving care, such as perceptions of their unworthiness of care or limited independence to resolve their health needs (Maree & Wright, 2010; Pronyk et al., 2001).

Finally, further improvement of gender norms and attitudes has the potential to empower women to be more in control of their health needs and enhance their low perceived worthiness of care (Maree & Wright, 2010).

#### 4. Remove barriers and reduce dissatisfaction with the public healthcare system

Dissatisfaction with the public health system is reported in this study and many others (Bogart et al. 2013; Goudge et al. 2009; Trupe et al. 2017). The barriers to the public healthcare system need to be addressed and removed as quickly as possible by increasing the number of clinics in inadequately served areas such as Diepsloot, hiring more health professionals, increasing the hours that clinics are open, and employing measures to encourage more respectful treatment of patients by health care providers.

5. Provide accessible and cost-effective transportation to clinics and hospitals for vulnerable populations

Implementing a strategy to provide cost-effective transportation to clinics and hospitals as part of South Africa's restructuring of the current health system could also significantly reduce one of the major barriers restricting low-income individuals from accessing health care. This will also serve to decrease costs to the system through a reduction in missed appointments and earlier presentation of disease. Dickens et al., (2014) demonstrates that individuals who live farther away from the hospital are more likely to present with advanced stages of BC in SA. It is recommended that public health funds be directed towards subsidizing taxi fares to clinics and hospitals for low-income individuals, or a system be established in which the Department of Health employs specific taxis to transfer individuals from marginalized areas to health care centers on a scheduled basis. This strategy is in line with SA's commitment to improving health outcomes for the poor and marginalized and reducing fragmentation of the healthcare system that has been established with the release of the new NHI (Naidoo 2012; National Department of Health 2015).

6. Improve treatment pathways and ensure the provision of resources for treatment

Although beyond the scope of this paper, general observation indicates that treatment for BC in SA is less than adequate, causing some oncologists to resign in protest over the lack of functional equipment available ('Last cancer doctor quits in Durban', 2017). Although public messaging is important to promote earlier presentation,

the appropriate treatment pathways need to be in place to ensure accessible and affordable treatment to those that are diagnosed. This issue is discussed extensively in the new BC prevention and control policy (National Department of Health 2017); it is hoped that the measures outlined in this policy are carried to fruition.

#### 7. Integration and training of traditional health practitioners

It is recommended that SA pursues greater integration of the traditional and conventional health systems, as recommended by the WHO's current traditional medicine strategy (World Health Organization, 2013, p. 35). Integration efforts should focus on improving the referral pathways between systems, encouraging collaboration and mutual respect between health care providers (Steyn & Muller, 2000), and facilitating the ability for patients to access both physicians and THs in the same physical location. These efforts could be beneficial at reducing delays to accessing the conventional system, decreasing the experience of fragmented care, and improving treatment adherence (Campbell-Hall et al., 2010). Furthermore, it may discourage secrecy surrounding the use of traditional healing services, which could reduce possible complications from receiving a variety of treatment plans from health care providers that are not aware of or coordinated with one another. In addition, since traditional healers appear to be more culturally and physically accessible than conventional health care professionals, training them on cancer prevention and detection could be an effective way to augment SA's overburdened healthcare system and reach individuals in low-income communities (Steyn & Muller, 2000). This strategy is also being pursued in the management of the HIV/AIDS

epidemic (Peltzer, Mngqundaniso, & Petros, 2006; Wreford, 2005) and the provision of community mental health services in SA (Campbell-Hall et al., 2010).

Finally, religion appears to be a prominent aspect in individual's lives, and these beliefs should be considered and incorporated when addressing an individual's health needs.

8. Greater collaboration within and between breast cancer civil society and the government

As outlined in Section 1.3.6, there are some structures in place (such as the Cancer Alliance & Advocates for Breast Cancer) to establish collaboration between various cancer organizations in SA. However, the researcher's experience volunteering with local breast cancer organizations indicates that improvements could still be made to ensure that efforts to increase awareness of BC are coordinated, and individuals can experience continuity of support in their BC journey. Organizations should extend considerable effort towards communicating their goals and strategies with one another and aligning their efforts; Pfeiffer (2003) points to evidence that the lack of coordination between health organizations and duplicated efforts can produce fragmentation of health services and negative consequences for users. Collaboration between civil society and the Department of Health, such as that which occurred in the creation of the current BC policy (National Department of Health 2017), will ensure that awareness, support, screening and treatment are provided as a coordinated effort. As illustrated by Brinkerhoff (1999), collaborations between the state and civil society can "extend the capacities of both state and non-state



actors beyond what they can accomplish on their own” (p. 83), as long as factors such as the specification of objectives, determination of roles, the establishment of trust, and nurturing legal and regulatory frameworks for partnerships are put in place.

9. Utilize research to further explore perceptions of cancer and the role of gender in health-seeking behavior in order to inform public health efforts

Although there is a body of literature regarding knowledge and perceptions of breast and other types of cancer in SA, there is a need for this research base to be expanded upon to inform public health efforts. Furthermore, the role of gender norms in health-seeking behavior needs to be more comprehensively explored given the patriarchal nature of South African society and the limited social and financial independence of women. Further research is specifically required to investigate the role of male partners in health decisions made during BC treatment and care in SA. Relevant research should be made accessible and available to policy makers, civil society, health care providers, and communities in order for it to effectively inform policy and awareness efforts. Research from outside of SA, such as the guidelines for low- and middle-income countries developed by the Breast Health Global Initiative (Saghir et al. 2011; Yip et al. 2011), should be utilized in the creation and refinement of SA’s breast cancer strategy. Finally, the people of South Africa themselves must be given the opportunity to advocate for what they need and want in regards to health care; this cannot be fully understood or defined by researchers, policy makers, or organizations.

#### **4.4 LIMITATIONS**

In addition to the methodological limitations described in Section 2.10., other limitations include that although the participant's ethnic/linguistic group was recorded, the sample size was not large enough to make any observations about the influence an individual's cultural identity might have on their opinions, specifically in regards to gender norms and relations. It also would have been highly beneficial to interview the men's partners in order to observe how their knowledge and opinions compare and contrast to the men; this was not possible due to practical limitations.

Furthermore, it is difficult to say how the results regarding knowledge and perceptions of BC can be generalized to other population groups in SA. As evidenced by the variations in results within the literature regarding South African women's awareness and knowledge of BC, awareness and conceptions of cancer may differ depending on the community's socioeconomic status, historical and social factors, and their specific cultural context. As this study is exploratory in nature, there is a need for further research to validate these findings in other communities and populations groups before distinct conclusions can be drawn. However, this study provides a base for further research to expand upon using both qualitative and quantitative methods.

#### **4.5 KNOWLEDGE TRANSLATION**

One of the most pressing concerns during the preparation, data collection and writing of this thesis was how to ensure that the results of this study are accessible to those that may be able to use it in practical ways, such as policy makers, BC organizations, and the community of Diepsloot. As advocated by the World Health

Organization (Chunharas, Lansang, and Tugwell 2005), “research...has to be a component of a strategic process rather than an end in itself” (p. 71). This belief is embodied by the field of knowledge translation, which has recently received a significant amount of international attention due to the recognition that there is a disconnect between research and its application in practice, particularly in LMICs (Santesso and Tugwell 2006).

Knowledge translation (KT) is defined by the Canadian Institute for Health Research (CIHR), as a process of applying knowledge and research to improve health outcomes and strengthen health systems; it is considered to be an integral pillar of CIHR’s mandate (Canadian Institutes for Health Research n.d.). Seminal work by Straus, Tetroe, & Graham (2009) has presented a refined model of the ‘knowledge-to-action framework’ (Figure 3). In this model, knowledge creation consists of inquiry, synthesis, and products/tools. Inquiry refers to primary research, synthesis refers to gathering research evidence through systematic or literature reviews, and products/tools refers to guidelines or briefs that can be used in practical ways. The steps surrounding the knowledge creation triangle (the ‘action cycle’), such as adapting knowledge to the local context, assessing barriers to knowledge use, and selecting, tailoring and implementing interventions, can be done iteratively and simultaneously (Straus, Tetroe, and Graham 2009).

This study contributes to the knowledge inquiry stage of knowledge creation through the collection of primary data. However, efforts have and will be made to ensure that the results of the study are accessible to individuals in SA through the creation of

products/tools. One of the primary reasons for volunteering with local BC organizations was to establish relationships in which to engage in KT efforts after the completion of the study. In order to enhance the accessibility of the study findings, a concise summary of the study has been created in the form of an in-brief (Appendix K), which will be disseminated to relevant contacts (see Appendix J). Organizations will also have the opportunity to indicate how it can be adapted to best fit their specific needs. This represents a form of end-of-grant KT, which refers to dissemination through the usual avenues of conference presentations and publications as well as more extensive efforts to adapt the medium and content to a specific audience (Canadian Institutes for Health Research, n.d.).

As described previously, participants were given information about BC and other relevant cancers after the interview took place; those who requested it will also be sent a summary of the study results (Appendix I). Furthermore, an educational document about BC was created based on the knowledge gaps and misconceptions that were found in this study (Appendix L). This information will be included in the summary of study results given to participants. It will also be given to a local organization striving to raise awareness of BC in Diepsloot (Sedumedi Hope Foundation) to adapt and distribute as seen fit. Finally, another avenue that will be explored is the creation of an accessible summary of the literature review presented in Chapter 1, which could be useful for non-profit organizations that may not have the time, resources, or access to examine relevant research on BC in SA.

The focus on KT in this study also stems from a recognition of how a lack of access to health information is an inequity that can lead to poorer health outcomes, such as advanced presentation to the healthcare system for cancer. In some ways, inaccessibility to education and information can be considered a form of poverty in itself, a concept broadly referred to as ‘information poverty’ (Britz, 2004). Information poverty can both be caused by and serve to perpetuate social inequities (Britz, 2004). In South Africa, where black individuals were systematically denied the right to information and a comprehensive education (Clark & Worger, 2016; Pillay, 2002), the concept of information poverty is extremely relevant and useful when examining the root causes of health inequalities.

## **CHAPTER 5: CONCLUSIONS**

This study was based on evidence indicating that a lack of knowledge of breast cancer and current gender norms may play a role in the advanced presentation of South African women to the healthcare system for breast cancer. It sought to determine the perceptions and knowledge that male partners have about breast cancer and what role they play in their partner's access to health care.

The study used a case-based approach to investigate these questions in a unique group of men in long-term heterosexual relationships living in Diepsloot, a resource-poor setting. The findings indicate that the level of knowledge of breast cancer and cancer in general is very little, and that education about cancer is desired by the community. In addition, the men in this study describe themselves as playing an active and mostly positive role in their partner's access to health care. Some of the discourse they use about their relationships with their partners defies what would be expected given the literature about hegemonic forms of masculinity in South Africa. Rather, the findings support the idea that men in South Africa are responding to a barrage of both hegemonic and challenging forms of masculinities in South African society, resulting in a complex embodiment of aspects of each form. The findings from this study offer a re-conceptualization of black South African men that differs from previous depictions of them as dominating men and perpetrators of crime.

The findings also provide opportunities for specific recommendations to improve the experience of breast cancer in South Africa. These consist of various considerations for public health messaging about breast cancer, including a recognition of the role of the

male partner, as well as ways to address structural barriers to health care access.

Significant efforts have and will be made to ensure that the results of this study are accessible to those that may find them useful.

## References

- Advocates For Breast Cancer. “Advocacy Pays Off!”  
<https://blogforbreastcancer.wordpress.com/> (October 16, 2017).
- Akarolo-Anthony, Sally N, Temidayo O Ogundiran, and Clement A Adebamowo. 2010. “Emerging Breast Cancer Epidemic: Evidence from Africa.” *Breast Cancer Research* 12(Suppl 4): S8. <http://breast-cancer-research.biomedcentral.com/articles/10.1186/bcr2737> (November 27, 2016).
- Aluisio, Adam et al. 2011. “Male Antenatal Attendance and HIV Testing Are Associated with Decreased Infant HIV Infection and Increased HIV Free Survival.” *Journal of Acquired Immune Deficiency Syndromes* 1(561): 76–82.
- Ameade, Evans Paul Kwame et al. 2014. “Reducing the Breast Cancer Menace: The Role of the Male Partner in Ghana.” *Asian Pacific Journal of Cancer Prevention* 15(19): 8115–19.
- American Cancer Society. 2015. *Global Cancer Facts and Figures*. Atlanta, USA.  
<https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/global-cancer-facts-and-figures/global-cancer-facts-and-figures-3rd-edition.pdf> (October 15, 2017).
- Anfara, Vincent A. Jr., and Norma T. Mertz. 2006. *Theoretical Frameworks in Qualitative Research*. eds. Lisa Cuevas Shaw, Sanford Robinson, and Taryn Bigelow. Thousand Oaks, CA.
- Asobayire, Alice, and Ruth Barley. 2015. “Women’s Cultural Perceptions and Attitudes towards Breast Cancer: Northern Ghana.” *Health Promotion International* 30(3): 647–57.
- Aurini, Janice D, Melanie Heath, and Stephanie Howells. 2016. *The How To of Qualitative Research: Strategies for Executing High Quality Projects*. eds. Mila Steele, Sunshant Nailwail, and Andy Baxter. London, UK: SAGE Publications Ltd.
- Azenha, Gustavo et al. 2011. “The Role of Breast Cancer Civil Society in Different Resource Settings.” *Breast* 20(SUPPL. 2).
- Babb, Dale A et al. 2007. “Use of Traditional Medicine by HIV-Infected Individuals in South Africa in the Era of Antiretroviral Therapy.” *Psychology, Health & Medicine* 12(3): 314–20.  
<http://www.tandfonline.com/doi/pdf/10.1080/13548500600621511?needAccess=true> (September 27, 2017).
- Bearak, Barry. 2009. “Constant Fear and Mob Rule in South Africa Slum.” *The New York Times*.
- Bogart, Laura M et al. 2013. “Barriers to Care among People Living with HIV in South Africa: Contrasts between Patient and Healthcare Provider Perspectives.” *AIDS Care* 25(7): 843–53. <http://www.tandfonline->



- com.libaccess.lib.mcmaster.ca/doi/pdf/10.1080/09540121.2012.729808?needAccess=true (October 9, 2017).
- Boonzaier, Floretta. 2005. "Woman Abuse in South Africa: A Brief Contextual Analysis." *Feminism & Psychology* 15(1): 99–103.  
<http://journals.sagepub.com.libaccess.lib.mcmaster.ca/doi/pdf/10.1177/0959353505049711> (March 26, 2017).
- Bordage, Georges. 2009. "Conceptual Frameworks to Illuminate and Magnify." *Medical Education* 43: 312–19. <http://tch-rsp.com/wp-content/uploads/2014/08/Concept-Framework-to-Illiminate-and-Magnify-Medical-Education-Research.pdf> (October 16, 2017).
- Breast Health Foundation. "Who We Are." *Breast Health Foundation*.  
<http://www.mybreast.org.za/about/> (October 16, 2017).
- Brinkerhoff, Derick W. 1999. "Exploring State–Civil Society Collaboration: Policy Partnerships in Developing Countries." *Nonprofit and Voluntary Sector Quarterly* 28(4). <http://journals.sagepub.com/doi/pdf/10.1177/089976409902801S01> (October 10, 2017).
- Brinton, Louise A. et al. 2014. "Breast Cancer in Sub-Saharan Africa: Opportunities for Prevention." *Breast Cancer Res Treat.* 144(3): 467–78.
- Britton, Hannah. 2006. "Organising against Gender Violence in South Africa." *Journal of Southern African Studies* 32(145–163). <http://www-tandfonline-com.libaccess.lib.mcmaster.ca/doi/pdf/10.1080/03057070500493852?needAccess=true> (March 26, 2017).
- Britz, Johannes J. 2004. "To Know or Not to Know: A Moral Reflection on Information Poverty." *Journal of Information Science* 30(3): 192–204.  
<http://www.who.int/bulletin/volumes/83/10/editorial21005html/en/> (October 16, 2017).
- Bryman, Alan. 2012. *Social Research Methods*. 4th ed. New York, USA: Oxford University Press.
- Canadian Cancer Society. "Symptoms of Breast Cancer." <http://www.cancer.ca/en/cancer-information/cancer-type/breast/signs-and-symptoms/?region=bc> (October 11, 2017).
- Canadian Institutes for Health Research. "About Us: Knowledge Translation and Commercialization." *Canadian Institutes for Health Research* . <http://www.cihr-irsc.gc.ca/e/29418.html#1> (October 16, 2017).
- Cancer Alliance South Africa. "About the Cancer Alliance."  
<https://www.canceralliance.co.za/about/> (October 15, 2017).
- "Cellphone Radiation: Only the Facts." 2012. *IT Web: Mobile Business* .  
[http://www.itweb.co.za/index.php?option=com\\_content&view=article&id=55369](http://www.itweb.co.za/index.php?option=com_content&view=article&id=55369) (October 8, 2017).

- Chamberlain, J et al. 2007. “Women’s Perception of Self-Worth and Access to Health Care.” *International Journal of Gynecology & Obstetrics* 98(1): 75–79.
- Chunharas, Somsak, Mary Ann Lansang, and Peter Tugwell. 2005. “Knowledge Translation in Global Health.” *Bulletin of the World Health Organization* 83(10): 721–800. <http://www.who.int/bulletin/volumes/83/10/editorial21005html/en/>.
- Clark, N.L., and W.H. Worger. 2016. *South Africa: The Rise and Fall of Apartheid*. 3rd ed. Abingdon, Oxon: Routledge.
- Coleman, Michel P et al. 2008. “Cancer Survival in Five Continents: A Worldwide Population-Based Study (CONCORD).” *Lancet Oncology* 9: 730–56. [http://ac.els-cdn.com/S1470204508701797/1-s2.0-S1470204508701797-main.pdf?\\_tid=5b9ddf7e-9e3a-11e7-a2d0-00000aacb35f&acdnat=1505936094\\_c8f50fecc2f9c958b0e12c7e873f5102](http://ac.els-cdn.com/S1470204508701797/1-s2.0-S1470204508701797-main.pdf?_tid=5b9ddf7e-9e3a-11e7-a2d0-00000aacb35f&acdnat=1505936094_c8f50fecc2f9c958b0e12c7e873f5102) (September 20, 2017).
- Connell, R. 1995. *Masculinities*. Cambridge, UK: Polity.
- Connell, Raewyn. 1987. *Gender and Power: Society, the Person and Sexual Politics*. Palo Alto, CA: University of California Press.
- Coovadia, Hoosen et al. 2009. “The Health and Health System of South Africa: Historical Roots of Current Public Health Challenges.” *The Lancet* 374(9692): 817–34. [http://dx.doi.org/10.1016/S0140-6736\(09\)60951-X](http://dx.doi.org/10.1016/S0140-6736(09)60951-X).
- Creswell, John. W. 2007. *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. 2nd ed. Thousand Oaks, CA: SAGE Publications Inc.
- Cubasch, Herbert et al. 2013. “Breast Cancer Characteristics and HIV among 1,092 Women in Soweto, South Africa.” *Breast Cancer Research and Treatment* 140(1): 177–86.
- Davison, Charlie, Stephen Frankel, and George Davey Smithy. 1992. “The Limits of Lifestyle: Re-Assessing ‘Fatalism’ in the Popular Culture of Illness Prevention.” *Social Science and Medicine* 34(6): 67–68. [https://journals-scholarsportal-info.libaccess.lib.mcmaster.ca/pdf/02779536/v34i0006/675\\_tlolritpcoip.xml](https://journals-scholarsportal-info.libaccess.lib.mcmaster.ca/pdf/02779536/v34i0006/675_tlolritpcoip.xml) (October 8, 2017).
- Deeks, Steven G, Sharon R Lewin, and Diane V Havlir. 2013. “The End of AIDS: HIV Infection as a Chronic Disease.” *The Lancet* 382: 1525–33. [https://ac-els-cdn-com.libaccess.lib.mcmaster.ca/S0140673613618097/1-s2.0-S0140673613618097-main.pdf?\\_tid=37b58926-ad0e-11e7-8c4b-00000aacb35f&acdnat=1507566403\\_989c162ea3d056e8f17042bd04c0c7cf](https://ac-els-cdn-com.libaccess.lib.mcmaster.ca/S0140673613618097/1-s2.0-S0140673613618097-main.pdf?_tid=37b58926-ad0e-11e7-8c4b-00000aacb35f&acdnat=1507566403_989c162ea3d056e8f17042bd04c0c7cf) (October 9, 2017).
- Dickens, Caroline et al. 2014. “Stage at Breast Cancer Diagnosis and Distance from Diagnostic Hospital in a Periurban Setting: A South African Public Hospital Case Series of over 1,000 Women.” *International Journal of Cancer* 135(9): 2173–82.
- Ditekemena, John et al. 2012. “Determinants of Male Involvement in Maternal and Child

- Health Services in Sub-Saharan Africa: A Review.” *Reproductive health* 9(1): 32.  
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3573948&tool=pmcentrez&rendertype=abstract>.
- “Do Cell Phones Cause Cancer?” 2017. *Cancer Association of South Africa* .  
<http://www.cansa.org.za/urban-legend-can-cell-phones-cause-cancer/> (October 8, 2017).
- Dunkle, Kristin L et al. 2006. “Perpetration of Partner Violence and HIV Risk Behaviour among Young Men in the Rural Eastern Cape, South Africa.” *AIDS* 20(16): 2107–14.  
<http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00002030-200610240-00013> (November 28, 2016).
- Dworkin, S. L., C. Colvin, a. Hatcher, and D. Peacock. 2012. “Men’s Perceptions of Women’s Rights and Changing Gender Relations in South Africa: Lessons for Working With Men and Boys in HIV and Antiviolence Programs.” *Gender & Society* 26(1): 97–120.
- Dworkin, Shari L, Abigail M Hatcher, Chris Colvin, and Dean Peacock. 2012. “Impact of a Gender- Transformative HIV and Antiviolence Program on Gender Ideologies and Masculinities in Two Rural, South African Communities.” *Men and Masculinities* 16(2): 181–202.
- Edge, Jenny, Ines Buccimazza, Herbert Cubasch, and Eugenio Panieri. 2014. “The Challenges of Managing Breast Cancer in the Developing World – a Perspective from Sub-Saharan Africa.” *South African Medical Journal* 104(5): 377.  
<http://hmpg.co.za/index.php/samj/article/view/2956>.
- eNEWS Channel Africa. 2013. “Tough Conditions for Black Kids - Stats SA.” *eNEWS Channel Africa*. <http://www.enca.com/south-africa/tough-conditions-black-kids-stats-sa> (October 19, 2017).
- Erickson, F. 1986. “Qualitative Methods on Research in Teaching.” In *Handbook of Research on Teaching*, ed. M.C. Whittrock. Old Tappen, NJ: Macmillan, 119–61.
- Espinosa de los Monteros, Karla, and Linda C Gallo. 2010. “The Relevance of Fatalism in the Study of Latinas’ Cancer Screening Behavior: A Systematic Review of the Literature.” *International Journal of Behavioral Medicine* 18: 310–18. <https://link-springer-com.libaccess.lib.mcmaster.ca/content/pdf/10.1007%2Fs12529-010-9119-4.pdf> (October 8, 2017).
- Ferlay, Jacques et al. 2015. “Cancer Incidence and Mortality Worldwide: Sources, Methods and Major Patterns in GLOBOCAN 2012.” *International Journal of Cancer* 136(5): E359–86. <http://doi.wiley.com/10.1002/ijc.29210> (November 27, 2016).
- Flyvbjerg, Bent. 2006. “Five Misunderstandings About Case-Study Research.” *Qualitative Inquiry* 12(2): 219–45.  
<http://journals.sagepub.com/doi/pdf/10.1177/1077800405284363> (October 12, 2017).

- Gale, Nicola K et al. 2013. "Using the Framework Method for the Analysis of Qualitative Data in Multi-Disciplinary Health Research." *BMC Medical Research Methodology* 13(1): 117. <http://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-13-117> (September 20, 2017).
- Gobo, Giampietro. 2011. *Qualitative Research*. 3rd ed. ed. David Silverman. London: SAGE Publications Ltd.
- Golooba-Mutebi, Frederick, and Stephen M. Tollman. 2007. "Shopping for Health: Affliction and Response in a South African Village." *African Sociological Review* 11(2): 64–79.
- Goudge, Jane et al. 2009. "Affordability, Availability and Acceptability Barriers to Health Care for the Chronically Ill: Longitudinal Case Studies from South Africa." *BMC health services research* 9(1): 75. <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-9-75>.
- Groot, M T et al. 2006. "Costs and Health Effects of Breast Cancer Interventions in Epidemiologically Different Regions of Africa, North America and Asia." *The Breast Journal* 12(Suppl 1): S81–90.
- Harding, Andrew. 2013. "South Africa Crippled by Rape Culture." *BBC News*. <http://www.bbc.com/news/world-africa-20971240>.
- Harding, Jamie. 2013. *Qualitative Data Analysis from Start to Finish*. eds. Katie Metzler, Anna Horvai, Ian Antcliff, and Rosemary Morlin. London, UK: SAGE Publications Ltd.
- Harris, B et al. 2011. "Inequities in Access to Health Care in South Africa." *Journal of Public Health Policy* 32(S1): S102–23.
- Health, Sonke Gender Justice and Wits School of Public. 2015. *One Man Can Randomised Control Trial in Diepsloot, Johannesburg: Sonke CHANGE Trial*. Johannesburg, South Africa. <http://www.genderjustice.org.za/publication/one-man-can-randomised-control-trial-in-diepsloot/>.
- Hoffman, M et al. 2000. "Breast Cancer Incidence and Determinants of Cancer Stage in the Western Cape." *South African Medical Journal* 90(12): 1212–16. <http://www.ncbi.nlm.nih.gov/pubmed/11234652>.
- Hosegood, Victoria, Nuala McGrath, and Tom Moultrie. 2009. "Dispensing with Marriage: Marital and Partnership Trends in Rural Kwazulu-Natal, South Africa 2000-2006." *Demographic research* 20: 279–312. <https://www.ncbi.nlm.nih.gov/libaccess.lib.mcmaster.ca/pmc/articles/PMC4340557/pdf/emss-61764.pdf> (October 14, 2017).
- "Husbands Initiated Movement Against Breast Cancer." 2016. <http://www.himinitiative.com/> (October 8, 2017).
- International Agency for Research on Cancer. 2012. "GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012."

- [http://globocan.iarc.fr/Pages/fact\\_sheets\\_population.aspx](http://globocan.iarc.fr/Pages/fact_sheets_population.aspx) (November 27, 2016).
- Jemal, Ahmedin et al. 2012. “Cancer Burden in Africa and Opportunities for Prevention.” *Cancer* 118(18): 4372–84. <http://doi.wiley.com/10.1002/cncr.27410> (November 27, 2016).
- Jewkes, R., and R. Morrell. 2010. “Gender and Sexuality: Emerging Perspectives from the Heterosexual Epidemic in South Africa and Implications for HIV Risk and Prevention.” *Journal of the International AIDS Society* 13(1): no pagination. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed9&NEWS=N&AN=2010237457>.
- Jewkes, Rachel et al. 2008. “Impact of Stepping Stones on Incidence of HIV and HSV-2 and Sexual Behaviour in Rural South Africa: Cluster Randomised Controlled Trial.” *British Medical Journal* 337113111(7666): 391–95. <http://www.jstor.org/stable/20510588> (October 11, 2017).
- Jewkes, Rachel K., Kristin Dunkle, Mzikazi Nduna, and Nwabisa Shai. 2010. “Intimate Partner Violence, Relationship Power Inequity, and Incidence of HIV Infection in Young Women in South Africa: A Cohort Study.” *The Lancet* 376(9734): 41–48.
- Jewkes, Rachel, Yandisa Sikweyiya, Robert Morrell, and Kristin Dunkle. 2009. “Understanding Men’s Health and Use of Violence: Interface of Rape and HIV in South Africa.” *Cell* 82(442).
- Kale, Rajendra. 1995. “Traditional Healers in South Africa: A Parallel Health Care System.” *British Medical Journal* 310: 1182–85. <https://www.ncbi-nlm-nih-gov.libaccess.lib.mcmaster.ca/pmc/articles/PMC2549561/pdf/bmj00591-0038.pdf> (September 30, 2017).
- Krombein, IW, and PJT De Villiers. 2006. “Breast Cancer – Early Detection and Screening in South African Women from the Bonteheuwel Township in the Western Cape: Knowledge, Attitudes and Practices.” *South African Family Practice* 48(5): 14.
- Krumpal, Ivar. 2013. “Determinants of Social Desirability Bias in Sensitive Surveys: A Literature Review.” *Quality & Quantity* 47: 2025–47. <https://link-springer-com.libaccess.lib.mcmaster.ca/content/pdf/10.1007%2Fs11135-011-9640-9.pdf> (October 16, 2017).
- “Last Cancer Doctor Quits in Durban.” 2017. *eNEWS Channel Africa*. <http://www.enca.com/south-africa/last-cancer-doctor-quits-in-durban>.
- Lehohla, Pali. 2008. “Income and Expenditure of Households 2005/2006: Analysis of Results.” *Statistics South Africa. Pretoria: Statistics South Africa*.
- Levitt, Naomi S, Krisela Steyn, Joel Dave, and Debbie Bradshaw. 2011. “Chronic Noncommunicable Diseases and HIV-AIDS on a Collision Course: Relevance for Health Care Delivery, Particularly in Low-Resource Settings—insights from South Africa 1–4.” *The American Journal of Clinical Nutrition* (94): 1690S–1696S.

- <http://ajcn.nutrition.org.libaccess.lib.mcmaster.ca/content/94/6/1690S.full.pdf> (October 9, 2017).
- LifeLine Johannesburg. “Your LifeLine.” *LifeLine Johannesburg* .  
<http://www.lifelinejhb.org.za/about-who.ashx> (October 16, 2017).
- Lomofsky, Lilian, and Sandy Lazarus. 2001. “South Africa: First Steps in the Development of an Inclusive Education System.” *Cambridge Journal of Education* 31(3): 303–17. <http://www-tandfonline-com.libaccess.lib.mcmaster.ca/doi/pdf/10.1080/03057640120086585?needAccess=true> (October 8, 2017).
- Luyt, R. 2012. “Representation of Masculinities and Race in South African Television Advertising: A Content Analysis.” <http://www.tandfonline.com/> (November 27, 2016).
- Mahajan, Sandeep. 2014. *Economics of South African Townships: Special Focus on Diepsloot*. World Bank Publications.
- Malan, Mia. 2016. “Diepsloot: A Place of Hell for Women.” *Sonke Gender Justice* .  
<http://www.genderjustice.org.za/news-item/diepsloot-place-hell-women/> (October 16, 2017).
- Malan, Mia, and Rosemary Leaver. 2003. “Political Change in South Africa: New Tobacco Control and Public Health Policies.” In *Tobacco Control Policy: Strategies, Successes, and Setbacks*, eds. Linda Waverley Brigden and Joy de Beyer. World Bank Publications, 121–53.  
<https://pdfs.semanticscholar.org/189b/e3052f740f8424a613997ba911e684bec311.pdf> (October 7, 2017).
- Maree, J.E., S.C.D. Wright, and T.P. Makua. 2011. “Men’s Lack of Knowledge Adds to the Cervical Cancer Burden in South Africa.” *European Journal of Cancer Care* 20(5): 662–68. <http://doi.wiley.com/10.1111/j.1365-2354.2011.01250.x> (October 7, 2017).
- Maree, Johanna E., and Susanna C D Wright. 2010. “How Would Early Detection Be Possible? An Enquiry into Cancer Related Knowledge, Understanding and Health Seeking Behaviour of Urban Black Women in Tshwane, South Africa.” *European Journal of Oncology Nursing* 14(3): 190–96.
- Mayo, Rachel, and Anita Hunter. 2003. “Fatalism Toward Breast Cancer Among the Women of Ghana.” *Health Care for Women International* 24(7): 608–16.  
<http://www.tandfonline.com/doi/abs/10.1080/07399330390217752>.
- Mayosi, Bongani M et al. “Health in South Africa: The Burden of Non-Communicable Diseases in South Africa.” *The Lancet* 374: 934–47. [https://ac-els-cdn-com.libaccess.lib.mcmaster.ca/S0140673609610874/1-s2.0-S0140673609610874-main.pdf?\\_tid=dbccf09c-ab94-11e7-93af-00000aacb35d&acdnt=1507404329\\_1f331574090b3f9a603cce8d411b08fa](https://ac-els-cdn-com.libaccess.lib.mcmaster.ca/S0140673609610874/1-s2.0-S0140673609610874-main.pdf?_tid=dbccf09c-ab94-11e7-93af-00000aacb35d&acdnt=1507404329_1f331574090b3f9a603cce8d411b08fa) (October 7, 2017).

- Mayosi, Bongani M. et al. 2009. "The Burden of Non-Communicable Diseases in South Africa." *The Lancet* 374(9693): 934–47.
- Mba. 2005. "Racial Differences in Marital Status and Living Arrangements of Older Persons in South Africa." *British Society of Gerontology* 15(2): 23–31.
- Mbewe, Samson, and Ingrid Woolard. 2016. *Cross-Sectional Features of Wealth Inequality in South Africa: Evidence from The National Income Dynamics Study*. Cape Town .  
[http://www.opensaldru.uct.ac.za/bitstream/handle/11090/843/2016\\_185\\_Saldruwp.pdf?sequence=1](http://www.opensaldru.uct.ac.za/bitstream/handle/11090/843/2016_185_Saldruwp.pdf?sequence=1) (October 16, 2017).
- McKinley, Dale T. 2003. *The State of Access to Information in South Africa*.  
[http://www.humanrightsinitiative.org/programs/ai/rti/international/laws\\_papers/south\\_africa/McKinley\\_FOI\\_in\\_South\\_Africa.pdf](http://www.humanrightsinitiative.org/programs/ai/rti/international/laws_papers/south_africa/McKinley_FOI_in_South_Africa.pdf) (September 27, 2017).
- Merriam, Sharan B. 2009. *Qualitative Research: A Guide to Design and Implementation*. 2nd ed. San Francisco: Jossey-Bass.
- Moodley, Jennifer, Lydia Cairncross, Thurandrie Naiker, and Mariette Momberg. 2016. "Understanding Pathways to Breast Cancer Diagnosis among Women in the Western Cape Province, South Africa: A Qualitative Study." *British Medical Journal Open* 6(1): e009905. <http://bmjopen.bmj.com/lookup/doi/10.1136/bmjopen-2015-009905>.
- Morrell, R. 1994. "Masculinity and the White Boys' Boarding Schools of Natal, 1880-1930." *Perspectives in Education* 15(1): 27–52.
- . 2001. *Changing Men in Southern Africa*. Pietermaritzburg/London: University of Natal Press/Zed Books.
- Morrell, R., R. Jewkes, and G. Lindegger. 2012. "Hegemonic Masculinity/Masculinities in South Africa: Culture, Power, and Gender Politics." *Men and Masculinities*: 1–20.
- Morrell, R, and Rachel K Jewkes. 2013. "Hegemonic Masculinity: Reviewing the Gendered Analysis of Men's Power in South Africa." *South African Review of Sociology* 44(1): 3–21.  
<http://www.tandfonline.com/doi/abs/10.1080/21528586.2013.784445>.
- Morrell, Robert. 1998. "Of Boys and Men: Masculinity and Gender in Southern African Studies 1." *Journal of Southern African Studies* 24(4).
- Morse, Janice M et al. 2002. "Verification Strategies for Establishing Reliability and Validity in Qualitative Research." *International Journal of Qualitative Methods* 1(2).  
<http://journals.sagepub.com/doi/pdf/10.1177/160940690200100202> (September 20, 2017).
- Motsoaledi, Aaron (Minister of Health). 2010. *Media Statement: Outline of the National HIV Counselling and Testing (HCT) Campaign*. <https://www.health-e.org.za/wp-content/uploads/2013/05/5933cbb60e74e4936cd4aaf7201906fb.pdf> (October 9, 2017).

- Mullany, Britta C, S Becker, and M J Hindin. 2007. "The Impact of Including Husbands in Antenatal Health Education Services on Maternal Health Practices in Urban Nepal: Results from a Randomized Controlled Trial." *Health Education Research* 22(2): 166–76.  
[https://journals.scholarsportal.info/pdf/02681153/v22i0002/166\\_tioihirfarct.xml](https://journals.scholarsportal.info/pdf/02681153/v22i0002/166_tioihirfarct.xml) (October 10, 2017).
- Naidoo, Shan. 2012. "The South African National Health Insurance: A Revolution in Health-Care Delivery!" *Journal of Public Health* 34(1): 149–50.
- Nair, M. Krishnan et al. 1993. "Overall Survival from Breast Cancer in Kerala, India, in Relation to Menstrual, Reproductive, and Clinical Factors." *Cancer* 71(5): 1791–96.  
<http://doi.wiley.com/10.1002/1097-0142%2819930301%2971%3A5%3C1791%3A%3AAID-CNCR2820710513%3E3.0.CO%3B2-W> (November 27, 2016).
- National Cancer Registry. 2013. *Cancer in South Africa 2013 Full Report*.  
[http://www.nioh.ac.za/?page=national\\_cancer\\_registry&id=41](http://www.nioh.ac.za/?page=national_cancer_registry&id=41) (November 27, 2016).
- National Department of Health. 2010. *National HIV Counselling and Testing (HCT) Policy Guidelines*. Pretoria, South Africa.  
[https://aidsfree.usaid.gov/sites/default/files/hts\\_policy\\_south-africa.pdf](https://aidsfree.usaid.gov/sites/default/files/hts_policy_south-africa.pdf).
- . 2015. *National Health Insurance for South Africa: Towards Universal Health Coverage - Version 40*. <https://www.health-e.org.za/wp-content/uploads/2015/12/National-Health-Insurance-for-South-Africa-White-Paper.pdf> (January 31, 2017).
- . 2017. *Breast Cancer Prevention and Control Policy*.  
<http://blogs.uct.ac.za/cancerphd/wp-content/uploads/2017/09/Breast-Cancer-Policy-2017.pdf>.
- National Department of Health, and National Department of Basic Education. 2012. *Integrated School Health Policy*. [https://www.health-e.org.za/wp-content/uploads/2013/10/Integrated\\_School\\_Health\\_Policy.pdf](https://www.health-e.org.za/wp-content/uploads/2013/10/Integrated_School_Health_Policy.pdf) (October 8, 2017).
- National Health Insurance South Africa. "National Health Insurance: Facts."  
[http://www.nhisa.co.za/D\\_Comments.asp](http://www.nhisa.co.za/D_Comments.asp) (November 29, 2016).
- Nelson, Heidi D. et al. 2012. "Risk Factors for Breast Cancer for Women Aged 40 to 49 Years: A Systematic Review and Meta-Analysis." *Annals of Internal Medicine* 156(9): 635–648.
- Nelson Mandela Foundation. "Nelson Mandela Day." *Nelson Mandela Day*.  
<https://www.mandeladay.com/> (October 16, 2017).
- Nxumalo, Nonhlanhla et al. 2011. "Utilization of Traditional Healers in South Africa and Costs to Patients: Findings from a National Household Survey." *Journal of public health policy* 32 Suppl 1(S1): S124-36.  
<http://www.ncbi.nlm.nih.gov/pubmed/21730986>.



- Opoku, Samuel Yaw, Martin Benwell, and Joel Yarney. 2012. "Knowledge, Attitudes, Beliefs, Behaviour and Breast Cancer Screening Practices in Ghana, West Africa." *Pan African Medical Journal* 11(28).
- Peek, Monica E, Judith V Sayad, and Ronald Markwardt. 2008. "Fear, Fatalism and Breast Cancer Screening in Low-Income African-American Women: The Role of Clinicians and the Health Care System." *Journal of General Internal Medicine* 23(11): 1847–53. <https://link-springer-com.libaccess.lib.mcmaster.ca/content/pdf/10.1007%2Fs11606-008-0756-0.pdf> (October 8, 2017).
- Peltzer, K, and N Phaswana-Mafuya. 2014. "Breast and Cervical Cancer Screening and Associated Factors among Older Adult Women in South Africa." *Asian Pacific Journal of Cancer Prevention* 15(6): 2473–76.
- Peltzer, Karl. 1999. "Faith Healing for Mental and Social Disorders in the Northern Province (South Africa)." *Journal of Religion in Africa* 29(3): 387–402. <http://www.jstor.org.libaccess.lib.mcmaster.ca/stable/pdf/1581530.pdf?refreqid=excelior%3A03dcf12ddc8913dd427cf32627dde4bf> (September 30, 2017).
- . 2008. "Tobacco Use Trends among Adolescents and Adults in South Africa." *Journal of Psychology in Africa* 18(2): 339–46. <http://www-tandfonline-com.libaccess.lib.mcmaster.ca/doi/pdf/10.1080/14330237.2008.10820207?needAccess=true> (October 8, 2017).
- Pfeiffer, James. 2003. "International NGOs and Primary Health Care in Mozambique: The Need for a New Model of Collaboration." *Social Science & Medicine* (56): 725–38. [https://ac.els-cdn.com/S0277953602000680/1-s2.0-S0277953602000680-main.pdf?\\_tid=a218bce8-ade0-11e7-be9c-00000aab0f01&acdnat=1507656776\\_dd260108d3eba479fe232fa048808113](https://ac.els-cdn.com/S0277953602000680/1-s2.0-S0277953602000680-main.pdf?_tid=a218bce8-ade0-11e7-be9c-00000aab0f01&acdnat=1507656776_dd260108d3eba479fe232fa048808113) (October 10, 2017).
- Pillay, Anthony L. 2002. "Rural and Urban South African Women ' S Awareness of Cancers of the Breast and Cervix." 7(2): 103–14.
- Pillay, Verashni. 2013. "Malema: South Africa's Feminism Champion?" *Mail & Guardian*.
- PinkDrive. "Our Mission." *PinkDrive*. <http://www.pinkdrive.co.za/our-mission/> (October 16, 2017).
- Pronyk, R M et al. 2001. "Assessing Health Seeking Behaviour among Tuberculosis Patients in Rural South Africa." *The International Journal of Tuberculosis and Lung Disease* 5(7): 619–27. <http://www.ncbi.nlm.nih.gov/pubmed/11467368> (November 27, 2016).
- QSR International. 2015. "NVivo 11 Qualitative Data Analysis Software for Mac."
- Rayne, S., L. Mokgatle, and C.A. Benn. "Socioeconomic Barriers to Breast Cancer Care in South Africa: The Impact of Multiple Hospital Visits on Costs and Compliance for

Patients.”

Rayne, Sarah et al. 2016. “Fear of Treatments Surpasses Demographic and Socioeconomic Factors in Affecting Patients With Breast Cancer in Urban South Africa.” *Journal of Global Oncology* 3(2): 125–34.  
<http://jgo.ascopubs.org/content/early/2016/06/18/JGO.2015.002691.full.pdf+html>.

Richter, Linda, Jeremiah Chikovore, and Tawanda Makusha. 2010. “The Status of Fatherhood and Fathering in South Africa.” *Childhood Education* 86(6): 360–65.  
<http://www-tandfonline-com.libaccess.lib.mcmaster.ca/doi/pdf/10.1080/00094056.2010.10523170> (October 16, 2017).

Saghir, Nagi S. El et al. 2011. “Breast Cancer Management in Low-Resource Countries (LRCs): Consensus Statement from the Breast Health Global Initiative.” *Breast* 20(SUPPL. 2): S3–11. <http://dx.doi.org/10.1016/j.breast.2011.02.006>.

Sankaranarayanan, Rengaswamy et al. 2010. “Cancer Survival in Africa, Asia, and Central America: A Population-Based Study.” *Lancet Oncology* 11(2): 165–73.  
[https://s3.amazonaws.com/academia.edu.documents/45303267/Cancer\\_survival\\_in\\_Africa\\_Asia\\_and\\_Centr20160503-4757-34bv4f.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1505939296&Signature=UvWCXbWfF1b7AJPz%2Fq7eiTT1Jfs%3D&response-content-disposition=inline](https://s3.amazonaws.com/academia.edu.documents/45303267/Cancer_survival_in_Africa_Asia_and_Centr20160503-4757-34bv4f.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1505939296&Signature=UvWCXbWfF1b7AJPz%2Fq7eiTT1Jfs%3D&response-content-disposition=inline) (September 20, 2017).

Santesso, Nancy, and Peter Tugwell. 2006. “Knowledge Translation in Developing Countries.” *The Journal of Continuing Education in the Health Professions* 26(26): 87–96. [https://journals-scholarsportal-info.libaccess.lib.mcmaster.ca/pdf/08941912/v26i0001/87\\_ktidc.xml](https://journals-scholarsportal-info.libaccess.lib.mcmaster.ca/pdf/08941912/v26i0001/87_ktidc.xml) (October 16, 2017).

Schooley, Janine et al. 2009. “Factors Influencing Health Care-Seeking Behaviours among Mayan Women in Guatemala.” *Midwifery* 25: 411–21.  
[www.elsevier.com/locate/midw](http://www.elsevier.com/locate/midw) (November 28, 2016).

Schwab, Terri, Julie Meyer, and Rosa Merrell. 1994. “Measuring Attitudes and Health Beliefs Among Mexican Americans With Diabetes.” *The Diabetes Educator* 20(3): 221–27.  
<http://journals.sagepub.com.libaccess.lib.mcmaster.ca/doi/pdf/10.1177/014572179402000308> (October 8, 2017).

Seekings, Jeremy. 2008. “The Continuing Salience of Race: Discrimination and Diversity in South Africa.” *Journal of Contemporary African Studies* 26(1): 1–25.  
<http://www.tandfonline.com/doi/pdf/10.1080/02589000701782612?needAccess=true> (September 27, 2017).

Sideris, Tina. 2004. “‘You Have to Change and You Don’t Know How!’: Contesting What It Means to Be a Man in a Rural Area of South Africa.” *African Studies* 63(1): 24–49. <http://www-tandfonline-com>

- com.libaccess.lib.mcmaster.ca/doi/pdf/10.1080/0002018042000226148?needAccess=true (March 17, 2017).
- Sonke Gender Justice. “About Sonke.” *Sonke Gender Justice*.  
<http://www.genderjustice.org.za/about-us/about-sonke/> (October 16, 2017).
- Stake, R.E. 2005. “Qualitative Case Studies.” In *The Sage Handbook of Qualitative Research*, eds. N.K. Denzin and Y.S. Lincoln. Thousand Oaks, CA: SAGE Publications Ltd, 443–66.
- Statistics South Africa. 2004. *Census 2001: Primary Tables South Africa: Census '96 and 2001 Compared*. Pretoria.  
[http://www.statssa.gov.za/census/census\\_2001/primary\\_tables/RSAPrimary.pdf](http://www.statssa.gov.za/census/census_2001/primary_tables/RSAPrimary.pdf) (September 30, 2017).
- . 2012. *South Africa's Young Children: Their Family and Home Environment, 2012*. Pretoria, SA. <http://www.statssa.gov.za/publications/Report-03-10-07/Report-03-10-072012.pdf> (October 19, 2017).
- . 2016. *Community Survey 2016: Statistical Release (P0301)*.  
[http://cs2016.statssa.gov.za/wp-content/uploads/2016/07/NT-30-06-2016-RELEASE-for-CS-2016-\\_Statistical-releas\\_1-July-2016.pdf](http://cs2016.statssa.gov.za/wp-content/uploads/2016/07/NT-30-06-2016-RELEASE-for-CS-2016-_Statistical-releas_1-July-2016.pdf) (October 14, 2017).
- . 2017a. *General Household Survey 2016: Statistical Release (P0318)*. Pretoria, SA. <http://www.statssa.gov.za/publications/P0318/P03182016.pdf> (October 16, 2017).
- . 2017b. *Mid-Year Population Estimates 2017: Statistical Release (P0302)*.  
<http://www.statssa.gov.za/publications/P0302/P03022017.pdf>.
- Stekelenburg, Jelle et al. 2005. “Health Care Seeking Behaviour and Utilisation of Traditional Healers in Kalabo, Zambia.” *Health Policy* 71(1): 67–81.  
<http://linkinghub.elsevier.com/retrieve/pii/S0168851004001150> (November 27, 2016).
- Straus, Sharon E., Jacqueline Tetroe, and Ian Graham. 2009. “Defining Knowledge Translation.” *Canadian Medical Association Journal* 181(3–4): 165–68.  
<http://www.cmaj.ca.libaccess.lib.mcmaster.ca/content/181/3-4/165.full.pdf> (October 16, 2017).
- Support Services. 1992. *National Education Policy Investigation*. Cape Town: Oxford University Press.
- Taplin, Stephen H et al. 2012. “Introduction: Understanding and Influencing Multilevel Factors Across the Cancer Care Continuum.” *Journal of the National Cancer Institute Monographs* 44(44): 2–10.  
[https://journals.scholarsportal.info/pdf/10526773/v2012i0044/2\\_iuaimfatccc.xml](https://journals.scholarsportal.info/pdf/10526773/v2012i0044/2_iuaimfatccc.xml) (October 10, 2017).
- The World Bank. 2014. “Health Expenditure, Public (% of Total Health Expenditure).”  
<https://data.worldbank.org/indicator/SH.XPD.PUBL> (October 19, 2017).

- Torre, Lindsey A. et al. 2015. “Global Cancer Statistics, 2012.” *CA: A Cancer Journal for Clinicians* 65(2): 87–108. <http://doi.wiley.com/10.3322/caac.21262> (November 27, 2016).
- Trupe, Lydia A. et al. 2017. “Knowledge and Attitudes About Breast Cancer in Limpopo, South Africa.” *Journal of Global Oncology*: JGO.2016.008102. <http://ascopubs.org/doi/10.1200/JGO.2016.008102> (May 28, 2017).
- Vorobiof, Daniel A, Freddy Sitas, and Gabriel Vorobiof. 2001. “Breast Cancer Incidence in South Africa.” *Society* 19(18): 125–27.
- Walker, Alexander R P, Fatima Adam, and Betty F Walker. 2004. “Breast Cancer in Black African Women: A Changing Situation.” *The Journal of the Royal Society for the Promotion of Health* 124(2): 81–85. <http://journals.sagepub.com/doi/pdf/10.1177/146642400412400212> (September 20, 2017).
- Walker, Liz. 2005. “Men Behaving Differently: South African Men since 1994.” *Culture, Health & Sexuality* 7(3): 225–38. <http://www.jstor.org.libaccess.lib.mcmaster.ca/stable/pdf/4005493.pdf?refreqid=excelsior%3Af4bfe87137025527b63d5049e3330721> (October 14, 2017).
- WHO. “Breast Cancer: Prevention and Control.” <http://www.who.int/cancer/detection/breastcancer/en/index1.html> (September 20, 2017).
- World Health Organization. 2013. *WHO Traditional Medicine Strategy: 2014-2023*. Hong Kong, China. [http://www.who.int/medicines/publications/traditional/trm\\_strategy14\\_23/en/](http://www.who.int/medicines/publications/traditional/trm_strategy14_23/en/).
- Yip, Cheng-Har et al. 2011. “Breast Cancer Management in Middle-Resource Countries (MRCs): Consensus Statement from the Breast Health Global Initiative.” *The Breast* 20: S12–19.
- Zelle, Sten G. et al. 2012. “Costs, Effects and Cost-Effectiveness of Breast Cancer Control in Ghana.” *Tropical Medicine and International Health* 17(8): 1031–43.

## **APPENDICES**

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## APPENDIX A: Aggregate participant demographic information

<b>Age (years)</b>	Median: 41	<b>Marital Status</b> (number of participants)	Married: 16
	Mean: 40.55		Engaged: 3
<b>Ethnic/Linguistic Group Affiliation</b> (number of participants)	Sotho: 2	<b>Length of relationship with partner</b> (years)	Not married: 1
	Sepedi: 5		Median: 9.5
	Venda: 2		Mean: 12.75
	Tsonga: 1	<b>Public/private healthcare users</b> (number of participants)	Range: 4-33
	Xhosa: 2		Public: 11
	Zulu: 3		Private: 5
	Ndebele: 3		Public or private: 4
<b>Religious Affiliation</b> (number of participants)	Shona: 2	<b>TH users</b> (number of participants)	Unknown: 1
	Christian: 6		Current user: 3
	Apostolic: 3		Faith-based healer user: 1
	Zion: 2		Past user: 6
	Lutheran: 2	<b>Medical Aid Status</b> (number of participants)	Does not use: 10
	Traditional culture: 2		Has medical aid: 2
	Unspecified: 2		No medical aid but partner does: 2
<b>Educational Attainment</b> (number of participants)	Not religious: 3	<b>Sonke Affiliation</b> (number of participants)	No medical aid: 14
	Less than secondary: 13		Unspecified: 2
	Graduated secondary: 4		Affiliated (CAT or volunteer): 4
<b>Employment Status</b> (number of participants)	Tertiary: 3		Participated in events: 2
	Formally employed: 4		No affiliation: 14
	Piece work or vendor: 8		
<b>Partner's Employment Status</b> (number)	Unemployed: 8		
	Formally employed: 13		
	Piece work or vendor: 3		
<b>Monthly Combined Income</b> (Rand/\$USD)	Unemployed: 4		
	Median: 4500/335		
	Mean: 5520/411		
	Range: 0- 20,000/0 – 1490		

## **APPENDIX B: Information form provided to participants**

As approved by the Medical Ethics Committee of the University of the Witwatersrand:

### **Study title: What men in South Africa think about breast cancer and how they help their partners receive care**

Hello! My name is Raquel Burgess. It is nice to meet you. I am a Master's student from McMaster University in Canada and I am doing research on breast cancer. Research is the way to learn the answer to a question. In this study, we want to learn what men in South Africa think about breast cancer and how they help their partners receive care. This will help to create better breast cancer programs in South Africa and may make it easier for people in your community to receive care.

I am inviting you to take part in this research study to help us learn the answers to our questions and to help make health care in South Africa better.

#### **What is involved in the study?**

With your permission, I would like to ask you some questions about breast cancer. I would like to talk to you for about 60 minutes in a face-to-face interview. I will ask you what you think the common symptoms and causes of breast cancer are, what puts a woman at risk for breast cancer, your opinions about breast cancer treatments and what you know about self-screening for breast cancer. I will also ask you about how you help your partner receive health care if they needed it and what advice you would give them.

Here are some of the questions I will ask you:

- What do you think causes breast cancer?
- If you partner had an issue with her breast, what advice would you give to her about it? In other words, what would you recommend she does about it?
- How might your partner having breast cancer affect your family?

We can set up a time and a place that works for us both to do the interview. With your permission, I will record your answers on this audio recording device, which records what you say but does not record any images or anything else. I will also write a few notes in my notepad, these are simply for me to remember what I have asked you and notes to myself. You may ask to see them if you wish.

I will also ask you a couple of questions about yourself. These are questions like: what is your age? What was your education like? This is so that I can determine how you are the same or different from other participants. Do not worry, all of this information will remain confidential. This means that nothing you say will be linked to your identity.

There are about 20 other people like yourself that will be participating in this study in your community. This study is being done in South Africa only.

**Are there any risks to doing this study?**

There are very few risks to doing this study. You may feel uncomfortable or anxious talking about some of these things. You may also find it stressful talking about a serious health issue like breast cancer or talking about what you would do if your partner had breast cancer. If you have negative feelings and wish to stop, you may take a break at any time or you may stop the interview altogether.

You may also worry about how others will react to what you say. Remember that nothing you say will be linked to your identity. Also, this is an open atmosphere in which you can feel free to talk about things without fear of being judged.

I have included here the phone number for the LifeLine Johannesburg, a telephone counselling service. This is a free service that you can contact at any time on any day if you have negative feelings and wish to speak to someone about it.

**LifeLine Johannesburg**

**Phone number:** 011 728 1331

**Email address:** [lifeline@lifelinejhb.org.za](mailto:lifeline@lifelinejhb.org.za)

**Website:** <http://www.lifelinejhb.org.za>

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. I describe below the steps I am taking to protect your privacy.

**Will I be paid to participate in this study?**

Yes. You will be paid 150 Rand in order to cover any transportation costs you may have getting to and from the interview location.

**How will I be paid?**

You will be paid in cash. This will be given at the end of the interview or when you wish to stop the interview.

**Are there any benefits to doing this study?**

The research may not benefit you directly, but it will hopefully help to improve health care in South Africa. We hope that by learning what men know about breast cancer and how they help their partners receive care, this will help those who make policies about health care to make it better and easier for you and your partner to receive care. In this way, participating in this study may benefit your community.

**What if I change my mind about the study (want to withdraw)?**

Your participation in this study is **voluntary**. It is your choice to be part of the study or not. If you decide to be part of the study, you can stop the interview for whatever reason, even after signing the consent form or part-way through the study or up until approximately **July 15<sup>th</sup>, 2017**. If you decide to withdraw, there will be no consequences to you, and no penalty or loss of benefits to which you are entitled. If you want to withdraw, any data you have provided will be destroyed unless you indicate otherwise. If



you do not want to answer some of the questions you do not have to, but you can still be in the study.

Your decision whether or not to be part of the study will not affect your continuing access to health care services.

If you wish to withdraw, you can tell me while I am here, or you can call me on the cell phone number I have given below. I will have this cell phone number active from 9 am to 5 pm every day until approximately July 15<sup>th</sup>, 2017. You can also email me at the email address listed below. If you tell me you wish to withdraw before July 15<sup>th</sup>, 2017, I will remove your data from the results. However, if you tell me after this time I cannot remove your information because the study will be finished.

**Are there any costs to me participating in this study?**

No, there will be no costs to you participating in this study.

**Confidentiality: Who will know what I said or did in the study?**

All efforts will be taken to make sure that what you say in the study is not linked to your identity, in other words it remains confidential.

Once we finish talking, I will put everything that I recorded on this device onto my computer and immediately delete everything you have said off of the device. On the computer, the information will be stored in a secure file with a password that only I know. A backup of your answers will also be stored on a secure backup drive, and in a secure online account that also has a different password that only I know. Once the information is on the computer, your answers will not be linked to your identity. Your name will be changed to a fake name and only I will know which names are linked to which participant.

However, absolute confidentiality cannot be guaranteed. There is a possibility that you will be able to be identified in your community through the stories that you tell. Please keep this in mind when you are talking to me. If you tell me any names of people in your stories, I will change their names to ensure this person's privacy. Your personal information may be disclosed if required by law. Some organizations, such as the Research Ethics Committee, can inspect my research records if they wish to in order to make sure I am doing the research properly. Your individual results and information will not be published, only summaries of what the entire group of 20 people have said. However, there is a small chance that people might be able to identify you if the results are published.

Once the study is complete, a copy of the data, without any information that could allow others to identify you, will be kept in the password protected file for a period of 2-6 years. After this time, it will be permanently deleted.

**How do I find out what was learned in this study?**

I expect to have this study completed by approximately December 2017.

If you would like to receive a summary of the results personally, please let me know how you would like me to send it to you.

**Contact Information:**

If you have questions or need more information about the study itself, please contact me at:

*Raquel Burgess, B.Sc.*  
*Phone number:* [REDACTED]  
*(you may contact me here if it is before*  
*July 15<sup>th</sup>, 2017)*  
*Email: [burgerc2@mcmaster.ca](mailto:burgerc2@mcmaster.ca)*  
*(you may contact me here if it is any time*  
*before or after July 15<sup>th</sup>, 2017)*

This study has been reviewed by the Health Research Ethics Committee at the University of the Witwatersrand in Johannesburg and has received ethics clearance.

**If you have any reports or complaints about this study or how it was conducted, you can report them to:**

Ms Zanele Ndlovu  
Email: [zanele.ndlovu@wits.ac.za](mailto:zanele.ndlovu@wits.ac.za)  
Phone: 011 717 1252/2700/1234/2656

## APPENDIX C: Consent form

As approved by the Medical Ethics Committee of the University of the Witwatersrand:

### CONSENT

I have read the information presented in the information letter about a study being conducted by Raquel Burgess of McMaster University, Dr. Ruari McBride, and Dr. John Eyles of the University of the Witwatersrand.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until approximately *July 15<sup>th</sup>, 2017*.

I have been given a copy of this form.

I agree to participate in the study.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Participant (Printed) \_\_\_\_\_

Consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

1. ... Yes, I would like to receive a summary of the study's results.

Please send them to me at this email address \_\_\_\_\_

Or to this mailing address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

... No, I do not want to receive a summary of the study's results.

## **APPENDIX D: Consent for audio recording**

As approved by the Medical Ethics Committee of the University of the Witwatersrand:

**Study: What men in South Africa think about breast cancer and how they help their partners receive care**

### **AUDIO RECORDING CONSENT**

I am aware that this interview will be recorded on an audio recording device that will capture what I say but does not record images or anything else.

I am aware that the interviewer will also be taking some handwritten notes during the interview.

I am aware that after the interview has occurred, the data will be put on the interviewer's personal computer in a password-protected file. I am also aware that the data will be immediately deleted off of the audio recording device.

I agree to be recorded.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Participant (Printed) \_\_\_\_\_

Recording consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

## **APPENDIX E: Oral demographic information form**

\*alterations made during the data collection process are demarcated with italics.

### **Oral Demographic Information Form** **What men think about breast cancer and how they help their partners receive care**

Raquel Burgess, (Master of Global Health student)  
(Department of Global Health – McMaster University)  
Dr. Ruari McBride, (Post Doctoral Fellow)  
(School of Public Health - University of the Witwatersrand)  
Dr. John Eyles (Professor Emeritus)  
(Centre for Health Policy - University of the Witwatersrand)

#### **General Information**

What is your age/how old are you?

Which ethnicity do you identify with? *Are you Zulu, Xhosa, Ndebele, Sepedi...?*

Are you religious? Which religion do you practice?

What is your highest level of education?

Are you employed? If so, what is your occupation? What is your partner's occupation?

How much income do you usually make per month? How much income do you and your partner make together?

Where do you receive this income from (you or your partner's jobs, grants, family members)?

*Do you have a social grant for your child(ren)?*

#### **Relationship Status**

Are you married?

Do you live with your partner full-time?

How long have you been together?

**Access to Health Care**

Approximately how far do you live from the nearest health centre *clinic*?

How much money does it cost you to get there?

How close do you live to a traditional healer?

Do you ever use the traditional healer?

*Why or why not?*

*If yes, which types of things do you use a TH for? Can you give an example?*

Do you have health insurance *medical aid*?

*Does your partner have medical aid?*

What type of health care do you and your partner typically access? Does your partner access different types of health care than you?

*Would you usually go to the clinic in Diepsloot, or a TH, or a private clinic? What about your partner, where does she go?*

How easy or hard do you find it to access health care? How easy or hard do you find it to afford health care?

*Are there ever times you can't get to health care because you don't have enough money?*

**Sonke Gender Justice**

*Have you ever heard of Sonke Gender Justice before?*

*Have you ever participated in their programs or events?*

*If so, what did you think of it?*

*For participants that work or volunteer for Sonke: why do you work/volunteer there? Do you enjoy it? Why?*

**Thank you!**

## APPENDIX F: Semi-structured interview guide

\*alterations made during the data collection process are demarcated with italics.

### Semi-Structured Interview Guide What men think about breast cancer and how they help their partners receive care

**Raquel Burgess, (Master of Global Health student)**  
**(Department of Global Health – McMaster University)**

Dr. Ruari McBride, (Post Doctoral Fellow)  
(School of Public Health - University of the Witwatersrand)  
Dr. John Eyles (Professor Emeritus)  
(Centre for Health Policy - University of the Witwatersrand)

**Information about these interview questions:** This gives you an idea what I would like to learn about what you think about breast cancer. The interview will be one-to-one and will be open-ended (not just “yes or no” answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: (“So, you are saying that ...?”), to get more information (“Please tell me more?”), or to learn what you think or feel about something (“Why do you think that is...?”).

#### **Part 1: Relationship with partner**

Tell me a little bit about yourself. What do you like to do? Do you enjoy your work? You told me you have a partner. Please tell me about your partner. What kind of relationship do you have? How long have you been together? Do you have children? If so, how many?

#### **Part 2: Thoughts about cancer**

There are many different diseases that affect people’s health. One of them is cancer. I am going to ask you about cancer and then I am going to ask you what you know about breast cancer, if anything.

- 1) In your opinion, what is cancer?
  - a. Why do people get cancer?
  - b. Do you know anyone who has had cancer? What happened to them? Did they receive treatment? If so, whom did they receive treatment from? If not, why did they not receive treatment?
  - c. How much of a problem is cancer in *Diepsloot* your community?
  - d. Do people in *Diepsloot* your community talk about cancer? Is it an appropriate thing to discuss? Why or why not?
  - e. What types of cancer do you know about?
  - f. *If someone gets cancer, do you think it is their fault?*

- g. *Where did you learn about cancer?*
  - h. *If someone gets cancer, do they always die or can they sometimes survive?*
- 2) Do you know about breast cancer? What do you know about it?
- a. Do you know if any of your family or friends have had breast cancer? What was that like?
  - b. How dangerous is breast cancer?
  - c. Whom does breast cancer affect?
    - i. Probes: Older/younger women? People of a certain race or religion? Good people/bad people? Big people/small people? Does it affect men?
  - d. How *easy* common is it for a person to get breast cancer? *Does it happen often?*
  - e. What do you think the signs or symptoms of breast cancer are?
  - f. What do you think causes breast cancer?
    - i. Probes: Biological/genetic? Spiritual? Behavioural? Other?
    - ii. *Can someone send you BC if they are jealous of you?*
    - iii. *Is BC contagious? Can it be spread to someone else?*
  - g. What do you think puts a woman at risk for getting breast cancer?
  - h. Which treatments do you know of that are used for breast cancer? Are these effective treatments? Why or why not? What is your opinion of these treatments?
    - i. Probes: treatments from hospital vs. health clinic vs. traditional healer? Herbal vs. medicinal vs. surgical treatments?
  - i. *Do men get BC?*
  - j. *Where did you learn about BC?*
- 3) *Is BC something your partner thinks or worries about?* Do you know if she checks her breasts for cancer? If so, how often does she do this? If not, why does she not do this?
- a. Do you know how to check breasts for cancer? Do you help your partner do this?
  - b. Have you ever seen advertisements about testing for breast cancer?
  - c. Is there anything else about breast cancer that you know and would like to tell me?

## **Part 2: Role in Partner's Care**

- 1) When your partner gets sick, what do you usually do about it? *what usually happens?*
- a. What help do you provide? Do you provide it or does another family member or friend typically provide it?
  - b. If it is another person that provides it, why is this the case?
  - c. What type of health care does your partner typically access?



- d. *When she goes to the clinic, do you go with her or does she go alone or with someone else?*
  - e. *Should she ask your permission before seeking care? going to the clinic?*
- 2) Has your partner ever had an issue with her breast that you know of? If she did, do you think she would talk to you about it? Why or why not? *Even though it's a women's health issue, do you still think she would talk to you about it?*
  - a. What was your advice to her/what advice would you give her about it? In other words, what would you recommend she does about it?
  - b. If you would advise her to receive health care, where do you think she should go?
- 3) What is your role in her health care?
  - a. Do you assist her financially? Are you able to afford care if she needs it?
  - b. Do you assist her with transportation?
  - c. Do you assist her emotionally?
  - d. Are there any reasons why you might advise her not to go to health care, or that she might not be able to get there even if you both wanted her to?
- 4) If your partner were to have breast cancer, how might this affect your relationship with her?
  - a. *Sometimes if a woman has BC, they must remove part of their breast, do you think this would affect your relationship?*
- 5) How would her having BC affect your family?
- 6) What other things do you think might happen in this situation?

**Is there something important that I forgot? Is there anything else that you think I need to know about breast cancer or how you and your partner access health care?**

**Thank you very much for your time and participation!**

## APPENDIX G: Results of thematic analysis

### **Final themes, categories, and codes:**

The numbers in brackets indicate the number of participants who reported the associated statement.

#### **Knowledge of (Breast) Cancer**

- a. *Eish about cancer ma'am, I don't want to lie to you, I don't know about cancer.* [Kyle]
- b. *Types of cancer (besides BC).*
  - i. Lung cancer (6)
  - ii. Blood cancer (3)
- b. *Risk factors for cancer.*
  - i. Smoking (14)
  - ii. Alcohol (10)
  - iii. Family history (9)
  - iv. Eating unhealthy foods (7)
  - v. Being overweight (3)
  - vi. Lack of exercise (3)
  - vii. Stress (2)
  - viii. Gender
- c. *Causes of breast cancer.*
  - i. Plenty of the ladies, they taking some money and putting right here in the breast. And even the wallet is put in there. Even the cell phone, is put in there. It's causing breast cancer. [Anthony] (2)
  - ii. It's a shortage of some...enzymes or something inside the blood. [Bonani] (1)
  - iii. Uhhh, sometimes maybe...maybe bath soaps. Something you bath with. If, if you're not used to it. [Rapula] (1)
- d. *Symptoms of breast cancer.*
  - i. A lump (9)
    - A blood clot (2)
    - A bruise under your breast (1)
  - ii. ...you feel something, maybe the, the pain in the breasts. [Jacob] (4)
  - iii. Sometimes they can scratch, scratch, scratch, scratch, see. [Lesebo] (3)
- e. *Treatments for cancer.*
  - i. I don't know much about treatments. [Matsimela] (11)
  - ii. I think for you to live, I think sometimes you have to cut it. [Nick] (7)
    - when now it's not curable, it's then now on the last decision to cut the breast. [Bonani]
  - iii. Chemotherapy (3)

*f. Awareness of self-examination for breast cancer.*

- i. No, she never, she never. [Bonani] (4)
  - But I think, it's important, to go and check it. [Bonani]
- ii. ...when they get pregnant, go to hospital, and find everything you see. [Luke] (2)

**Perceptions of Cancer**

*a. Can cancer be spread to others?*

- i. I don't think someone can send breast cancer to you. I think it just happen like naturally, it's a natural thing. [Mark] (12)
- ii. She didn't cause herself cancer. That thing just happen. [Lesebo]
  - I think they are meant to be. [Akhumzi].
- iii. Through breastfeeding (3)
- iv. Through sex (2)
- v. Through using another's deodorant or washing rags (1)
- vi. Through eating off the same plate (1)

*b. Confusion between cancer and HIV/AIDS.*

*c. Importance of seeking health care.*

- i. And they check it, if they find it, still early, when it's still developing, yeah it can be cured. [Jacob] (11)
- ii. We will just go and see the doctor. With the treatment, everything will be fine. [Rapula] (12)

*d. Cancer doesn't discriminate [Mark](12)*

- i. ...to the blacks, it can be very dangerous... [6]

**Cancer Education**

*a. Source of cancer information*

- i. Television (health programs, the news and 'soapies') (7)
- ii. Famous figures (5)
- iii. Books/magazines/newspapers (5)
- iv. From people talking (4)
- v. Radio (4)
- vi. Pamphlets at the clinics (2)
- vii. School (2)
- viii. From knowing someone with cancer (11)

*b. Breast cancer advertisements*

*c. I think people are just in the dark. [Akhumzi]*

- i. In Diepsloot eh, ehh...I've never heard of somebody having cancer. [Jacob]
- ii. No, it needs to be discussed about. Yeah, I never heard someone discussing about it before. [Boipelo] (15)
- iii. The only that we are, that's talked about, it's HIV, HIV, HIV. I think they know about HIV, but not cancer. [Khuselwa] (3)

*d. Education about it can be...an answer to it. [Bonani]*

- i. I also want to learn. I know nothing about this. I want to know more. [Rapula] (10)
- ii. I don't know what...first step I can take. [Khuselwa]
- iii. Desire to spread knowledge of cancer to others.

### **Access to Health Care**

#### *a. Issues with the public clinic*

- i. I must wake up VERY early. And sometimes the queue is just cut, so it's that problem. [Bonani]
- ii. Because it's only two clinics with what, a population of what, 750 000, close to a million. [Mark]
- iii. And according to my idea, clinic was supposed to open 24 hours. [Thuso]
- iv. Just walking there and going there, you can get robbed, get shot or get killed, something, or get raped if you're a woman. [Sicelo]
- v. ...these ladies working there sometimes don't treat people nicely. [Luke]

#### *b. Like eh, I enjoy too much [the private clinic]...you pay there. So there is no problem. [Luke]*

- i. ...that one is convenient. [Akhumzi]
- ii. ...we go to the private doctor because they say it's better than the public centers. [Matsimela]

#### *c. Barriers*

- i. If you don't have the money [for transportation and/or the clinic], you can't go. [Thuso]
- ii. Ambulance issues.

#### *d. Traditional healing*

- i. ...when I go to the clinic, it is when eh, my body does not feel well. And also when I go to the traditional healing, yeah, I'm going to check my life. [Anthony]
- ii. Since I've grew up and I've became a Christian, I'm no longer concerned with the traditional healers. [Matsimela]

### **Gender Norms, Roles and Relations**

#### *a. I wish one day I'll go find a good job to protect my wife and my child. [Bhekimuza]*

#### *b. Openness with partner.*

- i. We are friends. We talk about everything. [Rapula]
- ii. She would talk to me about an issue with her breast. (18)

#### *c. Role in partner's health care.*

- i. Financial
- ii. Sometimes she walks with me [to the clinic], if I am free. Then if I am busy, she can go alone. [Lesebo] (11)


- iii. Everything that she used to do, I used to do when she's getting sick. [Thuso]
- iv. She have to ask me permission [to go to the clinic]. [Kyle] (9)
- d. *We must be together....we'll have to stick with it.* [Anthony]
  - i. Because, we've been through a lot together. [Khuselwa]
  - ii. Because that will be the time that she needs my support more than before. And I need to be there for her. [Mark]
  - iii. I don't think it could affect my relationship with her. I think I would love her more. [Sicelo]
  - iv. ...after all, I love her, not her body. [Matsimela]

**Responsibility to Community**

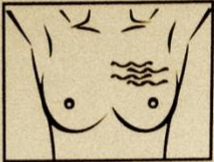
- a. *It's because I want to bring difference within my community.*
- b. *You see here actually, for me, at this moment, I am say thank God, to meet Sonke.*

**APPENDIX H: De-briefing: Educational information given to participants**

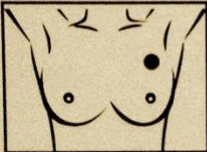
## The early signs of breast cancer



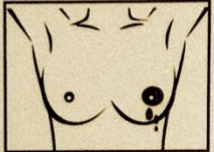
A hot, tender breast



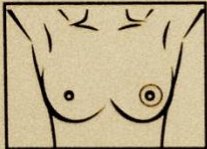
Changes in the breast's skin



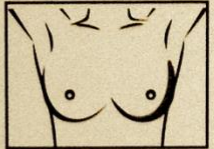
A lump or swelling in the breast



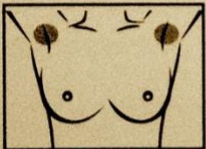
Collapsed nipple or spontaneous discharge



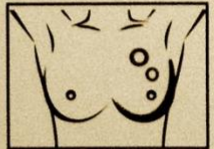
Itching round the nipple or change in skin



Change in the shape of the breast



Unusual swelling in the armpit



Specific area of pain or tenderness


**iThemba**  
CRUSADE OF HOPE  
**AVON** *Justine*

<http://www.ithembawalkathon.co.za/>


## Examine your breasts

Feel for any change in breast tissue that could feel like a thickening, or a hard lump.

1. Do this lying down, in the shower or bath when your hands are wet & soapy. With your right hand behind your head, use the pads of the 3 middle fingers on your left hand to examine your right breast. Here's how...
2. Using light pressure, then medium then firm pressure in a circular motion on your breast, follow an up and down pattern (diagrams A & B below)
3. Now feel for any changes above and below your collarbone and in the area of your armpit.
4. Now repeat these steps on your left breast.



A



B

**IF IN DOUBT, SEEK MEDICAL HELP AND INSIST ON AT LEAST AN ULTRASOUND OR MAMMOGRAM. REGULAR SCREENING AFTER THE AGE OF 40 IS RECOMMENDED**

**BOSOM BUDDIES**  
breast health foundation

**0860 283 343**

@BreastBHF @BosombuddiesSA  
[www.mybreast.org.za](http://www.mybreast.org.za)

## **APPENDIX I: Summary of study results to be distributed to participants**

**Study:** What do men in Diepsloot know about breast cancer and how do they help their partners receive health care?

### **Why was this study done?**

This study was done to find out what men in Diepsloot know about breast cancer. It was also done to find out how men in Diepsloot help their partners receive health care.

### **What was done?**

Interviews were done with 20 men living in Diepsloot.

### **What was found?**

- Men do not know much about breast cancer.
- Half of the men knew that a lump is a symptom of breast cancer.
- Most men know that having a history of breast cancer in the family can increase the risk of getting it.
- Most men agree that not smoking, not drinking a lot of alcohol, getting enough exercise, and eating healthy can help protect you from breast cancer.
- Some men thought that men cannot get breast cancer, although some knew that they can.
- For treatments, men mostly know about cutting off the breast but don't know about other treatments, such as chemotherapy.
- Many men did not know if their partner examined herself for breast cancer or thought that she didn't.
- Most men knew that cancer can affect any person, of any race.
- Breast cancer is not something that is discussed very often in Diepsloot.
- Most men learned about cancer through television, the radio, magazines, or famous people that have been diagnosed with cancer.
- Many men want to learn more about cancer. There is a need for more education about cancer in Diepsloot.
- Some said that not having enough money for transport to the clinic was a problem.
- Some men go with their partner to the clinic, or sometimes she goes alone. Some men pay for their partner's transport to the clinic, whereas other men say that she uses her own money or they share their money.
- Some men say that their partner should ask permission from him to go to the clinic, but some say that she doesn't have to do that.
- Some said that they would need to cook and clean if their partner was sick.
- Most were very positive about receiving health care for breast cancer, and thought that a person would survive cancer as long as they got treatment.
- Men described their relationships with their partners. They talked about the openness they have together and how they are friends. Some talked about wanting a job to support their family.

- Most said they would stay with their partner if she was diagnosed with breast cancer and would need to support her more during this time.
- Some said that they would encourage her to check her breasts for cancer in the future.

**Why is this important?**

Knowing this information can help us to make information about cancer to give to people in Diepsloot. This will help people to find cancer earlier and help them to survive.

Thank you. If you have any further questions you can contact Raquel Burgess by email at [burgess.raq@gmail.com](mailto:burgess.raq@gmail.com).



## APPENDIX J: Relevant contacts for Knowledge Translation

Organization	Brief Description
Advocates for Breast Cancer (ABC)	Described previously.
Breast Cancer Awareness South Africa	Increasing awareness of BC.
Breast Health Foundation	Offers counselling services to diagnosed women.
Breast Interest Group of Southern Africa (BIGOSA)	Group of medical professionals trying to standardize breast healthcare in SA.
*Breast Sens	No longer operational.
*Cancer Association of South Africa (CANSA)	Does cancer research, public education and provides support to individuals with cancer.
Cancer Dojo	App that uses ‘positive thinking’ to help those diagnosed with BC.
Cancer Vive	Survivor-driven, uses art and media to increase cancer awareness.
*Department of Health	Primary government entity administering the public health system, BC policy and implementation of the NHI.
*Department of Social Development	Responsible for referral process of those who receive a positive test with PinkDrive’s screening. Provides support to vulnerable populations.
Discovery Health	Prominent medical insurance company.
Momes Foundation	Hosted a BC awareness event in Diepsloot last year.
*PinkDrive	Awareness and screening in townships.
Reach for Recovery	Emotional and practical support for BC patients. Also do breast health education in communities.
*Sedumedi Hope Foundation	Breast cancer organization in Diepsloot.
Wings of Hope	Survivor-driven, provides support to those diagnosed, also BC awareness.

\*Organizations that are particularly relevant to the current study.

## **APPENDIX K: In-brief for organizations (Knowledge Translation)**

### **Study: Black South African men's knowledge and perceptions of breast cancer and their roles in their partner's access to healthcare**

The following is a summary of a study completed in South Africa in 2017 in partnership with the University of the Witwatersrand in Johannesburg and McMaster University in Hamilton, Canada. For questions, further information, and to access a more detailed report or other materials, please contact Raquel Burgess at [burgess.raq@gmail.com](mailto:burgess.raq@gmail.com).

#### **What is known about breast cancer in South Africa?**

Breast cancer (BC) is becoming an increasingly prevalent health issue in South Africa (SA).<sup>1</sup> Many South African women are presenting to the healthcare system at very advanced stages of the disease, which results in poor survival rates.<sup>2, 3, 4</sup>

Advanced presentation is likely the result of low awareness of BC and misconceptions about the causes.<sup>5, 2, 6</sup> BC is not openly discussed in a lot of communities and many women do not think they are at risk of getting it.<sup>2</sup> Many South African women also face barriers such as not having enough money to get to the clinics,<sup>5</sup> long distances to healthcare centers<sup>7</sup>, and a lack of access to regular cancer screening.<sup>13</sup> They may see traditional healers because they are in close proximity and culturally-appropriate.<sup>8</sup> Women may also fear a diagnosis<sup>9</sup>, and are concerned that their husbands will leave them. For women that are diagnosed, their treatment may be less than optimal because of a lack of adequately trained health professionals and resources in the public health system.<sup>10, 12</sup>

#### **What is being done about it?**

- Release of the National Health Insurance (NHI) plan to increase coverage of low-income individuals<sup>11</sup>
  - Release of the new Breast Cancer Prevention and Control policy to promote early detection and set standards of care; efforts include training health professionals on breast health and providing educational materials in clinics<sup>12</sup>
  - Awareness and screening efforts by local breast cancer organizations
- 

#### **Why was this study done?**

This study was done to determine what male partners in SA know about BC and how they are involved in their partner's access to health care. This is important because, due to traditional gender norms, many women in SA have limited independence<sup>13</sup>, may not feel worthy of receiving care<sup>13</sup>, and do not make the final decisions about their health care.<sup>14</sup>

#### **What was done in the study?**

Interviews were conducted with 20 men living in Diepsloot, a township 50 km north of Johannesburg. The men in the study were all in long-term relationships and had

been living with their partner for average of 13 years. Their partners did not have BC currently or in the past.

### **What was found?**

#### *Cancer awareness & knowledge*

Knowledge of cancer in general was very low (including BC). Roughly half could identify a lump as a symptom of BC. Many mentioned smoking and drinking alcohol and about half mentioned family history as risk factors for BC. Most had very little knowledge about treatments, except for removing the breast. In contrast to previous reports of BC being a “white women’s disease”<sup>13</sup>, almost all of the men thought that cancer affected individuals of all races equally. A small number of participants believed that breast cancer was caused by putting a wallet or cellphone in your bra, or by using soap or deodorant you are not familiar with. A few participants thought BC is contagious, and that a person affected with cancer should be careful about spreading it to others. Some confused cancer with characteristics of HIV, including thinking that it can be spread to a baby through breastfeeding or to others through sex. The majority did not use traditional healers and did not think that breast cancer could be ‘sent’ as a curse; they thought it occurred naturally and that it is not a person’s fault for getting it. Almost all participants thought it was very important to seek health care for BC, and mentioned that it was important to do so early before the cancer progressed. They believed that an individual would survive cancer as long as they received treatment. However, they recognized the specific barriers they have to accessing health care, such as not having enough money for transportation to get regular check-ups.

#### *Cancer education*

Most had learned what they knew about cancer from television (health shows and ‘soapies’), famous figures who had been diagnosed with cancer, the radio, and magazines or newspapers, although many had never seen information about BC specifically. Most had never heard of someone in Diepsloot having cancer, and said that cancer is not something that is discussed in their community. The men said that their lack of knowledge about cancer is an issue because they wouldn’t recognize signs of it and would also be fearful if their partner was diagnosed (fear of the unknown). Most participants wanted to know more about cancer, although they didn’t know where they could find information about it.

#### *Health care access*

Most individuals were dissatisfied with the public health clinics in Diepsloot. To access them they need to wake up very early in the morning, walk to the clinic in the dark (which can be dangerous), wait all day in line, and they still may not be seen. The clinic hours are inconvenient and sometimes they are not treated with respect when they go there. This causes them to prefer private clinics. Not having enough money for transportation or the private clinic fee caused some of the men to miss their scheduled appointments.

### *Role in their partner's healthcare*

The men felt responsible to be the providers for their family, and were frustrated that they could not find a job. In terms of healthcare, some thought that he should be providing the money for his partner to get to the clinic, some said she used her own money, or that they share their money. Most preferred to go to the clinic with her but said she would go alone if he was busy. About half indicated that she needs permission from him to access health care. They talked about the openness they had with their partners and thought that their partner would tell him if she had an issue with her breast. They also felt strongly that they would stay together if she was diagnosed with BC because they had already been through a lot together. They mentioned that they would need to support her more during this time, and might need to take on roles such as cooking and cleaning. Although they thought she might have self-esteem issues by losing a breast, they did not think it could not affect their relationship. Some specifically mentioned how, after learning about BC, they would encourage their partner to complete self-examination, go for check-ups, and get treatment if she was diagnosed.

### *What are they key takeaways?*

Men's knowledge of BC is very low, but they appear to be playing a prominent role in their partner's access to health care. Despite the presence of some traditional gender norms, such as their partner requiring permission to access health care, this role appears to be mostly positive. They are aware of the importance of receiving health care early for cancer and are optimistic about the chances of survival. They expressed the desire to support and stay with their partner if she was diagnosed with BC. The specific barriers individuals in low-income communities face to accessing health care should be considered in efforts to promote earlier diagnosis.

### *Recommendations for the government & civil society:*

#### **1. Strategic health messaging to promote earlier cancer presentation, particularly among low-income groups.**

This is an inexpensive way to produce better health outcomes and reduce costs to the healthcare system of treating advanced cancer. Messaging should specifically focus on:

- Changing the misconceptions that BC is caused by putting things in your bra, can be spread to a baby through breastfeeding, and the belief that cancer is contagious.
- The differences between cancer and HIV should be explicitly stated.
- Further knowledge is required about treatment options. Since the only known treatment is mastectomy, this could contribute to fear of a diagnosis.
- Television and endorsement by popular figures may be effective ways to educate communities about cancer.
- Education about self-examination should be directed at both women and men, as men may encourage their partners to do so.
- Messaging should be provided in all of South Africa's eleven official languages and in visual as well as written form so those who are illiterate have access to the information.

**2. Recognition of the role of the male partner in women's health issues.**

The importance of the male partner and gender norms should be recognized in BC campaigns. Campaigns should target men as well as women to foster dialogue about BC between the genders. This may serve to calm some of the fear women have about their husbands leaving them. Men may also play an important role in encouraging their partner to complete self-examination or go to the clinic. In India, men are encouraged to do so through the HIM Initiative ([www.himinitiative.com](http://www.himinitiative.com)).

**3. Inclusion of cancer education in schools.**

Information about the signs and symptoms, treatment options and the importance of early detection for cancer should be a part of South Africa's Integrated School Health Policy<sup>15</sup> in order to educate future generations about cancer.

**4. Provision of accessible and cost-effective transportation to clinics/hospitals for low-income individuals.**

Providing low-cost transportation from vulnerable areas to breast clinics may be an effective way to promote earlier diagnosis.

**5. Improve treatment pathways and ensure the provision of necessary treatment resources.**

More resources and health professionals are required to diagnose and treat BC in the public sector, given the increasing health burden the disease poses.<sup>1,16</sup>

**6. Integrate and train traditional healer practitioners.**

Integrating traditional healers into the conventional healthcare system may reduce delays in presentation that could occur due to seeing a traditional healer before seeing a physician. It may also improve the coordination of care and reduce complications due to taking multiple healing regimens at the same time. Training traditional healers on cancer prevention and detection could be an effective way to reach individuals in low-income communities.

**7. Greater collaboration within breast cancer civil society and between civil society and the government.**

This will ensure that individuals can receive continuity of support throughout their breast cancer journey.

**8. Utilization of research in educational campaigns.**

Research specific to SA, as well as guidelines for BC care in low- and middle- income countries<sup>17,18</sup>, should be used in the development of educational campaigns and policies.

**Limitations of the study and ideas for further research**

This study was conducted with a unique group of South African men who are in long-term relationships with their partners. It is difficult to say how the findings related to what other men know about BC. More research should be done to determine how other groups of men perceive BC and gender norms in regards to health care. Further research should also be done on what role the male partner plays during treatment and recovery for women who have been diagnosed with BC.

## Acknowledgements

The supervisors of this study are Dr. John Eyles (McMaster University) and Dr. Ruari McBride (University of the Witwatersrand). Guidance was also provided by Dr. Dorothy Pawluch (McMaster), Dr. Rob Wilton (McMaster), and Dr. Nicola Christofides (Witwatersrand).

Many thanks also to the Sonke Gender Justice team in Diepsloot, specifically Mr. Brown Lekekela, without whom the study would not have been possible to complete.

## References

1. National Cancer Registry. (2012). Cancer in South Africa 2011 full report. Retrieved November 27, 2016, from [http://www.nioh.ac.za/?page=national\\_cancer\\_registry&id=41](http://www.nioh.ac.za/?page=national_cancer_registry&id=41)
2. Moodley, J., Cairncross, L., Naiker, T., & Momberg, M. (2016). Understanding pathways to breast cancer diagnosis among women in the Western Cape Province, South Africa: a qualitative study. *British Medical Journal Open*, 6(1), e009905. <https://doi.org/10.1136/bmjopen-2015-009905>
3. Walker, A. R. P., Adam, F., & Walker, B. F. (2004). Breast cancer in black African women: a changing situation. *The Journal of the Royal Society for the Promotion of Health*, 124(2), 81–85. Retrieved from <http://journals.sagepub.com/doi/pdf/10.1177/146642400412400212>
4. Cubasch, H., Joffe, M., Hanisch, R., Schuz, J., Neugut, A. I., Karstaedt, A., ... Jacobson, J. S. (2013). Breast cancer characteristics and HIV among 1,092 women in Soweto, South Africa. *Breast Cancer Research and Treatment*, 140(1), 177–186. <https://doi.org/10.1007/s10549-013-2606-y>
5. Trupe, L. A., Rositch, A., Dickerson, L., Lucas, S., & Harvey, S. C. (2017). Knowledge and Attitudes About Breast Cancer in Limpopo, South Africa. *Journal of Global Oncology*, JGO.2016.008102. <https://doi.org/10.1200/JGO.2016.008102>
6. Krombein, I., & De Villiers, P. (2006). Breast cancer – early detection and screening in South African women from the Bonteheuwel township in the Western Cape: Knowledge, attitudes and practices. *South African Family Practice*, 48(5), 14. <https://doi.org/10.1080/20786204.2006.10873386>
7. Dickens, C., Joffe, M., Jacobson, J., Venter, F., Schüz, J., Cubasch, H., & McCormack, V. (2014). Stage at breast cancer diagnosis and distance from diagnostic hospital in a periurban setting: A South African public hospital case series of over 1,000 women. *International Journal of Cancer*, 135(9), 2173–2182. <https://doi.org/10.1002/ijc.28861>
8. Nxumalo, N., Alaba, O., Harris, B., Chersich, M., & Goudge, J. (2011). Utilization of traditional healers in South Africa and costs to patients: Findings from a national household survey. *Journal of Public Health Policy*, 32 Suppl 1(S1), S124–36. <https://doi.org/10.1057/jphp.2011.26>
9. Rayne, S., Schnippel, K., Firnhaber, C., Wright, K., Kruger, D., & Benn, C.-A. (2016). Fear of Treatments Surpasses Demographic and Socioeconomic Factors in Affecting Patients With Breast Cancer in Urban South Africa. *Journal of Global Oncology*, 3(2), 125–134. <https://doi.org/10.1200/JGO.2015.002691>
10. Last cancer doctor quits in Durban. (2017). *eNEWS Channel Africa*. Durban, SA. Retrieved from <http://www.enca.com/south-africa/last-cancer-doctor-quits-in-durban>
11. National Department of Health. (2015). *National Health Insurance for South Africa: Towards Universal Health Coverage - Version 40*. Retrieved from <https://www.health-e.org.za/wp-content/uploads/2015/12/National-Health-Insurance-for-South-Africa-White->

Paper.pdf

12. National Department of Health. (2017). *Breast Cancer Prevention and Control Policy*. Retrieved from <http://blogs.uct.ac.za/cancerphd/wp-content/uploads/2017/09/Breast-Cancer-Policy-2017.pdf>
13. Maree, J. E., & Wright, S. C. D. (2010). How would early detection be possible? An enquiry into cancer related knowledge, understanding and health seeking behaviour of urban black women in Tshwane, South Africa. *European Journal of Oncology Nursing*, 14(3), 190–196. <https://doi.org/10.1016/j.ejon.2009.10.009>
14. Vorobiof, B. D. A., Sitas, F., Vorobiof, G., & Vorobiof, D. A. (2001). Breast Cancer Incidence in South Africa. *Society*, 19(18), 125–127.
15. National Department of Health, & National Department of Basic Education. (2012). *Integrated School Health Policy*. Retrieved from [https://www.health-e.org.za/wp-content/uploads/2013/10/Integrated\\_School\\_Health\\_Policy.pdf](https://www.health-e.org.za/wp-content/uploads/2013/10/Integrated_School_Health_Policy.pdf)
16. Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M., & Bradshaw, D. (2009). The burden of non-communicable diseases in South Africa. *The Lancet*, 374(9693), 934–947. [https://doi.org/10.1016/S0140-6736\(09\)61087-4](https://doi.org/10.1016/S0140-6736(09)61087-4)
17. Saghir, N. S. El, Adebamowo, C. A., Anderson, B. O., Carlson, R. W., Bird, P. A., Corbex, M., ... Cazap, E. (2011). Breast cancer management in low-resource countries (LRCs): Consensus statement from the Breast Health Global Initiative. *Breast*, 20(SUPPL. 2), S3–S11. <https://doi.org/10.1016/j.breast.2011.02.015>
18. Yip, C.-H., Cazap, E., Anderson, B. O., Bright, K. L., Caleffi, M., Cardoso, F., ... Khaled, H. M. (2011). Breast cancer management in middle-resource countries (MRCs): Consensus statement from the Breast Health Global Initiative. *The Breast*, 20, S12–S19. <https://doi.org/10.1016/j.breast.2011.02.015>

## **APPENDIX L: Tailored information about BC for Diepsloot residents**

### **What is cancer?**

Cancer is a disease that starts deep inside the body. As it grows, it forms a lump called a tumour. The tumour can be cancerous or not cancerous. You can tell if it is cancerous by having it checked at a clinic or hospital.

### **What is breast cancer?**

There are many different types of cancer, including lung cancer, skin cancer, prostate cancer and breast cancer. Breast cancer is a disease that affects the breasts. Both men and women can get breast cancer, although it happens more often in women. Breast cancer can affect anyone, of any race and any age. It is more likely to affect people who are older, although even people in their 20s and 30s can get breast cancer.

### **Is breast cancer a problem in South Africa?**

Yes. Breast cancer is very common. It is the most common type of cancer for women in South Africa. Also, breast cancer is a problem in South Africa because women don't usually find the cancer until it has already grown a lot.

### **Is there anything I can do so that I won't get breast cancer?**

Nothing you do can completely prevent you from getting breast cancer as it is a natural disease. But by doing healthy habits you can reduce the chances of getting it. This means getting enough exercise, eating healthy foods such as vegetables, not being overweight, not drinking a lot of alcohol, and not smoking. You are more likely to get breast cancer if someone in your family has had it before.

### **How would someone know if they have breast cancer?**

There are symptoms of breast cancer that are shown in a picture at the end of this document. The most common symptom is a lump in the breast. Breast cancer can be painful, but it usually isn't.

### **What can I do if I think that I or someone I know has breast cancer?**

You should go to the clinic immediately and tell them to check for breast cancer. If you receive treatment, you can survive breast cancer. You have an even better chance of surviving if you find the cancer early, before it develops.

### **What are the treatments for breast cancer?**

The treatments for breast cancer are chemotherapy (medicine), radiation (a non-painful way to kill the tumour from the outside), and surgery (removing part of the breast). If surgery is needed, the breast can often be reconstructed back to normal.

### **Where can I get treatment for breast cancer?**

You can get treatment for breast cancer at the Helen Joseph Hospital in Johannesburg. The breast clinic there gives treatment to people who do and do not have medical aid.



They also give treatment to people who are South African and people from other countries. You can call this number if you have questions: 0860 283 343.

**The truth about breast cancer:**

- Although HIV can spread like this, breast cancer cannot be spread from a mother to a baby through breastfeeding.
- Breast cancer cannot be caused by putting money, a wallet or a lip balm container in your bra.
- Cancer is not contagious. It cannot be spread to someone else through coughing, sex, sharing drinks or food, or using the same washing rag, toothpaste or deodorant.

**What can I do to help someone with cancer?**

You can help them by talking with them, cooking them a meal, or doing something nice for them. You can also help them get to the clinic, encourage them to get treatment, or provide support to them when they are feeling sad.

**Where can I find out more about breast cancer?**

If you have access to the internet, you can read about breast cancer on the Breast Health Foundation's website: [www.mybreast.org.za/breasthealth-breast-cancer](http://www.mybreast.org.za/breasthealth-breast-cancer). You can also call them at 0860 283 343.

You can also talk to the Sedumedi Hope Foundation, which is an organization to help people learn about breast cancer in Diepsloot. This is the facebook page: [www.facebook.com/pg/SedumediHopeFoundation/about/](https://www.facebook.com/pg/SedumediHopeFoundation/about/)

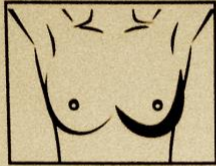
You can also ask for information at the clinic.

**How can I protect my partner from getting breast cancer?**

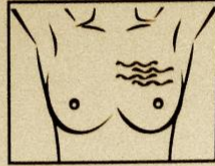
As a man, you can help protect your partner from breast cancer by encouraging her to check her breasts for cancer. You can also encourage her to go to the clinic for check-ups or if she feels any changes in her body. You can also get checked for breast cancer because men can also get breast cancer.

On the next page is information about the symptoms of breast cancer and how to examine yourself for breast cancer.

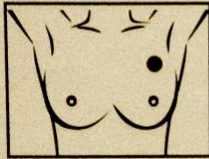
## The early signs of breast cancer



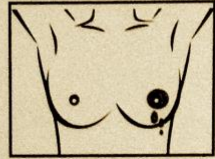
A hot, tender breast



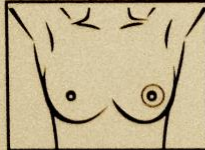
Changes in the  
breast's skin



A lump or swelling  
in the breast



Collapsed nipple or  
spontaneous discharge



Itching round the  
nipple or change  
in skin



Change in the shape  
of the breast



Unusual swelling  
in the armpit



Specific area of  
pain or tenderness



<http://www.ithembawalkathon.co.za/>

## Examine your breasts

Feel for any change in breast tissue that could feel like a thickening, or a hard lump.

1. Do this lying down, in the shower or bath when your hands are wet & soapy. With your right hand behind your head, use the pads of the 3 middle fingers on your left hand to examine your right breast. Here's how...
2. Using light pressure, then medium then firm pressure in a circular motion on your breast, follow an up and down pattern (diagrams A & B below)
3. Now feel for any changes above and below your collarbone and in the area of your armpit.
4. Now repeat these steps on your left breast.



**IF IN DOUBT, SEEK MEDICAL HELP  
AND INSIST ON AT LEAST AN  
ULTRASOUND OR MAMMOGRAM.  
REGULAR SCREENING AFTER THE  
AGE OF 40 IS RECOMMENDED**



**0860 283 343**

@BreastBHF

@BosombuddiesSA

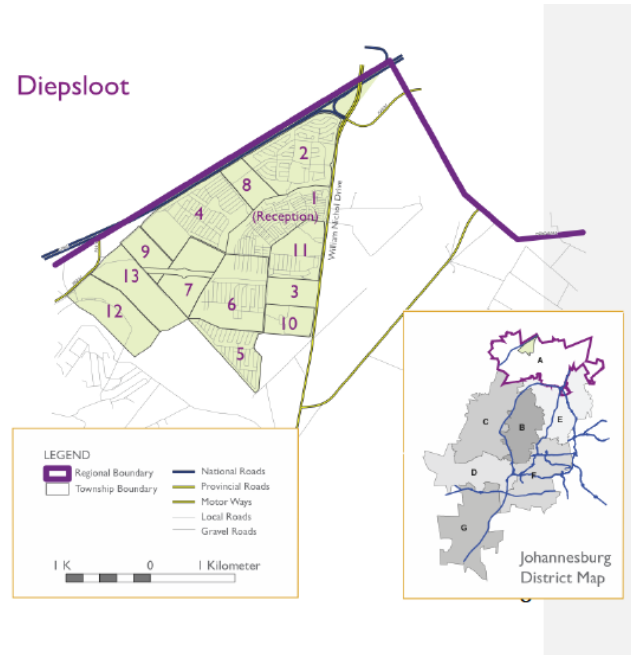
[www.mybreast.org.za](http://www.mybreast.org.za)

#### APPENDIX M: Summary of edits made to thesis in September, 2019

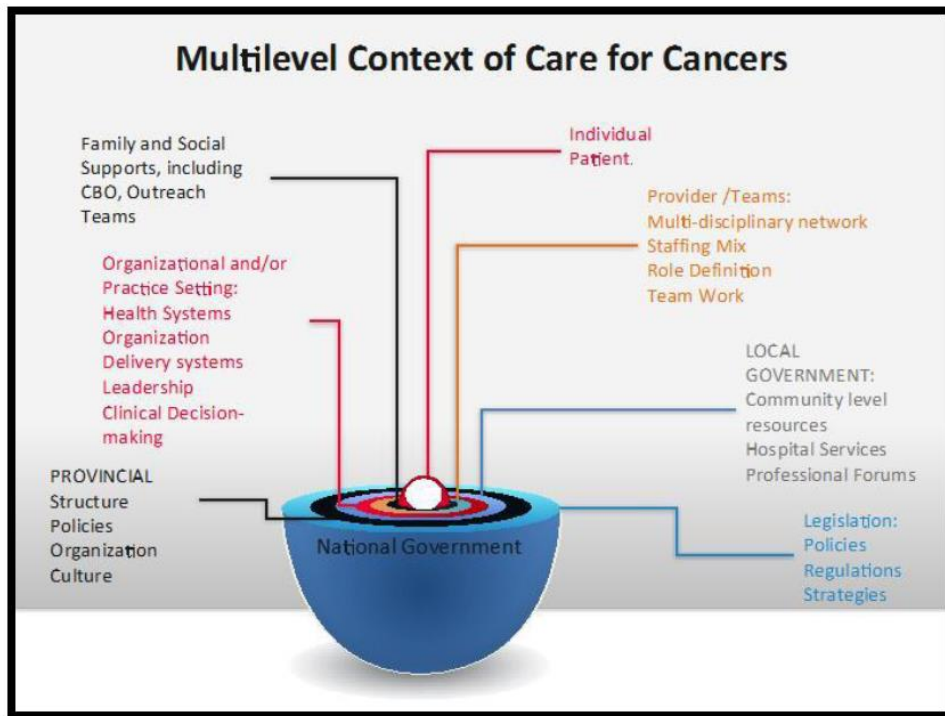
The following edits were made to this thesis in September 2019 in order to ensure the protection of the identity of those involved:

1. Removal of participant demographic table #1 in Appendix A.
2. Removal of any information regarding the participants' connection or lack of connection to Sonke Gender Justice.
3. Removal of specific details surrounding the researcher's engagement in volunteer opportunities with local breast cancer organizations; broad summaries of these activities are maintained.

## FIGURES



*Figure 1.* The geographic division of Diepsloot into 13 extensions (Sonke Gender Justice and Wits Department of Health, 2015).



*Figure 2.* The multilevel context of care for cancers model that is referred to in SA's current BC policy (National Department of Health, 2017, p. 21). Original source is Taplin et al. (2012).

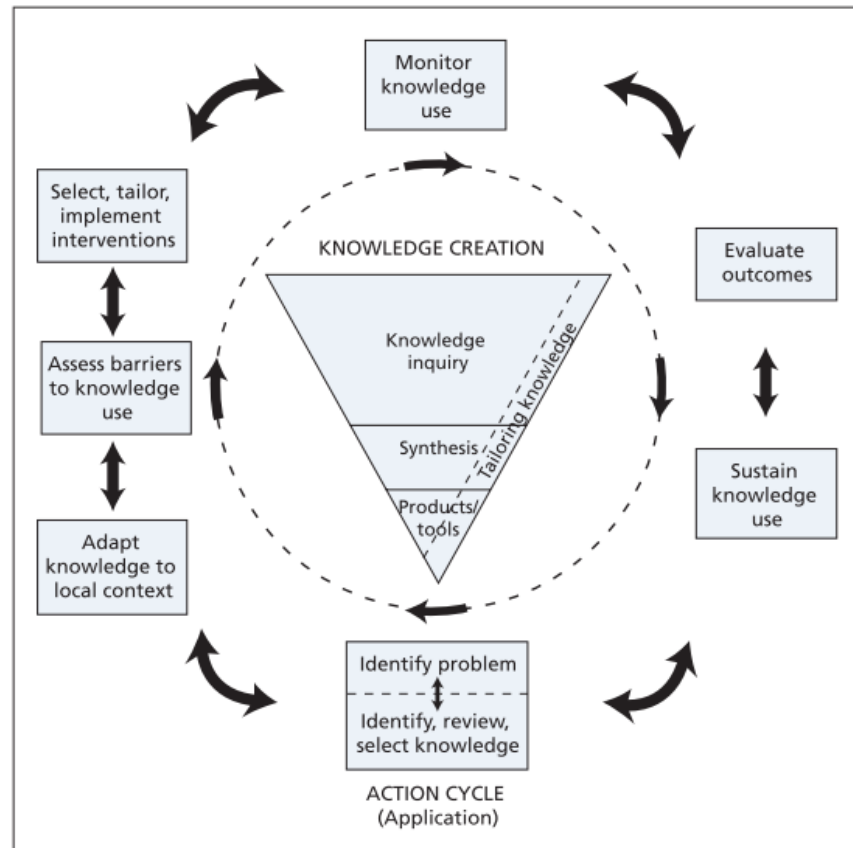


Figure 3. The refined knowledge-to-action framework (Straus, Tetroe, and Graham 2009).