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**Renegotiating Body Image and Sexuality after Surviving Breast
Cancer: Narratives of Young Black African Women**

by

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Declaration

I, Nokwanda Yoliswa Nzuza, confirm that this work is my own and is expressed in my own words. Any uses made within it of the words of other authors in any form are properly acknowledged at the point of their use, a full of the references employed has been included.

Signed: _____

Date: _____

As the candidate's supervisor, I agree to the submission of this thesis.

Supervisor: Prof. M Naidu

Signed: _____

Date: _____

Dedication

This work is dedicated to my daughter, Kwandokuhle Sabusiswa Ndlela. I am grateful to the God I serve for entrusting me with you. Having you has taught me so much about myself and life in general. Before you, I did not know I could love and care so much. I never imagined a blessing as great and as beautiful as you. You have fulfilled a desire that I never knew I had. You are my testimony of God's existence and greatness. I am humbled and grateful to have you as my daughter. May the light within you always shine. May this work always remind you that you have the ability to do anything and everything you wish. May you always seek God's wisdom in your future endeavours. Lastly, may you never forget that you are the perfected version of me and no blessing will ever be as great as having you. I love you 'My Perfected Self'.

'Pursue excellence, and success will follow, pants down' (Rancho: 3 Idiots, 2009)

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‘I can't find the words to describe You
It would take a million years
It would take a million years to explain the way I feel
You are the epitome, You are the epitome of everything I'll ever need
I'm so in awe of You, Lord You leave me speechless’
(Speechless: Anita Wilson)

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Abstract

This study provides a contemporary contextualisation of the challenges that young Black African women face once they are diagnosed with breast cancer. It focuses particularly on 15 young Black African women in the age category of 24 and 40 living in Durban, South Africa. Using the interpretative paradigm, social identity theory as well as social construction theory, this study analyses young women's understanding of their bodies as 'African assets' before and after breast surgery. This study used data collection methods such as focus groups, open-ended interviews, and observations to collect thick descriptions of the challenges that have been faced by young women, as well as stories of how the women have renegotiated their body image and sexuality. The findings of this study indicated that sociocultural expectations play a vital role in how young Black women understand themselves as individuals, partners, and family members. The findings also reveal that women are led to believe that 'real' African women can be seen through their appearance and physical attributes. The young women shared a common understanding of how Black African men prioritised when choosing potential partners. This construction of a women's body was understood to be challenged once young Black African women started cancer treatment as this affected their physical and emotional well-being through medical challenges such as breast reconstruction, hair loss, depression and infertility. In an attempt to preserve their African assets and fertility, this study reports on the traditional and spiritual measures that young women engaged in with the help of traditional healers and spiritualists, to renegotiate their body image and sexuality.

Keywords: breast cancer, Black African women, cultural matrix, body image and sexuality

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CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

1.1 Introduction

A number of medical studies have accounted for reasons that lead to changes in women's body and sexual relationships due to cancer treatment. These include Cavalheiro et al. (2012) who wrote about sexual dysfunction and poor sexual quality of life due to breast cancer treatment as well as Panjari, Bell and Davis (2011) who investigated the prevalence of sexual function among Iranian breast cancer patients. These authors have addressed such issues from a biomedical perspective and have (limited) findings in that they present biologically influenced results which have been significant, but from the medical perspective only. Moreover, there has been a very limited focus on the social aspects and how 'culture'¹ influences the manner in which young Black women identify themselves as sexual beings after potentially invasive surgery and cancer remission. A few scholars such as Rapport and Overing (2003) have explored the social-cultural dimension. One scholar, Joseph (2006) asserted that 'culture' plays a significant role in shaping health-related values, beliefs, and behaviour. To better understand the influence of culture in the process of renegotiating self-image, one needs to employ the bio-psychosocial model of the body and health to comprehend the role of 'culture' and the cultural environment and context within which young African women attempt to 'reclaim' their sexuality after breast cancer. A significant research on the bio-psychosocial model of body image has been done by Rodgers, Paxton and McLean (2013). This research focused on disordered eating in early adolescent girls and the effect on negative self-image.

The topic of body image and sexuality focusing specifically on women is not new social science (see Anderson-Fye, 2012; Krayner, Ingledew and Iphofen, 2008; Jones, Vigfusdottir and Lee, 2004; Hudson 2008; Thompson and Heinberg, 2002). However, the majority of literature on body image has focused on eating disorders (see Thompson and Heinberg, 2002; Han, 2003; Harrison and Cantor, 2006) and highlighted unrealistic media representations of female body appearance, size, and shape (see Presnell, Bearman and Stice, 2004; Stice and Whitenton, 2002; Snooks and Hall, 2002; Engeln-Maddhox, 2006 and Sparhawk, 2003). These, while important

¹ This study adopted Taylor's definition of culture. He stated that "culture... is that complex whole which includes knowledge, beliefs, arts, morals, law, customs, and any other capabilities and habits acquired by [a human] as a member of society" (1871). This study further emphasises that culture is learned through the process of enculturation and that it is not fixed, hence an individual may identify with a number of different cultures.

in attempting to understand the importance of body image and sexuality for women, do not necessarily account for the experiences of women who have suffered from breast cancer. Nevertheless, scholarly knowledge of this nature is essential in studies concerning women's perceptions of their bodies. They are foundational in understanding how women construct their 'sense of self' and identify themselves as attractive sexual beings. Other concerns include how they define sexuality, and what they consider as a 'good' or even 'ideal' body image *after* reconstructive surgery.

An ideal body image becomes rather short-lived once women are diagnosed with breast cancer, which affects their breasts, and which are considered as an important symbol of femininity and sexual intimacy. Breast cancer treatment may require that women undergo surgery which may lead to partial or even complete removal of the breasts with limited treatment to mastectomy which Manos et al. (2005, p. 103) described as "a mutilating type of surgery of an organ closely associated with the feminine body image and sexuality". Breast cancer treatment and surgery is dependent on the stage by which the cancer cells are identified in a person's body. In some cases, early detection of these malignant cells may enable women to undergo 'breast conserving' surgery which includes lumpectomy and a partial mastectomy. In more advanced cases, women undergo a complete mastectomy. As with many treatment regimes, these treatments lead to significant side effects which may be in a form of hair loss, weight gain, skin problems and even premature menopause due to chemotherapy and radiation (Deniz et al., 2007 and Connell, 2005). These side effects in turn affect women's body image, how they identify themselves and their sexuality, which may potentially lead to poor (romantic and sexual) relationships (see Przewdziecki et al., 2013; Manos et al., 2005; Freedman, 1994; Hopwood and Maguire, 1998).

The relation of sexuality to this discourse has also been explored by some scholars. "Sexuality can be seen as a deep, pervasive and integral aspect of the total human personality" (Sheppard and Ely, 2008, p. 177). It exists in all interactions and contexts, and relates directly to our well-being and experience of ourselves as sexual beings (Sheppard and Ely, 2008). Robinson et al. (2002) cited in Edwards and Coleman (2004, p. 190) defined sexual health as "an approach to sexuality founded in accurate knowledge, personal awareness, and self-acceptance, where one's behaviour, values and emotions are congruent and integrated within a person's wider personality structure and self-definition". The elements that define sexual health are thus closely linked to a person's body image which Furnham, Badmin and Sneade (2002, pp. 852-

854) described as the perception that a person has of their physical self, but more importantly the thoughts and feelings the person experiences because of that perception. Perez et al. (2002) cited in Caples (2008, p. 11) viewed body image as “the personal evaluations and affective experiences of one’s physical attributes and attractiveness”. Thus, in relation to body image, sexuality is informed by physical attributes and people’s understanding of attractiveness. This understanding of attractiveness is influenced by their shared and learned patterns of behaviour, in other words, their socioculture.

Dettwyler (1995) argued that in the so-called western industrialised ‘cultures’, breasts symbolise sexuality, femininity and maturity. She further claimed that men and women in western industrialised countries are taught by their culture to perceive breasts this way, from a very early age. Such westernised cultural perceptions are associated with relatively few cultures around the globe. This so-called westernised cultural construct has over the years infiltrated to non-western societies. In her study, Dettwyler (1995) noted that, contrary to western culture, in many African cultures, particularly in Mali, breasts are not culturally constructed to signify sexuality. Dettwyler shared an experience of having witnessed several women being bare-breasted, which she argues, is mainly because breasts are seen for their biological function, which is feeding children. This suggests that for this particular society, breasts ‘*may not*’ form part of a ‘sexual’ body image. This, however, does not seem applicable within the context of young Black women living in Durban, South Africa.²

Among the so called westernised societies, there appears to be tremendous pressure on women to attain the ‘ideal’ body, one that is culturally constructed and portrayed as attractive and with (often large and full) breasts being considered desirable. The ‘western societies’ have portrayed the ideal body shape as slender, with narrow hips and large breasts (McDonalds, 2003). Consequently, authors such as Millsted and Frith (2003, p. 456) argued that “large breasts have become over sexualised as highly prized objects of sexual desire”. In addition, scholars such as McDonalds (2003) and Frederick, Peplau and Lever (2008) have stated that embedded on the Barbie image are connotations of what an ideal female body is and the appropriate shape

²Even though there is no direct literature on this aspect, my personal experience as a young black woman and my casual observations of my peers indicate that to a large extent, the western cultural understanding of sexuality and the ideal body has been adopted. This includes a ‘sexual’ understanding of breasts as being linked to women and sexuality. This in turn has been popularly argued as being due to exposure to the media and contact with other cultures.

and size of a woman's body. The fascination with women's breasts and sexuality has led Frederick, Peplau and Lever (2008, p. 200) to state that "the pervasiveness of the 'ideal' breast has led some researchers to posit that women's concerns about their breast size and shape can affect their self-esteem, feelings of attractiveness, and sense of femininity and sexuality". This culturally influenced objectification of the breasts, has influenced the manner in which many young Black African women have come to understand their 'sexual' bodies.

1.2 Background and significance of the study

Breast cancer is not only considered as a dread disease, but it is also a disease that has a negative impact on women's body image due to its potentially invasive treatment and surgery. Consequently, Anderson and Johnson (1994) stated that cancer treatment has the potential for permanent impact on body image and self-esteem. They further posited that "physical changes that impose cosmetic and appearance challenges (through surgery) can be psychologically immobilizing for women with cancer" (p. 346). Like Anderson and Johnson (1994), Manos et al. (2005, p. 103) asserted that "most types of cancer have significant physical repercussions, and the corresponding treatment produces significant bodily changes". Manos et al. (2005, p. 1040) further elaborated that "a factor that has greatly complicated the impact of breast cancer on body image has been the fact that the treatment of choice up until recently was mastectomy, a mutilating type of surgery of an organ closely associated with feminine body image and sexuality". Depending on when the cancer was detected and how far it has spread, some women have the opportunity of undergoing breast conserving surgery, which includes lumpectomy and a partial mastectomy, and in the worse cases women undergo a complete mastectomy. Body changes, especially those relating to the 'feminine' parts of a woman's body, such as the breasts may negatively influence the image the patient has of her body and may produce effective disorders and changes in sexuality and self-esteem (Przedziecki, 2013). Subsequently, Quick (2013) asserted that changes in appearance and functional limitations of the body with chronic diseases (such as cancer) place individuals at greater risk for negative body image and poor psychosocial and medical outcomes compared with their healthy peers. This suggests that for young³ women, especially those between 24 and 40 years, the process of renegotiating their self-image is not without difficulty as their breasts, after surgery may be shaped differently compared to their peers.

³ In this study, young has been broadly conceived to mean women between 24 and 40 years old, i.e. women who are of child bearing age.

Body image is a social-cultural construct; it depicts how society and culture have conceptualised ideals and expectations of how a body should look. Thus, self-worth, body image and sexuality are social-culturally constructed in the sense that women understand their bodies through their particular societal and cultural lenses. Stice (2002, p. 103) stated that “sociocultural influences have long been suspected of promoting disturbances of body image and eating”. In addition, Quick (2013) claimed that sociocultural pressures from the media, family, and peers, as well as social comparison processes to some extent, explain the development of negative or positive body image in young people.

Treating breast cancer requires not only medical attention as women are also social beings. Women also must be psychologically prepared for the observable changes in their bodies, most especially their breasts. Such changes may be viewed and understood negatively within their respective cultural frameworks. Against this backdrop, this study aimed to investigate whether young Black women between the age of 24 and 40 years, living in Durban, KwaZulu-Natal, renegotiate and reaffirm their body image and their sexuality having undergone breast cancer treatment of a mastectomy or double mastectomy.

This qualitative study is important for several reasons. Firstly, a ‘gap’ exists in social science studies concerning body image, sexuality and breast cancer where young Black African women share their experiences and perceptions about the challenges of renegotiating their sense of womanhood. Current international studies that have focused on other races include Christie, Meyerowitz and Maly (2010) whose study explored depression and sexual adjustment following breast cancer amongst the Hispanic and non-Hispanic white women; Martínez-Ramos (2009) whose focus was on Latina women; Buki, Reich and Lehardy who also documented experiences relating to body image and acceptance amongst the Latina breast survivors; and Ashing-Giwa et al.(2004) whose research involved Asian Americans and Caucasians. Moreover, the available literature has mainly focused on body image and its implications relating to diet and medical explanations that lead to changes in the women’s body and sexual relationships due to cancer treatment. A large segment of the literature has been mainly clinical and has concentrated on epidemiological and biomedical interventions. These include studies by Elena et al. (2013) who discussed the “Leveraging Epidemiology and Clinical Studies of Cancer Outcomes”, “Hormone replacement therapy, cancer, controversies, and women’s health...” by Krieger et al. (2005) and a review of the biomedical literature focusing on breast cancer patients by Jacobson, Workman and Kronenberg (2000). This study

offers a unique yet suitable perspective as it works, though an anthropological perspective and focuses on qualitative findings in order to gain an in-depth understanding of how young Black African women renegotiate their body image and sexuality after surgery. It also probes the role and influence of the cultural matrix in this process. Thirdly, breast cancer is regarded as the cancer with the highest survival rates (see CANSA statistics and Cancer Research UK website) which implies that more and more young people will need to find ways to reaffirm their sexuality having undergone reconstructive surgery. The fourth reason is based on this study's population group; that is, young Black women. The majority of literature concerning body image within the Black population mostly focuses on body weight-diet (Ogana, 2014; Puoane et al., 2005 and Utley, 2002) and the influence of the media which has resulted in very limited literature on the renegotiation of a positive body image and sexuality after breast reconstruction.

1.3 Motivation for study

The motivation for this study came about when an elderly relative was diagnosed with breast cancer. Prior to this unfortunate event, I had limited knowledge of breast cancer. I initially considered it as a 'white' disease. This coincidentally happened in September, prior to breast cancer awareness month in October. Consequently, I started reading all cancer related material that was at my disposal which I could not fully understand, but the statistics gave me hope, hope that she too would become a success story. Even then, I did not fully understand the brutal effect that cancer has on its victims. It was only when I saw that her breasts were observably unequal and that she was not concerned with people's remarks about her now small breast that I started questioning my own ideas of the ideal body image and sexuality. While delving deeper into this topic, I became aware of the noticeable gaps in the literature with respect to young Black women and their body images after surviving breast cancer. This was followed by casual conversations with my peers, both men and women concerning this topic. Their responses began to form a pattern or what researchers would term a hypothesis, one which was highly critical of women without their most observable sign of womanhood, their breasts, and that which assumed that the culture of young Black women poses a challenge for breast cancer survivors⁴ when they attempt to renegotiate their body image.

⁴ In this study, breast cancer survivors are women who are in complete remission i.e. they have no evidence of disease.

1.4 Research problem and objectives: Key questions asked

The effects of breast cancer on women's body image and sexuality are important social science topics as they contribute to the well-being of women. It is therefore important to investigate how the aftermath of this dread disease affects the way women understand their sexuality. The limited social science literature on this rather 'understudied' area has mainly focused on the biological, and reasons that lead to changes in women's body and sexual relationships due to cancer treatment as well as the reconstructive surgeries that are said to improve women's body images. Such literature is positioned mainly within bio-medicine and has overlooked the influence of culture in renegotiating sexuality for breast cancer survivors, especially for young Black women. Thus, this area has very limited studies (Ubi Lwara and Alonge, 2014; Ngubane, 2010; Scott, 2009; Langen, 2005)⁵ focusing on the influence of socio-culture with regard to how women renegotiate their role in society and in relationships as sexual beings. Given the improving survival rate in breast cancer patients, the issue of renegotiating body image and sexuality after cancer remission remains an important research area in the social sciences, especially within the under-researched populations like that of young Black African women. Hence, it is necessary to conduct a study focusing on body image and sexuality on this population.

The research questions are as follows:

1. How do young Black African women understand their bodies and sexuality prior to being diagnosed with breast cancer?
2. How does cancer treatment and surgery affect the women's body image and sexuality?
3. How do the young Black African women renegotiate their sense of body image and confidence in how they see themselves as sexual beings after surviving breast cancer?
4. How are breasts linked to sexuality for the young Black women?
5. How has breast surgery affected the way their families and communities see the women?
6. How does the culture of young Black African women influence the women's understanding of their self-image?

⁵ These studies, while relevant, have focused on women who are HIV positive.

7. How does cancer treatment and surgery affect the women's ideas of fertility and motherhood?

1.5 Research problem and objectives: Broader issues investigated

For some women, living with breast cancer requires that they undergo breast removal surgery. Such surgery brings about several side effects and permanent changes for women. These include losing what many would regard as a woman's sign of femininity, her breasts. This change is not easily accepted by some women due to their sociocultural understanding of their bodies, especially since culture shapes the context in which body image and sexuality are formulated. In addition to the influences of culture, authors such as Sparhawk (2003), Presnell, Bearman and Stice (2004) asserted that body images are closely linked to people's diet and the media's portrayal of the ideal body image, which McDonalds (2003) and Frederick et al. (2008, p. 200) associated with the commercialised Barbie image with highly sexualised 'busty breasts'. One can therefore assume that breasts play a major role in how women are understood within their cultural frameworks, which then poses a question of their sociocultural understanding of reconstructive surgery.

This study, therefore aims to determine the sociocultural understanding of reconstructive surgery for young Black women and to determine the relationship between breasts and sexuality for young Black women.

1.6 Study challenges

Most of the participants were interviewed in their homes during weekends due to their work commitments. This posed a major challenge as interviews were usually interrupted by their family members and at times participants were busy with house chores. Thus, interview sessions took longer than planned. For example, sometimes I started the interviews and could not complete them the same day due to several interruptions, making the interview process a bit tedious both for the researcher and the participant. Also, often, I had to re-schedule the interview time and date due to these interruptions. Some interviews were cancelled at the last minute as, at times, the participants would receive emergency calls and would have to leave their homes. Re-scheduling also proved problematic as it interfered with other interviews which were scheduled and confirmed. In some cases, participants offered to have telephonic and online interviews to make up for the lost time.

Fluency in certain terminology was another barrier. While I had initially taken for granted that both the young Black African women and myself were fluent isiZulu speakers, I found that I was somewhat lacking appropriate terminology, especially when it came to appropriate words of body parts and terms that were generally used by women. Fortunately, the young Black women were open to explaining the terms they used. The terms ‘African assets and African queens’ are examples of this. During the process of learning the different terms, my participants became ‘the other’, meaning that there were now observable differences between us which motivated me to learn more about their world and encouraged cultural relativism. Through this, I could understand how their perceptions were constructed and how their illnesses had led them to identifying with each other. It soon became clear that while some of the women did not know each other, their similarities united them while excluding me as the ‘outsider’. I also had to be consciously aware of my own thoughts and perceived understanding of the young Black women and their experiences; it is through this that I was able to minimise the influence of ethnocentrism in this study.

This study also interrogated how young women’s sexuality and body images were seen and understood within their communities after breast cancer treatment. While much relevant data was collected, it would have been beneficial to include the perceptions of their partners, family members and some of the community members. This was not possible due to the scale and objectives of this study. Identity is fluid and highly influenced by the environment and community’s perceptions would have enlightened and enriched this study as both the community and participants’ perceptions could have been compared and theoretically analysed.

1.7 Survey of existing research

This literature review section analyses and discusses scholarly publications related to the bodily images and sexuality of women who have been diagnosed with breast cancer and have survived the treatment. It is widely agreed that these women experience certain short and/or long-term challenges with readjusting to their normal lifestyles after breast cancer treatment. These challenges have been seen to be physical, psychosocial, psychological relational and medical. To date, there has been very limited literature relating to studies on bodily image renegotiation among young Black African women. This justifies the need for the current research which sampled participants from the African context as against popular European and Asian-focused studies. This literature survey begins by positioning this study within anthropology and specifically, medical anthropology.

Health studies are of great interest to the field of anthropology due to the socio-culturally dynamics that are embedded in different illnesses (Hassler et al., 2008; Jain, 2007 and Mathews, 2000). Developed in the mid-1960s, medical anthropology forms part of the four sub-fields of anthropology. Baer et al. (1997) cited in Bhasin (2007, p. 1), defined medical anthropology as “that branch of anthropological research that deals with the factors that cause, maintain or contribute to disease or illness, and the strategies and practices that different human communities have developed in order to respond to disease and illness”. According to Király (2014), “medical anthropology studies human health and disease, health care systems, and biocultural adaptation”. This field of anthropology investigates issues beyond the biological aspects of health and the human body; rather, “it views humans from multidimensional and ecological perspectives as it considers the social understanding of illness” (Baer, 1997). It is one of the most highly developed areas of anthropology and applied anthropology, and is a sub-field of social and cultural anthropology that examines the ways in which culture and society are organised around or influenced by issues of health, health care and related issues (see Király, 2014). It is through anthropological research methods that social science researchers can collect thick descriptions of the experiences of patients, especially that of the minority and the so-called ‘exotic’ groups such as young Black women living in South Africa.

Every cultural group has its respective explanations for illnesses (Vaughn, Jacquez and Baker, 2009;⁶ Versola-Russo, 2006⁷). Social scientists generally agree that culture is learned, shared, transmitted inter-generationally and reflected in a group’s values, beliefs, norms and practice patterns of communication, familial roles, and other social regularities (Duque, 2010; Singleton and Krause, 2009; Kreuter and McClure, 2004). It is through the process of enculturation that people learn of their own cultures and cultural beliefs. The process of enculturation is lifelong as cultures evolve with time. Culture⁸, like identity is fluid; changes are based on the environment. This influences people’s perceptions about their world. Similar to the process of enculturation, socialisation plays a key role in human development, and specifically in shaping personality and mental health. “Socialization is the process and result of individual inheritance, learning and transfer of the mankind’s accumulated experience which takes place under the particular conditions for the society to which the individual belongs to” (Brisko, 2012, p. 1).

⁶ This article accounts for the cultural health attributions; it includes factors such as migration, and acculturation and culture bound syndroms.

⁷ This article focuses on the different interpretations of schizophrenia; it is an example of the socio-cultural influences in understanding mental health.

⁸ Golubović 2011; van Meijl (2008); Sokefeld (1999)

Brisko (2012) further stated that culture is all-powerful in shaping biological predisposition; as a result, what takes place during socialisation is determined largely by culture. Hence, culture, while fluid and dynamic, influences a great part of human life and its shapes identities and understanding of life events and phenomenon.

With this understanding, one can assume that 'culture' forms an integral part of people's worldviews; it serves as the lens through which they understand their lives. Kreuter and McClure (2004) argued that the cultural characteristics of any given group may be directly or indirectly associated with health-related priorities, decisions, behaviours, and with acceptance and adoption of health education and health communication programmes and messages. Similarly, Craigie et al. (2002) stated that "culture affects every aspect of an individual's life, including the way that health and illness are perceived by patients, their family, the doctor-patient relationship, and the health-care-seeking behaviour". It is due to this cultural influence in understanding illness that social scientists, and particularly medical anthropologists, have argued against the sole application of a biomedical approach to health care; rather, they have advocated for a bio-psychosocial approach which considers the psychological, social and biological aspects when looking at illnesses.

Bailey (1994, p. 47) stated that "medical anthropologists are trained to view the health status of each individual and population from a biopschosociocultural perspective". Ember and Ember (2004, p. 547) claimed that medical anthropology studies are holistic; this is due to the nature of medical anthropology studies which considers all factors that contribute to the well-being or sickness of a person or a population. There is a growing need for a 'holistic' approach to studying health related issues. Wade (2009, p. 4) argued that including a holistic approach in studying health care is beneficiary as it "identifies all the major factors relevant to the causation and understanding of illness [and] predicts or explains observed interrelationships and other phenomena concerning illnesses", hence the need for anthropological studies concerning health and related challenges face by human beings.

Helman (1997, p. 67) asserted that "anthropologists have pointed out that any society's health care system cannot be studied in isolation from other aspects of that society, especially its social, religious, political and economic organization". It is regarding this assertion that Witeska-Mlunarczyk (2012) stated that "the scope of interest for medical anthropologists includes such themes as culturally sensitive concepts of body and health, the experience of illness, medical pluralism, biomedicine, complementary and alternative healing methods, the

economics of health, or cosmopolitan biomedical culture”. Additionally, “illness challenges identity, sense of time and routine, relationships and body undergo significant change” (Hall, 1998, p. 255). It is due to these challenges that are experienced by patients that social science studies are needed, as illnesses and especially chronic illnesses such as cancer are shown to have effects that are beyond physiological and which include lived experiences.

More than a decade ago, it was predicted that one of the greatest challenges that will face health systems globally in the twenty-first century will be the increasing burden of chronic diseases (WHO, 2002). Chronic illness can be defined as “the lived experience of long-term bodily or health disturbance, whether related to a communicable or non-communicable disease, condition, syndrome, or disorder; and how people live and cope with the disruption” (Martin, 2007, p. 2086). Chronic illnesses confront patients with several needs that require them to change their behaviour and engage in activities that promote physical and psychological well-being. These changes include interacting with health care providers and adhering to their medication instructions, and where necessary, attending social meetings with other patients (Wagner et al., 2001; Piping-Jordan, 2004).

Chronic illnesses include cardiovascular conditions (mainly heart disease and stroke), chronic respiratory conditions, type 2 diabetes and some cancers (Daar et al., 2007). Chronic illnesses differ from acute illnesses which are usually isolated to one bodily area and respond to treatment. In contrast, long-term conditions frequently involve multiple systems and have an uncertain future (Murrow and Oglesby, 1996). Mayosi et al. (2009, p. 1) argued that in South Africa, “non-communicable diseases [such as cancer] are emerging in both rural and urban areas, most prominently in poor people living in urban settings, and are resulting in increasing pressure on acute and chronic healthcare services”. Cancer is currently rated as a fatal illness in the world. About 7.1 million people die each year from cancer (WHO, 2003). Cancer, being an example of a non-communicable illness is considered to be the cause of high mortality worldwide and South Africa is no exception. Even though South Africans are victims of all the types of cancers, Doyal and Hoffman (2009) stated that in the case of South African women, particularly those living in the rural areas, cervical and breast cancer have always been more prevalent.

Cancer

Cancer is an illness that affects all humankind, regardless of their gender, race, and social class. Cancer is a word used to describe many kinds of diseases, where the cells reproduce out of

control. According to Ross and Deverell (2004, p. 116), “each organ of the human body has a unique cell type and it is these cell types that define the type of cancer”. According to the Cancer Association of South Africa (CANSA, 2005), more than 10 million people worldwide are diagnosed with cancer every year. The Cancer Association of South Africa (CANSA, 2005), further estimates that approximately one in four South Africans may be at risk of becoming a cancer statistic. Among the different forms of cancer, there is cancer of the skin, cervical cancer, prostate cancer, colorectal cancer, lung cancer and breast cancer. Breast cancer is the second most prevalent cancer that affects Black women.

Being diagnosed with cancer has many implications for people, especially women. The physical symptoms of cancer and its treatment can have serious social and emotional consequences for its patients as it may also affect their physical appearance. Such consequences may include stigma, hair loss, and change in physical appearance and shock, on the part of the patients, their partners but also the larger community. Dye (2008, p. 9) stated that “once a woman undergoes surgery, they may experience feelings of loss about their altered breasts and feelings of anxiety about how they will look afterward and even if their new bodies will be accepted by their partners”. This adds to the challenges that women experience as they undergo treatment and attempt to reconstruct their lives and renegotiate their identities within their communities and cultures which may have a stigma towards the illness. As human beings, women cannot live without association, hence, their lives are constructed and influenced by their immediate environment. Hossain and Ali (2014) argued that individuals cannot be understood apart from their relations with one another; the relations cannot be understood apart from the units (or terms) of the relationship. Consequently, investigations on the challenges faced by young Black women should interrogate the role of the environment, culture and society that influence the women’s understanding of illness.

To understand the effect of cancer on women, one cannot overlook the cultural understanding of specific groups of people. Langdon and Wiik (2010, p. 460) stated that “culture serves as an instrumental concept for health professionals conducting research or health intervention among rural or indigenous populations”. They further claimed that, due to cultural differences, “patients present unique behaviours and thoughts with regard to the experience of illness, as well as particular notions about health and therapeutic practice” (2010, p. 460). Due to cultural differences, concerns with health and illness are common and while expressed differently between groups people, they are present in all societies. Accordingly, Parry (2004) emphasised that each ‘culture’ has its own specific way of perceiving medical symptoms and how they

should be treated. Anthropologists have pointed out that any society's health care system cannot be studied in isolation from other aspects of that society, especially its social, religious, political and economic organisation (Helman, 2001). Additionally, Dein (2004) argued that culturally embedded factors determine the ways in which symptoms are expressed and the psychological response to cancer. This correlates with Langdon and Wiik's (2010) assertion that there are elements with which social actors construct meanings for concrete and temporal social interaction, as well as sustain existing social forms, institutions, and their operating models. Culture includes values, symbols, norms and practices. In essence, culture is what influences people's worldviews. It informs their understanding. Culture shapes the context in which body image is shaped and understood; hence it is a critical element to consider when attempting to understand how body image is understood within a particular group of people (Vilakazi, 1962 and Ngubane, 1977). The influence of enculturation can also be identified in exploring the choices women make when it comes to healthcare and especially in choosing the type of treatment that Black women with breast cancer undergo.

Considering the biopsychosocial model in health studies does not preclude the study from discussing the biomedical model. Breast cancer is known for its medical side effects and these effects, while understood differently by different patients, need to be discussed from the medical perspective. This is also the perspective that Black women are confronted with when seeking medical health care from public hospitals. The treatment of breast cancer has evolved dramatically over the years. Recent advances have also taken into account cosmetic outcomes. The treatment usually involves two types of therapy, localised and systemic therapy.

Localised therapy is intended to treat the tumour in the breast only. Examples of local therapies are radiation and surgery. Surgery, radiotherapy, and chemotherapy are the three main forms of treatment for cancer. Surgery is used to remove as much cancer as possible. Surgery is often the treatment of choice when treating cancer that is completely contained in one area and that has not spread (Ko, Dollinger and Rosenbaum, 2007, p. 40). The type of surgery is determined by a number of health-related factors which include size, type, and location of the tumour as well as the patient's health which may affect recovery after surgery (Tewari and Shukla, 2004). The type of surgery impacts on the therapy that the patient will undergo for the procedure. The different types of surgery are mastectomy and lumpectomy.

Radiotherapy involves the administration of radiation into the tumour with the intention of damaging cancer cells. Chemotherapy is as important as radiotherapy as its functions include

curing cancer, keeping the cancer from spreading, slowing cancer's growth, killing cancer cells that may have spread to other parts of the body and relieving symptoms caused by cancer (see Ko et al., 2007, p. 40). Radiotherapy and chemotherapy have similar side effects. These may include nausea and vomiting, hair loss, fatigue, skin irritation and infertility.

Lumpectomy is a breast-conserving surgery. It is an operation that removes the lump and some tissue around it; hence the whole breast is not removed (see Ross and Deverell, 2004; Ko, Dollinger and Rosenbaum, 2007, p. 40). Lumpectomy usually does not significantly change the physical appearance of the breast, but as with most treatments, lumpectomy has side effects. Common side effects after lumpectomy include temporary swelling of the breast, breast tenderness, hardness due to scar tissue, and fluid trapped in the wound (see Ross and Deverell, 2004, p. 117). Most of these side effects are temporary. Most women can do normal activities within two weeks post-surgery. The full healing and formation of scar tissue occurs over months, so the final look of the breast may not be seen for some time. This surgery is usually followed by radiation therapy. "After the lumpectomy procedure and recovery are complete, the remainder of the breast is treated with additional (or adjuvant) radiation therapy." According to Ross and Deverell (2004, p. 118), radiotherapy is "a form of treatment that uses ionising radiation, which deposits energy that injures or destroys cells in the area being treated", which minimises the chances of cancer returning in the breast, which would then require a mastectomy. During this therapy, patients may experience fatigue, swelling and discomfort. Ko et al. (2007) shared that some patients prefer not to undergo radiation after lumpectomy which increases their risk of cancer returning in the breast. They further added that this raises the risk of reoccurring cancer to 40% as compared to being between 4% and 20% with the radiation. Should breast cancer return, a mastectomy will be needed.

Mastectomy is a breast-removing surgery. It is a surgical procedure that involves the removal of the breast; the underlying muscles of the chest wall, most of the lymph node chains that drain the breast and the skin over the breast (Tewari and Shukla, 2004). The chance of cancer returning at the site where the breast was after this kind of treatment is 2% to 9% in eight to ten years after the surgery (Ko et al., 2007; Ross and Deverell, 2004). Patients who undergo this surgery also have the opportunity to go for breast reconstruction surgery. Reconstructive surgery can be performed immediately after a mastectomy or after any chemotherapy or radiation therapy. According to Rubin and Tanenbaum (2001, p. 408), breast reconstruction may be a strategy used by women to symbolically defend against existential anxieties, both for

themselves and for others. There are also treatment options that are less invasive than localised treatment. These are referred to as systematic treatment.

“Systematic treatment is used in non-metastatic breast cancer to treat systemic disease earlier, decrease tumour bulk ideally to a complete pathological response and reduce the extent of surgery” (Sachelarie et al. 2014, p. 574). The three main types of systematic treatments are chemotherapy, hormone therapy, and immune therapy. The primary goal of chemotherapy is to eliminate cancer cells and prevent recurrence. Chemotherapy can be used as an adjuvant or as a neo-adjuvant treatment. As an adjuvant, it is given after surgery or radiation therapy and its function is to kill any cancer cells that may remain after the former treatment. It is also used to shrink tumours prior to surgery. Hormone therapy is the treatment that changes the amount of hormones in the body, which helps because several types of cancer can only grow and spread when certain hormones are present (see CANSA Fact sheet). This form of therapy is carried out through the use of drugs in patients with breast cancer related to oestrogen. These drugs seek to suppress the oestrogen hormone, which has the potential of making breast cancer cells grow provided the breast cancer reacts to oestrogen (see breastcancer.org). Immune therapy is a treatment that uses certain parts of a person’s immune system to fight diseases such as cancer (Cancer.org).

The above treatments have rendered positive results for women. However, they have also affected their external body parts. Due to the above treatment, women lose their breasts, their hormones are disrupted and for many, body image and their sense of sexuality are also affected. In addition, the results of the treatment sometimes clash with the ideologies and cultural perceptions of women. This is arguably the case as women’s body image and sexuality that is constructed and expected by society, changes after treatment, often leaving women with the need to identify with their bodies, other women in their societies and to face the constructed fears of exposing their new bodies to their societies.

Society places tremendous pressure on women to attain the ideal body, one that is culturally constructed and portrayed as attractive and desirable. The western ideologues have portrayed the ideal body shape as slender, with narrow hips and large breasts (McDonalds 2003). Authors such as Millsted and Frith (2003) have argued that breasts, especially large breasts, have become over sexualised as highly prized objects of sexual desire as evidenced in the international image of the Barbie doll. In addition, scholars such as McDonalds (2003) and Frederick, Peplau, and Lever (2008) have stated that embedded in the Barbie image are

connotations of what an ideal female body is and the appropriate shape and size of a woman's body. The fascination with women's breasts and sexuality and the pervasiveness of the 'busty' [big breast] ideal has led some researchers to posit that women's concerns about their breast size and shape can affect their self-esteem, feelings of attractiveness, and sense of femininity and sexuality. This culturally influenced objectification of the breasts has influenced the way women understand their 'sexual' bodies. These ideas and perceptions of ideal sexual appearances and body image are often challenged when women are diagnosed with breast cancer.

Several studies undertaken on the experiences of breast cancer survivors after treatment have revealed a variety of adjustment challenges for these women (Benedict et al., 2015; Champion et al., 2014; Champion et al., 2014; Bloom et al., 2012; Sadovsky et al., 2010; Cappiello et al., 2007; Collie and Long, 2005; Bloom et al., 2004). These studies have differed in focus and contexts, but have covered delineating factors like body image adjustment and sexual problems (Lehmann, Hagedoorn and Tuinman, 2015; Champion et al., 2014; Sadovsky et al., 2010), fatigue, depression, cognitive difficulties (Champion et al., 2014), distress (Ussher, Perz and Gilbert, 2012a), notions of meaning (Collie and Long, 2005) and partner support and activities (Mackenzie, 2015; Lehmann, Hagedoorn and Tuinman, 2015; Sporn et al., 2015; Milbury and Badr, 2013). These factors contribute to these women's renegotiating of their identities, body image and sexualities after undergoing breast cancer treatments.

Several studies have focused on their sexual functioning and adjustments (Grion et al., 2015; Champion et al., 2014; Sobota and Ozakinci, 2014; Frechette et al., 2013; Safarinejad, Shafiei and Safarinejad, 2013; Sadovsky et al., 2010; Graziottin 2010; Gilbert, Ussher & Hawkins, 2009; Graziottin, 2008; Kornblith et al., 2007; Collie and Long, 2005). These studies have been diverse from their experience of the sexual act, lack of interest in it and difficulties associated with feeling less of a woman, fertility, parenthood and sudden signs of menopause. Literature is also reviewed on survivors' information needs to care for, manage and facilitate their adjustment experiences (Runowicz et al., 2016; Pauwels et al., 2013; Rabin et al., 2006; Mishel et al., 2005). The focus is firstly directed to challenges that arise from the body image of cancer survivors. This review begins with an analysis of literature that focuses on issues of body image and self-esteem of women treated for cancer.

Fobair et al. (2005, p. 580) offered a definition of body image "as the mental picture of one's body, an attitude about the physical self, appearance, and state of health, wholeness, normal

functioning, and sexuality”. In addition to this, Manos et al. (2005) defined body image as a “construct that refers to what one thinks, feels, perceives and does in relation to one’s own body” (p. 04). For women, this includes feeling feminine, attractive and enjoyment of one’s body as a symbol of social expression and as a way of being in the world. It includes issues of body size, competence, and function (Fobair et al., 2005). Better body image has also been found to be directly associated with women’s capacity to cope with cancer treatments (Pikler and Winterowd, 2003, cited in Fobair et al., 2005). It is also strongly related to the notion of a sense of meaning (Taylor-Ford et al., 2013). Consequently, Smith et al. (1999), cited in Manos et al. (2005, p. 104), argued that “cancer and its treatment are powerful stressors that can have negative consequences on body image and self-esteem”.

Nevertheless, breast cancer treatments impose challenges on the cancer survivors’ body image (Champion et al., 2014; Fobair et al., 2005). Treatment options like mastectomy and other possible reconstruction surgery are often invasive to the defining features of women’s body in ways that can alter their perceptions of their body image and sexuality (Fobair et al., 2005; Anderson and Johnson 1994). Alternative treatments to mastectomy for breast cancer have only been discovered recently. Mutilation to the female breast often has a huge impact on survivors’ sense of their feminine body image and sexuality (Manos et al., 2005). This is especially so for those women who detected cancer late and thus tried to treat it at a later stage. Treatment in such cases would range from partial to complete mastectomy. However, with early detection where cancer has not spread too far, conserving surgery like lumpectomy and partial mastectomy might be all that is required.

In his study, Przewdziecki et al. (2013) focused on the changes that occur in women’s body images after breast cancer. Two hundred and seventy-nine participants from an Australian community-based breast cancer consumer organisation were studied for the relationship between the body image disturbance, self-compassion, and psychological distress. This study also attempted to determine whether the body image difficulties were associated with more distress through low self-compassion amongst women who have survived breast cancer. It found that distress mean scores were depression 7.13; anxiety 5.71 and stress 10.52. The mean body image score was 10.59 which indicated greater body image dissatisfaction (Przewdzeike et al., 2013).

Many factors were found to have contributed to psychological distress and its alteration. However, distress was associated with greater body image disturbance. This was especially the

case for the Australian women at 12 months of post-diagnosis when most experienced body image disturbance. Therefore, it cannot be assumed that body image disturbance will diminish over time. This need must be adequately addressed and self-compassion will assist in alleviating the psychological distress of breast cancer survivors concerning body image changes. Especially during the post-treatment phase, women's self-compassion needs to be reinforced to lessen the impact of body image disturbance. Self-compassion is effective in reducing depression and anxiety (Przedziecki et al., 2013)

Przedziecki et al. (2013) argued that changes relating to the feminine parts of a woman's body like the breast may negatively impact her body image, producing negative disorder and changes in her sexuality and self-esteem. Such a negative body image and changes in appearance and functional limitations of her body have been reported to place the individual at greater risk of negative body image and poor psychosocial and medical outcomes compared to their healthy peers (Quick, 2013). Hence, younger women between 24-40 years of age find it more difficult to renegotiate their self-image after breast surgery than their healthy peers (Champion et al., 2014; Quick, 2013; Przedziecki et al., 2013).

Chemotherapy, as a form of treatment, is associated with hair loss and concerns with weight loss and has been reported to lead to abrupt menopause (Aslam et al., 2014; Sadovsky et al., 2010). Other body image challenges have included poorer mental health, and lower self-esteem (Fobair et al., 2005). A direct impact on their competence and functioning (Fobair et al. 2005) have also been their struggles with fatigue, depression, sexual difficulties and cognitive problems (Champion et al., 2014). These treatment challenges impose significant self-esteem difficulties to women who survive cancer treatments. Physical changes of the kinds outlined above have been reported to lead to appearance challenges that are psychologically immobilising for the cancer treatment survivors (Anderson and Johnson 1994).

Meanwhile, Champion et al. (2014) noted that survivorship research on the physiological and psychological and social distress of breast cancer diagnosis has focused on those who recently completed treatment, identifying, however, that "quality of life problems persist long after treatment and diagnosis", hence justifying the need for research to inform the problems faced by long-term survivors. These long-term survivors happen to be those diagnosed at a younger age and having to face the impact of the disease for a long time. Champion et al. (2014, p. 2237) related that "young survivors seem to experience more decline in health-related quality of life than older survivors".

The review of literature in the previous section indicates that there are considerable health constraints resulting from cancer treatment. These challenges result in certain health care needs. The assertion is that to renegotiate bodily image and sexualities, survivors need to address the prevailing health care needs that follow cancer treatment, especially younger survivors, who, according to Champion et al. (2014), are most vulnerable to threats to their well-being and survival.

After cancer treatment or surgery, women experience health care needs and a variety of physical and psychological symptoms (Champion et al., 2014; Cappiello et al., 2007). Thus, cancer treatment and surgery affect women's body and sexuality in a way that constitutes another health care need. A survey conducted in the United States of America in 2006 by the national cancer institute on cancer survivors (that is, people living with and beyond the diagnosis of cancer) found that there were about 2 million women surviving cancer (Cappiello et al., 2007). Improvement in health care treatment continues to extend the lives of cancer patients and boosting research focus on cancer survivors.

Nevertheless, there are risks of later side effects of treatment and recurrence of cancers (Rabin et al., 2005). These warrant special health care needs that are persistent physical, psychological symptoms, such as pain, sleeping disorders. Other persistent symptoms include but are not limited to fatigue, decreased functional ability, changes in sexuality, induced menopause (Cappiello et al., 2007).

Kurowecki and Fergus (2014) noted that approximately one third of women with breast cancer also struggle with sexual dysfunction post-treatment, while premenopausal women are concerned about fertility leading to additional distress. Other studies like Cappiello et al. (2007) also indicate reproductive health challenges associated with cancer treatments. Some survivors of breast cancer faced sexual problems.

Out of the 360 participants that were contracted for the study by Fobair et al. (2005), 52% reported having two or more problems in the areas of sexual functioning, while others had at least one area where they had a serious problem (Fobair et al., 2005). Changes in sexuality and sexual function were also reported in the post-treatment phase and were attributed to decrease in libido (Cappiello et al., 2007). While most studies are from outside Africa, it is likely that these factors are even more serious in Africa considering the values placed on issues like fertility and one's ability to reproduce, especially if the individuals are in the prime of their

lives. The current study aimed to bridge this gap in the literature with an African case study on how diagnosis and treatment do, in fact, affect a woman's overall quality of life.

Cancer-related treatments affect women's intimate relationships as they challenge a couple's ability to cope with illness related relationship changes such as increases in sexual dysfunction, loss of fertility, fear of mortality and an uncertain future. They are also reported to create communication difficulties between couples (Kurowecki and Fergus, 2013). Problems faced by married couples appear to be far greater than those who are unmarried. According to the research conducted by Holmberg, break-ups occur during the early phase of treatment, leaving the woman with fewer social and marital resources during a vulnerable time (Kurowecki and Fergus, 2013). Comparing the effect of treatment on men and women, it was reported that the effect of cancer diagnosis and treatment on women is greater (Kurowecki and Fergus, 2013).

Sexual functions which the diagnosis and treatment tend to affect include problems were associated with vaginal dryness as well as poor mental health. Amongst married couples and those with long-term partners, there appeared to be growing difficulties in understanding feelings and more body image problems (Fobair et al., 2007). This dramatically affects sexual intimacy as there is a growing loss of desire and depression, difficulties in getting mentally and physically aroused, dyspareunia because of vaginal dryness, orgasmic difficulties for biological and psychosexual factors (Graziottin, 2008).

Sadovsky et al. (2010) concluded that the management of breast cancer treatment has a significant impact on sexual function and satisfaction. Evidence from medical and psychosocial literature reviews and extensive group discussion and open presentations informed their discussion on the impact of cancer on men, children and women. The study found that women with a gynaecological cancer diagnosis consider their sexual health to be one of the three most important aspects of quality health care.

Cancer and its management have a significant negative impact on sexual function and satisfaction: "These negative effects can be somewhat mitigated by understanding pre-diagnosis sexual functioning level, counselling, careful treatment choices, and, when indicated, therapy post-treatment using educational, psychological, pharmacological, and mechanical modalities" (Sadovsky et al., 2010, p. 370). In their study on sexual morbidity of cancer survivors, Lindau, Anderson and Gavrilova (2007) found that 74% of participants believed their physicians should discuss sex but this discussion did not occur 62% of the time. Moreover, sexual dysfunction can be the primary source of distress from symptoms related to cervical

cancer treatment. Between 30% of women and 63% of women that undergo treatment for cervical cancer experience some sexual complaint.

Sexual complaints after the diagnosis of breast cancer appeared to be common 30% to 100% of the time, from desire disorder to organic concerns. A recommendation was presented to help reduce cancer impact on sexual activity: there is a need to manage pre-treatment sexual problems the same as in persons without cancer, using treatment techniques least likely to damage the nerves, manage any hormonal results of treatment and finally to make use of appropriate post-treatment.

One primary response to a woman's body image is an attempt to adjust in order to assume control over self-esteem and to function optimally. The effect of cancer treatment can also bring about a turning point in the life of women. It impacts the trust that some women have on their bodies, their future ability to cope with the symptoms and their struggles to survive as treatments tend to reshape their priorities. According to Cappiello et al. (2007), most women struggle to return to the life they led before the diagnosis and treatment. Most complain of being treated as children, or being seen as fragile and being pitied, while others face isolation from family and friends. In other words, it affects women's quality of life (Champion et al., 2014; Sadosky et al., 2010; Fobair et al., 2005).

Champion et al. (2014) attempted to understand the unique survivorship issues facing young survivors by comparing findings from the sample of 505 young survivors, 622 older survivors, and 404 age-matched controls. The study investigated the quality of life problems that may linger over time with participant survivors who were three to eight years from diagnosis without recurrence of breast cancer. Comparison of the three groups identified the degree to which diagnosis of breast cancer at a young age accounts for their overall quality of life. This included their physical health functioning, depression, and anxiety as well as their overall quality of life (Champion et al., 2014). Cappiello et al. (2007) also found a prevalence of physical distress symptoms among respondents, where 60% to 80% had difficulty in remembering things.

Similarly, Ussher, Perz and Gilbert (2012b) identified that change to sexuality after breast cancer treatment was significantly affecting survivors' quality of life (Ussher et al., 2012b). This was generated from 98.8% female respondents in a mixed method analysis of qualitative and quantitative responses to an online survey gathered from 1 965 individuals with breast cancer. Respondents were members of a national Australian breast cancer organization. 85%

of the participants reportedly experienced changes to their sexual well-being after breast cancer treatment. 68% of the study participants also indicated that they needed some written information on such changes to guide them.

This finding supported the study's hypothesis that after breast cancer, women experienced changes in their sexual lives that affect their way of life. The lack of information associated with such changes contributed to the survivors' experience of distress. Ussher et al. (2012b) examined the physical and psychological changes to sexual well-being and considered (a) the importance of information about breast cancer and sexual well-being, (b) satisfaction about the information obtained from sexual well-being, and (c) this also dealt with satisfaction, about discussing the changes to sexual well-being with others. Thus, Ussher et al. (2012b) believed the range of modalities of information about sexual well-being must meet the specific needs and preferences of individuals with breast cancer.

In the study of Champion et al. (2014), differences among the young survivors, older survivors and aged matched controls were compared; the results showed that younger survivors had more depressive symptoms $P = .005$ and fatigue, poorer self-reported attention function and poorer sexual function $P < .001$, than either the older survivors or age-matched controls. The study concluded that younger survivors fare worse on body image, anxiety, sleep, marital satisfaction and fear of recurrence and this indicates that younger survivors more have long-term quality of life problems than survivors diagnosed at a later age (Champion et al., 2014).

Fobair et al. (2005) surmised that breast cancer treatment and diagnosis affect the life of its survivor, including their sexual identity, their sexual function, and their sexual relationships in ways that requires them to make major life adjustments. They concluded that treatment and cancer diagnosis can also affect one's sexual identity. They conducted reports, in which 546 participant sexually active women aged 22-50 years were surveyed. The report indicated that half of the women experienced two or more body image problems. This was in line with findings from other studies that given the challenges that breast cancer treatment survivors' face, the availability of any information regarding their adjustments is essential.

Other studies have identified that survivors of breast cancer have specific information needs, but they also remarked that this information is often lacking or where available, it is limited or unsatisfactory (Ussher et al., 2012b; Cappiello et al., 2007). Cappiello et al. (2007) noted the importance of comprehensive information and support for breast cancer survivors to negotiate their transition after treatment or therapy. Ussher et al. (2012) undertook to provide clinicians

and cancer organisations with specific suggestions about sexual information needs after breast cancer and the modalities which are preferred, to prevent and ameliorate distress.

This is in line with the Cappeillo et al.'s (2007) concern that little is known about the crucial resources needed to enhance recovery and self-care management, and for developing an understanding of what women need in their post-treatment period. This lack of information often contributes to the level of distress experienced by these survivors (Cappeillo et al., 2007). Both agree about the value of information to ameliorate the distress among cancer treatment survivors.

Participants in Cappiello et al.'s (2007) study were from the national cancer institute in the USA who had stage 0-IIIa breast cancer. Seventy-five percent of the study population received chemotherapy, 60% received hormonal therapy and the remainder received either mastectomy or reconstruction surgery. The common physical and emotional symptoms and women's experiences were interrogated by the study in relation to the extent to which the amount of information they received in preparation for the transition was useful in enhancing their transition. Of the participants, 45% reported that they had received no information on what to expect. Those with information claimed that the information was inadequate.

Ussher et al. (2012) found that information on physical changes, sexual response, relationship issues, psychological consequences, and body image or identity, were rated as very important by a substantial proportion of participants. Only 41% had obtained such information; however, 65% had spoken about sexual changes, to partner (76%), G.P. (49%), friend/relative (47%), oncologist (39%), or breast-care nurse (21%). Ratings of satisfaction with the discussion were highest for breast-care nurses (60%) and lowest for oncologists (34%).

The implications of this lack of information were reported to include survivors' struggles to return to the life that they led before they were diagnosed (Cappiello et al., 2007). Breast cancer survivors often feel unprepared for the side effects that linger after therapy. And thus there is a need to provide comprehensive information and support to help women with this transition. Although there have been a few interventions, the level of information and support must increase. Some of the information needs that are common are expressed in the following sections.

In emphasizing the importance of information needs about breast cancer and sexual well-being, Ussher et al.'s (2012b) survey indicated that N=1355 of the participants deem this information

very important, and 71% see the importance of information about breast cancer and body image and appearance. The level of satisfaction with the information obtained about sexual well-being saw the number drop drastically to N=790. Ussher et al. (2012b) also gave us statistics on other people's satisfaction about the changes to sexual well-being of cancer treatment survivors as rating about N=680. Generally, the information needs associated with such changes are very limited, hence the absence of a knowledge base to guide information provision aimed at preventing or ameliorating distress (Ussher et al., 2012b). The limited available information is often not understood by survivors.

Finally, little is known about the role played by socio-demographic, socio-economic and clinical characteristics in the capacity of the patient to retain their professional situation after diagnosis. The effect of cancer on labour market outcomes needs to be considered. Bouhnik et al. (2015) undertook a longitudinal survey in France to assess the condition of cancer survivors and their lives after cancer. The study focused on a less researched variable of the adjustment of cancer survivors after treatment and how this affected their employability need. It also shed some light on the effect of cancer on working life of individuals. Another objective of the study was to determine the factor that affects the quality of life and daily life of cancer survivors, and the evolution of those individuals over two and five years of cancer diagnosis. These factors are no doubt critical in the assessment of women's definition of their well-being, and therefore introduce an important element that should inform the current study.

One of the ways in which women can renegotiate their body image and confidence as a sexual being after surviving cancer is by being united; sharing and solidarity by the couple who are facing breast cancer is important (Sadovsky et al., 2010). Many other studies are being conducted to help combat the effect of the diagnosis and treatment of cancer. There are many treatments and treatment modifications that can minimise the negative sexual effects of cancer; the first step in finding a solution that will help the survivor renegotiate her body is through a conversation about sex and sexuality.

The question of accessing valuable information that would facilitate adjustment is crucial and has been considered an effective way of treating and helping to renegotiate one body image and sexuality of cancer treatment survivors. Sadovsky et al. (2010) suggested other recommendations as follows:

- a. Manage pre-treatment sexual problems the same as in persons without cancer,
- b. Make use of treatment technique least likely to damage the nerves,

- c. Manage any hormonal results of treatment, and finally,
- d. Make use of appropriate post treatment.

Regarding the second part of the question, the impact which treatment has on women's fertility and ability to become mothers is very high, as surgical removal remains the mainstay of treatment for many gynaecological cancers, especially ovarian.

1.8 Conclusion

Breast cancer has a negative impact on women's health, body perception and sexuality. This introductory and literature review chapter has offered an appraisal of literature concerning body image, sexuality and the reproductive health of breast cancer survivors. It has also briefly summarised the different treatment options for breast cancer patients. A discussion of the role of social scientists, especially anthropologists in health-related studies has also been discussed.

1.9 Structure of dissertation

Chapter 1: Introduction and Literature Review

The introductory chapter includes the background of the study; looks at the social aspects of illness which affect women's understanding of their bodies and sexuality. This chapter also includes key questions which were used for this investigation, as well as the objectives of this study. Finally, it gives a brief outline of the chapters which are to follow.

Chapter 2: Methodology

The second chapter of this study discusses the methodological approaches which were employed for this study. It discusses the different qualitative tools that were used to gather rich qualitative data on how young Black women renegotiate their body image and sexuality after breast cancer. It also provides an overview of the sampling techniques, limitations of this study, and ethical issues such as informed consent, anonymity, and confidentiality. The conceptual framework is also discussed, paying attention to the interpretative paradigm as well as the social constructive and social identity theories.

Chapter 3: Diagnosis and disclosure

This chapter discusses stories of the changes that were experienced by young Black African women in the preliminary stage of their illness. It includes the memories that young Black African women recalled with respect to breast cancer. The chapter also interrogated the

sociocultural constructions that are associated with bodily changes for young women. This is done with the aim of assessing how the bodily changes were interpreted by the women within the African cultural matrix. The chapter further discusses how women learned of their diagnosis and the challenges they encounter in terms of disclosure.

Chapter 4: My Perfect African Body

This chapter explores the sociocultural constructed connotations associated with human bodies. This is done paying particular attention to how young Black African women understand their body image, attractiveness, and sexuality; this includes the young Black women's interpretation of these terms. The theories of social construction and social identity are used to understand how young African women understand their sexual selves. The chapter also probes the African interpretation of breasts and body image prior to being diagnosed. It further includes a systematic recollection of the young women's marriage prospects before cancer.

Chapter 5: The effects of cancer treatment on young Black African women

Breast cancer treatment affects women physically (through breast surgery) and emotionally (often through depression). Breast reconstruction and decreased desire for (sexual) intimacy are some of the common side effects of breast cancer treatment. This chapter explores some of the physical effects of cancer treatment which include premature menopause, fertility, hair loss and changes in breast appearance. It also critically discusses the emotional issues which include relationships with previous and current partners and depression. These are discussed in an attempt to understand not only the challenges posed by the treatment but also the measures used by Black African women in renegotiating their sexuality and body image. The chapter further discusses how some women rely on their African beliefs to minimise the side effects of cancer treatment.

Chapter 6: Traditional and spiritual beliefs: Cancer and young Black African women

The well-being and health of humans is linked to their traditional and spiritual beliefs. This chapter interrogates the role of traditional and spiritual beliefs in the construction of illness. It discusses the different traditional and spiritual beliefs and practices that influenced the young Black African women's interpretation of their illness. The role of spirituality is also discussed with the aim of exposing its influence on how African women interpret and manage breast cancer.

Chapter 7: Intimacy after Breast Cancer: Young Black African women and their stories of intimacies

Breast cancer treatment can affect sexual intimacy. Premature menopause is one of the greatest concerns before and after breast cancer treatment as it leads to loss of fertility which can be challenging and difficult to accept for young women. This chapter discusses the participants' intimate relationships before and after surgery. It discusses the changes caused by surgery and describes ways in which young Black African women attempt to renegotiate their sexuality.

Chapter 8: My perfected Black African body

This chapter discusses the socio-cultural constructions that young Black African women use to describe and discuss their womanhood after breast cancer treatment. The chapter also discusses how young Black African women reintegrate themselves in society and how they identify with other women in their respective societies and cultures. This chapter uses data that was collected through a letter writing exercise entitled 'letter to my younger self'. This methodological technique was used to acquire an insight into the women's youthful years and what they wished they had known about the sociocultural construction of their own bodies and how they had learned to collectively interpret their sexuality and body image.

Chapter 9: Conclusion

This final chapter presents a critical appraisal of the main themes that formed part of this study as well as the significant contributions of the study and suggestions for further research. This chapter reviews the fundamental findings and arguments of the study illustrating that the study successfully achieved its primary objectives.

CHAPTER 2: METHODOLOGY

2.1 Introduction

The second chapter of this study discusses the methodological approaches which were used in this study. It describes the different qualitative tools that were used to gather rich qualitative data of how young Black African women renegotiate their body image and sexuality after breast cancer. It also provides an overview of the sampling techniques, limitations of this study and ethical issues such as informed consent, anonymity and confidentiality.

2.2 Methodology: Research design

Data gathering is crucial in research, as the data is meant to contribute to a better understanding of a theoretical framework (Bernard, 2002 cited in Tongco, 2007). This study was highly qualitative in nature and employed qualitative research methods. Qualitative research methods are known for their ability to allow researchers to “examine how people learn about and make sense of themselves and how they structure and give meaning to their lives” (Hox and Boeije (2005, p. 595). According to Newman (2003, p. 22), “qualitative research methodology is an approach that describes and gives meaning to particular social phenomena”. Through its data collection tools, qualitative methods enable researchers to gain a deeper understanding of people’s perceptions on the subject areas being studied. Such methods are normally used in situations or studies where little is known as they enable the study to probe into people’s understanding of their experiences and attitudes regarding the phenomenon being studied, such as the experiences of young Black women who are breast cancer survivors. These methods aim to answer questions about the ‘what’, ‘how’ and ‘why’ of a phenomenon rather than ‘how many’ or ‘how much’, which are answered by quantitative methods (Al-Busaidi, 2008). Consequently, Creswell (2009) stated that qualitative research is intended to penetrate to the deeper significance that the subject of the research ascribes to the topic being researched which involves a naturalistic approach to its subject matter and gives priority to what the data contributes to important research questions or existing information.

This study utilised methodological tools such as focus groups, case studies, semi-structured interviews and observations. Information gathered through this study assisted in gaining an in-depth insight into the experiences of the young Black survivor’s lives and their opinions of the issues that were uncovered. Using qualitative methods allowed this study to be investigated “from real world settings where the phenomenon of interest unfolds naturally” (Patton, 2001, p. 39).

2.2.1 Data collection

Data collection commenced immediately after attaining ethical clearance from the University of KwaZulu-Natal. The process of ethical clearance took a month longer than expected, which interrupted the scheduled work plan but no information was collected prior to attaining the clearance from the university. Once permission was granted, I began by attending social events that were organised by Sinothando, a non-profit organisation that had granted me permission to utilise their resources and which assisted me in identifying potential participants.

This qualitative study used a qualitative methodology and data was collected through individual interviews and focus groups of 15 young Black African women aged between 24 and 40 years, residing in Durban. These women are proud breast cancer survivors who have undergone a single or double mastectomy. This study focused on research interviews as it aimed to explore the views, experiences, beliefs of individuals related to breast cancer (Gill et al., 2008). Qualitative interviews are known to be “a popular method of data collection in which interviewees are given the opportunity to talk about their experiences and views” (Hox and Boeijs, 2005, p. 595). This study did not make use of any quantitative data collection methods as it was interested solely in the feelings and experiences of the women.

The study employed individual interviews as the main tool for data collection. Such interviews were chosen as the main data collection tool because of their ability to provide the researcher with an in-depth understanding of how young Black women renegotiate their self-image after surviving breast cancer. This study used in-depth semi-structured and unstructured interviews to collect data. According to Boyce and Neale (2006), in-depth interviewing is a “qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation” (3). Writing about this technique, Morris (2015) maintained that while the length of each interview may vary, researchers should be encouraged to have flexible and free-flowing interactions with the interviewees. The advantages of choosing in-depth interviews over surveys include acquiring detailed information about the phenomenon in question and allowing participants to lead the interview while navigating with an interview guide.

Several interviews were conducted in this qualitative study; repeat interviews were conducted with all participants. Interviews were scheduled at least a week in advance to provide participants with ample time to get organised. Not all individual interviews were conducted timeously as participants often had other urgent commitments. Two participants had to leave

in the middle of the sessions. As a researcher, I understood that I had to be patient and re-schedule. Where this was the case, I tried to ensure that I arranged a more suitable time for follow-up interviews. Where this could not be done within a few days, I used other forms of communication to collect data. All interviews were conducted at the participant's chosen venues and conversations were held in isiZulu and English, depending on the language the participant was comfortable with. Individual interviews occurred before and after focus groups.

Throughout the interview process, I made use of social network platforms such as WhatsApp, BBM, Facebook and Twitter⁹ to communicate with the participants. Permission was requested prior to all social media correspondence. At first, all participants agreed to be part of a chat group on WhatsApp. Some of the participants complained of being flooded by messages. Some of the participants who were unemployed and are living on their own were very keen on the chat group to the extent that they created their own group and invited me to be part of it. This was very helpful as at times it served as a virtual focus group where I could seek clarity on some of the information that would have transpired during focus groups. I also conducted individual chats with the participants. Using WhatsApp, Facebook and BBM also assisted in connecting me to participants who could not attend follow-up interviews due to other commitments.

Scholars' such as Chadwick (2016), Fox (2015) and Spry (2001) have illustrated the importance of using innovative methodologies especially in social science studies. Chadwick (2016, p. 2) further advocated for the need for 'fresher' research which involves the usage of advanced methodological techniques in data collection. In agreement with these scholars, this study also made use of a letter writing activity to collect data; the activity was called 'Letter to my younger self'. In their book on research methodology, Garner, Wagner and Kawulich (2009) considered letter writing and collection as a data collection technique. The idea to use this activity developed when I attended a ladies conference where we were encouraged to think about our current social positions and reflect on our past challenges, then write letters to our younger selves. In listening to the different letters that the women had written to themselves, I realised that there were many challenges that women have been through and that their past actions and decisions influenced the manner in which they currently identify with the people

⁹ Consent to communicate using social media platforms was requested and only participants who agreed to use them were contacted. BBM, Whatsapp, Facebook are popular social media applications that enable people to communicate individually and with groups. They are relatively convenient to use when conducting research as the researcher is able to send instant messages to participants and can even hold group discussions.

around them. I decided to ask the young Black women to share their thoughts and feelings about their younger lives and the challenges they may have to undergo due to cancer. The women who were willing to participate in this activity were given two weeks to write and submit their letters. The letters were not restricted in length and the women were simply encouraged to express their feelings to their younger selves in the best possible way. These letters have been included in this study with the purpose of engaging with the young Black Africans' understanding of their body image and sexuality. This was important as through the letters this study could attempt to understand some of the sociocultural constructions that influenced the women's understanding of their bodies.

This study aimed to conduct three focus groups. Gill et al. (2008) defined a focus group as “a group discussion on a particular topic organised for research purposes. This discussion is guided, monitored and recorded by a researcher”. These topics concern attitudes and feelings, and beliefs may be partially independent of a group or its social setting, but are more likely to be revealed via the social gathering and the interaction which being in a focus group entails (Gibbs, 1997). In addition, Wisker (2001) cited in Dilshad and Latif (2013, p. 191) stated that “the use of interview is highly desirable for obtaining information based on emotions, feelings, experiences, sensitive issues, and insider experience, privileged insights and experiences”.

The initial aim was to have at least eight participants for each of the sessions and to have a total of four focus group sessions. However, due to logistical challenges, only two focus group sessions were conducted with only six participants for each session. These were in between observations and one-on-one interviews. This was a strategic attempt to discuss some of the issues that would have emerged during observations and individual interviews and I was able to delve into some of the issues that I was not aware of and that were interesting for the study. One of the examples of this is covered in Chapter 4: during an interview I was introduced to the term ‘African asset’ and in an attempt to fully enter my participants’ world, I raised this new term during the first focus group and it was interesting to learn that it is a well-known and understood term that survivors often used to discuss their body image. Such rich information would not have made much sense if it was only discussed during individual interviews as some participants were rather reserved during these interviews, but they openly expressed themselves when other participants commented.

Organising focus groups was challenging. One of the major constraints was time. I was initially unable to organise focus groups during the week due to work-related commitments. In addition,

the participants were almost always occupied during weekends with Saturday being the day they attended funerals, celebrations, church for some of the 7 Day Adventists and Shembe religious members, while the rest attended church on Sundays. What also proved difficult was organising venues. Community libraries and shelters were often fully booked for the weekends. Eventually, I was able to get time off work for the focus groups and participants were able to attend. While it would have served this study better to conduct at least three focus groups, much rich data was collected over the two sessions as each group had a good mixture of participants. These participants varied with respect to age, marital status and religious backgrounds, all which added a different texture to each session. What was also of great benefit was that some of the women had met during the Sinothando gatherings which made sharing their experiences easier.

Some participants proved to be more vocal than others; others waited to be 'led' by fellow participants to share their experiences. The younger participants were initially shy to share their sexual experiences with the 'older' participants. Older participants did not find it easy to talk about their body image with the younger participants. My petite body also added to this dynamic as none of the participants believed my age or the fact that I was conducting this research for my studies. Fortunately, I had my work staff card and driver's license as evidence of my age. It was only after introducing myself several times that they could openly share their experiences.

Focus groups enabled me to document not only the discussions that were raised, but facial expressions and body movements as well. For example, the young Black women often smiled when they were asked questions relating to their intimate relationships. They shared details of their relationships, often through their body and gestures. The focus groups consisted of six women per session who were selected according to their availability. These participants were selected from the fifteen participants who formed part of the one-on-one interviews. Focus groups were utilised in the hope that discussions would produce data and insights that would be less accessible without group interaction. Thus, the idea was that participants would be able to listen to others while they shared their experiences, which in turn would stimulate memories, ideas, and experiences of individual and personal journeys associated with breast cancer. This indeed was the case as even the shyest of these women could express their feelings. I have highlighted some of the data that was collected during the focus groups in the discussion chapters that follow.

Kawulich (2005, p. 2) defined participation observation as “the process enabling researchers to learn about the activities of the people under study in the natural setting through observing and participating in those activities”. Subsequently, Schmuck (1997), cited in Kawulich (2005), asserted that participant observation provides researchers with ways to check for non-verbal expression of feelings and to determine who interacts with whom, grasp how participants communicate with each other and check how much time is spent on various activities. By employing participant observation, the research aims to build familiarity with the participants’ which in turn creates useful interaction with the subjects being studied. Hence, during the first half of 2014, participant observation was made in a form of home visits, ‘hanging out’ with participants, engaging in shopping activities and accompanying the women on their hospital visits.

The majority were happy with the idea of being visited. One participant, Zibuyile, even invited me to a baby shower that she had organised for her friend (see pictures in Appendix 5). I decided to attend as it would give me an idea of how cancer survivors behaved amongst other women. This was the first time I had met any of the participants outside the formal and informal settings of being participants. During the focus groups, the participants were my guests, they waited for me to direct or at least start the conversations. Being a guest at the baby shower shifted the positions and I was happy to be hosted. Fortunately, the shower was held three weeks after I had met Thina who introduced me to the term ‘African Assets’. Hence, I could understand what the women meant by African Assets and being African Queens. I was also fortunate to ‘hang out’ with some of the other participants; I joined three participants on a shopping spree. While I feared that they may not be comfortable trying on clothes in my presence, they seemed to be happy to have an outside opinion and they all claimed that I had a different fashion sense. This, according to Mpilonhle, was mainly since none of my clothes were revealing and that my assets were overly covered. During the shopping trip, they made me try on different styles of clothing, clothing that enhanced my assets. While I was uncomfortable with trying on clothes that I had no intention of buying I ended up buying a top that reminded Nosizwe of having two equal breasts (this she highlighted as she now has one breast and wears a prosthetic on her right-hand breast). The rest of the observation was held in the participants’ homes and work areas.

2.2.2 Ethical concerns

According to Edwards and Mauthner (2012, p. 15), “ethics in social research refer to the moral considerations on the part of researchers throughout the research process”. This study complied

with the universal research guidelines and all possible ethical concerns and precautions were followed as per the guidelines outlined in the consent form (see informed consent forms in isiZulu in Appendix 1 and in English in Appendix 2). This includes the usage of pseudonyms and attaining consent from participants before interviews and observations.

In the process of conducting this research and in writing this , I have gone to great lengths to protect my participants. Firstly, their names have been protected through the usage of pseudonyms. I gave participants the opportunity to choose names they felt suited them. Some preferred to use their own names and full identities. This was a personal choice as I had explained the benefit of using false names, which included not being easily identified as members of the study. Some of the women, however, felt the need to share their full identities as they felt their names had more meaning especially after the traumatic experiences they had overcome. Zibuyile, who explains the meaning of her name in Chapter 4, is an example.

Prior to signing consent forms, participants required clarity on several issues. Issues pertaining to compensation were amongst the most important. The question of what they would benefit from participating in the study was also raised a few times. Some of the women even thought I was from a cancer organisation that would assist them in getting prosthetic breasts. I had to constantly remind them of the consent form that clearly stipulates that there would be no form of remuneration for participating in this study. I shared the benefits of participating in this study, which included an opportunity for the participants to share their experiences as a group, which in a way can be seen as a form of healing. The consent form raised questions for some of the participants, especially those who were married and those who were in serious relationships or as Zibuyile often put it, were in straight relationships. As a researcher, I had had several years conducting research both professionally and as part of my study and I had taken for granted that participants would easily sign off the consent forms without having to contact and get consent from their partners and family members; after all, none of the participants were under the legal age of 18. After Thandaza requested that I email her a copy of the consent form and interview questions I realised that some of the participants preferred to get a second opinion before partaking in my study. Thandaza indicated that this was due to the nature of my study, which she found to be “very sensitive and personal”. I had to wait for her husband’s consent before meeting her for an interview. I was also surprised by Thandeka’s partner who preferred to be at home on the day I visited for the interview. I was uncomfortable with the idea, but she assured me that he would not be in the same room with us and she shared that she would not be able to openly share her experience without him in the house as he was

her “strongest pillar during her treatment”. This was the first time I had come across such a situation and I was unsure about the ethical concerns, but after rereading the consent form and notes on research ethics I realised that it was ethical if this was what the participants were comfortable with and it did not hinder the research process in any way.

Throughout the data collection process, participants were reminded of their right to withdraw from the study and not to answer any questions they were not comfortable with as outlined in the consent form. Great care was also taken to minimise stigmatisation of the participants in all documentation. Permission to record information was requested prior to all interviews. As per the university ethical requirements and agreement, all recordings were saved on a flash disc, which is currently stored in a secured place. Fortunately, none of the participants objected to being audio recorded, but some did request that I delete any recordings once I had finished transcribing. Participants were assured of this. I also made the effort to transcribe within a week of the interviews. I called each participant to reassure them that I had deleted their recordings. Some participants shared photographs of their breasts during social media discussions. Only photographs of women who agreed to have their photographs included in this report have been used. Others were deleted as per the participants’ wishes.

Notes were also taken in a private fieldwork book and were typed and stored on the same flash stick as the audio material. None of the women’s real names appear on the stored files as all folders have pseudonyms. It was expected that the participants of this study would be fluent in isiZulu and English, and the language used depended on what the participants were most comfortable with. Focus groups were mostly in isiZulu as I tried to include all the participants. Where slang words were used, I asked the participants to translate or at least explain what they meant. This was to ensure that all participants were fully engaged throughout the focus group sessions. Participants were also encouraged not to be shy in sharing their experiences and to contact me should they wish to withdraw any of the information that they had shared during the interviewing process. Only one participant withdrew her experiences. These were memories of how her intimate relationship had changed due to breast cancer treatment. She claimed that she did not wish for any readers to learn of the hardships she had gone through due to her appearance. Her wish was taken into consideration and I deleted her recording and tore off a page from my notebook with this information. She was pleased to have seen me doing this in her presence and she shared that she was terrified that I might have included her experiences. Where necessary, data was translated into English, and stored in a secure place. I enjoyed the privilege of having direct contact with my participants through participant observation as this

encouraged my participants to trust that I was going to represent their experiences in the most respectful manner.

2.2.3 Sampling and sample selection techniques

It was envisaged that identifying participants would not be easy due to the nature and sensitivity of this research area. For this reason, this study made use of the snowball technique. Snowball sampling is “a non-probability sampling method used when the members of a special population are difficult to locate” (Rubin and Babbie, 2009, p. 149). This study focuses on a specific group of survivors from Durban: young Black women aged between 24 and 40 years¹⁰. These survivors would have undergone single or double mastectomy surgery between the year 2011 and 2012. These dates have been selected in an attempt to minimise the potential distress and trauma that participants may experience in sharing their experiences: several years have passed since their diagnosis and surgery and as breast cancer survivors, they are in remission and using the public health care system. This timeframe was also been carefully chosen in an effort to attain data that is contemporarily relevant. Women using private medical care and private hospitals may have had appreciably different health care experiences, and possibly more easy access to psychological counselling around the body and sexuality issues as opposed to those who would have been patients of state hospitals.

Since developing an interest in this topic, I have become acquainted with three young breast cancer survivors. While they had not been formally recruited (as I did not initially have ethical clearance) as participants of this study, they indicated that they would be able to connect me with other survivors. None of conversations or casual discussion, prior to gaining ethical clearance and obtaining informed consent, were used in this research. Participants were women who were married or unmarried (with or without partners), some with and some without children. I was interested in examining the social and familial relationships of these women after surgery. In addition, the supposition was that, regardless of their marital status and whether they had children or not, all the women would go through a process of renegotiating their sexuality and would wish to engage in romantic and sexual relationships. Also, because

¹⁰ The rationale for limiting this study to women aged between 24 and 40 is the recognition that increasingly, breast cancer has inflicted young women, as well as older women. Although women over 40 years are also sexually active, I have consciously chosen women below 40, as I believe that older African women might be somewhat reticent and ‘self-conscious’ in sharing their stories around sex and sexuality. The proposed group was therefore adopted with the understanding of taking into consideration the different perspectives on issues pertaining to sex and sexuality. The selected age group also acknowledged the ethical socio-cultural dynamism which could enue during fieldwork. It also enabled this study to prioritise its focus on women within childbearing age.

they were young they may wish to have children and live ‘normal’ lives regardless of their breast shapes. I chose to include both women with and without children with the understanding that their experiences would provide different perspectives of the cultural definition and function of breasts for young African women. I was able to compare the women’s experiences and the role of having family and spousal support in renegotiating their body image and sexuality.

Therefore, this study made use of the snowballing technique to recruit participants. While snowballing as a sampling technique allowed for the identification of potential participants through referrals, I feel it also limited the study in terms of identifying a variety of participants.

2.2.4 Data processing and analysis

Unlike quantitative data that is highly numerical and analysed using statistical software, qualitative data is based on meanings expressed through words. The process of qualitative data analysis generally involves the development of data categories, allocating units of original data to appropriate categories and recognising relationships within and between categories of data to produce well-grounded conclusions (Sarantakos, 2005). The different forms of data collected were transcribed into texts representing the women’s experiences and perceptions. The data was then analysed based on the conceptual framework, the research questions, and existing literature to identify recurring themes.

Data was analysed using the thematic analysis approach. This is an approach that is useful and is usually adopted when researchers deal with coding data (see Ryan and Bernard, 2003). This qualitative process involves “identifying, analyzing, and reporting patterns [themes] within data” (Braun and Clarke, 2006, p. 79). Once data was collected, it was important to carefully read through the information looking for correlations. Similar information from participants formed themes which Braun and Clarke (2006) described as capturing “something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set” (p. 82).

Because qualitative studies are interested in analysing the lived experiences of informants, the first step in analysing data was to identify patterns of experiences as they were transcribed in my fieldwork book. This included the information that was shared by informants as well as my observations. This first step is known as coding. Maree defined coding of data as the “careful scrutiny of your data and taking note of all the relevant and meaningful sections and items” (2007). Gibson (2006) argued that coding refers to the assembling or grouping of data

according to the likeness of responses. Immediately after coding, I identified patterns that had already started to present themselves. This was not without difficulty as I realised that some of the information that was shared and that I had recorded was not relevant for this study. Therefore, I had to reserve such narratives for future studies. In some cases, I had to go back to ask more relevant questions pertaining to the data that had already emerged. Working with such raw coded data enabled me to further classify responses according to sub-themes. It was at this stage that I started to formulate the themes that would form part of this dissertation. It is through these sub-themes that patterns became more concrete. In many cases, each narrative could be codified as more than one theme, where this was necessary, narratives were classified in comparison to what other informants had shared on similar issues.

The thematic analysis tool enabled this study to identify the themes and views of informants, giving precedence to data over theories. Boyatzis (1998, p. 160) stated that:

Descriptive use of thematic analysis is desirable if the methodology chosen for the study requires it ... it does not preclude scoring or scaling of themes and then using this numeric representation to check the consistency of judgments ... neither do they preclude using the information to portray the themes and describe the units of analysis.

Thematic analysis is concerned with interpreting human experiences, from an emic perspective whereby responses from informants are to be interpreted as the informants share them. Gibson (2006, p. 1) argued that:

One of the central positions associated with qualitative research pertains to the idea of interpretivism: that we are interpretive in our actions and in our understanding of the actions of others; that we impose meaning on the world; that we inhabit cultural worlds and engage in cultural practices that are defined by shared interpretations.

Within this backdrop, analysis of data adopted an emic approach. This was done with the intention of interpreting data from the informants' perspective.

During fieldwork, data was jotted down in both English and isiZulu. As an isiZulu first language speaker, I found this helpful when it came to describing the informants' gestures and body language. Notes were later translated into English if required. Most of the interviews were conducted in isiZulu with the participants adding in English words and phrases. It was apparent that most participants were comfortable in conversing in isiZulu so most interviews had to be translated. When I did not fully understand what was being said or I did not properly understand the context, I was able to ask some of the participants for clarity once the translation process had begun. I have chosen to include the isiZulu version of the interview transcripts as they

captured the participants' experiences exactly. Temple and Young (2004) argued that while translating interviews is not an easy task, it is more bearable when the researcher is fluent in the language that the participants speak. They further argued that "it offers opportunities in terms of research methods that are not open to other researchers in cross language research. The researcher can use the experience of translating to discuss points in the text where she has had to stop and think about meaning" (p. 161).

2.3 Validity and reliability

In their research guide, Braun and Clarke (2006) discussed the six phases of conducting thematic analysis. These are: 1. Becoming familiar with the data, 2. Generating initial codes, 3. Searching for themes, 4. Reviewing themes, 5. Defining and naming themes, and 6. Producing the report. These are crucial in ensuring that the participants' experiences are well documented. Following the process of searching and formulating themes, it is also important for the researcher to search for possible 'gaps' or data which may not cooperate. This is done through the process of validation. Winter (2000, p. 1) saw validity as a "contingent construct, inescapably grounded in the processes and intentions of particular research methodologies and projects". He argued that there are multiple ways of achieving validity when using qualitative research methods. Joppe (2000, p. 1) defined reliability as

The extent to which results are consistent over time and an accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology, then the research instrument is considered to be reliable.

All data that was collected during this study was validated. Validity and rigour are of great importance in qualitative studies as they enable the researcher to review data that concerns the participants. Morse et al. (2002, p. 1) asserted that "without rigour [and validity], research is worthless, becomes fiction and loses its utility." This study relied on the rapport that was established with the participants in attempting to ensure that data was true. Data was also cross-checked using triangulation. Triangulation has risen as an important methodological issue in naturalistic and qualitative approaches to evaluation to control bias and establishing valid propositions because traditional scientific techniques are incompatible with this alternate epistemology (Mathison 1988, p. 13). Triangulation was done through using different data collection methods in gathering data. These included participant observation, interviews, and recordings that were collected from the young women.

During the course of this study, I was also blessed with a daughter. While many researchers may have seen this as a stumbling block, I found it made me ‘connect’ with my femininity. Through watching my body change daily and stretching my breasts, stomach and hip area I was able to understand some of the challenges that the participants had complained about. While I initially did not understand the link between breast cancer, pregnancy and menstruation periods, I was now able to understand the relationship that was often mentioned by participants

Because I had been interviewing participants about their diagnoses and bodily changes, I was shocked and fearful when I first felt my own breasts being lumpy. Pregnancy was not the first thought I had; rather, I thought I had breast cancer. Out of curiosity, I googled the instructions of testing breast tests for cancer and according to my analyses of my breasts, I was cancer positive. It was only after I realised that my periods were late by a week that I started suspecting that I was pregnant. Due to the pregnancy, I lost a full year of being active in my research. Upon resuming, I tried to work as hard as possible in securing more appointments and collecting more data.

Transcribing was not easy, especially following focus group meetings; at times two informants would speak at the same time. While they were constantly reminded kindly to avoid this, I at times felt overpowered; this will be further discussed under limitations.

Identifying literature relating to this study was very difficult as the majority of studies pertaining to breast cancer came from the so-called pure scientists. These mainly focused on the medical causes of cancer, treatment options and body image with respect to food consumption. Most of the literature was written from the western perspective and lacked the African outlook of this disease. While this served as a good motivation for conducting this research, it made finding supporting information very difficult.

For ethical reasons, the university requires a gatekeeper’s letter from the community that the researcher will be working with. This process took a long time as most of the organisations I had approached were unable to assist as their head offices were in Johannesburg with only supporting branches in Durban. The organisations that were open to offering the letter proposed changes in the study. Some of the changes included involving women older than the age of 40 as well as interviewing their staff members who had never been cancer patients. Ultimately I did not choose these organisations as I felt that such demands were unnecessary and would redirect my study. I was, however, fortunate to find Sinothando which only required my

research proposal to approve my request. Upon receiving the gatekeeper's letter, I was able to submit my application for ethical clearance.

As scholars of anthropology, we often pride ourselves on being culturally relative. This was very difficult in practice as I often felt as if I was crossing the imaginary relativity boundary. While I share many characteristics with the women who participated in this study, I often felt pity and disheartened. While I had known the impact of cancer and its treatment from my aunt whose diagnosis and journey with cancer was the main motivation of this study, I often felt discouraged by listening to the survivors' cancer stories. Sometimes I regretted making participants remember the cruelty of cancer treatment. For this reason, I often took 'data collection breaks' in an attempt to retreat from their stories and experiences. This proved beneficial as I could re-focus on the topics I needed to cover without dwelling too long on the hardships of the survivors. Reading and watching movies on cancer survivors also assisted me in realising how brave these women are and the importance of documenting their stories.

2.4 Conceptual framework

2.4.1 Interpretivist paradigm

A paradigm can be defined as a "worldview or the broadest unit of consensus within a given science" (Skrtic, 1990, p. 126). Interpretivism is an important paradigm within social science. Within this paradigm, an individual experience of reality is internalised, according to Neuman (1997, p. 69). This internalised experience is then founded on the understanding that reality is a construction, existing as a social agreement among individuals within a given context (Greene, 1990, p. 234). Interpretivists are of the view that reality is relative and ever dynamic. Understanding of individual action entails taking into consideration the belief and the context of those actions in relation to the individual institutional affiliation. "The world is therefore socially constructed through the interaction of individuals and does not exist independently of individuals' knowledge of the world" (Grix, 2004, p. 83).

Greene (1990, p. 235), writing on the epistemological assumptions within the interpretivist paradigm argued that "knowledge through research is gained from field-based, inductive methodologies and that understanding that knowledge requires considering the context embedded within that knowledge". Interpretivists therefore pay particular attention to the understanding of social events rather than explanations and thus do not rely on observation in order to make sense of social phenomenon. They believe that human beings cannot be studied

in the same way as objects are studied in natural science; this is prompted by that fact that unlike objects, human beings are constantly undergoing changes in their social environment. Du Plooy-Cilliers, Davis and Bezuidenhout (2014, p. 28) explained that “unlike positivists who want to discover and explain casual relationships in an attempt to predict and control the nature and behaviour of humans and animals alike, interpretivist merely want to understand human behaviour”. They stated that in social science, researchers should study and describe meaningful social interactions. As an example, instead of studying to provide statistics on the number of young Black women who have undergone breast cancer surgery from Durban, interpretivists would opt to understand what it is like to deal with the challenges and side effects of treatment and perhaps how women renegotiate their sexuality after treatment. Hence, through utilising the interpretivist paradigm, this study could attain an emic perspective on the different negotiating methods that are used by young Black women after cancer treatment.

“Because the aim of interpretivist research is to gain in-depth understanding, it is often required the researcher to spend many hours in direct contact with those being studied, to be able to appreciate how they experience daily life and gain an understanding of what is meaningful to them” (Du Plooy-Cilliers et al., 2014, p. 28). They equally believe the view that common sense guides people in their day to day engagements. In addition to this, understanding a set of people entails grasping what they view as a common sense. Interpretivists are sceptical of objective knowledge and truth. For them, fact is embedded within a particular meaning system and it is fluid. For example, loss of hair is known as a sign that indicates a person is undergoing cancer treatment. While this is scientifically proven, it is not limited to breast cancer treatments as other medical treatments could have a similar effect. “For interpretivists, facts are not objective and neutral, especially in the social sciences, rather what is factual depends heavily on the context of people’s interpretation of information” (Skrtic, 1990, p. 126). Interpretivists are equally not interested in generalising their findings since truth is dependent on people’s interpretation of facts. They believe that people cannot grasp reality as the same because of their different circumstances, cultures and experiences.

The theory of social constructionism was used in conjunction with the interpretive paradigm. Both these theories focus on meaning and power. The social constructionism theory is concerned with the ways we think and use categories to structure our experiences and analyse the world. It is a perspective which believes that a great deal of human life exists due to social and interpersonal influences (Gergen, 1985 cited in Owen 1995, p. 161). Young and Collin (2004) saw social construction as the process by which people continuously create, through

their action and interactions, a shared reality that is experienced as objectively factual and subjectively meaningful. The interpretive theory, on the other hand, examines the construction of interpretations in different social contexts. Thus, Darke, Shanks and Broadbent (1998, p. 276) posited that “the interpretative approach is based on an ontology in which reality is subjective, a social product constructed and interpreted by humans as social actors according to their beliefs and value systems”. This theory affords researchers the opportunity to understand the phenomenon in question from an emic perspective. This also allows the researcher to probe deeper into the issues that cannot be easily understood using an etic understanding. Schwandt (1994), cited in Adrade (2009, p. 43), asserted that the interpretive theory allows for “the complex world of lived experience from the point of view of those who live it.” Thus, these theories can assist in understanding how African women reconstruct and interpret the effect of their illness and the impact it has on their self-image. Such perspectives were based on these women’s social and interpersonal influences.

2.4.2 Social constructionism

Miller (2005, p. 27) asserted that social constructionism has been highly influential in social research since the 1960s, and that social constructionism is based on the premise that social reality is an intersubjective construction created through communicative interaction. Crotty (1998, p. 42) reiterated this understanding of social constructionism stating that it is “the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context”. This point marks the basic difference between social constructionism and constructivism. Although social constructionism and constructivism tend to be used interchangeably, there is a sharp distinction between the two.

Constructivism pays peculiar attention to individual’s unique experience as a basis for his or her own generation of meaning by inferring that cognitive process in which the generation of meaning takes place within the individual, while constructionism is the collective generation of meaning [referring to the social generation of meaning as a group by taking into consideration that culture has an influence on an individual’s view of the world] (Crotty, 1998, p. 58). According to Crotty (1998), with constructivism, everyone has their own unique interpretation of the world and reality. This point is validated by the individual internal process of understanding and making sense. But constructionism considers the social environment of an individual to have a strong impact on their belief system and understanding of the world.

Geertz, cited in Jones (2003, p. 53), stated that “culture is a system of significant symbols and that those symbols are a guide to human behaviour.” For Geertz, culture is the source rather than the result of human interactions. Culture serves as the social, interpersonal basis that influences a great of human experience. Miller (2005, p. 56) used the example of the term ‘mother’ as a significant symbol. It is a term that has some degree of shared meaning between individuals of the same culture. Social constructionism argues that a social phenomenon exists because of sequels to some social interaction of human persons. A palpable example of this is gender; individuals in different contexts have various understandings of what it means to be male or female and culture plays a key role in establishing this meaning.

With regard to objective truth, Crotty (1998, p. 44) asserted that truth that exists independently from the individual can be said to be non-existent. Social constructionists argue that there is no subjectively created truth; reality fits somewhere in between the views that reality is totally objective and totally subjective (Miller 2005, p. 27). Berger and Luckmann (1991, p. 6) view “society as existing both as objective and subjective reality; the former is brought about through the interaction of people with the social world, with this social world in turn influencing people resulting in routinization and habitualization”. The construction of meaning is at the mercy of individuals who makes use of social reality around them to arrive at this purpose. Using the example of an ideal body image as a social construct for young Black women, women come to terms with this reality from their shared experiences of what is it to be an ideal Black woman and to possess certain body features in their particular context. Constructionists also argue that “individual’s comprehension of society is constituted through language, which means that language should be the object of study, where language is seen as a system of meanings and practices that construct the social world” (Terre Blanche and Durrheim, 1999, p. 149). In the given context, the usage of language and particularly the terminology that young Black women associate with beauty and being sexually attractive, was analysed.

For Allen (2005, p. 38) “language is the means by which individuals make sense of the world, share experiences, objectify subjective meanings and internalise constructed meanings”. Language in this context goes beyond the dictionary meaning of the word. Language originates in everyday activities of the individual and it is characterised by the meanings of the present and future actions. Turner (1997, p. 311) claimed that “language does not describe reality, it actually constitutes it”. Language plays a vital role in how people comprehend and create reality. For Schwandt (2003, p. 19) “Social constructionism understands the fundamental role of language and communication and this understanding has contributed to the linguistic turn

and more recently the turn to discourse theory”. Since reality is not given or objective, constructionism understands that individuals are actively involved in the creation of their realities.

2.4.3 Social identity

Social identity/self-categorisation theory originates in the discipline of psychology, and deals with the structure and function of identity as related to people's membership in groups (Hogg, Terry and White, 1995, p. 259). The basic idea is that a social category (nationality, political affiliation, sports team) into which one falls, and to which one feels one belongs, provides a definition of who one is in terms of the defining characteristics of the category-a self-definition that is a part of the self-concept (Hogg et al. 1995, p. 259). Social identity is a knowledge that one possesses that one belongs to a certain social category or group (Stets and Burke, 2000, p. 225). Stets and Burke (2000, p. 225) further defined a social group as “a set of individuals who hold a common social identification and view themselves as members of the same social category”. Through the social comparison process, people that are similar to the self are categorised with the self and labelled in-groups, while persons who differ from the self are labelled out-group. Turner et al. (1987, p. 23) believed that “much of social identity theory deals with intergroup relations; that is how people come to see themselves as members of one group (in-group) in comparison with another (out-group)”. Hogg and Abraham (1995, p. 342) further clarified that “social identity in which persons places themselves are part of a structured society and exist only in relation to other contrasting categories”.

In summary, one's identity is characterised by the self-view that springs from the reflective activities of self-categorisation or identification in accordance with membership in a particular group: “Each of these memberships is represented in the individual member's mind as a social identity that both describes and prescribes one's attributes as a member of that group-that is, what one should think and feel, and how one should behave” (Hogg et al., 1995, p. 260). Following the important self-evaluative activities attached to social identities, members of a group see it as an obligation to uphold behavioural strategies for achieving and maintaining in-group and out-group that favours the self and in-group. Hogg et al. (1995) stated that social identity invokes the operation of two underlying sociocognitive process. Firstly,

Categorization sharpens intergroup boundaries by producing group distinctive stereotypical and normative perceptions and actions, and assigns people, including self, to the contextually relevant category. Categorization is a basic cognitive process that operates on social and non-social stimuli alike to highlight and bring into focus those aspects of experience which are subjectively meaningful in a particular context. (Hogg et al. 1995, p. 260).

Secondly, self enhancement guides the categorisation process such that the in-group norms and protocols greatly favour the in-group. There is a need for people to see themselves in a positive light in comparison to the relative others. Hogg et al. (1995, 260) established that “an important feature of social identity theory is that in order to explain group members’ behaviour, it formally articulates these basic sociocognitive processes of categorization and self-enhancement with subjective belief structures. The latter points to people’s belief about the nature of relation within their own group and a possible out-group. Thus “social identity is highly dynamic: it is responsive, in both type and content, to intergroup dimensions of immediate social comparative contexts” (Hogg and Abraham 1998, 342).

“Having a particular social identity means being one with a certain group, being like others in the group and seeing things from the group perspective” (Stets and Burke, 2000, p. 225). Social identity theory is actually able to specify how a person’s position in the social world (mediated by self) affects social behaviour. From a sociological perspective, however, research has focused mainly on individual and group rather than on individual and society. Social identity theory pays attention to intergroup relation and behaviour and the role played by the out-group. It considers gender, race and nationality as the most significant source of social identity. For example, this study was concerned with understanding how a group of young Black women identified with each other due to being diagnosed with a common disease, breast cancer. Further to this, this group of women underwent a similar treatment plan which included chemotherapy and a single or double mastectomy. These women are also considered to be from the same race group and the same age group. Additionally, the young Black women were all part of the public health care system, hence their hospitalisation and treatment had similarities.

On the issue of roles and group, Hogg et al. (1995, p. 264) explained that “social identity theory does not explicitly discuss roles, though it would probably consider the roles to refer to positions in a given group (e.g., leader, comic, and bureaucrat)”. One might argue, based on this perspective that roles provide within a group, a distinctive individual identity. “Social identity theory, therefore permits a conceptual differentiation between the roles [differential behavioural prescriptions within a group] and identity based on group membership” (Hogg et al. 1995, p. 265). Finally, social construct sees social identity as an enduring construct that changes only with the changing intergroup relations.

Lastly, social identification refers to how individuals see themselves as part of a group, and how they may use their common interests in defining themselves. Jenkins (1996, p. 90) defined

social identity as, “the constitution in the social practice of the intermingling, and inseparable, themes of human similarity and difference”. This theory eliminates individualism as identity is derived through group membership. It encompasses all necessary groups of which an individual may be part. Such groups may include ethnicity, religion, political affiliations, and relationships. Thus, belonging to such groups, enables people to collectively share ideas and even maintain their identities. Consequently, this study will investigate how young Black cancer survivors collectively understand their sexuality and reaffirm their identity as not only women and sexual beings after surviving breast cancer. Bhugra and Becker (2005, p. 4) defined identity as “the totality of one's perception of self, or how we as individuals view ourselves as unique from others”. Furthermore, Jenkins (1996, p. 5) asserted that “social identity is our understanding of who we are and of whom other people are, and, reciprocally, other people’s understanding of themselves and of others”. Hence, Bhugra (2004), cited in Bhugra and Becker (2005, p. 21), argued that “components of cultural identity include religion, rites of passage, language, dietary habits and leisure activities”. Deaux (1996) further stated that each person has many different identities and attributes which are inclusive of gender, ethnicity, professional status, and weight, a parental status that both construct and impact on the self-concept.

The theories and paradigms discussed above were integrated with the aim to investigate the role played by culture and societal interpretations of the ideal body image and sexuality in identity formation. By engaging with social constructionism and the interpretivist paradigm, this study could engage with subjects relating to the young women’s worldviews, how their cultural matrix and societies have influenced their social world and how they have constructed their reality. This was done through decoding their shared experiences.

2.5 Conclusion

This chapter has discussed the methodologies and methods that have been used in this research study. It motivated for the use of the qualitative research method in an attempt to understand breast cancer and its side effects in the lives of young Black women. It highlighted the importance of detailed documenting of the perspectives of the participants. This chapter also highlighted several research methodological tools that were used in collecting data, including focus groups and interviews. It further gave an account of and motivated for the research design, sampling techniques, methods of data collection, proccession and analysis and ethical

issues that were considered for this study. The discussions in the chapter situate this study within a critical and interpretive perspective where both the researcher and the participants are involved in constructing meaning.

CHAPTER 3: DIAGNOSIS AND DISCLOSURE

3.1 Introduction

Patients seek medical treatment for various health conditions. Some concerns may be easily identified and defined by patients while others are only discovered by medical practitioners through medical screenings and other tests. The results of such tests enable medical practitioners to diagnose illnesses. Diagnosis brings about many emotions for patients; some may be hurt, traumatised and even shocked. Once diagnosed, patients are advised to disclose their medical status to family members and other people who may be affected by their diagnosis. Disclosing an illness is part of accepting a health-related condition and is an integral part of the healing process. It is through disclosing to their loved ones that patients can be fully supported during their illnesses. This chapter discusses how the young women in this sample community were diagnosed with breast cancer. It begins by offering stories pertaining to how they were diagnosed with the illness. These are followed by their individual disclosure stories .

3.2 Early detection and diagnosis

Early detection of breast cancer is beneficial for women as it gives them a chance to learn about their diagnosis and to be treated timeously (Howell et al., 2014). Kissal and Beser (2011) claimed that late diagnosis of any illness limits the treatment options for patients and in some cases, leads to premature deaths as the patients' health would have deteriorated at a faster pace. This is arguably the case for most breast cancer patients. Studies by Champion et al. (2014) and Bloom et al. (2012) indicated that despite the advancement in terms of treatment and its options, late diagnosis leads to premature deaths. Singh-Calson, Nguyen, and Wong (2013) argued that patients present their cancer late because they lack knowledge of the human body and especially the changes that may occur to their breasts. Kissal and Beser (2011) further argued that due to this lack of knowledge, women do not know about their treatment options which often lead to them opting for a mastectomy. Studies by Kissal and Beser (2011) as well as Smith et al. (1996) have indicated that many women 'surrender' to single and even double mastectomy because of the spread of cancer by the time they present their cases.

It may be said that diseases have similar physical symptoms regardless of the patient's background and environment, but they are experienced differently by patients. However, Kidd (2003) stated that even medical symptoms do not present themselves in the same manner and

at the same time. This is because our bodies do not respond to illnesses and viruses in the same manner. In their scientific studies, Cho and Diamond (2012) and Kidd (2003) have gone to the extent of arguing that the human body does not respond to treatment in the same manner. Thus, women often do not realise or understand their bodily changes and their symptoms until they are in late stages of their illnesses as argued by Singh-Carlson et al. (2013).

According to CANSA Org¹¹ breast cancer symptoms include the swelling of all or part of a breast (even if no distinct lump is felt), skin irritation or dimpling, breast or nipple pain, nipple retraction (turning inward), redness or thickening of the nipple or breast skin and nipple discharge other than breast milk. The most common symptom is lumpy breasts.

3.2.1 Lumpy and Bruised Breasts

Countless sources¹², especially within the multi-layered domain of the internet, advise women *not to* self-diagnose. Finding a lump in a woman's breast may be due to several hormone related issues. Scholars such as Buccimazza (2011) and Singh, Azad and Gupta (2008) have argued that in most cases, lumps in breasts occur during the women's menstrual cycle. These are harmless. Despite this understanding, lumps in the breast are disfavoured bodily changes that are often associated with breast cancer by women. Buccimazza (2011, p. 19) stated that lumps in breasts cause fear of breast cancer in women, 'irrespective of age'. This corresponds with Singh et al.'s (2008) assertion that with "palpable lumps in breasts, it is the scare of breast cancer, which most of the times makes women consult a doctor" (2008, p. 186).

Changes that are seen in benign breasts can be classified into four types, namely generalised breast changes, solitary lumps, nipple discharge and infection and inflammation. These changes, while worrisome to some women, are not always linked to breast cancer. Moss (2006, p. 90) asserts that from the time a girl begins to menstruate, her breasts undergo regular changes each month. He further added that "eventually about half of all women will experience symptoms such as lumps, pain or nipple discharge" (2006, p. 90). The generalised breast lumpiness is often referred to as fibrocystic breast changes and benign breast changes (Moss, 2006). These common lumps are often reported by middle aged women unless they are taking replacement hormones (A-Z Breast cancer). This lumpiness generally goes away after menopause. As already mentioned, a women's monthly cycle also affects the feel of her breasts. Moss (2006, p. 90) noted that women experience swelling, tenderness, and pain before and

¹¹ <http://www.cansa.org.za/>

¹² These include personal blogs and independent medical websites.

sometimes during their menstruation cycle. Women are relieved of these symptoms at the end of their cycles. Pregnancy also triggers breast lumpiness as “milk-producing glands become swollen and the breasts may feel lumpier than usual” (Moss, 2006, p. 90).

Solitary lumps are not usually triggered by any particular condition. A-Z Breast cancer (n.d.) described these lumps as “large or small, soft or rubbery and fluid-filled or solid”. The three types of solitary lumps include fibroadenomas which Lau and Flores (2010) attest to be painless lumps that usually affect women in their late teenage years and early twenties. Such lumps are usually found by women themselves. They also state that they are rubbery and can be moved around. Cysts are another type of solitary lump. They are usually found in women between the age of 35 and 50 years, before women enter their monthly cycles. They are also painless, round and firm lumps formed by damaged and disintegrated fatty tissues; they are called fat necrosis (A-Z Breast cancer, n.d.). Signs and symptoms of these lumps are very similar to those of breast cancer as they cause redness in the skin around the lump. Such lumps are usually due to a bruise or blow to the breast.

Nipple discharge is said to be found in most benign breast conditions. Pregler and DeCherney (2002, p. 245) asserted that a nipple discharge may be caused by taking birth control pills, sedatives, and tranquilizers. Nevertheless, when the discharge is caused by a certain disease, it is usually benign and not cancer (Health Services).

Not all lumps are harmful to women; therefore, not all lumps require medical attention nor a biopsy. According to Oliver, Sloan, and Pemberton (2004, p. 329) “a biopsy is often the only way to diagnose lesions and diseases and as with most procedures there is often more than one method of undertaking the surgery successfully”. A breast biopsy is done when a mammogram and other diagnostic tests show changes in breasts that are not normal and might be cancerous. Often, it is through such tests that women are relieved of their fear of breast cancer or that their greatest fears are confirmed.

Lumps in breasts, regardless of their cause and size are alarming for women. The majority of the women who formed part of this study, stressed that *prior* to being diagnosed they did not understand why their breasts were suddenly lumpy, painful and bruised. They also shared that they tried to use home remedies to relieve their pain. Hence, in constructing their understanding of the changes they were experiencing, women showed very limited knowledge of the link between their breast changes and cancer. Also, the young Black women expressed the sudden changes in their bodies and associated it with previous accidents or incidents. In engaging with

Minnie, who amongst other fears had thought her breast changes were due to a training accident that she had previously experienced, shared that she was shocked to see the bruises. She also shared that she had done her usual injury routine to ease her symptoms.

Being an active person I thought the bruise on my left breast was from my last netball practice. I mean training gets rough and times and because I focus on the ball I often have no time to step aside and check if I have any bruises from knocking myself on the poles. When I saw the 'reddish-purplish' marks I thought it was no big deal. I pressed my breast with an ice bag and applied olive oil to it. The bruises didn't get any better even after two weeks. That's when I started to feel the pain. [Minnie]

For Minnie, the bruise was not very different from others that she had had in the previous games and training sessions. What can be considered different in this instance, was the pain and the time that had passed without seeing and feeling any improvement. From her excerpt, it is also clear that it was not the first time that she had experienced this bruising. Thandeka's first 'breast irritation' memory was when she felt a lump in her breast. Unfortunately for her, this occurred at a time when her community members were still suspicious of the HIV/AIDS epidemic. She claimed that her community members were 'diagnosing' people, and especially women based on the bodily changes that were visible. Thus, she hid her condition with the hope that it would eventually 'go away' without her family and community members realising that she had medical problems.

Ayebuhlungu amabele ami, ebuhlungu esho esinda engathi anetshe. Ngicabanga ukuthi aze abe makhulu kunalokhu. Esho ewakala ngehaba. Ngangithi into engatheni nje edlulayo kodwa cha yaqhubeka into emva kwesonto impela kwa caca ukuthi ayiyi ndawo lento. Kodwa phela angizange ngisho ekhaya. Naye uyazi osisi babezocabanga isifo kuthiwe nginengculazi. So nje ngathula. Futhi babengasho nokuthi ngiloyiwe. When ngingizoya enyangene nkosyami. Uyabazi abantu abamunyama banehaba nje bahlezi becabantu izinto ezimbi. Yazi ngingibalinda osisis bami bageze baqede bese kuba ima ngizixaka ngokugeza ngoba phela ngibafihlela. Ngingizithoba ukuze kehle uzinhlungu oe. Kwathi sekuvele izinto ezibomvu ngaya eklinic ngizicabangela nje ukuthi ngishayekile.

My breasts were unbearably sore; they were as hard as a rock. I think they even became bigger [uses both hands to exaggerate her breast size changes]. You know I just thought it was a passing thing, but when it continued for a week I realised it was a serious matter. But of course I did not tell my family, I mean my sisters would have thought I had HIV, or they could have blamed it on witchcraft something. You know how Black people are like, they overreact all the time. You know I used to be the first to take a bath just so I could get dressed before my sister and cousin. I would spend about 20 minutes in the shower; I used to soak my bath cloth with hot boiling water then press on my

lump. It worked as a pain reliever, but not for long. It's only when I saw reddish marks that I went to the hospital, but of course, I thought I had bruised myself. [Thandeka]

Thandeka's case was similar to Minnie's. They both experienced changes in their breasts and they both did not want other people to learn about the problem. One could argue that Thandeka did not see the need to consult medical assistance since the red bruises only became visible a week after feeling the lump on her breast. Similarly, Minnie had overlooked the fact that she did not recall hurting her chest area during her practice. Thandeka's excerpt also introduced this study to the culturally embedded interpretation of illness, that which involves traditional medicine. This rich data is discussed in the fifth chapter of this study.

Changes that are seen in benign breasts can be classified into four types, namely generalised breast changes, solitary lumps, nipple discharge and infection and inflammation. The visible scars and bruises were said to have affected intimate relationships for some of the young Black women. Nontando recalled this ordeal in the following excerpt:

The bruises almost ruined my relationship. My partner and I were cuddling when I started to feel pain on both my breasts. He immediately stopped to see if he had hurt me. When he saw the sort of red marks he freaked out. I mean he jumped off the bed and started accusing me of cheating on him as he thought it was love bites. I was confused as I had not been with anyone. So he decided to leave that night, it was very late at night. Soon after he left I decided to vigorously rub the red mark an onion. That was my home remedy growing up, it always worked for love bites ... pity it didn't work this time. [Nontando]

Images of cancer infected breasts appear to have red bruise-like marks (see image below. This image was sent by Minnie, she shared that she had accessed it from the internet as it was the closest image of how her breast looked before she was diagnosed). These marks were mistaken by Minnie, Nontando and Thandeka as having been caused by previous accidents.



Nontobeko, Minnie, and Nontando's experiences as shared above have much in common. This includes lack of knowledge of their bodies. This, I argue as none of them associated the bruises

and lumps with breast cancer. Instead, they tried to find immediate remedies which they believed would help ease the appearance of the bruises. They used items such as iced books, onions and olive oil as these were items that were at their disposal and that they had used before, remedial items that they could easily identify with as young Black women. One could wonder why they had not attempted to conduct a home test for breast cancer within the comfort of their homes but they did not think they needed medical attention.

It is common for patients to try to reduce symptoms of their assumed diseases. The above excerpts from Minnie, Thandeka and Nontando are examples of this. During this study, I learned that Dimphoe also associated her lump and red bruise on her left breast with the accident she was involved in the previous year. For Dimphoe, it was expected that she would see the bruises in different parts of her body as she believed that she had internal bruises. She elaborated her experience by saying:

Kuze kube inamuhla angakavumi kahle ukuthi lokhuyakudumba kwakudinga odokotela nokuthi kwakuyikhensa. Yazi ekhaya sasingakaze nje sibe nezifo ezixakile nje ngaphandle koshukela nje okuyinto ebamba yonje umuntu. Yazi ngesikhathi ngikhala ngezinhlungu umama wangikhumbuza ngengozi yemoto engaba kuyona eminyakeni edlulile ngenkathi ngise ngozini yetekisi engangikuyo. Lapho ngandiza ngisuka esihlalweni sesithathu ngaya ezihlalweni zesibili. Ngashayeka phakathi ngaba nezibanzi ezimbi nje kwaba sengathi ngophela phakathi nje. Yazi kwangenza ngaqonda ukuthi umama wayethini ngoba phela ngangingazi ukuthi ngingayichaza kanjani indaba yokuvuka senginebala elibomvu. Umama wacela omunye umelaphi ukuthi angenzele umuthi wokusiza lento eyayivelile. Ngenxa yalokho ngadlala inyanga yonke ngigquma zonke izinsuku ebusuku. Ngangigcoba nomuthi owawunuka nje wenziwe ngamafutha engwenya. Ngebhadi akukho okwangisiza kwaba bengathi ngenza kube worse nje. Kunokuthi ekhaya bangiyise kudokotela noma esbhedlela bangiyisa kuyena futhi nomelaphi, kwashuba ngoba ngaba worse. Kunokuthi umuthu engawunikwa ikwathi wa ustrong kakhulu ungisize wamane wangikhiphisa ngesisu. Kwasiza umzala wami owathi ake kuzanywe udokotela noma isibhedlela ngoba kwakubonakala ukuthi umelaphi uyahluleka.waze wathi noma ngingaseyela amabele ngodwa ngiyele ukuskhishwa isisu ngoba phela ngase ngiphelelwa amandla. Udokotela wangithethisa waphindelela engisola ngokungayi nakekeli impilo yami.

Till today I haven't completely accepted that the lump was medical. I mean at home, we did not have a history of any bad diseases except for things like diabetes which affect everyone. You know when I felt and complained of the pain, my mother reminded me of the taxi accident that I was involved in years ago, where I literally flew from the third-row seat in the second row. I flew forward and I had bruises on my chest. It was so bad it was as if I had sustained internal injuries. So yes, it made perfect sense. My mom asked her friend who is a traditional doctor to make me a concoction. And so I spent

the whole month steaming every night, applying the stinking lotion that was made using crocodile fat. Unfortunately, none of it worked and instead of my family encouraging me to go to the hospital, they asked for a stronger concoction which was to cleanse me from the inside since the traditional doctor had said I had internal bleeding. Well, the only cleansing that happened was me having a running stomach for two weeks. It was my cousin who suggested that I should go to the clinic at least for the running stomach if not for the breasts. When I got there I was asked to undress and wait for the doctor, who reprimanded me for not taking my condition seriously.

The cases of Nontobeko, Minnie, Nontando and Dimphoe have similarities as all were not aware of the symptoms of breast cancer and all had understood their bruises to be associated with previous incidents. One could argue that Nontobeko could have been diagnosed much earlier if she had shared her concerns with her family. But her greatest fear was being stigmatised as being HIV positive or even as being bewitched, thus one can understand why she chose to hide her condition.

The above excerpts are examples of the consequences of not knowing one's body. It is worth mentioning that all four participants shared that they did not once think that their bruises were caused by cancer. Instead, they blamed their past experiences of accidents. By alluding to the idea that her family would have associated her condition with witchcraft, one can assume that Nontobeko's family might have consulted a traditional doctor for her condition. This could have been her rationale for not sharing the pain she was experiencing. Dimphoe communicated her concerns and they were misinterpreted, leading her to be treated by a traditional doctor which resulted in a late diagnosis.

As noted by Buccimazza (2011), some women immediately associate lumps in breasts with breast cancer. Depending on the level of knowledge they have about cancer and their bodies, the decision to book for a mammogram is often delayed to the very last minute. Nosizwe claims she 'had a good knowledge of biology' with an A aggregate in her matric examination in the year 2000. She was proud of her understanding of how the human body works.

You know since I obtained an A in biology I always knew what was happening in my body, I could even calculate when my cycle was due and that how I prevented pregnancy, I never used any [contraceptives]. But tables changed when I felt a lump two weeks before my periods were due. Well, of course, I didn't take it seriously. I just thought my body was playing tricks. I mean all bodies do that from time to time. My periods eventually came and I was overjoyed as pregnancy was the only reason I could associate with the lumpy breasts. I noticed after my period that the lump was still there. This was shocking because it did not go away. In fact, I got used to it till I started feeling

excruciating pains, especially on my upper arms. That's when I consulted a doctor. The doctor was impressed with my knowledge and even recommended that I study to become a nurse [smiles and gives me a high 5]. He was not shy to mention that should I had continued with biology I would have known that I needed to test for breast cancer.

Laila's diagnosis was somewhat different from Nosizwe as she practically diagnosed herself. Laila had been a home-based caregiver for four years when she felt a lump on her right breast. She shared that having dealt with a number of patients and families she was well equipped to take care of herself.

Ngaba unompilo ngisako20 so ngangazi nje ngeBreast cancer. Ngangazi ukuthi nzima kangakanani kumuntu. Ukuthi ikhahlazana kangakanani. Kwathi sengizwa isigaxa ngaqala ngabhekisisa kwiInternet ukuthi konje umuntu engazilapha kanjani ekhaya. Kwamaningi engawathola ngathole nenye eyayikhuluma ngowesimame owayengakaze asebenzise imishanguzo yekhensa wamane nje waqinisa ekudleni izithelo eziluhlaza. Wayephuza aphinde adle igalikhi futhi ezivocavoca. Name ngaqala ngenza njengaye. Zaphela izinyanga ngingatshelanga muntu ngemuohumela yadokotela, kodwa ngaqhubeka ngadla lezizidlo ngaohinda ngaqinisa ekuzivocavoceni. Zaphela izinyanga ezintathu ngiphila ngalezinto ngingayi kwadokotela. Kwathi ngenyanga yesine aqala amabele avuvukala aba buhlu lokhu okungabekezeleki. Ilaphoke engaqa ngaya eClinic. Bangithethisa onesi bathi angiyihloniphi impilo. Kodwa phela babenmgaqondi ukuthi name bengincenga yona impilo ngodla lezinto. Kusukela ngaleliylanga sengaba into kadokotela. Ngiyayihlonipha imiyalelo yadokotela.

Being a caregiver since I was in my early 20s I sort of knew about it [breast cancer] I knew how invasive it was and what I would have to expect if I was to have it. So, when I felt a lump I started googling for home remedies. Amongst many odd remedies, I found a testimony about a lady who had not taken any medication from the doctors. Rather, she had been eating greens, drinking and chewing ginger and exercising. And I pursued it. For months I did not tell anyone and I only used that lady's advice and every now and then I used antibiotics as I had read somewhere that they could fight off any bacteria. I was fortunate to have lived through the three months. On the fourth month both my breasts were swollen and lumpy. That is when I decided to visit my clinic. Since that day I have been following doctor's orders. I respect his instructions.

Laila is not the only participant who used academic training and experience to treat herself. Thandaza, a nurse who has been happily married for three years, used her nursing knowledge to 'cure' herself. The 40-year-old wife shared that while she was training to become a nurse, part of her practical duties included assisting senior nurses from the oncology department. She claims that her heart was torn each time she had to assist breast cancer patients as they all "looked hopeless and in pain".

I will never forget working at Addington hospital, seeing women, young and old crying helplessly at each visit. You know I would tell my fiancé about my day at work and he would be so touched and almost teary. This one time he came to fetch me and I was speaking to one of the patients at the parking lot. When I got into the car he didn't even greet me, he just asked why my patient shaved her hair and I told him that it is part of cancer treatment. All he could say was 'good thing we never have to worry about cancer, I don't know if I can have a bald wife' I was shocked at what he said but then I remembered that he was an accountant so he didn't know much about health related issues. [...]. On my first year working as a qualified nurse, I felt a lump on my breast; I did the whole stand on a chair with one leg thing to check if it was cancer. Every single self-test was positive but of course, I couldn't tell my husband after who couldn't imagine his wife with a bald head and so I had to make it go away. I started making friends with friends from the oncology department, started being curious about breast cancer all over again.

Yazi mina ngaba nekhensa ngingakabi nayo phela uma no gogo babenayo so nje bekuyinto ehlala ingihlukumeza ngoba ngangiyisaba. Kuyafana nokuthi lamabele auka eminyakeni ewu3 ngaphimbi kokuthi ivele ikhensa ngoba nje ngase ngazi ukuthi kuzongishubela so ke ngazama nje ukuziqhlekkanisa nokuthanda amabele. Ngesikhathi sekushona iwele la ma ngenxa yeCancer ngazibonela nje ukuthi kubi name ngiyalandela. Ukube benginemali ngabe ngahamba ngayowasusa ngaphambi kokuthi ngize ngigule ngoba npehal nganisaba ukuthi iyeza. Yazi ukubo eKlinikhi bangibhalela incwadi yokuthi ngiwowasusa ngangiyoya nje.

I suffered from breast cancer before I was officially diagnosed. [Touching her flat chest] these babies that used to be here were removed about 3 years before I even saw a doctor [she had accepted that she may lose her breasts to cancer]. You see in my whole life I have witnessed people battling cancer. My grandmother died of breast cancer and so did my mother and her twin sister. Let just say all the women in my family died of breast cancer. I saw them die as I waited for my turn. I remember when my aunt (mother's twin sister) died in 2009 I lost all hope because I knew I was the last one. I used the knowledge I had gained from taking care of them and I started using it on myself. I ate well and took supplements way before the doctor told me to. If I had the opportunity and money I swear by late mother's grave I would have removed my breasts while I was completely healthy, just like that beautiful actress with a handsome husband [referring to Angelina Jolie]. But what can we do? No nurse from the clinic could write me a referral letter to Inkosi Albert Luthuli Hospital; they would have thought I am crazy. [Mpilonhle]

Mpilonhle is one of the three participants who had witnessed family members battle with cancer. She had a close experience with cancer before she was formally diagnosed. Witnessing her family members undergoing treatment was not only painful but it pushed her to start thinking about her own health and some of the ways she could avoid becoming a victim of cancer. Her story speaks of what the other two participants had wished for: to undergo a double

mastectomy while healthy. Unfortunately, this option is not viable for patients who are treated in government hospitals. Nosizwe shared that this option was considered as cosmetic surgery that was to be self-funded. During my first interview with Dimphoe, she had shared that she felt that finances are the main challenge when it comes to treating and preventing illnesses such as cancer. At the time of her diagnosis, Dimphoe was covered by medical aid but she was advised by her medical aid scheme consultants to have the surgery done in a public hospital as this was to ensure that she continued with the same doctor throughout her treatment as her entry level medical plan could not cover all the treatment costs.

3.2.2 Am I pregnant?

Painful and lumpy breasts are often associated with pregnancy. According to Cacala (2010), swollen breasts are one of the main symptoms of conception especially in the early stages of pregnancy. Cacala (2010, p. 510) added that “during pregnancy and lactation there is an increase in the glandular component compared with adipose tissue in the breast, making the breast firmer and lumpier and abnormalities more difficult to detect”. Three of the participants in this study attested to this by sharing their feelings when they first felt a lump or had painful breasts. Thina for example shared that while she was overjoyed by the prospects of her first pregnancy, she was concerned about the health of her unborn child since she was 39 years old. She claims that she had been trying to conceive since she was 28 but had never been “fortunate to be pregnant”. She claims that her breasts became lumpy when she had given up on her dream to become a mother.

The painful and lumpy breasts brought mixed feelings; a part of me was overjoyed while the other was torn because I knew the risks of conceiving at such a late age. As a result, I decided not to take a home test but to go to a general doctor. He was astounded by my assumption as he felt that my breasts did not have pregnancy lumps, rather he referred me to his friend who was to do a proper check-up. Because he had not given me anything concrete I still believed that I was expecting a child. In fact, I was contemplating whether to tell the father or not. On my way to the next doctor, I decided to Google reasons behind swollen breasts and the first page of google spoke about pregnancy so I was reassured. I arrived at the doctor's rooms at 3.55 pm and I was told that I had missed the doctor by a minute and that he was fully booked for the following day, which was Saturday. And so I got home and I shared the news with my partner who was as excited as I was, or at least as I pretended to be. We started guessing whether we would have a boy or girl. Either way, he said the child's name would Uzwire, meaning 'He [God] heard'. That very moment I really felt in love with myself and with my stomach. I remember looking at the mirror naked I started praising my breasts for they were in the process of being a fountain of nutrients for Uzwire. I

remember my partner caressing them saying 'Uzwile is going to survive on these till he turns one'. I was beyond excited.

The case of Thina, while different from the participants already mentioned in this study, speaks for a number of other women around the world. Breast cancer is not always the first consideration for women who notice changes in their breasts. Mandisa, who was 26 at the time of her diagnosis, claimed that she was late for her menstruation cycle by three days when she went to see the doctor and she was also excited by the prospects of being a mother as she had been trying to conceive for two years. However, she shared that her “excitement was rather short lived as [she] ended up learning that [she] was not pregnant, rather, a cyst was growing on both [her] breasts... a cyst that [she] later learned was cancerous”. Mandisa and Thina were not the only survivors that had mistaken pregnancy signs for breast cancer symptoms. Samantha, who described herself as a happily married and deeply in love with her hero, shared that when she first felt pain in her right breast, she thought she was pregnant. She claimed that she was very ashamed of herself as her first child was only six months at that time. Scared of disappointing her husband, she bought two home pregnancy tests which showed conflicting results. She claims to have booked an appointment with her gynaecologist who “relieved [her] fears” by assuring her that she had not conceived.

Ngiyakhumbula ngilindele imiphumelo lapho udokotela wami wabuya nobuso obungaqondakali. Kwakunenjalubo nokujabha futhi. Wathi, nginezindaba ezinhle, imiphumela yakho ityhi awukhulelwe kodwa angijabule neze ngebele lakho ngakho ngizokufhlulisela kudokotela ozokuhlolisisa. Ukushaya amanqaphu nqaphu nje imiphumela yabuya ithi nginekhensa yebele.

I remember waiting anxiously for the results and my gynaecologist came back with mixed facial expressions. He said, I have good news, your results are negative but I am not happy with your breasts so I need to refer you to a doctor that will do thorough tests for you. To cut the long story short, the results from the next doctor came back cancer positive.

These three participants, despite their different circumstances and feelings with regard to pregnancy, shared that, given the chance, they would trade their diagnosis for being pregnant. Mandisa shared that she is still hoping to fall pregnant as it was always her wish to have a big family. Thina shared that while she was unsure of whether she wanted the child or not, she wished the lumps on her breasts were a sign of pregnancy. When asked about her fears of conceiving at such a late stage, she tearfully shared that the child would have been a blessing from God and that she would have found ways to cope with her child's disability if it had been

born disabled. Like Thina and Mandisa, Samantha also felt that sharing the news that she was expecting a child would have been easier for her and her family.

Yazi ngke ngithi mangicabanga ngibone ukuthi ukube angibanga nemicabango emibi ngokuba neye ingane ngabe mhlampe inkosi ayinginikanga ikhensa. Mhlampe indlela nje yokuthi ngiphanishwe. Yindaba nje kwathlakala ngesikhathi ngisa ncelisa? Mhlamp ukube ngakhulelwa ngabe angizange ngibe nekhensa.

You know looking back I can't help but think that it was my negative attitude towards getting a second child so early that caused breast cancer. I sometimes think that this is God's way of showing me that he can do anything at any time. I mean, did I have to be diagnosed while I was breastfeeding? Like if I had been excited by the possibility of being pregnant again who knows maybe I wouldn't have lost my breast. [Samantha]

One of the factors that made Thina's story unique was the fact that after being diagnosed with breast cancer, she tried to fall pregnant. She claims that her lack of knowledge about breast cancer led her to believe that she would not be able to conceive once she had undergone surgery.

...I remember thinking to myself, this is your last chance Thina, your last chance to be a mother, after this you will die alone. You know I drove my partner away with this mentality as he was totally against the whole idea. He thought it was impure to have sex before undergoing such an operation and knowing me I just thought he didn't want to be with me anymore. I mean this is a guy that I had been with for a good eight years, we were making love since the first day we met so what could possibly scare him especially with my breasts. I mean they were not bruised or scary in any sense. I was the only one who felt the burning sensation. And even though I felt it, I was still willing to make a baby. Well, Sipho [partner's name] eventually gave up on us and I was left with no baby on board just an odd looking pair of breasts...

While Thina has moved on from her relationship with Sipho, she felt that she lost the most important person in her life. She claims that despite their differences, she now appreciates the fact that Sipho 'was a brave man' for not agreeing to make love to her at her 'most fragile point'. Unfortunately, Sipho died two months after their break-up. She claims that Sipho saved her and that she is glad that she will forever be grateful to him for not leaving her with the burden of taking care of their child Uzwile. Similar to Thina, Samantha claimed to have learned to appreciate her family even more after her diagnosis. She shared that while she was at some point angry at herself and her whole family; her husband stood by her and understood her diagnosis better than she did. She claims that he even went to the extent of taking her to a support group.

He arrived one night with an invitation letter that requested us to wear pink and attend a gala dinner for one of the organisations affiliated with his company. I was excited, I mean any reason to dress up and show off my breasts one last time was a must. And so the day came and I wore a beautiful pink dress with a sweetheart neckline, showing off my assets (breasts) for the last time. When we got there everything was pink, way too pink for my liking. We finally found our table; we sat next to a couple that had survived cancer three times. I was torn throughout the night, as teary as I was, he never removed his arm from my shoulder.

Samantha shared that attending the gala dinner changed her perspective about breast cancer as she heard success stories from survivors. Even more, she was certain that she was going to be able to conceive after her surgery. The case of Samantha also indicated that social support is important for patients. Such support was not extended to all participants. It is for such reasons that Thandeka did not openly share her symptoms with her family as she feared being alienated or being seen as a bewitched person, instead of being supported.

The above examples of how lumps can be assumed to be linked to pregnancy have shown that fertility is important to some women and that being diagnosed with breast cancer leads to many fears in women.

3.3 My fears

Being diagnosed with any illness leads to fear in patients. Such fear is manifested in different forms and at different times. This may be informed by previous experiences with the disease. Even if the patient had never experienced a similar situation, it is still difficult to accept and understand the situation. Mulder (2012) argued that the most difficult aspect of being diagnosed with an illness is the unknown. Mulder (2012) further argued that while some information is available from all sorts of sources, finding and choosing the most relevant for one's illness is never without difficulty. This is supposedly since individuals understand and experience diseases differently. It is not only their demographic differences that inform their understanding but their personalities and understanding of their bodies as well.

Authors such as Weed (1996) and Singer and Grismaijer (1995) have considered the influence of gender in understanding illness and the notion of the body. Weed (1996) asserted that men do not view nor understand their bodies in the same way as women who are more intimate with their bodies than men. This may be due to the societal influences on perception of what the body is. This may also be due to the pressure presented by the media with regard to the ideal body for women. It is without question that many women, regardless of their 'cultures', do

aspire to look beautiful and attractive. This, according to Weed (1996), is something that many fear, when their fragile bodies are diagnosed with an illness. Singer and Grismaijer (1995) described cancer as one of the most terminal diseases as it affects patients from within as opposed to some diseases that show external symptoms from an early stage of infection.

There are several fears that were shared by patients after their diagnoses. Most of their fears were prompted by their lack of knowledge on the subject. An example of this is Nontando who claimed to have had very limited knowledge of cancer prior to her diagnosis. She shared that her fears were mainly based on assumptions as she thought all cancers were terminal, hence, she feared death. On the contrary, Nosizwe who had a working knowledge and experience with cancer and knew that breast cancer was treatable, feared the outcome of the surgery which would “leave her breastless”.

Similar to Nosizwe, Nontobeko was confident to share that she did not fear the outcome of cancer treatment as much as she feared the actual treatment she was going to undergo. She shared that if she had a good understanding of the illness, she would not have wasted months trying to decide whether to continue with surgery or not. Sisanda shared that she feared breast cancer even before she was diagnosed. She shared that she had watched several movies where patients died from cancer. She even shared that she used to tell her friends that she would rather be HIV positive than have cancer.

Yazi ngangihlezi ngisho ngithi uma uJehova efisa ukungithatha kuyomele angithathe ngengozi yemoto kukhulunye indaba yokuthi ngishone ngengozi ngingalokhu nje ngihlala ngigula ngoba ngangingathandi ukuhlupha abantu. Ngiphinde ngisho ukuthi uma kumele ngihambe ngokugula kuyomele inkosi ingithathe nge ngculaza nje straight. Kunokuthi ngiphathwe ikhensa ngigcine sengiyinto yombhede. Ngoba phela ngangazi ukuthi uma ngiphethwe ingculaza bengizokubambelela kumuntu oyedwa nje ngisebenzise isivikeli ngidle imishanguzo bese ngiba right ngiphile iminyaka eminingi. Kodwa ikhensa iyisela nje ifika ngesikhathi ungayinakile. Ifika icashe nje ebusuku la kungekho khona oyinakile bese iyacaasha kuze kufike isikhathi la ongeke ukwazi kwenza lutho ngayo bese iyavela ungesanakusizakala. Kuze kube inamuhla ngisayisaba ikhensa, ngiyasaba ukuthi isangabuya empilweni yami. Mhlampe ngingabi nalenhlanhla imane ibuye isisemvimbeni wonke.mayingabuya ngingamane ngingazixaki ngokuphinde ngokudla amaphilisi. Ngiyomane ngilinde usuku lokufa, ibuhlungu leyanto.

You know I would tell them straight and say if God wants to take me he better use a car accident and make sure I die instantly. If I have to get sick, I would rather have HIV instead of cancer because at least I can stick to one partner, condomise and take my medication and be guaranteed at least five to ten years to live. Oh but cancer is a thief.

It creeps in at night when no one can see it, it hides until it's too late to do anything. Till today I still fear cancer, I fear that it may return in a different form, maybe even affect my whole body at once. If it was to return I would just give in and not take any medication, I would wait till the day I die. Treatment is unbearable.

The challenge of cancer symptoms not being easily detected was also shared by Nontobeko:

Inkinga enkulu ngomdlavusa webele noma iyiphi ikhensa ekuhlaselayo ukuthi ikudla ngaphakathi ngaphambi kokuthi ibonakale ngaphandle. Cabanga ukotapheya nje, uyawubna ubukeka umuhle futhi uluhlaza ngaphandle bese kusasa uwubona ukuthanda ukubansundu. Wena ucabanga ukuthi into eyenzeke ebusuku kanti cha kade kwabheda ngaohakathi kuyona. Injaloke neCancer. Ngangihlzi ngisaba ukuthi mhlampe iyobonakala kudala nje uma ngase ingiphathe.

The problem with breast cancer and any kind of cancer is that it affects you from the inside before it comes out. Imagine something like an avocado, you see it can look good and green on the outside today and tomorrow morning it will be dark brown. You think it happened overnight but truth is, it was already rotten on the inside. That's what happens with cancer. I always feared that I would be diagnosed late should have ever had this stupid disease.

Both Nontobeko and Sisanda felt that one of the greatest challenges with cancer is that it is not usually diagnosed in time as symptoms may not show in the early stages. This fear, according to Mpilonhle, is “what kills people because as soon as you hear the word cancer the next question is ‘how far had it spread’”. Late detection of this disease was not the only fear mentioned by participants. Another major concern was lifestyle changes that might have prevented the disease. Dimphoe, for example, shared her fears by saying:

ngaphambi kokubanjwa ikhensa ngangingakaze ngigule nje, ngisho nje ukugula lokho ukufika ngezikhathi zonke. Kodwa futhi ngangisaba ukugula ngiphathwe izinto ezinjengo shukela nokhensa ngoba phela ayikho indlela yokuzivikela futhi zihamba ngozalo.

Prior to cancer I had never really feared being sick, I mean of being just sick. But I have always feared things like diabetes and cancer because there is no way of preventing it and it's hereditary.

Like Dimphoe, Mpilonhle shared that she had lived in fear of having inherited breast cancer from her maternal family. She asserted that there were days where she wishes she had been born into another family as that could have at least lessened her chances of being diagnosed with breast cancer.

When it was just my aunt (mother's sister who also had breast cancer) and I would share my fears with her and she will try to talk me out of it. She once told me that her mother had told them that breast cancer was not a curse but an illness that was always looking for a brave family to challenge. Her mother had convinced her and my mother that they were the brave family and because of that, it has affected us all. Of course, I tried to make sense of the whole story but it wasn't comforting at all. But of course, she believed it because it was one of the last conversations they had heard with my grandmother. In a sense, it made me want to fight for my life once I was also diagnosed. In fact, now that I have shared this little childish story with you I feel a lot better and no, I do not wish I was born into a different family because cancer ended with me. I conquered it.

Not all fears were directed towards not being able to prevent the illness. Some of the participants reported the effect of breast cancer on their body image to be the most challenging fear that they had not yet overcome. Body image fears were mostly directed towards losing African assets and hair. Consider the following excerpts:

My greatest fear was losing my hair and breast. I mean breast cancer is one mean disease; it takes the most valuable feminine assets. Like what is a woman without her hair? What about her breasts. When I was diagnosed I was like 'oh God did you make a mistake by making me a woman, are you trying to correct your mistake by taking both my breasts and hair? [Mpilonhle]

The thought of losing my African assets was worse than losing my virginity. I mean I knew how sick people looked and how treatment often changes how people look. I didn't want that. I honestly didn't. [Samantha]

I didn't fear death, no. I knew death would eventually find me so I wasn't scared of dying. I was scared of the cruel treatment that was going to steal my hair which I had been growing for more than ten years, my nails which were only treated at the salon, my flawless skin which my partner always complimented and my 36D breasts which were envied by all my friends. [Dimphoe]

Engakusaba kakhulu ukuthi ngiyoba njani nje emva kokulwa nekhensa, nokuthi ngabe ngiyoba yini nezingane. Ngiyozincelisa kanjani. Yazi ngangizibuza njalo ukuthi ngisazogana yini njengoba sengizoba ukuntu oshodelwa amabele. Kwakungidida kona. Ngihlezi ngicabanga ukuthi ngabe ngizobanjani. Ngabe izophela yini. Ukuthi ngiyokwenzenjani uma iphinda ibuye. Ukuthi yini le engiyenzile ngize ngithola lesisifo. Ngabe ubaba uyoke ayithole yini into ayayeyifisa nhlazane ngizalwa.

What I feared the most was how I was going to look after treatment. If I was ever going to have children and how I would breast feed if I could. I would wonder if any man would ever propose to make a wife out of me, to honour me. I always thought of the outcome of the treatment. I also wondered how I would be if it was to come back. I had

so many things on my mind. Like, what did I do to deserve this cruel disease? If my father was ever going to be honoured with lobola. [Zibuyile]

The fears expressed above dealt with issues of body image; the participants expressed their feelings towards the negative effects of breast cancer treatment. They acknowledged that they could not escape these as they knew that losing their hair and breasts was a crucial part of their treatment. Again, this is linked to the lack of understanding breast cancer and its treatment. During interviews, most participants shared that their fears were mainly triggered by the fact that they knew nothing tangible about breast cancer; they had very limited knowledge that they could use to comfort and encourage themselves.

In response to the question about their fears some of the participants shared the following:

I can say my fear was in five stages, the first was when I thought I was pregnant, and I was torn. The second was when the doctor sent me for more test. The third was when I was sent for counselling without my consent and the fourth was when I was when I was finally diagnosed with breast cancer. I was scared of the surgery but not as scared as I was before I attended my second counselling which included the survival statistics. [Nontando]

As much as I had cold feet after my diagnosis I was somehow relieved. I think it's because the three generations before were also affected by cancer. My great granddad had pancreas cancer, my father's younger brother had stomach cancer and his aunt had cancer everywhere. I think I got the 'better' cancer if that makes any sense. [Minnie]

Ukubona umdeni wami ubulawa ikhensa noshukela kwangenza ngabandikindiki nje ngangasaba izinhlungu. Ngalahlekelwa kakhulu nje eskhaleni sezinyanga ezintathu ngangingazitshela ukuthi kukhona into eyoba nzima ibe buhlungu ifike kukulahlekwa izithandwa zami. Kodwa ngathuka ngesikhathi kutholakala ukuthi ngiyagula ngaquleka amahora aw 3 cabanga. Onesi babengazi nokuthi bazothini noma bazofonela bani ngoba phela ngangingayi bhalanga inamba yocingo yomuntu wasekhaya noma yomuntu ongaziyo osondelene name. Ngangifake enye inamba yami yocingo eyayingasebenzi. Ngangithi ngenzela ukuthi umfowethu omncane engatholi ngoba wayezophatheka kabi kanti phela umuntu engangimthemba ngixoxa naye ekhaya kodwa angifikangaka inamba yakhe.

Seeing my mother and grandmother die of cancer and diabetes made me immune to fear and pain. I mean I had lost my whole world in a space of three months so what could have possibly been worse? Surprisingly I was so shocked when I was diagnosed that I passed out for three hours. The nurses didn't even know what to do as I had cheated my forms by putting down my other cell number as an emergency number. Well,

I thought I was protecting my younger brother who I had a close relationship with. [Mpilonhle]

Some respondents mentioned fear of sharing the diagnosis with family and fear of rejection.

Kwakunzima bandla kumina. Yazi ngangingenaso nesiqiniseko sokuthi umdlavuzi yini ingakho kwakunzima ukuthi ngixoxele abantu ngoba phela kwamina ngangingazi ukuthi kwenzekalani kimi.

Disclosure was difficult for me, I mean at first I wasn't even sure of what breast cancer is so sharing it with my mother was a problem let alone telling my sisters... they all would have made a big issue of the whole thing. [Thandeka]

I wanted to share the bad news with my family, I promise you I did but it wasn't easy Nokwanda. Between constantly trying to convince myself that I was OK and pretending to be OK and strong before my family, I think I lost myself. I lost the battle. Maybe if I had known more about breast cancer, it would have been a different case. I mean my dad had prostate cancer and her brother had cancer of the blood so I knew how bad those were. But I didn't know about breast cancer so I had a lot of fear. I had known the good statistics I don't think I would have worried myself so much. [Minnie]

I had wanted and planned to keep my diagnosis secret for three months not because I didn't want my family to know but because I feared that my limited knowledge would make matters worse. I knew my mother's first question was going to be 'are you going to live for long?' I wasn't ready for such questions, I mean I didn't even know what stage 2 cancer was. [Dimphe]

The above excerpts are some of the common challenges that patients go through regardless of the nature and stage of diagnosis. Patients, especially if they care dearly for their families, do not wish to bring up topics or share information that may hurt their loved ones. For example, Sisanda decided to wait until she was comfortable with the questions she could be asked by her family members before she would share her diagnosis. During one of the focus group discussions, three other participants also shared their fear of sharing the bad news. Minnie who was diagnosed three months after her graduation, shared that she feared that she did not have enough information about breast cancer to convince her parents that she was going to survive the illness. "I remember reading posters at the clinic while waiting for my turn. I saw how terrible the breasts could be affected but there was nothing about the survival rates. I was completely torn." One could argue that Minnie suffered an incredible amount of fear and frustration after seeing and reading the pictorial description of cancer on the clinic wall. This would have been easily avoided if she had a working knowledge of breast cancer and its survival statistics.

Like Thandeka and Minnie, Mpilonhle feared that her aunt, who was her only female surviving relative, was going to ask her several questions which she wasn't going to be able to answer as she "did not know much about this white disease". Six of the eight participants who were part of a focus group shared they had very limited knowledge of breast cancer when they were first diagnosed: their knowledge can be summarised as "breast cancer is a disease that kills from the inside and you only realize that you are dying when it's too late. Very few people survive breast cancer." Mpilonhle further shared that she also feared that she would be rejected by her family and friends.

Fear of rejection was mostly cited with respect to sharing the diagnosis with family members, husbands, partners, and children. The following excerpts exemplify this:

Ngangisashade iminyaka emithath, kuleminyaka emithathu ngingasho nje ukuthi ilonyaka wokugcina la esazwana khona nomyeni wami. Nganginokwesaba. Ngisaba ukuthi ukumchazela ngokugula kwami lokhu kwekhensa kuzoqeda umshado wethu umshado engase ngiqede iminyaka ngiqakha.

I had only been married for three years, in those three years, I can safely say it was in the third year that my husband and I got along. I feared that sharing my diagnosis with him would destroy my marriage, the marriage I had spent years building. [Thandaza]

Even though I had undergone three months of counselling it was still difficult for me to tell my husband that my lack of sex drive was due to breast cancer. I feared that he could easily replace me with another woman who had fewer health issues. [Nontobeko]

The above excerpts refer to some of the challenges that are experienced by cancer patients. They also reveal that even married women become insecure once they are diagnosed with breast cancer. Similar to Thandaza, Samantha feared that her husband could have easily given up on their rocky marriage and found another woman. Thandaza broke one of her marriage vows by not being honest with her husband and secretly seeking help without his knowledge. She could have received care and support from her husband and she would not have had to carry the burden and stigma of cancer alone. Unlike Mpilonhle, Thandaza feared that her already visible symptoms would drive her husband away as she had very low interest in any sexual activities. While she was initially shy to share her bruises and lumps, she was able to express that she "had no libido whatsoever". She shared that instead of being enticed for sex, she would be irritated and end up fighting with her husband.

The case of Phiwe is somewhat different from that of Thandaza and Samantha. Phiwe was happily married to her “high school sweetheart” [as she proudly puts it] and five years into their marriage, she lost her mother-in-law due to cancer. She shared that this death was her “first encounter with cancer”. She claims that what she was shaken by the death of her mother-in-law and that she was somewhat relieved that it was not her biological mother as she might have inherited the disease. As a result, she was hoping to take her two daughters for screening once they reached 21 years. Haven seen how “heartbroken and inconsolable” her husband was, she decided to keep her diagnosis to herself until she started treatment. She justified maintaining her silence in the following excerpt:

Phela umyeni wami wayekade eshonelwe umama wakhe ngayo ikhensa ngonya owawu dlulile manje ukumxoxela ukuthi name senginomdlavusa kwaba nzima ngoba phela ngangibona ukuthi uzolahlekelwa ithemba nje mhlame agcine esengishiyile naye ezama ukungelokhu ephatheka kabi uma sengigula futhi engalokhu enakekelana nami ngenkathi sengidla imithi.

My husband had lost his mother due to stomach cancer a year ago so sharing the news with him was very difficult as I felt that he would lose hope and possibly divorce me to avoid being associated with my illness and taking care of during treatment. [Phiwe]

In the above, one learns of yet another fear, that of being rejected due to the illness. She tearfully shared that she feared that she may have had to face her illness alone as her husband could have left her after learning about her condition, after all, her husband had recently recovered from the pain of losing his mother due to cancer. These three unique yet related cases exemplify some of the reasons women may choose not to disclose their illnesses in the early stages.

3.4.1 I have cancer, who do I tell?

“I didn’t realize how many people I did not trust until I had to disclose my diagnosis.” (Laila)

Laila had worked as a caregiver for three years before she was diagnosed. As a caregiver, she was always encouraging patients to share their diagnosis with their family members as this, according to her, was a step towards getting support. She shared that she used to never understand why patients, especially women, were always shy to share their diagnoses. She also shared that patients would compliment her for her strength and positive outlook towards life as she often agreed to share the patient’s diagnosis whenever this was requested.

Yazi ngangiyitheba kuleziguli zami, babekhaleli kimi bethi ayi angeke ngikwazi ukusho ekhaya ukuthi ngiselelisisifo ngoba bazophelelwa ithemba kwakungiphathakabi lokhu.

Kodwa ngangiba gqugquzela ngithi abashe emindenini yabo ukuthi bayagula ngoba phela ngangikholelwa ekutheni lokhu kuzosiza kubalulamise. Ngangingayibooni nje inkinga kakhulukazi kulabantu abashadile ngoba phela abayeni babo kwakumele bazi ukuthi kwenzakalani

I was a hero to my patients, they would cry and say ‘no I can’t tell my family they will lose hope and that would stress me’ but I would encourage patients to open up and telling their families and loved ones because I believed it was going to accelerate their healing process. I honestly did not understand what the big deal was especially amongst married women, I mean their husbands deserved to know.

Laila shared that when she was diagnosed and did not want to tell anyone she understood what her patients had gone through and she wished she could go back in time and not put pressure on them. She shared that her diagnosis made her realise that disclosing an illness has nothing to do with people's relationships with each other; rather it depended on how much patients trusted the people they wanted to share the news with. Like Laila, Thandeka shared that she could not think of anyone who she trusted enough to share her diagnosis. She came from “a very loving and united family” but she could not imagine sharing her diagnosis with any of her family members because she feared that they would associate her condition with HIV and witchcraft. Minnie, who was a sports fanatic, was also unsure who to share her diagnosis with. She was very close to her coach and captain but she did not trust them enough with her “pain and life-threatening disease”. The above cases are related in that they address issues of trust for women. These participants expressed that while they had strong relationships with their families and peers, they feared sharing their diagnoses, mainly because they “couldn’t trust anybody with the life-threatening disease”.

Thandaza also feared to sharing the heartbreaking news with her husband until she had to start taking her medication. She shared that she waited for so long because she wanted to test if her husband was going to stay with her after learning of her illness. She claims she would wake him up at night and ask him what he would do if she had diabetes and she had to have her leg amputated or if she had to undergo head surgery that would leave her bald. She claims that she only told him when she was “satisfied with his responses and assured of his love”. Nontobeko, who attended the focus group, was shocked when she learned of the measures Thandaza took and accused her of having manipulated her husband’s feelings. This is what she said to Thandaza:

Love, I feel what you did was wrong, you should have just told him without testing if he was going to stay or not. I wouldn’t like for my partner to do the same to me. Our

partners and families should only stay because they want to be with us not because of manipulation.

As a researcher, I was uncomfortable with Nontobeko's opinion and I had tried to stop her from continuing but Thandaza wanted to hear it to the end so she could justify her actions. And this was her response:

Nontobeko, you are single women who has no children and husband. So I understand why you think I was being selfish and you are right I was being self-centred for the first time in my marriage. My marriage had always been about my children and husband. I was not about to let cancer take all that away from me. So I tricked my husband, asked him endless questions about our future because I wanted to know if I could rely on him.

This response was cheered by the rest of the participants which in the words of Laila was an "honest and a true reflection of the challenges that women face when they have to disclose to their partners". Nosizwe followed Laila by sharing that she too was uncertain about her future and she shared that she lost her self-confidence even before she was treated for breast cancer. While she was a reserved participant who nodded more than she spoke, she was eager to share that sharing the news with her partner was the only way she could "find sanity" since they had a strong relationship and she knew that he was not going to leave her because of her condition. Even though she trusted him, she shared that she started the conversation by reminding him how she was the only person who supported him when he was on TB treatment. She shared that she fully understood Thandaza's actions.

Ngangesaba mina, ngamane ngaqala ngokumukhumbuza konke esasidlule kuko othandweni lwethu ngamukhumbuza ukuthi ngama naye ngesikhathi kungesekho muntu ngase ngamtshela ukuthi utheni udokotela. Wathuka bandla. Wathuka impela nje. Kodwa bandla wazwelana name wangithembissa ukuthi angeke angishiye.

I was scared to tell him so I decided to start by reminding him that I was with him during his worse days and once he started appreciating my patience with him I told him about my diagnosis, he was caught off-guard but he understood and promised not to leave me.

The above indicates that even when people love and trust each other, disclosure may be difficult. It also shows that women fear rejection and dealing with breast cancer alone.

3.4.2 Sharing the diagnosis with family

I knew I had to tell my family but I didn't know how I didn't know how they were going to react. After torturing myself for a good three weeks I decided to tell them during my son's birthday. [Nontobeko]

Openly disclosing a diagnosis is a major challenge for patients as they do not know how they may be received by those they care about. The survivors who participated in this study harmoniously agreed that sharing their diagnoses with family was one of the most beneficial steps towards their healing. Despite this, only ten of the fifteen survivors disclosed to their family members before disclosing to close friends and partners. Samantha, Dimphoe and Thandeka shared that they decided to share with their partners before sharing with their families. This according to Dimphoe was done so they could have support from “at least one person who mattered”. Dimphoe continued by sharing that she was not sure if her family would continue supporting and being in contact with her.

My family is unpredictable, today they can make you feel like an important member and tomorrow they can just ignore you. I didn't want a situation where I would have had to beg them to understand my sickness and new lifestyle so I decided to strengthen my relation with my partner and sharing my diagnosis with him. Once I had his full support I knew that I could easily move in with him, should I be rejected by my family.

Similar to Dimphoe, Phiwe felt that it would be difficult to tell her family about her diagnosis before telling her husband. She openly shared that she had never had a good relationship with her parents and siblings as she had defied her parents by not marrying the man they had arranged for her. She further claimed that her very religious parents would have seen her illness as God's way of punishing her for not obeying their wishes.

I remember sitting with the counsellor trying to make sense of my diagnosis. She asked if there was anyone I wanted to share the news with so she could call and make arrangements. I just froze not knowing whom to suggest. The counsellor started sharing how confiding in her mother and aunt helped her to get through cancer. I couldn't control my tears so I cried in her office. She must have thought I was crazy, I mean there she was trying to help me but I was weeping like a little child. It took three consultations with her for me to open up about my family and how distanced our relationship was.

Upon hearing this information, Zibuyile, who had shared her disappointment and disbelief of Thandaza's 'selfishness' when she emotionally blackmailed her husband, shared that she now understood why Thandaza had taken drastic measures to secure her relationship with her husband before telling him that she had cancer. Thina also shared that she would have 'cemented' her relationship with her husband before considering sharing the news with a family that was not in contact with her.

Thandaza you don't have to feel bad about your decision, it is totally justifiable, I would have done the same. At least you had the heart to tell them at the end. I know I wouldn't

have bothered myself. I mean, if they had not been supportive for years why on earth would you want to suddenly be close to them? What difference would it have made? I mean, it's not like you needed one of them to donate a breast for you.

Some members receiving diagnoses in the company of a family member was beneficial to them as they did not have to go through the stress of having to share the news. For example, Nontando who was with her sister when she received her results shared that she and her sister both decided it would be best to wait until she was about to start treatment before sharing with her family. Like Nontando, Samantha shared that having her cousin with her when she received her results helped her to accept her condition as her cousin was HIV positive so she had had experience of being ill. Samantha shared that her cousin could encourage her and to make her believe that she could still survive cancer. She shared that it was her cousin that contacted her maternal family for lunch at Samantha's house. It was during lunch that her cousin and husband shared Samantha's diagnosis with her family. She claims she doubts she would have been brave enough to talk about having breast cancer while holding her six-month-old baby.

Unlike Samantha and Nontando, some participants did not appreciate being diagnosed in the presence of their families. For instance, Dimphoe felt that her right to privacy was violated when the nurse openly shared her diagnoses in the presence of her older brother.

I wish there was a rule that forced nurses and doctors to treat cancer results as confidential because my older brother who was driving me to a hospital wouldn't have learned that I have cancer. Thanks to him the whole family found out before I could even wrap my head around the diagnosis.

She shared that she felt uncomfortable when she reached home as her younger brother and mother were waiting for her outside with a wheelbarrow.

I think my brother misinformed my mother. I still don't know what he told her but it was from the truth because the whole thing was exaggerated. I mean I got home to find my mother and brother waiting in the driveway with a wheelbarrow which had pillows and a blanket. They thought I couldn't walk. Now tell me Noks (standing up pointing to her breasts and then her legs) how does being diagnosed with a breast related illness connect to not being able to walk? I mean I had left that very morning, did they think the doctors have operated my legs in the four hours that I was gone? I was really disappointed at my brother for telling them without checking with me.

Nontando also received her diagnoses in the presence of her sister. She too did not appreciate the lack of confidentiality of the hospital staff. She shared that while she knew that there was a great chance that she had cancer, she would have appreciated receiving her results in private. She shared that while she would have told her sister on the same day, she wishes she had the

opportunity of grieving and sobbing at least for an hour without anyone trying to calm her down.

The moment received my results I cried my lungs out because I was shocked and my sister who happens to be the most insensitive person on earth just stood up and told me to stop crying because it was not the end of the world, like how cold is that? How can you just tell me to get over the fact that I was going to lose my breasts? On top of that, she decided to share my diagnoses with my whole family via a WhatsApp group and everyone was sending get better messages. Like who does that? Shouldn't she had asked me if it was OK for her to tell them? But I blame that old lady who shared my results without my consent.

Four other participants shared that they felt the hospital staff were insensitive to their diagnoses and illness as they did not ask for their consent in sharing their cancer status. Nontando who also felt her results were given in an unprofessional manner shared that she wished there was a hotline where should report this unfortunate encounter to avoid more people undergoing the same stress and embarrassment. She felt that such instances happened in public hospitals. She further shared the following:

Noks I have been to a private hospital before. At that time the doctor had thought I had meningitis. I remember I had to sign consent forms if I wanted my diagnoses to be shared with anyone regardless of our relationship. This is why I didn't understand why I wasn't called into a private room and told that I have cancer. Sure I understand the importance of sharing my diagnosis with my family, but shouldn't I had been the one to decide on this?

You know because we do not pay, the nurses treat us anyhow. I have been mistreated by nurses before. They can make you feel like nothing. Like not a woman, more like some animal. I remember while I was admitted I once asked for a tissue and the nurse asked me how much I was paying for my hospitalisation since I was asking for a tissue. She was so rude to me but I could not complain because I feared that she will learn of my complaint and the rest of her colleagues would also mistreat me. But like Nontando I knew my rights, but when you are weak and fragile you have no time to worry about nurses you focus on getting better, paying the R40 hospitalisation fee and leaving the hospital. [Zibuyile]

Like Nontando, Zibuyile and Dimphoe also felt humiliated by not being able to decide if they wanted the people accompanying them to learn of their diagnosis.

When I found out I had cancer I was with my sister so that's how she found out. If she wasn't there I wouldn't have told her. In fact, I wish the doctor asked if I was comfortable getting my results with her around.

I still don't understand why my results were not private, I mean I was with my sister when I was told I had cancer. Sure I was asked not to come alone but I didn't think the nurse could be so mean and just tell me I have breast cancer without asking for my consent to disclose information.

During both focus groups and individual interviews, most participants shared that they were going to share their diagnoses with their family members but in their own time. Even Laila who was a caregiver shared that it would have been better if the hospital staff worked and followed the same rules. She shared her disappointment in the manner that the other survivors had received their diagnoses.

Yazi angazi ukuthi ngangizokwenzenjani ukube kwakuyimi lo. Kodwa engikwaziyo nje ukuthi kwakungeke kube kuhle ngoba phela ngiyawazi amalungelo ami. Kumele ngizikhethela ukuthi ngitshela bani ngokugula kwami.

I don't know how I would have handled this but I know I was not going to be kind about it because I know my rights and besides, who I decide to share my diagnoses with is my decision.

3.5 Conclusion

This chapter has described the first changes that young Black women experience and notice in their bodies. It has also shared some of the memories that the young Black women recalled with respect to breast cancer. This chapter has further discussed the medical symptoms of breast cancer and how they were experienced by young Black women. The chapter has displayed similar fears and challenges that women shared and how women shared their diagnoses with their intimate partners and family members. The chapter has argued that young Black women have limited knowledge of breast cancer which for some led to late diagnosis and extreme treatment options. The fears of how cancer diagnoses would be handled by family members were also highlighted. What was also discussed in this chapter was the way in which women learned of their diagnosis, with some expressing their dissatisfaction of the public hospital staff sharing their diagnoses without their consent. This was argued as a disadvantage for some of the women, as they felt they were not ready to be questioned about their diagnoses. The young Black women also felt disadvantaged by the diagnosis as they were not psychologically prepared for the changes that would occur in their lives.

CHAPTER 4: MY PERFECT AFRICAN BODY

4.1 Introduction

There are many connotations associated with human bodies. Women, in general, have a number of ways by which they understand their body image, attractiveness, and sexuality. This chapter interrogated what these terms meant for young Black women. This highly qualitative part of this research therefore, explores the social construction of a woman's body, paying special attention to how young African women understands their sexual selves. It delves into the survivor's interpretation of breasts and body image prior to being diagnosed. It also includes a systematic recollection of the young women's marriage prospects before cancer.

4.2 African assets: The epitome of beauty

“A thin body is considered the epitome of beauty and sexual attractiveness, and has been linked to social status, health, and even moral worth.” (Williams and Germov 2004, 338)

Beauty and attractiveness are of course highly subjective. The above quote indicates differences in the manner that different socio-cultural groups construct and come to understand beauty. Tambone et al. (2015) asserted that there are two fundamental paradigms that people use to identify and understand beauty. The first is a subjective view. They argue that “subjectivists believe that the grounds for the experience of beauty are connected to the experience of the subject” while objectivists “present the notion of beauty starting from the material dimensions of the problem” (518). The quotation by Williams and Germov (2004) applies to most women who aspire to have a Barbie-like body. Such women are always looking for ways to enhance not only their facial beauty but they are continuously looking for ways to enlarge their breasts as well. Dimphoe, a participant of this study, shared that breasts have for years been seen as a sign of womanhood and of fertility for African women. Mpilonhle, another participant, shared that breasts are a signifying mark that separate women from men and recently, from gay men.

Most women who participated in this study were not shy to express how “less of a woman” they felt when they first learned of their disease and its treatment. Some even went to the extent of sharing that their femininity was taken away by the cancer treatment. Nonetheless, some women were willing to share about their perfect African bodies prior to the illness; these bodies, they claimed were their African assets. I was first introduced to the term ‘African assets’ when I asked Thina, my first individual interview participant, when we met at her home in Umlazi. This is how our first encounter went:

Thina: Whoooo (getting up and clapping her hands as a sign of approval) such a beautiful young makoti (maiden). I want you to marry my brother. We need your African assets in our family.

Me: (Smiling in an attempt to hide my confusion). You must be the lovely Thina, you look even more beautiful in person. The photo you have on your WhatsApp profile picture doesn't do justice.

Thina: Thank you, love! What can I say I still have some 'African assetanya' left! (She hugs her one breast, butts, and points to her thick legs)

She shows me a chair and I sit.

Thina: Ooooh love and you don't even have your beautiful face as your profile picture not to mention those African Assets. Good thing you don't show your face and body I would have asked my brother to be home so he can ask you out (she laughs as she sits opposite me).

Me: Thina you know I have seen people writing about African assets on Facebook but I have never had a chance to have anyone explain it to me. Please tell me all you think I need to know.

Thina: African assets are things like breasts, big and strong butts and thick legs. These are things that you don't often find in the other races.

Me: I see. Why are they considered African?

Thina: Lovey don't get it twisted ... we say African in reference to being Black. It's a term that is used to that appreciate the big warm Black African women's bodies.

Me: That is so interesting. So do men use this term or is it just amongst us women?

Thina: Yes African (Black) men use it. That's why a guy will call you his African queen it's because you have all the assets. My boyfriend used to call me his AQ (African Queen) ... too bad I no longer have all three assets. You can see I'm now a two and a half (touches her one breast).

Me: So to be an AQ you must have all three?

Thina: of course that is the ideal combination. Some men compromise with the legs cause some Black women have thin legs and of course some have flat butts but BREAST (says it in a louder voice and clicks her fingers) ... breast are the main asset. That's why women are now wearing padded push-up bras; they want to make them as big and attractive as possible.

This was supposed to be a 'full interview' guided by an interview guide, but because of the complexity of qualitative research, it ended up being an informative conversation when I was introduced to a term that enriched my study and enabled me to enter into a world I was not aware of, a world that is relevant only to young African women. This led to the restructuring some of the questions on the interview guide to accommodate acquiring more data on the relationship that young Black women have with their bodies and especially their breasts.

4.2.1 Our lives as African Queens

Having being introduced to African assets and African queens by Thina, I decided to delve further into the relationship between breasts and beauty. Being more aware now of the terminology, I was more comfortable in discussing this new phenomenon.

It was Saturday morning when we gathered at a community centre for a focus group interview. I had brought a Barbie doll and a poster of a 'think' Black woman as props for an icebreaker exercise. Before officially beginning the session, one of the participants saw the props and exclaimed "oh no you didn't. You didn't bring a perfect AA to a group of AAnyana (incomplete African Assets)". This was followed by a chorus of laughter until Thembeke who looked rather confused and asked if she had attended the correct group as she thought she was a gathering of cancer survivors and not alcohol anonymous. As expected, Thina rose up and modelled before the group and claimed that she was showing off her AAs. To this, I requested the participants to explain what AA stood for and how it applied to the group.

African assets are the rare body features that other races don't have. You know the big thighs, big breasts and big butts. [Laila]

AAs are what attract Black men to us, Black women. They are what lead to love at first sight... you know how a guy just looks at you and follow you instantly declaring his love for you. [Nosizwe]

African assets are said to be what make Black African women sexually attractive. According to Laila, a participant, these assets are what lead to love at first sight as they are what attract Black men to Black women. Dimphoe was not shy to add that she believes Black men prefer plump women:

You know Noks, real Black men are not into toothpicks, they are into thick, curvy women with bi---g breasts [exaggerates the size of breasts using her hands]. It's your breasts that a guy sees before he imagines the size of your vagina. If you have a flat chest then you are as good as men...

Like Dimphoe, three other participants were quick to define African assets. Thina, who seemed relatively shy to discuss the topic could not contain herself and voiced out that she once had had all three assets. She identified these assets as big breasts, fuller and muscular buttocks and muscular legs. She further claimed that not a single man resisted turning their head when she walked around the street wearing her bandage dresses and a push-up bra which “pushed boobs to their maximum size”. Nontobeko, Samantha, and Mpilonhle also attested to this. During the focus group discussion, while Dimphoe was sharing her views, Samantha was frantically scrolling through her phone and I realised she was looking for something that she wanted to share with the group. A moment later, while Thina was sharing, Samantha shouted and said “I found it, I found a photo of my African assets!” Having allowed Dimphoe to finish her sentence I asked Samantha to show us the photograph. After seeing the beautiful photograph of Samantha, I asked her to describe it for the group and for documenting AA since she was rather uncomfortable with giving me a copy to include in this report, the following is her description.

Noks, what you see here is a higher grade, first class, business class, top of the range lady with real African assets. She is wearing a bandaged figure hugging dress which exposes her 40 DD non-sagging breasts, size 38 fresh thighs and butts. She is your ideal women, the kind that a guy takes home to introduce to his family. Look at the breast, she is wearing the right size bra, her breasts are steady.

During this description, fellow participants were making sounds and gestures which showed that they were agreeing with Samantha. Thandeka added that Samantha's photograph signified what every African falls in love with when they see a woman.

Sam wayemuhle bo kakhulu futhi, ngiyacabanga nje ukuthi obhuti babehlanya ngaye, kodwa uwabonile amabele akhe? Mahle adlula lonodoli osikhombise wona. [ngangihathe unodoli owawuzosiza ukuthi abantu bavuleleke ngesikhathi sengxoxo]. Yazi indoda engaqondile, eyisitabanyana kuphela nje futhi engafuni ukuphumela obala eyayingakwazi ukuziba uSam.

Sam was absolutely gorgeous, I can imagine how guys went crazy over her, did you see her breasts they look so perfect, even better than the Barbie doll you showed us [I had brought the doll as an ice breaker for the focused group discussion]. Only a gay Black man who is in denial about his sexuality would have resisted her.

This idea of ‘sexualising’ breasts among Black Africans is not new, yet not many scholars have investigated this. In her research, Ogana’s (2014) participants had similar assertions about breasts being sexual organs. One of Ogana’s participants was quoted claiming that “breasts should be like cushions; cushions for men [to enjoy in bed implied]” (Ogana, 2014, p. 222). Ogana, in the words of her participant further stated that “on the relatively recent development [...] like their counterparts in the West the present-day, Zulu men have developed a penchant for breasts as sexual objects” (Ogana, 2014, p. 227). While Ogana’s main focus was investigating perceptions of obesity amongst Black women, her findings correspond with this study’s assertion on the relationship between breasts and sexuality amongst Black women in Durban.

From Ogana’s study, we learn of the fourth component that makes up the African assets, the African legs. According to Ogana (2014) not only do women have to have big breasts, fuller and muscular buttocks and muscular legs as previously asserted by Laila, but Black women also have to have African legs.

Continuing her running commentary Palesa reiterates, but this time laying emphasis on marriage material concerning the Zulu female’s ideal body: “So if you have got big breasts, a big bum, and you have got such legs, iyoh, you are the best!... If you are like that in the rural areas, you know that you are going to get married because you have met the requirements. (Ogana, 2014, p. 222)

As with Dimphoe who casually shared on the Black men’s fascination with breasts, another participated cited in Ogana’s study shared similar sentiments. “Zulu men like big butts [sic]. Us guys [sic] also like cleavage – big breasts. Breasts should be straight [not droopy], which indicates that a woman has never slept with a man” (Ogana, 2014, p. 226).

Scorgie (2002, p. 59), cited in Ogana (2014), stated that amongst other features young Black women are culturally expected to have “taut (not flabby), buttocks and breasts are firm, and the abdomen is flat and taut” (p. 227). Again, this correlates with Mandisa’s argument where she boldly shared that in her experience it is “only women with African assets that are still fresh that are marriage material”. She also shared that the woman’s breasts should not only be big but it should also be “strong and firm like an avocado and not flabby like a deflated balloon”. This assertion steered a lot of introspection amongst the participants as they individually thought about how surgery had altered the way they look. In response to this, Nolwazi shared that she did not have the typical firm breasts that most participants were

attesting to; rather, she had very small breasts which she someday hoped to enlarge with surgery.

Nolwazi, while she also believed that men were attracted to big and firm breasts also believed that it was hypocritical of men to only desire women with big breasts.

I don't understand men's fascination with breasts because it's not like you ask God for a certain type of breasts and breasts change shape as we grow. This is why we end up deceiving men with big padded push-up bras; they give us the vavavum that men want.

The idea of wearing padded bras was attested by other participants. Thina continued to share that she doesn't think adding volume to breasts is deceiving men as she thought that it's not different to wearing make-up or even a wig to enhance one's beauty. The topic of African Assets is an example of Crotty's understanding of social construction. Crotty (1998, p. 42) stated that social construction is "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context". The understanding of African assets is based on the young women's interpretation of their African body image. Thus, the young women saw themselves differently from the other women and even from their previous body images.

4.3 Marriage prospects: Before cancer

Marriage is important amongst Black Africans (Kaba, 2012; Allen and Olson, 2001). Marriage is seen beyond the unity of two individuals who claim to want to create a family of their own, it unifies families as well. Most women who formed part of this study shared that they grew up obsessing about marriage. The young Black women who came from traditional and religious families even shared that they grew up knowing who they would marry as their parents had already informed them of their marriage arrangements.

Mina ngikhulele kaShembe, ngikhona ekuphakameni. Ngangilithanda isololo nenkolo ungeke ungighlukanise. Ngangizihamba zonke izinkonzo ingekho engiphuthayo ngaphandle mangixakeke ngempela. Ngangizihambela ngiveze amabele enkonzweni futhi ngingakaze ngibe nenkinga ngalokho ngoba ophela kwakunyinqubo yenkolo yami. Iyona ndlela engangikhombisa ngayo ukuthi ngisemusha angakathathwa. Yayitshengisa nalaba ababesafuna ukuganwa ukuthi ngisakhona angishadile futhi amabele ami azokwazi ukunakekela abantwana.

I grew up as a proud member of the Shembe church, I was very religious. There is no church service that I missed unless the situation was really tight. I enjoyed walking

around church bare breasted. It showed potential husbands that I was growing into a young maiden who would mature to nurture her children. [Zethu]

The Shembe religion philosophy shares characteristics with the Zulu beliefs when it comes to grooming young Black women and how they are expected to portray their femininity. Muller (1999, p. 194) cited in West (2007) shared that “Shembe’s belief in the power of the pure female body was derived from ‘traditional Zulu beliefs regarding the power of young female virgins to safeguard the well-being of communities’”. When it comes to women, the traditional Zulu beliefs are strict in terms of identifying characteristics and bodily features that indicate that women are ready for marriage. Zethu who identified as both a member of the Shembe church and as a ‘typical Zulu girl’ attested to having satisfied the “expected marriage criteria which [should have] guaranteed [her] marriage before the age of 30.” She shared that she was a prominent member of the young maiden group in her church and that she enjoyed wearing her church attire during the religious and traditional events. She wore young maidens’ attire which included skirts made of African skin and beads which symbolise purity amongst this religious group. According to Zethu, being bare-breasted “gives the young men a chance to fantasize about potential romantic affairs”. She shared that some of her male friends shared their “breast related fascination after each church service”. Dimphoe who is not a member of the Shembe church but grew up attending reed dances shared that while men often did not openly fantasise about breasts, they did have secret engagements with the young virgins who attended the reed dance celebrations. She shared that she had met her former boyfriend in Mbumbulu Township (rural area outside Durban) where she had attended a coming of age ceremony. She claimed to have been a leader of her group for six years as she had maintained her virginity till the age of 25. Dimphoe further shared that men were fascinated by her breasts even though they were small. She was a size 32A.

Yazi wonke amadoda, amancane namadala, ngisho amakhehla Noks ayehlezi ekhuluma ngomzimba wami namabele ami. Ngangingawathandi amabele ami ngoba ayemancane kodwa ayemile bandla etshengiswa nje ukuthi ngisayibambilelento, ngisayintombi. Ngicabanga ukuthi ileyonto eyabenza bathatheka kimi ngoba phela kwakubonakala ukuthi ngisayintombi. Kwangenza ngathendeka. Ngangingayona kahle kahle I African queen ngonba phela ngangingenawo anmabele amakhulu but ayemahle wona. Ayekwazi ukuheha abantu besilisa bakhele ngami baze bacele umshado.

Men, both young and old, I mean grandpa old, Noks were always commenting about my body and breasts. I didn’t really like my breasts because they were small but they were upright so you could easily see that I was a virgin. I think that is what made me attractive. I was far from being an African Asset Queen but I had upright breasts and

that was good enough for men to submit their marriage proposals to my very traditional father.

Zethu was not the only person to have received a number of marriage proposals because of having a ‘pure’ body as Sisanda was also approached. During an observation which occurred during a baby shower that was organized by Zibuyile, Sisanda also shared that her father always forced her to participate in traditional ceremonies that were hosted in their neighbourhood and those that were hosted in Port Shepstone where her father was born. She claimed that she was always suspicious of her father’s interest in her likes and dislikes, her future goals and aspirations and his willingness to sponsor her trips to Port Shepstone. She claimed she was not surprised when her father told her that the royal family (of the Cele clan in Port Shepstone) came to visit and she had to be home. She shared that she later learned that her soon-to-be husband was a prince who was almost twice her age and who was looking for someone who will give him an heir. This is how the Cele had proposed to her:

Sisanda, I have seen keeping an eye on you and I have enjoyed seeing you grow. You may not remember but I used to see you and help you cross the gravel road when you were in grade one and I was in in grade 11. I have always loved you. You inspired me to be a member of the young men’s forums just so I could attend all the ceremonies that you had and make sure that you are protected. I love everything about you and I have no doubt that you will be able to nourish our children with your beautiful cushions. I have no doubt that I will also find pleasure in your cushions every day of my life as I have adored them for years and I have been single in hope that when this time comes you will not hesitate to give me a chance to love and celebrate your cushions and the rest of your African body with you.

This is similar to some of the other proposals that participants of this study received before undertaking cancer treatment. Throughout the baby shower, Sisanda kept emphasising how the Cele Prince was interested in her appearance and not her personality. To this Zibuyile added that she also felt that the Prince was not attracted to Sisanda’s personality and that apart from “making babies not much would have happened between them (Sisanda and the Prince)”. Dimphoe further added that what proved that the Prince was attracted to her appearance was his response when she started feeling sick. She shared that her traditional parents sent her to a traditional healer who gave her several herbs. Her diagnosis is covered in Chapter 3. During the baby shower, Zibuyile also commented about how she recalled receiving calls from Dimphoe at midnight where Sisanda was crying and confused as her father blamed her for the illness.

I had only met Sisanda once at the local clinic and we exchanged numbers. Back then we were not into WhatsApp but we were using MXit. I remember I woke up in the morning and saw her endless messages where she was complaining about how she felt she had let down her family since they felt she was no longer going to be able to have children. She also went on to tell me that her father had to explain to the Cele Chief that his son was to look for another suitor as his daughter had an incurable disease and she was not going to be able to nurture their heir.

Zibuyile shared that she could not believe that there were still men who used fertility as the only criteria when looking for a wife. Needless to say, the marriage never took place. The issue of marriage was also highlighted during one of the focus groups where participants felt that their illnesses minimised their chances for marriage. Thina, who had initially mistaken lumpy breasts for pregnancy, also shared that her partner left her after her diagnosis (this was discussed in the previous chapter).

Yabona nje ukuzwa ukuthi nginekhena kwashintsha izinto eziningi. Kwashintsha impilo yami futhi ngamane ngabona ukuthi sengikude nokushada. Yazi ukukhulelwa kwakuzongisiza nje ukuthi ubhuti lo angisshade ngoba phela wayezohlawula bese eyalobolo. Ingakho nje ngajabula ngoba lendoda yayingeyona lenhlobo eshadanayo. Wahamba ke esedwa ukuthi nginekhensa futhi ngangizama ukuthi angikhulelise ngaphambi ngokuthi ngiyohlinzwa lokhu kwamenza ukuthi acabange ukuthi ayibusisiwe nje inkonzo yasekamele ngaphambi kokuthi umuntu ayohlinzwa.

Learning that I had cancerous lump changed a lot of things. It changed my life as I lost my partner and my chance to get married. You know the pregnancy would have sort of pushed my partner to paying for damages and lobola so I was sort of excited because my partner was not really the settling type. Needless to say that he left after finding out that I had cancer and that I had been sort of tricking him to impregnating me even before the surgery which he thought was impure.

During one-on-one interviews, Mpilonhle had shared that she was satisfied with her body image prior to breast cancer treatment. She shared that she was a ‘yellow-bone’ African women who always used make-up to enhance her beauty. She claimed that she “fitted the marriage material profile exceedingly well [since she had] bracketed legs, a small figure, avocado shaped breasts and a butt to die for”. The idea of marriage appeared to be of high importance to the young Black women and they often mentioned the importance of having and preserving their African assets as they were considered to be the marker of a potential wife. When I visited Zibuyile at her home for a baby shower, she jokingly shared that she was embarrassed because she had not lived to fulfil her father’s wish for her to be married by the age of 35. This seemed like a joke that only I did not understand, not wanting to be left out, I also laughed and having

heard one of the women shouting ZI-BU-YI-LE and signalling a return sigh with her fingers, I asked if her name had anything to do with the embarrassment. Laughing to tears she nodded and said: “yes Noks, I am Zibuyile izinkomo zababa” (fathers cows have been returned... returned to the father after having paid them to Zibuyile’s maternal family as bridewealth). She claims she was meant to benefit her family through *ilobolo*:

Kodwa vele ubani ofuna umfazi ongenabele? Phela nangisahlukile nendoda angeke nje ngijabulise indoda futhi angeke ngikwazi nokuncelisa izingane noma ke ngingashada ngibe nabantwana. Yazi indoda yayiyomane ingigangele nowesimame onamabele nje futhi ngangingeke ngithke. Ngoba phela indoda eyisitabanyana nje engafunana nentombi engenamabele

But of course who wants a wife without breasts. I mean I am as good as a man, I can never fully satisfy a man and even worse I will never be able to breastfeed my children even if I was to get married and have children. My partner would probably cheat on me with a woman with breasts. Only a gay guy who is in denial would want a woman without breasts.

These words are indicative of the many thoughts and negative perceptions that women develop due to losing their breasts. They also challenge issues pertaining to femininity, sexuality, and marriage. Such issues are further discussed in Chapter 4. As stated by Jenkins (1996, p. 90) social identity is “the constitution in the social practice of the intermingling, and inseparable, themes of human similarity and difference”. It follows therefore that when a unique characteristic that defines a young Black African woman, such as her breasts, has been severed through mastectomy, she feels a sense of alienation from womanhood and inevitably from the possibility of procreating. This affects her sense of identity and sexuality.

Mpilonhle who had a family history of cancer supported Zibuyile’s thoughts. She felt that men were no longer interested in her as she had decided to keep her hair short after losing it due to treatment. She further shared that losing breasts was more emotional even though she had witnessed her family members recover from cancer and live for a couple of years. She claims she understood why she was no longer ‘attractive to men’ as she felt that not having breasts and keeping her hair short has made her look like a tomboy. When asked about being a tomboy with African assets she shyly responded by saying:

Yabona Noks ngiyabona ukuthi ucabangani, uyazibuza nje ukuthi indaba nje ngiphonse ithawula kwezothando ngibe ngisako 30. Kodwa ke njengoba wawe ubona ngingaba nesifuba esiflat ngoba phela senginganamabele. Ngase ngiwumuntu ohlezi efake amabele afakiwe ukuze ngizoba namabela nyana nje ngibukeke name njengamane

amantombazane. Kodwa emva kwesikhathi ngakhathala nje ukufaka amabele. Ngabona nje angeke ngikwazi ukufakana namabele kuze kube phakade futhi ke impilo yami yayimisiwe amabele okusho ukuthi ngizokwazi ukuphila uma ngima.

Noks I understand what you are thinking, I know you are wondering why I just give up on this relationship thing while I'm only in my early 30s. Well, I have a flat chest. My chest is so flat I had gotten used to using prosthetic breasts to add a bit of a definition. But after some time I realized that I couldn't do it forever and besides it's not like my life depended on putting them on so I chose to stop.

Nontando who had mistaken cancer symptoms for pregnancy also shared that not having breasts worked to her disadvantage when it came to getting married and having a family of her own.

Weh emva kokulahlekelwa amabele ngamane ngabona nje ungeke ngisakwazi ukugana ngibe nabantwana. Nguyazi kona ukuthi bakhona abakwazile ukuzimela babe nemindeneni emba kokuhlinzwa kodwa labo bebevele benamadoda abathandayo ngaleso sikhathi ngakhoke abazange babe nenkinga yokufunana nomaqondana njengami. Futhi nje amadoda abo abesevele esethande ububona nje bengasathandi nje ukuthi babukela kanjani. Angiboni nje ukuthi bengisazokwazi uku

You know Noks after losing my breasts I just knew that I wasn't going to be married and have children. Yes sure some women were missing a breast and even both but they managed to keep their men but most managed because they were already married. Their husbands were already in love with not just their bodies but their personalities and their presence. I think not being in a steady relationship is important for me because before my diagnosis I was in a relationship but I guess being a cancer survivor is part of the reason for not wishing to be married or in a steady relationship.

Nontando also shared that she felt her diagnosis was part of the reason she never found any men that found her attractive enough to introduce to their families. She firmly believed that she would now be married and with children if she still had all her African assets.

4.4 Conclusion

African assets are among the different measures used by women to understand their body images and especially their relationships with their breasts. While the African culture may have previously limited women's breasts to signify motherhood and nurturing of infants as noted in Ogana (2014), many women associate breasts with their sexuality and African breast cancer survivors are no different. This section has, through narratives, discussed how women experienced their bodies, and especially their breasts, prior to their diagnoses.

The chapter has also highlighted the challenges that have come with having breast cancer for these women. These include lack of self-confidence and a poor body image as well a negative outlook towards marriage. It has also introduced the terms 'African assets' and 'African queens'. These terms have indicated that young Black women have a sense of identity when it comes to how they understand and take pride in being Black. This chapter has further argued that Black women identify with each other based on their physical attributes. It has indicated the importance of understanding sexuality from an emic perspective as the young Black women participants have been shown to identify strongly with body parts such as breasts and thick bodies.

CHAPTER 5: THE EFFECTS OF CANCER TREATMENT ON YOUNG BLACK WOMEN

5.1 Introduction

Breast reconstruction and decreased desire for (sexual) intimacy are some of the common side effects of breast cancer treatment. The effects of breast cancer treatment can be broadly grouped as physical and emotional. This chapter unpacks some of the physical effects of cancer treatment which include numbness, vaginal dryness, fertility, and breast appearance. It also critically discusses the emotional issues which include relationships with previous and current partners and depression. These will be discussed in an attempt to understand not only the challenges posed by the treatment but also the measures used by women in renegotiating their sexuality and body image. Issues pertaining to the construction the young women's social identities in the context of body image and sexuality will also be discussed.

5.2 Physical changes

“Body image reflects a direct personal perception and self-appraisal of one's physical appearance, whereby negative thoughts and feelings related to one's body indicate a disturbance of body image and lead to dissatisfaction with one's self” (Frederick-Recascino cited in Przewdziecki, 2012, p. 1)

Having knowledge of breast cancer and its treatment enables women to make sound decisions regarding their treatment. However, the previous two chapters have highlighted that most of the women who participated in this study had very limited knowledge of cancer as a whole and even about its treatment options. Scholars such as Przewdziecki (2013), Manos et al. (2005), Freedman (1994), Hopwood and Maguire (1998) have discussed a number of treatment options and their side effects that were unknown to some of the research participants. This is what led participants such as Dimphoe and Thandeka to wishing they knew and understood their treatment options. It is also the main reason Zethu wished she had acted on her illness sooner as it would have increased her treatment options:

I was diagnosed with stage cancer two which was a bad state for me considering that I had other health complications. So while my sister was hoping simple treatment would be sufficient for my condition, it turned out it was getting worse really fast. This led to

being hospitalised immediately as my family was told that if they don't remove my breasts I would not survive for more than 6 months.

Zethu is amongst the four participants which Thandeka termed 'unfortunate' as they learned of their condition at a late stage. Thandeka shared this as she felt that these women were robbed of their health.

Unlike me who couldn't afford fancy treatment from a private hospital when I was diagnosed, these women were very unfortunate. I feel they were robbed of their chance to survive. Pity we can't question God but I guess it's better this way ... at least they don't have to blame their family members cause this was God's doing. I mean if He wanted to save their babies [referring to breasts], He would have. But no they had to be victims of cruel cancer and lose one or even both of their babies.

Physical appearance is important to all. It is through physical appearances and discerned features that human beings have a sense of (aesthetic) beauty which in turn influences their body image and confidence. It is also through physical appearance that women consider themselves beautiful, attractive, appealing and even sexy (Champion et al., 2014; Cappiello et al., 2007). As sexual beings, women (and men) prefer to be considered attractive by their counterparts. This is why most of this study's participants were quick to comment on their bodies prior to cancer as seen in Chapter 3. In Chapter 3 this study documented how women considered losing their breasts to have a major effect on their confidence as it also took away their identities as women with African assets (see Chapter 4). In commenting on their previous body images, women also shared how cancer treatment affected their marriage prospects as they no longer felt they could no longer be considered African Queens.

In discussing the challenges faced by cancer survivors, authors such as Przewdziecki (2013); Deniz et al. (2007); Manos et al. (2005); Connell (2005); Hopwood and Maguire (1998) and Freedman (1994) have discussed issues pertaining to the side effect of medication. In particular, Przewdziecki (2013) argued that the side effects pose a challenge for women as they lead to low self-esteem and they affect their feminine identities. This argument was problematised throughout this study and was discussed during individual interviews, focus groups and observations. While some women were initially shy to comment about their treatment journey, others focused on this as soon as the topic was introduced. During one of the focus groups, there was a discussion on the physical changes that were caused by breast cancer. At the end we drew up a list using a flip chart and participants voted (by a show of hands) the most problematic or prevalent indicators of breast cancer (see image below). The first, which was

agreed by all the women who were present, was ‘developing a lump in your breast or developing a thickened breast tissue’. This was followed by ‘skin changes on and around the breasts’. The third was ‘discharge from your nipples’ and lastly, ‘change in size or shape in breasts’. According to the group, these were the ‘markers’ of the different health stages that they were entering. Amanda added that these symptoms were unexpected, unheard of and even unnoticeable at first. This is amongst the many reasons that led women to seek westernised medical healthcare or traditional healthcare as they had no prior knowledge of it.

The reason behind focusing on the bodily changes that were experienced by women is to indicate the changes that were further caused by treatment. As already mentioned in the previous chapters, women were initially shy to share some of their experiences as they felt that the experiences were rather ‘disgusting’ and ‘embarrassing’. At the end of the first focus group, some of the participants shared that if it was not for the time I had invested in hanging out and establishing rapport which allowed me to immerse myself in their world, they would not have had the courage to openly share their embarrassing and humiliating treatment experiences. During my first individual interview with Thina, she highlighted the bodily changes that she experienced due to breast cancer and its treatment. She dwelled on losing her African assets and shyly added the impact of losing her hair and nails. More than once she mentioned that ‘a bald head and weak nails were not a big issue’ as to her, losing her breast and weight impacted on her body image more significantly.

As a woman who was socialised to believe that a women’s hair is her crown, I felt the need to delve deeper into the issue of hair loss. Having learned that hair was not a major challenge for Thina, I was interested in understanding the rest of the participants’ views. To my surprise, in one of the focus groups, the participants were all interested in sharing their hair related stories as they felt it was an important issue which affected their beauty and body image. While the story sharing began as a ‘recital’ with all survivors beginning with ‘I was shocked to lose so much hair in such a short period of time’, Thandeka was the first survivor to openly share how ‘strange’ and ‘heartbreaking’ the experience was.

I remember like it was just yesterday. I was in the middle of my chemo when my 7-year daughter entered the room and asked if she could do my hair like she normally did every Saturday. I wasn’t really up to it but I couldn’t disappoint her. I mean, she had her full toy salon equipment with her. So I thought argg man that hair dryer doesn’t have any heat and that straightener doesn’t even use any power. Well, of course, I was right, it did not use any heat. But... oh but Noks, I forgot that her comb and brush had teeth so they could really brush. All she did was to brush my hair once and the next thing she

was crying and apologizing of breaking my hair she even cursed herself saying that she was a bad hairdresser. That was how I started losing my hair. It was heartbreaking in two ways. Firstly, as my daughter blamed herself, secondly I felt I did not do myself justice by not checking with the hospital and reading about losing hair during treatment.

Thandeka is one of the participants who had a hard time dealing with her hair loss. She shared that the experience was ‘like no other and *yangehlisa isithunzi* [it stripped away my confidence]’; she felt her femininity was taken away when she lost her hair. During the group discussion, Laila expressed her empathy by sharing the following:

Love ngiyacabanga nje ukuthi kwakunzima kangakanani. Ngiyacabanga ukuthi waphatheka kabi usuziblema nje ngokunganaki kanti phela nawe wawungeke unbhule wazibona usephutheni ngokuvumela indodakazi yakho ukuthi idlale ngezinywele zakho ngesikhathi esibucayi kangaka. Kodwa ngikholwe, ngikholwe sisi. Anginayo indodakazi koswa ngiyacabanga nje ukuthi wawufisa ukujabukisa umtanakho ngokuthi adlale ngekhanda lakho ngesikhathi upretenda sengathi usanamandla ukuze ezojabula. Kodwa khululeka lokhu akubona nangeke kususe ukuthi wena utyiqhawe lakhe. Usakubona ungowesimame futhi okwazi ukunakekela.

Love, I can imagine what you went through. I can imagine how disappointed you must have been blaming yourself for not being cautious by allowing your daughter to play with your hair at such a critical time. But I understand trust me. I don't even have a daughter but I can imagine how you wish your little one could have played with your hair while you pretended to be strong for her sake. But just know that what she saw and felt did not take away the fact that you are her hero. She still sees you as woman and as her nurturer.

Laila's comment changed the atmosphere for the focus group as all participants began to share their experiences. What was noticeable in the memories shared by participants was their sense of guilt which Thandeka argued was due to not being emotionally prepared for the treatment side effects.

You know Noks I still feel guilty for not asking the correct questions at the clinic and hospital. With the opportunity to ask anything at the clinic, I only asked about my survival chances and if I would be able to have breast reconstruction. Nothing about how I would look and anything like that. And because I was impatient with the nursing staff they did not tell me anything apart from the questions that I had asked. I really believe that things would have turned out differently if I had known what would happen and how I would have avoided some of the side effects like losing my hair.

Thandeka is one of the six participants who openly blamed themselves for not being ‘prepared’ for losing her hair. Laila who lost her hair two months into her treatment claims that she had

high hopes for being able to maintain her hair. She shared that she had bought a number of hair treatment products that she believed would help her against hair loss. However, none of the hair products lived up to their promise as she shed all her hair in a space of three days. She recalled this unfortunate ordeal through sharing the following:

When I started my treatment I was very curious of the hair problems that I was going to encounter and so I asked the nurses and fellow patients when I was most likely to lose my hair. I remember three of the five ladies I asked said they lost their hair within a month of treatment and so I thought the same would happen to me. To avoid this I went to the foreign African hair shops and I bought their anti-breakage products which they swore would prevent my hair from breaking regardless of the cause. So after eight weeks and my hair was still healthy I was happy. I thought I was amongst the lucky few who did not lose their hair. But I guess I was wrong because I lost more hair in a space of a week than I could ever grow in years.

Laila was among the most positive survivors amongst the research participants. The rest of the participants were always inspired by her perceptions and stories and she was considered to be the leader of the focus groups. She had hoped for the best results throughout her treatment she even shared that she had initially refused to sign off her consent for the provisional surgery dates because she believed medication on its own would destroy the cancer cells that had found a home in her body. When her hair remained strong she was even more dedicated to using more hair products from her Cameroonian supplier. She claimed that she used more than R2000 in buying the hair products. Laila shared her experience during the second focus group of this study. She was not the only women who shared that she had high hopes for maintaining her hair. Zethu also shared that she maintained her ‘authentic afro hair’ with the best treatments and always ensured that her scalp was well moisture, which according to her experience, should have protected her hair from falling out.

I was intrigued by the lengths that women went to in maintaining their hair even though they knew that hair loss was inevitable during chemotherapy treatment. I, therefore asked Thandeka if she believed there was a relationship between hair and being a woman. To this she gave a gentle smile and nodded her head as a sign of approval and continued to share as reflected in the following except where she revealed why losing her hair was so difficult to accept:

Noks, losing hair is like losing what makes you a woman ... it's no different from losing your nails and breasts but it hurts more. You see once you lose your hair you are forced to do something but of course, there are a few options. Either you remain bald or you get a wig. While wearing a wig is often a convenient choice for some Black women, they still have to take it off at the end of the day and be confronted by their messy hair

or bald scalp. In my case this was different. I wore a wig because I didn't want anyone to know that cancer was eating my hair so I would turn heads [people appreciating her wig] during the day while silently praying the wind wouldn't blow my wig off. And then at night, after all the compliments of how nice my hair was, I would come home to see how much cancer was eating my hair. It was very painful. You know just seeing that you no longer have what other people have. Women were into keeping their natural hair and having cornrows those months and I was stuck with a wig that I did not even like. I felt more like a man as I could no longer compete with women. I was far from being beautiful. Far from being attractive.

Other participants could relate to Thandeka, such as Nontando who shared she had not anticipated being demotivated and discouraged by losing their hair because she had 'weak African hair that needed to be hidden anyway'. However, her appreciation for her hair increased as soon as she noticed that her hair was receding and she had developed a bald patch.

Noks, bengivele nginomqothuko, bengihlezi ngixhumile nje. Bengazi nje ukuthi after 3 weeks ngiyokwenza ikhanda futhi nje bengiright ngalokho. Bengizivukela ekuseni ngibrashe i-weave bese ngiya emsebenzini. Empeleni i-weave besiyinxenye yempilo yami ngoba benginezinwele zaseSomalia [ehleka aze athwale izandla esephuma nezinyembezi] nje noGuy ubazi ukuthi kuyabheda ekhanda lami ubeze aze asho ukuthi uyethemba ukuthi mhla Inkosi isibusisa ngomtwana, angeke abe nomqothuko njengami. So nje bengazi kahle ukuthi kungishubele so bengingenandaba ngoba bengizibona inywele ngalesoskhathi. Kodwa mhla ngibona ukuthi seziyaphuma ngahlala phambi kwesibuko ngakhihla esikaNandi nami angazi ukuthi ngangitetemiswa yini ngoba phela angikaze ngibenenhlanhla yezinwele. Mhlampe ila ngabona khona ukuthi userious kangakanani umdlavuza ngoba phela umuntu waphenduka indoda nje esenembunculu. Ngazizwa ngiwumfane nje, engathi lento ebingihlukanisa nafana ibingasekho. Kwakubuhlungu shame, kakhulu futhi.

Noks I had always had weak thin hair so I always had a weave on. I always knew that I had to change my hair at the salon every three weeks and I was absolutely fine with that. I would wake up in the morning and brush my weave then go to work. In fact hair weave became a part of my life because I had weak hair much like the Somalian hair. [She laughs until she cries and puts her hands on top of her head.] Even my boyfriend knew about my hair, he would joke about it and say he hopes our child would be hairy like him. So I knew that hair wasn't my best feature, as a result, I didn't really care about it because I would see my hair at least once a month. But the day I realized that I was shedding hair I sat in front of my mirror and wept like a child. I honestly don't know why I cried because I was never blessed with hair but I did. I wept. I think it's where I realised how serious cancer was I literally turned into a man because of my bald head. I felt like a boy, like what separated me from other boys was gone. It was a heartbreaking experience.

From the above conversations, I realized that for some of the young Black women, hair was associated with femininity. It was apparent to me that without hair, some of the women could not fully associate themselves as sexual beings or even consider themselves to be attractive. The issue of bodily changes was also discussed during a shopping trip where I accompanied Mpilonhle and Nosizwe. Nosizwe shared that since being diagnosed with cancer she had felt the need to ‘put on fake things to look like a woman and be attractive to African men’. She shared that losing her right-hand breast had left her with many ‘fake’ body parts. She claims that it is because of the invasive treatment that she now had ‘fake hair, fake nails, fake breast and fake butts’. Because this information was new to me I decided to probe further to find the link between wearing these ‘fake body parts’ and body image. Nosizwe shared that prior to cancer she was an African queen who was ‘all natural’, she showed me a picture that she had taken a year prior to treatment. In the picture, she was wearing a bandage fitting dress that accentuated her hips and figure. She has natural virgin afro hair that looked like it had never been straightened by a relaxing cream. She also had full eyebrows and long uncoloured nails. I am emphasizing these aspects of her appearance because she looked like a completely different person when I interviewed her. She explained her ‘dramatic’ changes in the following manner:

Nokwanda ngifisa sengabe wangibona ngingakadliwa icancer. I was beautiful mtakaMah. Ngangiphelele ngingadingi twa. Ngishaya ngesihluthu seAfro kwakungathi ngiwuPitch Black Afro. Ngangiyibhubesi kahle kahle ekhaya bengibiza ngemfene oe. Ngangigcwele ngishaya ngefiga ngesinqa samtakabani. Inzipho ngangingazipendi nhlobo. Ngangizigcina nje zizinde. Angiyazi nje lendaba yokuxhuma izinwele nezinipho mina before 2010. Aibo ngangiyiOriinali futhi oGuy bebengithandela kona. Weh yafika ikhensa nesihluku sayo yangishiya ngiqothukile nginezinzipho ezimnyama. Yazi ngaqothutha ngaze ngaqothuka namashiya nezinkophe ngish namakhwapha nesitho sangasese ungibona sengizipendile nje angithandi ngasuka ngaphoxwa ukugula. Manje sengihlala ngifakene namawigi. Sengaze ngathenga nezinga ngoba itreatment yangishintsha ukuma ngafunda nokuzipenda ngoba abantu belokhu bengikhuluma bethi ngathi ngiyinkukhu echuthiwe. Kwakumele nje ngenze okuthize ukufihla ihlazo.

Nokwanda I wish we had met before I was diagnosed. I was so beautiful. I was complete, not needing any enhancement. I had afro hair, similar to Pitch Black Afro. I looked like a lion to be precise, at home they use to call me Monkey or Chimpanzee. I was a fully bodied woman with a slim figure and a backside to kill. I never used to colour my nails because they were originally strong. I never used to put on weaves and fake nails before 2010. I was an original and guys loved that about me. And then cancer came about and took my hair and left me with Black bristle nails. I lost most of my hair including my eyebrows and eyelashes even my armpit and private part, you see me with

fake eyebrows and lashes I don't like being like this but I was forced by my illness. I even resorted to fake butts as treatment changed my body shape and people were gossiping and calling me a chicken without feathers. I had to do some. I had to hide my problem.

The above is an example of the challenges that a number of women experience when they undergo cancer treatment. Similar to Nosizwe, Thandaza who is a 40-year-old nurse with two daughters, shared that her physical appearance during and after treatment was very 'unhealthy'. She lost all her hair. During her individual interview, she had shared that she had feared losing her hair as her husband had once commented about a patient that they had met in a hospital parking. This is how she expressed herself:

When I found out I was stage 2 cancer I sort of knew what to expect and my treatment options. I also knew my survival chances and trust me they were high because the cancerous cells had not metastatic so I just needed minor surgery or I could have just had a chemo to destroy as many bad cells as possible. So I was OK. I was prepared for the medical side of treatment but I feared for my relationship. I feared that my husband who at that time was a structural engineer would not understand that his wife had to be bald. Like he would have a reason to leave me and I became very insecure. I also feared the comments from my in-laws. How they would have thought I was a person who had brought bad spirit to their family. I feared that my in-laws would think I brought a curse to their lives. I also feared for my daughter, what she would go through and how she may be rejected and judged because of my condition. [Dimphe]

Women become uncertain of their physical appearance once they are diagnosed. Even the participants that had no knowledge of cancer and its treatment had fears for their appearance. The following is what Minnie who was a sports fanatic at the time of her diagnosis had to share about her appearance fears:

Ngazama ngakho knke engikwaziyo ukusuza lezibazi kodwa lutho. Kwathi sengizwa ukuthi nginekhensa kwaphela konke. Yazi kwaphela ngisho ukuzethemba. Konje ukuzibona ngiSexy. Nawe uyazi ukuthi ngangizijimela so nje ngangifithi futhi umzimba wami wawumuhle. Kodwa kwapphela konjke. Ngithi konke ntombi. Ngangilokhu ngicabanga ukuthi ngizoba mubi kangakanani nokuthi umzimba wami uzobamubi kangakanani nokuthi nje ngizoshintsha nendlela engimi ngayo ngoba phela kwakuzoshintsha izinto eziningi. Kwakuthusa bandla. Ngiyakhumbula nje ukuthi ngangikhuleka kujehova ukuthi agcine amabele ami nendlela engibukeka ngayo. ngangikhulekela ukuthi lekhensa igcine ngaphakathi ingaphumeli ngaphandle ukuze abantu bangayiboni kalula. Bangamane babuke izinzipho nezinywele zami bese bayabiona ukuthi nginekhensa.

You know I did my best to remove the bruises. But as soon as I learned that I had cancer I lost it all. All the confidence and sense of sexiness. You know I was fit so I had a good body and flawless skin which was a result of being active. But none of it was left. I mean all I could think of is how ugly I was going to be, and obviously, I was going to change my body shape. This was traumatic. I remember I used to pray from God to save my breast and appearance. I prayed for the effect of cancer to only be on the inside, that people may not easily detect my diagnosis by looking at my hair, nails etc.

The issue of hair loss was the most prominent challenges cited by participants. During one of the WhatsApp group discussions, Laila shared her excitement as eyebrows were growing back. She claimed that she had waited for fifteen months for them to grow back. Two other participants envied her as they feared that their eyebrows would never grow back. Nontobeko decided to have her eyebrows permanently tattooed.

Hair loss was further discussed during individual interviews and observations. When I visited Zethu for her first individual interview I was wearing a straw hat as it was a very sunny day. While I thought my dress code of a summer dress, sandals, and straw hat were appropriate for a Shembe household I soon learned that the hat was rather offensive to Zethu's aunt as she felt I was drawing attention to my hair and being insensitive to her niece's condition. I pretended not to hear the conversation that continued in the kitchen while I was sitting on a bench on the veranda and I carefully took off my hat and laid it next to me. Zethu noticed my now exposed hair and asked why I was no longer wearing the hat. I replied that the hat was for walking in public as I had a sensitive skin that reacted to the sun. When her aunt appeared with a jug of water she said:

Oh, MaNzuza besengithi uwuspense [Ms. Nzuza I was beginning to think you were a snob] ... a snob that is self-centred and that doesn't care about other people's feelings. You know some of the people that come here to check up on Zethu come wearing baggy t-shirts that hide their breasts and big expensive hats that don't show a single thread of their hair.

When her aunt left, Zethu explained:

My aunt gets irritated by this, I mean people's attitude once they know what I have been through. She doesn't think they do it in solidarity with me, she thinks it's just another way of mocking me and what I have been through... you know, just reminding me that that I am different. I think she gets irritated because I spent months trying to recover from not having hair and so I wore scarves on my head and sometimes hats like the one you had on. So she doesn't like it when people remind her of all that we have been through because of my condition. When she saw you walking down she thought you were one of them but I understand MaNzuza. You seem like a person who genuinely

cares about this condition. You are also the only one who hasn't asked for a piece of my skin to take to a laboratory like the UKZN students once did. We were a bit sceptic about you and that hat.

This was one of the major fieldwork challenges that I experienced but I had to bear with this misunderstanding. I decided to use this incident to begin the conversation about hair and identity that I now feared to start. Fortunately, Lindi was more than willing to share her experiences. In unpacking my conversation with Thembeke, I realized a number of issues which I had taken for granted that affected the survivors. I had witnessed a number of African women at Sinothando who had covered their hair. Having noticed that they were wearing bridal rings I understood the act of covering their hair to be associated with being a respectable wife. My conversation made me realise that there were other reasons why these cancer survivors covered their hair. Unfortunately, as they were survivors of other forms of cancer, they did not qualify to participate in this study.

The above introduces several issues that have not yet been interrogated. Thandeka shared that Black women, especially those who are married, are usually expected to cover their hair. According to Thandeka, this is done so women cannot be easily identified and so their beauty cannot to be seen by the whole world. Samantha, who was married, shared that she covered her hair when she was with her in-laws. She shared that this is considered to be a sign of respect and not doing so was considered as blasphemy by her in-laws. She further shared that she wears a *doek* or head wrap only when she enters her husband's family home but she does not wear anything when she is at home. She further shared that her husband prefers to see her well maintained African hair. This served as an advantage for some of the married women as they were forced to cover their hair due to cancer. The issue of 'African hair' was also brought up during a baby shower where Zibuyile shared that prior to losing her hair to chemotherapy, she had 'authentic' African hair. I tried to ask further questions on 'authentic African hair' but the women who attended the baby shower were wearing artificial weaves and wigs, hence this topic proved too sensitive to some of the women who claimed they were more comfortable with artificial hair than natural hair.

During a focus group, Laila shared that she had no choice but to invest in wigs when she began her treatment.

Noks you are blessed if you will live your entire life cancer free. I had a very difficult time dealing with the side effects, especially with hair loss. I was the kind of woman who prided herself for not wearing weaves but treatment changed everything. It made

me feel fake. Most people think breast cancer is just about losing one or two breasts but it's a lot more than that. You know I used to try and enhance my beauty. I learned to draw eyebrows and put on eyelashes because they were all gone and I was scared of people seeing me so naked. So different. And so ugly.

Laila, much like Zibuyile, preferred being 'natural'; both kept their virgin coarse hair and preferred not to relax or condition with harsh chemicals. Zibuyile even went to the extent of sharing that she was not the 'salon type' and that she preferred doing her own hair. However, with cancer and the need to 'maintain beauty,' these young Black women resorted to wearing wigs which, judging from the photographs they shared with me, were close to being Black coarse hair.

Not all participants were embarrassed by wearing weaves and wigs. Some shared that they also owned a number of wigs prior to being diagnosed which made their experience somewhat different as their hair identities were not changed in terms of appearance. However, some, such as Nontando, shared that while she had appreciated her Brazilian hair more than her natural hair prior to her diagnosis, she felt depressed when she realized that she was shedding her hair.

ngangiwuGlamour wangempela sisi. Lenhlobo obungaze udideke uyibingelele ngesingisi ngoba bengifaka oPeruvian, Indian noma iBrazilian. Emateksini nje abantu abehleli emva kwami babekhuluma isingisi mabecela ukuthi ngidlulise imal [ehleka eze ashaye izandla]. Kodwa kwenzeka nje kwaphela konke loglamour wanyamalala futhi ngayeka ngisho ukuthanda ukuba uglamour ngesikhathi sengiqala ukuqothukelwa izinywele. Ngase ngingasazithandi izinywele ngihlezi ngizifihlile ngasso sonke isikhathi kodwa ngangizithanda nkosi yami. Yazi ngangihlezi ngazi ukuthi nje noma ngingakhathala ukuxhuma amweave kodwa nganginazo izinwele yami. Futhi ke nje ngangazi ukuthi zisakhona izinywele yazi uma kwezweka ngithole iwiki noma iweave iqathaka endleleni

Like I was the glamorous kind women. The kind that you would greet in English because my hair was either Peruvian, Indian or Brazilian. In taxis people sitting behind me would ask me to pass money in English [she laughs and claps her hands endlessly]. But somehow all the glamorous image was no longer appreciated once I started losing my hair. I know I had not appreciated it before cancer but I think cancer was too harsh on me because I was always confident of having good hair underneath the weave. I always knew that anything happens to me and the weave falls off in public I would show my real hair. So I feel losing hair was harsh.

The case of Phiwe was similar to that of Nontando in that she also had previously appreciated wigs and weaves more than their natural hair. The subject of women and hair is universal. Scholars such as Johnson and Bankhead (2013) have interrogated topics pertaining to hair and

identity and how natural hair impacted on the Black women's sense of pride in the work place. This study found that some Black women preferred having so called natural hair, no straightening hair chemicals were used to alter the texture of the hair. In essence, this study revealed that Black women appreciated having hair, both natural and unnatural hair. Such findings allude to the importance of hair for young women. This current study attested to the importance of hair as the young Black African women shared that they were not able to cope with hair loss as it altered their appearance which affected their body image.

Some of the young women shared that hair loss was a challenge to them as they experienced it as a form of oppression that they had experienced in their earlier years. An example of such oppression and misrepresentation of identity was shared by Zethu who shared that hair loss was a mark of change for her. She claimed that it was common for Black African families to cut their young children's hair whenever there was death in the family. She claimed that this mostly affected the women as the men usually had very short hair, hence, there were not many observable differences after a family member's funeral. Zethu's experience was also shared by Sisanda:

Growing up in a Black African family meant that there would be haircuts after each death. You must know that back then we were not allowed to keep or use chemicals in our hair as our parents thought it wasn't African enough and that Black women should maintain coarse hair. So we would keep our hair short and just after the September holidays we would start plaiting to try and grow if for the December holiday. But you know, a distant family would suddenly die and we would have to cut our hair and remain bald. Just like guys. But of course they did not mind because short hair suited them but for us it meant no more hairstyles for Christmas and that we would no longer have pride. We hated cutting our hair. It was oppressing. Much like a way of showing our loss to the rest of the world.

The issue of cutting hair was seen and understood by the participants as a ritual which signified a beginning of a new life for the young Black women. Thandeka shared that her father explained it as "respecting the dead and starting afresh without a loved one". Sisanda recalled her grandfather explaining to her that cutting hair after death was a way of expressing dark emotions since their lives were covered by a dark cloud. Participants further shared that losing their hair from cancer brought back these unpleasant feelings which they had not experienced in several years.

Nokwanda you know having grown up shaving my hair whenever there was a death in the family I sort of felt the same pain when I realised that I was losing my hair. Like it

all became real. Hair loss was a marker which exposed my loss. Like how it used to be in the past. Right there and then I realised that there was no way of hiding that I was having cancer treatment ... like the world could now see what I was going through without me saying a word. Just like our loss was always exposed when a family member died. [Zethu]

Some of the women felt that wearing headwraps was a good alternative to their natural hair. According to Laila, it was easier to hide behind a *doek* than it was to share the reasons for hair loss.

You know being Black was sort of an advantage for me because I could easily wrap my hair and go to work. Some even thought it was stylish. While I missed my hair and wished it would regrow healthily I appreciated that in my culture women are seen to be appropriate when they do not expose their hair.

All but one of the participants' hair had grown back. Laila recalled how her husband noticed that her hair was growing when they were on a date and her weave was receding. She shared that it was an embarrassing yet joyous moment as the one feature she was covering, was showing.

*Noks [she stands up looks me in the face and claps her hands in laughter] you will not believe what happened. So hubby and I are eating right and my hair gets itchy I use *ihlokoloza* [hairpin used to stretch itchy scalp] to scratch and the next thing uMbulazi (her husband) starts laughing and pointing to my hair. I was so embarrassed because I thought he was laughing because my wig was falling off. But this was not the case, he laughed so hard because he could see my scalp and was amazed at the fact that my hair was growing.*

This was not the case for Nontando who even after her eleventh chemo was still hairless. She shared that she was initially ashamed of herself and blamed herself for being bald as she felt she was not taking enough vitamins and hair growing supplements. She further shared that it was only after seeing other patients who had been on treatment longer than hair that she realised that "hair behaves anyhow while on treatment". She felt not having hair was more of a disability for her as she felt incomplete without her hair and she felt she could not compete with other women in terms of beauty.

Noks losing hair is much like losing a leg or arm and you have to put on that plastic arm or leg. It's more like torture and even worse there are limited options for us who cannot afford cosmetic surgery like Khanyi Mbau and Mshoza¹³. You know you are reminded each and every day that you do not have hair; seeing normal women pains

¹³ Khanyi Mbau and Mshoza are Black South African media personalities who are known for their artificial hair and using plastic surgery to enhance their beauty.

you. And I am not referring to other races here. I am referring to Black women like who may even look poorer than you but they have healthy hair. Even if it's short it would still be healthy. Plus doctors recommend that you do not wear anything permanent like a weave that you can change after three to four weeks. So you end up with no choice but to get a wig and wear it daily. Much like Oscar Pretorius whenever he has to leave the house. It's really hard to keep up and to wear a wig every morning and sometimes even after hours when you are entertaining guests.

Hair was not the only issue; some participants complained of how 'dark and ugly' their nails became due to the harsh cancer treatment. Zethu worried that her nails would never turn back to their original colour and that she could no longer survive without painting them.

Aibo weOe bangigila oNails. Yaz bamane bashintsa nje over a couple of days. Bashintsha bamnyama nje eskhalene. Odokotela babecabanga ukuthi lento idalwa ifangi kodwa futhi bahluleka ukuthola amaphilisi ayezongisiza aphinde angaphazamisi imithi yekhensa so I ended up ngihlala nalabobolile nje. It's been two years awukho umehluko futhi sengize ngazijwayela nje. Kodwa phela ngiyazifihla ngokuzixhuma at the salon.

Oh, sister, I had real problems with my nails, they changed colour and texture over a few days. They turned black. The doctors thought it was due to fungi but they were unable to find suitable antibiotics which were not going to go against the medication I was already on. I ended up getting used to the idea of having black nails. It's been two years but not much improvement has occurred. I hide them by putting on fake nails at the salon.

The following is another participant who was disappointed with the changes she saw in her nails.

Noks phela icancer yashintsha indlela ebengibona ngayo ubuhle. Uyazi ukuthi bengiyiloluhlobo elizithandayo kodwa lokhu kwashintsha sisi. Zasala phansi izinzipho ezinde nezinkophe zamtakabani. Umama wayehlezi engithethisa ethi abesifaze abamnyama akumele nje bafake izinzipho nezimwele kumele bathendeke bengafakanga lutho. Kodwa ke ngokungenzwa kwami ngaqhubeka sisi ngizifka izinzipho nezinkophe. Langa linye ngazicwilisa phela emanzini afudumele ukuze ziphume izinzipho zasathanda kwazisholo umama. Ngiyakhumbula ngibona amabala amnyama esithupheni sami. Ekugcineni ngathiola ukuthi ziwu 4 izinzipho ezinenkinga. Ngacabang ukuthi mhlampe iglue yokufaka izinzipho ayayenze lenkinga oe. Futhi angizange ngiyinake kunalokho ngamane ngaya kofaka ezintsha. Ngesikhathi sekutholakala lesisifo kwathiwa angikhiphe lezinzipho nginqume nezinsipho zami zibemfishane. Kwathi sengiphindela kadokotela kwashiwo ukuthi lenkinga yezinzpho ibidalwa yikhensa.

Yoh Noks, cancer redefined beauty for me. You know I was glamorous young Black women with long nails and lashes. My mother always scolded me and told me a Black woman should not be so fake but of course, I continued with my artificial nails always well-manicured until of cause I had to soak them in warm water and remove my devilish red nails as my mother called them. Heeeee is I remember seeing dark lines on my left thumb and I thought it could have been the nail glue so I soaked my hands for 5 more minutes only to realize that about 4 of my finger nails were affected. But I didn't take it seriously and I went to renew my nails. When I was diagnosed, I was commanded to remove my fake nails and to clip my nails short. In my next visit, the doctor confirmed that the changes on my nails were due to cancer.

Hot flushes, menopause and infertility for Black African women

Hot flushes are a general medical challenge for women, usually experienced during menopause, which affects women between about 45 and 60. The participants in this study complained about hot flushes. Dimphoe shared that they had heard of the 'fever like' experience that 'older' women experienced but she did not expect to find herself being a victim especially since them as she still considered herself as 'young'. Many participants felt this was a culturally bound illness and they shared that their hot flushes were "different compared to the clinic discussed symptoms". Thandeka was one of the participants who felt and believed that her hot flushes did not need medical attention; she chose to see a herbalist who would help her.

I went to see a herbalist because I grew up knowing that fever is caused by a cold. Even as a child my mother would warn me not to expose myself to cold weather as the cold would build up and cause things like pneumonia. To help ease the fever my mother would make us drink a hot mixture of ginger bush and magnesium. It would warm the body much like the Med Lemon flu medication. But because the ginger bush and magnesium were raw and not mixed with any chemicals, they were more effective. So when I started feeling extremely cold I did not even bother to mention it at the clinic as I felt that my mother's mixture was the best solution.

Thandaza, who is a nurse, found the idea of using a traditional raw mixture hilarious as she claimed she understood what the body was going through when she had hot flushes. Despite this, she also shared that she did not use the medication from the pharmacy during the first month of her hot flushes as she too was in denial of her menopausal symptoms. Dimphoe shared her experience with hot flushes and how she first understood the changes in her hormonal functioning body.

Noks oe aibo I was only 36 ngaqala ngezwa lo ON and OFF. Ayi engqondweni yami ngizitshela ukuthi umkhuhlane nje odlulayo. Ay into eyayingidida ukuthi ngangimane

ngishiselwe kakhulu, yabo ngibe nesfuthe futhe nje eskhaleni kodwa futhi ngipphinde ngibe normal. Ay kudlule insuku mhlamope isonto nje. Lutho ukukhqwehlela kodwa ngiyafa ukushiselwa. Ay, ngize ngiyixoxe lento eClinic ngesikhathi ngisashikisha amabhentshi. Ai oe kwasuka isalukazi nje esizigugele esasihleli emva kwami sathi 'aibo mtanami usaya nje eskhathini' ngiphendule ngithi 'cha mah angisayi sezidlulile izinyanga ezintathu'. Ay sihleka kancane isalukazi bese sithi 'shuthi sengizoba ugogo'. Yazi ngamane ngoma insini ngoba phela ngangingasayazi inkonzo yasekameleni. Ngase ngamuchazela ugogo ukuthi sengaphenduka ivajini. Awu ugogo wamane wabamba umlomo wathi 'mtanami kungabe yini ukuthi usujoyina thina esingasabatholi abantwana'. Ngathuka yazi ngoba ngakhumbula amazwi anesi mhlazane engiyala. Washo ukuthi kungenzeka ngifikelwe isikhathi sokukhula njengoba sengidla imithi yekhensa. Kodwa ke loyagogo washo wathi ngingadlali nje odokotela nonesi bethi ayikho into engingayenza ngoba phela ozifozonke bayayiqeda lento.

Noks I was only 36 years old when I started feeling a strong heat in my body that would come and go. In my mind, I thought it was just flu and fever that would soon pass. What puzzled me is the fact that I would suddenly get hot, like feel very hot for a few seconds then cool down again. So I decided to share my problem while sitting in the clinic queue. The next thing a very old lady sitting behind me says 'my child do you still get your menstrual periods' and I replied by saying 'no mother I have not gotten my monthly periods for the past three months'. The old lady laughed and replied 'I guess I am going to be a grandmother'. I laughed so hard as I explained to her that I have turned into a virgin. To my surprise, the old lady covered her mouth and said 'I hope you have not joined us, who can no longer have children'. I was so shocked and I remembered the words of the nurse that was assisting me as she had mentioned that I might reach menopause since I have started taking cancer medication. But of course the old lady said I should not listen to the nurses and doctors as the African traditional medication could heal hot flushes.

Phiwe is another participant who was shocked by experiencing hot flushes at her young age of 30.

I had seen my mother sweating on a windy day. Her temperature would rise and she would be soaking wet in a space of seconds. She would shower with cold water for more than 15 minutes because she was feeling hot. Just after finishing her cold shower she would sweat again. We all used to laugh at her. She was about 55 at that time and I was in my early 20s. My younger sister would keep saying 'mum you are a real granny now' and I would laugh and joke about having to give her grandchild because it was not fair that she reached menopause without a grandchild. You know my sister once asked my mother if she felt less of a woman now that she knew she could no longer have children. My mother easily replied to her saying she was too old to even think of having another child. It never occurred to me that menopause could mean not being able to have a child. Like I knew what it did to your system but the infertility part? No. so when my GP confirmed that I was menopausal it all came back like a video. I realized that

my hopes of having twins at the age of 32 were never going to come true. I was never going to experience the joy of being a woman.

The example of Dimphoe is a reality for women who have undergone breast cancer treatment. While this may not be a major issue for women who have already had children and are in comfortable relationships, it was cited as being problematic for the young Black women who took part in this study. Much like Dimphoe, Phiwe said reaching menopause prematurely was sad for her as she had hoped to have a child even after her cancer treatment.

I honestly don't understand what I did to deserve such a harsh punishment from God and my ancestors. I mean I did everything I could to please my ancestors. I understand if they could not stop God from giving cancer because they knew they could see me through it but the menopausal part? I really don't know. You know after finding out I went back to my traditional healer who had thought and believed that it was impossible for me not to conceive. And as expected he gave me bottles to drink which were to cleanse me of the hospital treatment which took away my fertility. His bottles did not work because I went to see a doctor find out if there were any changes but there were none. So I guess the traditional healer only helped me to lessen the hot flushes but he could not do anything about the biological aspects of it.

The above experiences are similar to what the women who were studied by Charif et al. (2015) experienced. Much like his study, this study's participants blamed themselves for not being able to conceive like other women and felt that their womanhood was stripped away. Also from the conversations and group discussions, I gathered that the young Black women who believed in traditional healing had attempted to conceive using traditional medicine. None of them have conceived and medical reports have indicated no changes in their ability to bear children again. Even the powers of Nosizwe's bishop's water and prayers had not been able to 'open her womb'. She expressed her disappointment in the following:

Yoh Noks I had high hopes. Yoh the bishop had prayed for a number of married couples who were having trouble conceiving and one couple was able to have not one child but two! They had twins. The bishop kept saying that is what the Bible meant by saying God would bless out double fold. But for me, God did not answer. He totally forgot about me. And what makes it worse is that I always responded to the altar call to be prayed for. I think for three full months the Bishop would lay his hands on me and I would go home believing that there was indeed a change but nothing would happen. I mean at least the doctors say I still cannot conceive. Now I'm OK with this. I have accepted that I cannot have children. My issue now is if I will ever find anyone who will love me enough to make me his wife especially since the congregation knows my situation. And there is no Black man in his right mind who would marry someone who cannot even give him a child. Just imagine how my in-laws would look at me. They would say all

sorts of hurtful things about me. I don't really understand why God took the time to create me as a woman when he could have just made me a man instead of giving me hopes of being fertile then suddenly taking it away. I feel it's not fair at all.

Thandeka described the above as challenges that could not be reversed but that needed to be accepted in their 'raw form'. She felt that several women had wasted their time and financial resources trying to get assistance with premature menopause. In this, she included herself as she too had spent more than three months going from medical specialist to medical specialist in the hope of finding a solution to her problem.

What I did was actually stupid now that I think about it. I mean I used to spend a lot of money going from Doctor A to Doctor B. To evaluate my chances I would not tell the doctors that I am menopausal I wanted to see if they could identify the reason I was infertile. I remember there was a doctor that had been recommended by my colleagues and I went there and the doctor said he could not understand why I was unable to conceive. A week later I learned that the doctor was practising illegally. I also saw a very young female doctor who asked me to be honest about my sexual history as she was convinced that my infertility would have been caused by the termination of pregnancy. Once I opened up with her she understood my situation and advised me to accept my medical condition as she did not know of women who conceived after menopause. But even then I couldn't just accept that I was no longer going to be able to be a mother. I mean I kept asking myself why God had chosen me. I understood what the young doctor had said but it was still not enough to convince me that I was never going to be able to feel a child grow in me. It was difficult but I had to let it since in. I took a long time and I am glad it did because maybe I would now be depressed by the whole situation or maybe I would still be in denial. So I'm really glad I took my time and I engaged with a number of different people because they all helped me too understand how the body worked and to come to terms that some people don't even have children and they had never been victims of cancer. So I had to be strong for myself.

She claimed that it was her conversation with the young doctor that encouraged her to accept that she was not going to have a child. She further added the following:

I believe the key to this whole issue is accepting that you are no longer like other women which is very difficult as we come from different family and some parents are forever asking about grandchildren which feels like adding salt to a wound. But now I convinced my family that being infertile was a gift in disguise is I told them that if I had a child the child would have high chances of developing cancer. I also explained to them that I would not wish for any other person to undergo what I went through hence it was best if I did not have a child. From this perspective, they were sort of convinced

that I was better off infertile than with a child. And for once my uncle and his wife stopped inviting me to their church which had a miracle worker that could make me conceive.

Despite her positive outlook towards her illness, Thandeka did share that hot flushes which were a sign of infertility and premature menopause, affected her relationship with her body. In our individual conversation, she opened up about how she felt less of a woman by learning that she was never going to be able to conceive. Her greatest challenge was “silencing the negative thoughts that occupied... [her] mind”. She further shared that she felt she had disappointed God and her family by not being able to recover from the treatment side effects.

The hardest part is that I was positive throughout the cancer journey. I mean I would encourage others to have high spirit but I got to a point where I did not even understand my own role on earth. I mean, I have always believed that God placed women on earth to nurture. You know, to have children and raise them to be decent beings. So what was the point of being a woman when I could not do this? Why did I not be born as a hermaphrodite? That way everyone would have believed that perhaps I was never meant to be women.

Similar to Thandeka, Sisanda also believed that a role of a woman was to procreate. She recalled how she was taught to differentiate between a man and a woman:

In the old days we were taught that the different between a man and a woman was a womb, hence WO-MAN. You see, this means that a woman's role was to having children through her womb. Now if I no longer was able to grow a child what was special about me? Like what stopped me from behaving like a man? Drinking my life away because I could no longer do the one thing that I was created to do.

Noks you cannot have a gathering of women and expect them not to complain and rave above weight issues. I had a hard time with weight as I had lost about 7 kg before being formally diagnosed. I don't really know why I lost so much but I guess my body was no longer appreciating my diet. I think weight loss was one of the issues that had my mother convinced was bewitched. I mean I used to be fit so I was not fat but I had a lot of muscle so I was like 60 kg and I suddenly lost 7 and I was feeling weak. [Mpilonhle]

Weight loss and gain

Weight-related issues were intentionally avoided during a focus group due to time constraints and I had hoped to introduce it during individual interviews and during my observations. Once Mpilonhle commented on her weight all women, even those who were concerned with time

agreed to add at least 15 more minutes to discuss this issue. The issue of weight was discussed in relation to African assets which the survivors claimed to have had prior to their illness.

Laila shared her weight-related story:

For me, it was not just about fat or thin. I was a healthy size 36 which my husband was very happy with. We have a bathroom scale at home so we used to always use it after bathing together. So the first time I realized I had lost weight was when we stepped on the scale together and realized that our weight was a lot lower. I thought it was my husband that had lost as I had not noticed that had shed kilos. But it turned out it was me. My husband though I was stressed by work and other personal matters. It made me feel very uncomfortable as I honestly did not know what was wrong. Once I started chemotherapy I gained so much weight but I was eating a lot less. This also troubled me as I ended up not knowing what I was not doing right. In complaining about it to my doctor she simply laughed it off claiming that my weight should have been the last problem in my mind as I had serious health problems that needed my attention. I feel the doctor did not take my concern serious. Even now I'm struggling to get to a size 36 is stuck on 38. Like I know Black women are expected to gain weight as it is considered as a symbol of being happy in the marriage but I felt uncomfortable with my new weight.

Laila shared that her husband was happy with her previous weight hence it is assumable that the additional weight affected her body image and sexuality before her husband. In reflecting on their weight challenges women added that they felt pressured to either gain or lose weight due to the negative connotations that some Black people associated with weight loss. Zethu, for example, shared that within her Shembe religious faith, slim bodies were discouraged. She claimed that even when young and older men looked for potential wives or additional wives, they looked for plump women as it is believed that such women were fertile, healthy and well maintained by their families. She further claimed that the weight loss affected their 'potential-wife' status before the church. This example alludes to the young Black women's need to identify with their social and religious groups. This, in some cases was heavily affected by the physical changes that they experienced due to breast cancer treatment.

Cancer treatment side effects differ between individuals. Some patients lost weight; others gained about three sizes. The survivors also shared stories of not being content with their current weight as they feel "outsiders judged their medical status through the weight changes".

The thing is, as a woman loses her weight she loses her shape. All the African assets either go away or they become so big that one cannot even be considered as an ideal African woman, rather you just look like a potato. You look completely shapeless. This

affects your confidence and you do not even believe anyone that compliments you.
[Zethu]

Having an ideal shape was not the only issue. One of the participants felt that weight loss and gain within African society are associated with how well fed a woman is and how good her marriage is.

I eventually got tired of receiving unduly compliments of my husband treating me well just because I had gained weight. It was just irritating. I wished I could stop the women and tell them that my weight had absolutely nothing with my marriage as it was the treatment that was expanding my weight. [Laila]

Thandeka added a different dimension to the issue of weight gain as she felt offended by weight related compliments and comments.

There is nothing I hated more than hearing people comment about my weight. You see I lost a lot of weight at the time where some of my neighbours had started ARVs and at that time they had lost a lot of weight because they had to have a low CD4 count before being on treatment. So I was counted amongst them. Now I am not trying to make inconsiderate comments about HIV-positive individuals but I felt the 'oh you have lost weight' comments were associated with thinking I am also positive. And as soon as I started gaining again I heard rumours that they were saying the ARVs are making a difference in my life. These comments were hurtful as people just assumed I was sick because I was promiscuous which was not true. Cancer is not something you avoid by not having sex or staying away from certain people

Mangingaphosisa ngehla ngo10 kg. Ilapho kwahamba khona amaAfrican asset. Kwathi sengehlile ngaqala ngezwa abantu behleba ngokuthi ngiyagula ngiseSandulela Ngculazi. Kwakubuhlungu shame. Kubuhlungu ngoba phela ngangiyigcina ingubo yenkolo yami so nje ngangimamazi umuntu wesilisa futhi ngangike ngehlola phambilini nase sbhedlela baphinde bangihlola so angazi ukuthi labadokotela abahlala elokishini babekuthathelaphi ukuthi nging gciwane. Babengijwayela nje akukho okunye futhi.

I believe I lost more than 10 kg and that is when the problems started as people started assuming that I was HIV positive since I had lost so much weight. It was very painful. What I did not understand the most was the fact that I was keeping to my church rules and not having sex but I ended up being painted as someone who was sleeping around. To make matters worse I had been tested two times. But the s- called doctors from my home town diagnosed me and unfortunately they thought I had HIV.

The above are some of the examples that the women shared concerning their weight and are an indication of the challenges that women face when it comes to their appearance and body

image. Again, while weight loss and gain maybe common amongst humans, they are understood differently within a different socio-cultural matrix. This often results in young Black woman losing their sense of identities, especially within their families and religious groupings. This can lead to self-doubt for women which affects their body image and confidence in themselves.

5.3 Psychological changes

Depression

Cancer treatment is known for its effect on hormones, which affect the health of its victims. A number of studies (Champion et al., 2014; Ussher et al., 2012; Fann, 2008) have accounted for the challenges faced by women in relation to stress and depression. However, in the course of reviewing literature for this study, I was unable to find any that dealt with Black African women who were cancer patients; scholars such as Mosotho et al. (2008) have investigated issues pertaining to depression in general amongst Black South Africans. Such research was broad in nature with a limited focus on the different medical treatments that cause depression. The topic of depression was discussed countless during focus groups and observations. What was of interest to this study was how African women understood depression and how the people close to them understood its effect, especially with Mosotho et al. (2008) arguing that depression is more prevalent among Black African women as opposed to men.

iDepression yami yaqala ngaphambi kokuthi ngithathe imithi yadokotela. Ngalolusuku umyeni wami ekhuluma kabu ngesiguli engangime naye eparking ngenxa yokuthi wayengenazinywele kwaqala laho nje ukuthi ngiphatheke kabi ngoba phela ngase ngazi ukuthi ngineCancer kodwa ngifihla. Ngangihlala ngisangene nje. Ngangihlezi ngicanga nje ukuthi ngabe iyoba njani inkulumo mhlazane kumele sixoxe ngokuthi ngiyagula. Wayeyongibona kanjani nje njengoba esetshengisile ukuthi akamuthandi umuntu ongenazinwele. Kwakunzima bandla.

My depression began before I even started my medication. The day my husband spoke negatively about a patient that had no hair because of cancer is the day I started losing my mind. You know I would imagine a conversation between the two of us. Somehow I would believe that he had said a lot of things to me only to realise months later that it was all stuff that I had created in my head. It was a hard moment. I was very emotional about it. [Thandaza]

Zibuyile was the first participant to share the effect of stress in her life, during a focus group discussion. She claimed that prior to cancer she had never paid much attention to the tension that was caused by the problems she encountered. The following is what she shared:

Yazi Noks ngingi strong nje, ngiyile type yentombazane strong. Nje ngingatetemi noma inini noma ikanjani. Ngisho kwenzeka izinto ekhaya ngangingalokhu ngikhala. Ngangithulisa abakhala nje ngasosonke isikhathi. Kodwa kwathi sengithola ukuthi nginge Cancer kwaphela kodwa, nje kewaphela ukuba strong. Kwakungakhona nje ukuba strong emzimbeni kodwa kwashuba nje nasemphefumulweni. Ingxenywe yami yayiziblame kungathi ngizenzile nje ukuthi ngibe neCancer kodwa futhi ngibuye ngizikhuze. Kodwa kakhulu kazi kwakungathi ngimuphoxile ubaba ngangazibuyisa izinkomo ekhaya. Nje ngibona ukuthi noma ngingaphila emva kwalesisifo ayikho nje indoda eyongihlonipha ingishade. Kwakunzima nje, kakhulu futhi. Ngangihlezi ongiphatheke kabi ngizidabukela usuku lonke ngihlezi nje ngidabukisa. Kwakungisinda nje. Yabo sengiyinto ehlezi ikhathele nje.

You know Noks, I was a very strong woman. The kind that doesn't just cry even when tragedies would occur in the family. I was always the strong one. But once I learned that I had cancer I sort of lost my strength. Not just my physical strength but my mental and emotional strength as well. A great part of me was ashamed of the fact that I would never live up to my name as my father's cows would never be returned because I was not going to live long so no one would want to honour me by paying lobola for me. It was hard. I was always down and under. You know all I used to do was to pity myself. I would spend hours at night just stressing about everything that was not going right. It was heavy. I was always tired.

Zibuyile is not the only participant who felt they had let down their families through their illness. Sphile was also a victim of feeling hopeless. She claims that she felt she was a failure in life since she was unable to see how stressed she was after learning about her condition. She feels that being stressed and depressed was a major challenge for her as neither herself nor her family knew how to deal with her condition.

The influence of 'culture' in understanding illness was also shared by participants when they discussed stress related issues. The idea of 'stress not existing within the Black African culture' was debated and only a few participants claimed to not have been depressed during the course of their illness. Samantha explained how she understood the issue of depression as a young African wife and survivor.

I learned a few valuable lessons from attending counselling sessions with a psychologist that my husband arranged. You see, in our culture, we are expected to always be understanding and to be able to let go of problems even when they have not being resolved. The fact that we even see prophets when we experience difficulties is a sign that we acknowledge that there are situations that are beyond us but that need to be resolved. So because he doesn't talk, the things that bother us bottle up. Much like a balloon. You may think you know its capacity but and the more you blow air into it the bigger it becomes. That is how we Blacks understand our brains. We think the harder

the challenges the bigger it becomes when its issues to do with our health and especially cancer which is something that we cannot even see but we feel within us. So for me, I learned that I was stressed by so many things. Included the fact that I got pregnant before I was married hence I disappointed my family. See I had never even thought of it until the psychologist started asking me personal problems. So I was really stressed because my balloon had reached its capacity and it bust. I can say that cancer was the final blow. If I had not accepted that I was stressed and without the scientific understanding of my husband when it comes to these things I too would not have been able to process what was happening. Who knows maybe my deeply Christian side of the family would have thought I was possessed by demons.

Mpilonhle was yet other participant who became very emotional about her stress-related experience as she too felt she did not get adequate support which was to help deal with her stress. She shared that the hospital and clinics did not provide enough support for her and that she ended up not attending the counselling sessions as the nurses, social workers, and psychology staff stigmatised her group and referred to them as ‘psyches’. She claims that on her last visit, she was approached by a security guard who asked her why she was attending the session for retarded people. When she tried explaining that the so-called ‘psyches’ group were actually a group of patients who were forced to attend counselling before undergoing an operation, the security guard laughing claiming that she was lying and that knew the nurses shared all the patient psyche related stories with him.

Yazi ukuthi thina bantu abamnyama asizazi izinto. Nje asifani nabamhlophe sihlezi sicabanga ukuthi sithakathiwe sibe singathakathwanga. Futh nje kwazwakala ukuthi unestress noma idepression kumele kube sengathi uyahlanya nje udinga ukohala lapha esbhedlela sabagula ngengqondo. Thina bantu abamnyama asi understandi ukuthi idepressuion idalwa yini. Ngisho noNesi bamane bahlekise ngathi. Ngathuka kabi nje ngibuzwa isecurity ukuthi ngifunani kubantu abagula ngengqondo. Aibo kahle hahle ubani owathi mawunestress udinga ukuya enyangeni ngoba usuyahlanya. Yazi ngesinye isiskhathi siding ukukhuluma nje siphimisele bese siba right empilweni ayi nje ngento yokuthi sibe sifuna usizo kodwa onesi babukise ngathi basibize ngezinhlanga.

You know we Blacks have real issues. We are not like white people who understand the working of the brain and how stress and depression works. We are so judgmental when a person had stress or depression. Even our nurses make fun of us. I still don't understand why the security guard was told that the psych department was for crazy people. Like he literally asked me what I was doing in the crazy people's department. Like where did he even get guts to say that? Why were the nurses discussing our problems with the other staff members? I wish I could take this up with the hospital but of course this is not just a hospital problem. Everywhere you go for Black people depression means being crazy and needing to see a traditional healer.

The issue of Black Africans not taking the issue of stress and depression seriously was shared by Minnie:

Breast cancer treatment had a number of effects on me but depression was the worst. You know it started to like having a headache then my body was sore like tense. I would keep dreaming of bad things that have happened to me. I would even hear voices of the hospital staff arguing about my condition. I didn't understand what happened neither did my family. They thought I was crazy. This was one of the reasons they thought I had been bewitched because I was 'seeing things' [Minnie]

The above excerpts are examples of the challenges that some of the survivors faced. This was a very sensitive issue to the participants; two participants later requested that I did not include their stories in this write-up. Thina, who claimed to be happily married when she was diagnosed, shared that after hearing how her husband felt about the effect of cancer treatment she started to lose her confidence. She further shared that her fear of losing her husband is what led her to deny her symptoms even when she had tested herself at her home. Like Thina, Nosizwe was also a victim of low self-confidence. She shared that learning that she had cancer led her to have constant headaches that did not improve even when she had used pain tablets that she had received from the clinic.

What was common in all the women was their constant headaches which they described as 'persistent and heavy'. These were the adjectives they used during a WhatsApp group session which was dedicated to depression and related stories. All three women also shared that their depression led to sleepless nights and days filled with sorrow as they always felt emotionally tired and physically drained. Nosizwe shared she was advised by her nurses to engage in a form of exercise to lessen the effect of her stress as this was believed to make her immune system more efficient and enable her to have energy. She claims that this was not effective for she then felt she did not have strength for any physical work.

It was hard Noks, you know I would try to exercise as advised by the clinic staff but it was so hard. All I wanted to do was to sleep. Like sleep all day and night. Even worse the medication I was on also made me drowsy. It was so bad my manager once found me sleeping in my till. It was embarrassing but I had to come clean or sign a warning. Fortunately, he understood and made me sign an unpaid leave form since I had exhausted my days. This made things worse as I now had no wages so it was difficult for me to contribute towards my family. [Nosizwe]

Another participant who felt pressured by her work environment was Mpilonhle. She shared that she had kept her sickness a secret because she was the least favourable employee in her

workplace. She did general work in temporary shifts. She further claimed that she felt sharing her diagnosis was going to make things harder for her as she was already being given fewer days to work in comparison with the other employees.

Emaqinisweni ngangicabanga ukuthi ukuphumela obala ngesifo sami kwakuzongifaka enkingeni. Phela mina angisebenzi into etheni so nje ngangihlezi ngicabanga ukth ngizothi ngiyasho ukthi isimo sinje kumane kubhede. Noma ongiphethe amane angasangifaki emsebenzini zonke izinsuku kanti phela bengiwudinga lomsebenzi ukuze ngikwazi ukunakekela umfowethu.

I honestly thought disclosing my illness was going to lead me to deeper waters. You know, I didn't have a good job so I always feared that sharing that I had cancer would lead my supervisor to give me even fewer shifts. It was very hard as I depended on my job and it was all I had to support my brother. [Mpilonhle]

5.4 Conclusion

The abovementioned challenges are stressful for young Black African women, especially when they are combined with health-related conditions. These are some of the issues that Gilbody et al. (2012) investigated in respect of the effect of depression in the workplace. Gilbody et al. (2012) also discussed issues that were similar to those of this study's participants. Challenges such as being uncertain about the positions at work and fearing unfair treatment were also highlighted. Issues pertaining to depression for ill persons were also discussed by Bolwer (2008). He concluded by stating that persons who are depressed may end up feeling very stressed which may lead to neglecting of duties. His findings were similar to Donovan et al. (2004) who were interested in learning more about women receiving chemotherapy and radiotherapy for early stage breast cancer. Deaux (1996) further stated that each person has many different identities and attributes which are inclusive of gender, ethnicity, professional status, and weight, and parental status that both constructs and impacts the self-concept. Body image is an important component that boosts a person's self-esteem and sense of being. Having overcome harsh cancer treatment, breast cancer survivors are then confronted with the challenge of regaining their sense of femininity.

This chapter has discussed issues related to physical and emotional side effects of cancer treatment. It has discussed how survivors feel about the changes in their bodies, how the treatment affected their body image and the idea of being sexual beings. While the medical conditions discussed in this chapter may not be uniquely Africa, the manner in which they are constructed and understood by the young Black African women indicated that they are

experienced differently. As repeatedly mentioned in this chapter, for the young Black Women, the majority of the health related conditions are understood within their sociocultural matrix. Therefore, overcoming unfavourable conditions requires consultations with a traditional doctor or spiritualist who is able to communicate with their ancestors. This is explored in greater detail in the next chapter.

CHAPTER 6: TRADITIONAL AND SPIRITUAL BELIEFS: CANCER AND YOUNG BLACK AFRICAN WOMEN

6.1 Introduction

Traditional and spiritual beliefs play an important role in the well-being and health of humans. Zuma et al. (2016) argued that “traditional health practitioners (THPs) play a vital role in the health care of the majority of the South African population and elsewhere on the African continent”. Through identifying with traditional and spiritual beliefs, most Black African people can construct an understanding of illness. For the purpose of this study, traditional beliefs are limited to ancestor worship while spiritual beliefs refer to the so-called western religion, Christianity.

Arazeem (2011) stated that prior to the colonial era, Black African people believed in ancestor worship as their societies were highly spiritual. Arazeem further stated that to some extent, colonialism, ‘western’ religion and education as well as globalisation phenomena have negatively affected the perception about traditional medicine in Africa, usually among the educated elites (2011, p. 20). By this, Arazeem means that some Black African people no longer only believe in ancestor worship, rather they have embraced westernised region. This is seen to have an influence on how people construct and interpret life events and circumstances, especially when it comes to matters pertaining to their health.

The young Black African women who participated in this study all indicated that they had a spiritual and traditional relationship with a ‘higher being’¹⁴. Such beliefs were said to be beneficial for young African women when they were affected by breast cancer. Similar to the participants who were interviewed by Arazeem (2011), participants of this study shared unique yet similar stories about their experiences with spiritual and traditional interventions of healing. This chapter discusses the influence of African traditional and spiritual beliefs on the process of socially constructing the impact of illness for young African women. It begins by discussing

¹⁴ For the purpose of this study, ‘higher being’ refers to a god, ancestors or any other spiritual connection that participants consider above their human status.

the most common belief among young women, which was the belief in traditional medicine and ancestor worship.

Black Africans are known to be sensitive to issues concerning witchcraft (Manala, 2004 and Van Dyk, 2001). The issue of witchcraft is said to date back to our so-called primitive years. Being born into a Black African family, I was also socialised to be aware of issues concerned with cosmology, the role of God and most especially, the ‘power’ of witchcraft. This upbringing encouraged me to be curious and always try to understand and acknowledge the power of humans, which is best seen once one is bewitched. I was taught to believe that evil spirits do not only bring bad luck, but they can affect the functioning of one’s body, which subsequently leads to illnesses. This chapter, through narratives from young Black breast cancer survivors, discusses how their illnesses were understood in the context of witchcraft.

6.2 African belief systems

The third chapter of this study introduced the participants and their challenges when they first discovered that they had symptoms of breast cancer. In collecting some of their stories I discovered a pattern in their understanding of illness. Prior to going for medical assistance, some young Black women had consulted with a traditional doctor as they had believed that they had been bewitched or that the traditional healers would be able to cure the symptoms that were bothersome at that stage of their illness. Also, the interviews revealed the belief that traditional doctors would be able to not only heal their visible symptoms, but they would be able to “clear their paths” (as revealed by Thandaza) as the traditional doctors could communicate with their ancestors. Such findings correlated with Arazeem (2011, p. 115) who claimed that in most indigenous African communities, the traditional doctors are well known for treating patients holistically. In addition, Kale (1995) argued that the belief in traditional doctors stems from Africa’s belief in ancestors and ‘higher beings’.

In responding to the question of seeking traditional medical assistance, Thandaza shared her experience with a traditional doctor. She claimed that she had always had a relationship with her ancestors whom she regarded as her ‘angels who are closer to God’. She also revealed that she was taught from a young age to respect her ancestors as they were angels who interceded on her behalf. For her, this meant that she had to make sacrifices to appease her ‘angels’ and to celebrate their presence in her life. This assertion was not unique in this study as a number of participants also revealed that they had a strong relationship with their late family members. According to Thandaza they are part of their “culture and heritage” and the ancestors “are never

totally gone [as they are] there to protect and guide” the people who are still alive. However, some also indicated that while they believed in traditional and ancestral beliefs, they were not firm believers in their powers and some had even converted to the so-called westernised Christian religion.

Sambo (2010, 1) claimed that “80% of the populations in Asia, Africa and Latin America use traditional health care services to meet their primary health care needs”. This is mainly due to the beliefs in ancestor worship and guidance for Black Africans. Consequently, ancestor worship plays an important role in Black Africans’ understanding of the world. Zuma et al. (2016) stated that within the Zulu tradition, when family members die, they are said to remain connected to the living. As a result, “ancestors are regarded to be a part of family functioning, and they are remembered by the living” (Zuma et al. 2016). Their function includes protecting their family members and interceding with God on their behalf. Hence, they are the first source of “strength, guidance and protection” as stated by Laila during an individual interview.

Consider the following abstract:

Mina bandla ngiyilenhlobo engafili ukuthhi ngisebenzisa imithi futhi ngiyangena enyangeni. Yabona ngiyilenhlobobo ekholelwa ekubhekeni umsamo uma izinto zingangihambeli kahle. Ngikwenza njalo nje noma sengishadile. Ngiya kwisangonga noia inyanga uma ngibona sengathi kukhona okungasahambi ngendlela. Kona ayi ngoba ngiyilegege yemithi kodwa kodwa ngakhulela ekhaya elizibhekayo nje elikholelwa nakwabangasekhoo so noma sengiganile angizikhohlwanga la engiphumakhona. Velle umyeni wami akazi konke okwenzeka kimi. Ngakho ke kuthe sengibona ukuthi sekukhona okungasahambi kahle egazini lami, ngisola ukuthi umdlavuzi ngahamba ngayobhula ngifuna nekhamba elalizongiqinisa liphinde lihlabulile igazi lami. Kwazi bani mhlawumbe yayiziqeda nekhensa egazini lami.

I am one of those women who are not ashamed to share about consulting a traditional doctor. You see I am a Black woman and so whenever there is trouble coming my way I have to consult. I do it often. Either I go to a sangoma or a traditional doctor. I have even consulted with prophets. It's not that I like traditional medicine, but I grew up in a home where my family believed in ancestors so even after getting married, I did not forget who I was and where I come from. And of course, my husband does not know about this. So when I started seeing that there was something wrong in my system. I had to see a traditional healer because I needed something that would make me strong and clean my body cells. Something that would make the cancerous cells disappear.

Ancestors are often the first form of guidance and support that people seek should they encounter misfortune of any form. Becken (1993, p. 336) cited Bae (2004) who argued that ancestor worship should be seen as having a strong social function. Bae premised this argument

on the communal identity of multiple African people. He believed that communion of the family is not altered by death, so that deceased family members still form an integral part of the family, and therefore still have an influence on the group identity.

The example of Thandaza illustrates the importance of social identity, which for her, began in her life prior to marriage. For Thandaza, identifying with her family of orientation meant maintaining a relationship with her ancestors. It could be argued that this is the direct result of enculturation as she was taught from a young age to be conscious of her family members who had passed on. Hence, they are a part of her life and spiritual culture. I was interested to find out why she did not see a medical practitioner before a traditional doctor since she was a nurse with a sound western knowledge of cancer. She had mentioned that during her nursing training, she had learned about chronic diseases such as cancer. The following was her response:

Noks uyabona mawusezinhlungwini ungenza nomayini futhi yonkinto ukuthi uzisindise. Uyazi nawe sengibe unesi iminyaka eminingi. Noma ngingazi kahle ukuthi idalwa yini iCancer kodwa bengihlale ngazi ukuthi lesisifo sikhona futhi siwumashayebhuqe. Ngiphiphe inqwaba yabantu abakade begula bebhuqwa umdlavuzwa. Kodwa ngithe uma sengizibona izimpawu zomdlavuzwa kimi ngaqala ngangakholwa. Besengiyiphika nje indaba yomdlavuzwa. Wemame ngangizibuka nginikine ikhanda ngingakholwa nkosiyami. [esho ezibuka ngokuziqhenya bese abuye abe nobuso obudangele]. Yazi kwakhona nje ukuthi umyeni wami wayehlekisa ngeziguli ezinomdlavuzwa kwakungigulisa. Ngasengisaba ukuthi abantu bazongibuka kanjani. Kwakumele nje ngithole ikhambi elalizongikhuculila umdlavuzwa, kwakumele kube khona engikwenzayo shame ngaphambi kokuthi umdlavuzwa ubukisa ngami emhlabeni wonke. Kwakumele nje ngizihlambulule.

Noks you know when you are in pain you can do anything and everything to save yourself. You know I have been a nurse for a number of years and while I do not know what causes cancer, I knew that it existed. I have taken care of a number of people who were critically ill due to cancer, but once I started to see symptoms on myself I was in denial. I would look at myself and shake my head in great disbelief [she looks at herself in great admiration then quickly switches to a disgusted face]. The fact that my husband used to make fun of cancer patients didn't help. I was actually scared of how he would see me. I had to find a remedy before cancer exposed me to the world. I had to do something that was going to cleanse me of cancer. [Thandaza]

Thandaza's reason for seeking traditional assistance was based on her traditional health related beliefs as well as her fears of cancer as she had witnessed the cruel effect of cancer on her patients' bodies. In response to her fears, she decided to engage in what she knew and believed: ancestor worship and traditional medicine. At this point, she did not reveal the outcome of consulting a traditional doctor, but she did share that she was proud of the fact that she tried to

seek alternative help before she even considered going to a medical doctor. For her, this was more than choosing traditional healing methods over the so called westernised health care; it was honouring her family and its belief system and she could identify with the traditional doctor's healing techniques.

In discussing the topic of traditional healers, Laila, who had been a community caregiver for more than three years when she first identified cancer symptoms also consulted a spiritualist and prophet when she felt a lump in her breast. Laila claimed that despite her health care training and experience, at her time of medical need, she turned to a traditional healer or spiritualist as she believed she needed to *hear* from her ancestors before seeing medical doctors. She further added that in her family, her father always reminded them of the importance of consulting the ancestors during illness and before making important decisions. This, she shared “was to ensure that the ancestors were acknowledged and to seek guidance from them”.

I remember when my brother was about 20 and had to have his ear surgery, my father called a traditional healer who was to cleanse our home and protect my brother before the surgery. My father believed that undergoing surgery was life changing as a patient could die at the hands of the doctors so it was important that he communicate with the late family members and appeal to them for the safe return of his son. [Laila]

The above excerpt is an example of the impact of enculturation in terms of how people construct their traditional and health related beliefs. It also indicates the influence of sociocultural dynamics when young women construct their understanding of illness and how they should best seek assistance. The case of Laila and Thandaza contradicts Arazeem's (2011, p. 20) assertion that colonialism and education have affected the role and perception of traditional healers in Africa. These young women indicate that their beliefs have not been affected by their education careers. Instead, their beliefs were what enabled them to understand and deal with their illnesses as they felt connected to their ancestors who could intercede on their behalf.

Nokwanda ukusebenza ngeziguli akukwenzi ukhohlwe inkolelo yakho. Ya phela uma siyobheka iziguli zethu sifike sizenze izinto eziserious ezingazisebenzisi izinto zesizulu kodwamase kuyithi sisi siyazisebenzisa. Ngiyakhumbula nje sihleli ehhovisini sidle ngixoxela ozakwethu ngezinhlungu engangizizwa bamane bathi nje angiphuthume kumprofethi owayehlala eMaritzburg owayedumile nje ngaleskhathi. Loyomprofethi wayeyisangoma so nje ngafika kuyena wanngibhulela wathi kunefu elimbi eliphezu kwami futhi ngiphethwe isifo esibucayi. Kodwa ke wazama ukungisiza ngoba into engangiyiyele kahle kahle kwakuwukuthi ngithole isakhamzimba ukuze ngingeke

ngishayeke emzimbeni nokuthike ngazi ukuthi idlozi lami alingiflathele ngalesiskhathi sobunzima.

Nokwanda working with patients does not make you forget your beliefs. I admit, when we go to check up on patients we pretend to be all serious and be like people who do not use traditional medicine but when we fall sick we use it. I remember when we were sitting at the office having lunch with my colleagues and I complained of the pains I had been feeling, they said I should go and see a prophet from Pietermaritzburg who was also a leader of a Zion church as he was very popular at that time. So when I got there the prophet saw that a dark cloud was over, me and that I was sick with a complicated disease. I already knew what was happening, but I need that sense of guidance before I could even see the doctors who would tell me all the bad news I did not have the courage to handle. So I went there just to know if my ancestors were not angry at me or if there was anything I could do to please them as I needed them to protect me. I knew if they protected me, people would not know that I was sick as the medicine I would have gotten from the prophet would have strengthened my immune system which would have helped me not lose too much weight.

Similar to Thandaza, Laila also works in health care which she claimed compelled her to advise patients against traditional health practices and to recommend that they seek medical health care. However, when the illness was personal, she consulted with a traditional healer without any hesitation to “seek guidance from [her] late family members who were living in the spiritual world”. She firmly believed in their healing power which would have manifested through the traditional healer. The young women’s stories allude to the importance of ancestor worship and traditional healers who are seen as closer to God and could ‘intercede’ on their behalf and who could communicate with their late family members (ancestors).

During the data analysis and coding process, I noticed that when it came to understanding illness and unfortunate events, cancer survivors could be classified into two groups. The first group consisted of those who believed purely in the so-called western medicine and the second, of those who believed in *both* western and African medicine and healing. For Laila and Thandaza, both these healing systems were important and because they prioritised their spirituality, they opted to consult with traditional healers prior to westernised health care systems.

What was also noticeable, was the women’s willingness to share their traditional belief systems. These women also appeared to have been comforted by their faith and ‘communication’ from their ancestors through the traditional healers. According to the women, the communication is through the traditional healer who is able to ‘speak’ to the ancestors on

their behalf. They felt comforted to know their ancestors were guarding them through their cancer illness. On the contrary, the women who only depended on the conventional medical system and were not proactive in seeking 'faith based healing' shared stories of fear and uncertainty. These women also shared their challenges as they were surrounded by family members who were either 'too traditional'¹⁵ or those who were very religious (firm Christians who did not believe in ancestor worship).

Consider the case of Phiwe who claimed that before she became sick she did not believe in any God or the power of traditional healers. She shared that she was raised by parents who were born again Christians, but because she did not fully understand the notion of a 'higher being', she left the church at 18 years old and never looked back. She shared that prior to being ill, she had not seen or had a reason to seek guidance from any power and she considered herself an atheist.

Ngangiwumuntu ongenandaba nje, ngiyilolo hlobo lentombazane omane anake izinto zakhe alale engenankinga nje enganake nokubonga unkulunkulu noma idlozi. Lokhu kwaqala ngesikhathi ngihamba ekhaya ngiyofunda enyuvesi. Ila engathola khona inkululeko ngaala ngakhohlwa isonto, vele nje ngangingayizwa indaba yokuya esontweni njalo lapho abazali babe kholwa lokhu kwangempela so nje kwakunzima kimi. Kwathi sengihambile ekhaya ngaba ilenhlobo engenandaba nje nezinto eziningi ngizina mina. Ngenhlahlala ngahlangana nomuntu ongakholelwa kulezizinto naye. Uzikhohlwa nje ekutheni ingqondo yomuntu inamandla yokwenza izinto. Ayike sashada nje kwabamnandi singazixakile nje ngezindaba zamadlozi nonkulunkulu. Ngebhadile ngagula ngisaziphilile nje nginganankulunkulu. Ay kwabanzima ngoba phela abazali bami bakholelwa kuNkulunkulu so bebefuna sense izinto ngendlela yabo. Thina ngapha besifuna ukuyeka nje sizidlele amaphilisi ngize ngibe right. Kona kwangithusa ukugula ngoba ngangingena nkulunkulu engangizothi uyena ovumele izinkinga zize kimi. Futhi kwakungekho dlovi elalingibanga ngoba ngangingakaze ngiwakhonze vele. Kwadimoni leli ababelibona ekhaya ngangingazi ukuthi lingifunani ngoba phela kumele engabe usathane akanandaba name ngenhla yokuthi angimkhonzi unkulunkulu. Konke lokhu kwangithusa nkosyami ngazithola ngisehlane ngingazi nokuthi kumele ngikhale kubani. Kwakuyinto nje engachazeki.

I was a carefree person, the kind of girl that gets up and minds her own business and goes to sleep not feeling guilty about thanking anyone for guarding me. This began when I left home to go to varsity. I became self-absorbed. I think it's because I had spent years under strict parental care. I was forced to believe in a God that I did not quite understand. I was fortunate to find someone who loved and understood where I stood in this whole believing. He is a psychologist and he owes his being to the human

¹⁵'Traditional' in the sense that they fully believed and surrendered to ancestor worship and traditional healers and ignored their bio-medical treatments.

brain. Still don't quite understand what it means. Anyways, so I got sick while living under that no God and definitely no ancestor bubble since my family is born again. As a result, I struggled to come to terms with my diagnosis. It was just unfair to me. I mean I was not under any spiritual guidance so I wasn't fooling anyone by pretending to believe in anything. But I got sick. I mean, if it was demons as my parents saw it, why did they target me? I wasn't a child of God so I was no threat to them. If it was ancestors, then they had no business fighting you own my soul because it did not belong to anyone but myself? It was just crazy. I did wish I had something or someone to blame apart from science, but science was all that made sense at that time as the doctors had explained that cancer is natural, there is no spiritual force behind.

From the above excerpt, it is apparent that Phiwe's experience is very different from the experiences of Laila and Thandaza who had consulted their ancestors for protection and comfort. This was based on their socialisation, which included consulting with the 'angels' and always seeking their guidance. This was not the case for Phiwe as she no longer believed in a 'higher being'. Rather, she believed that the "universe would ensure that [she] always gets what [she] deserves and that during times of ill-health [she] would be able to recover". In listening and critically analysing the difference between Phiwe, Laila and Thandaza's belief systems I realised that while the young women are classified as Black Africans, they construct and understand the process of illness differently. The story of Phiwe led me to the assumption that perhaps there is a major psychological role that is played in having faith in a 'higher being' when it comes to understanding illness and providing hope for sick individuals.

In collecting, coding and reviewing data, I also realised that Phiwe was not the only participant who had a difficult time coming to terms with cancer, more especially from a spiritual point of view. Participants such as Nontando who had an in-depth knowledge of cancer and claimed not to believe or have any relationship with any form of 'higher being' claimed also to have experienced difficulty in managing her illness. Some of the participants who had reported not being spiritual in any sense shared that at times they felt compelled to surrender to their families' beliefs. Even when some participants did not believe in ancestors, being ill and having family members who believed in ancestor worship and traditional medicine influenced the participants' decision-making process. This was apparent as even the participants who had converted from ancestor worship found themselves visiting traditional healers in an attempt to appease their ancestors as they believed that there could be a link between their illnesses and witchcraft.

Her: After being born again for more than 10 years I found myself thinking of all the people I had ever wronged. This was to try and find the person who could have done something to me.

Me: Done something to you?

Her: Yebo sisi. Ngasengithi ngithakathiwe nje straight. [Yes, I somehow believed straight that I had been bewitched.]

Me: Bewitched? [I was honestly confused as born again are known to understand negative forces in a form of demons that God Himself allows to prosecute them]

Her: I can see you are confused Noks. You are not the only one. Even people from my prayer group were confused as I confessed to them that I thought I had been bewitched.

Me: I see. What led you to that conclusion if I may ask?

Her: It's the fact that I was a healthy person who believed in God and God had protected me from a number of challenges so only jealousy could explain how I got the illness. I mean, how could I get it. I know demons exist, but I had never known God to give people cancer. Poverty, yes, unemployment, yes but never something as cruel as cancer. Even worse at that time, I was financially stable, but no medication could take it away permanently.

It was apparent that in their difficult times, some of the women were forced to listen and follow orders from their family members and relatives who at times had different spiritual beliefs from them. Data revealed that the participants had surrendered their faith in order to find comfort from their family members.

I had to let my glamorous life pass as I realized the listening to my family was all I had. My relationship with my partner as good as non-existed, so I needed help, I needed hope. I allowed my family to decide on what they believed was good for me. I was desperate for someone who would love me and I figured my family were the best option as they loved me unconditionally. So I had to follow their orders and do as they said even when it meant I consulted with a traditional doctor. [Nontando]

The association of cancer with witchcraft stems from the understanding that cancer, like bewitchment, destroys the immune system which affects the functioning of the human body. This line of thought was mentioned by several participants as summarised by Sisanda:

You see cancer is not like something that you wake up and see in your body. It is very much like being bewitched. When an enemy puts a spell on you, they make sure that it will finish you from the inside. You can start by having something like a rash today and

three days it can develop into something hectic like shingles. See if it was shingles from the word go you would have gone straight to the doctor from the moment you see it, but because your enemy wants you gone they begin with the things that are not considered too bad. The same applied to cancer. You think you have a lump then you find out it's a cyst before you even learn what as the cyst is you find out it has spread all over your body making it difficult to catch it in time.

This was further explained by Zethu who was taken to a traditional healer before being medically diagnosed. She believes her 'very traditional and old school' mother had thought she was bewitched as had once happened to her before she met her father.

Noks my mother respects witchcraft, she calls it 'ichem' [term used by Black Africans, which is short for African Chemistry]. I think it's because she has been a victim of it a number so times so she believes in consulting with her healer before seeing doctors. I honestly believe the reason my mother was so eager to take me to a traditional doctor is that she was afraid. Afraid that whatever was affecting me had already destroyed me from the inside as I felt bruises, but I could not remember ever bumping into a netball training pole during any game or practice.

It also appeared that some of the participants' families who were strong believers in ancestors, believed in the importance of seeking traditional revelations when it came to having 'foreign and white people's diseases'. Dimphoe's family is an example of believing that at times ancestors communicate in an unfavourable manner. To Dimphoe's family, this included being sick. Dimphoe's family believed that her sickness was related to her calling to become a sangoma.

Kwakuwumsombuluko ngangilaliswe ngolwesithathu esbhedlela udade wabo mama oyisangoma wafika esbhedlela ezongibona. Ngimbona nje namagobhozi amaqanda ekhanda ngazizwa nje ngingekho right ngoba angithi pehel wayekholwa ukuthi ekhaya sibiziwe. Sibizelwe ekubeni izangoma kodwa nguyi kuphela owayenesibindi sokuba isangoma. Engakafiki nasembhedeni wami waba esekhipha ishoba lakhe waqala wakhuzi imimoya emibi ebiza naba ngasekho. Ngamane ngalala embhedeni ngangazi nje ukuthi kumele ngithini noma kumele ngenzenjani. Yazi ngangingakholwa ukuthi engamane abe neDrama nje esikhaleni. Lapho washo wathi ngiyosinda mhla ngivume ukuthwasa futhi ngiuthwasiswe nguyi.

It was Monday and I had been admitted to a hospital the previous Wednesday when my mother's sister who is a sangoma came to see me in a hospital. Seeing her with egg shells on her hair made me feel uncomfortable and scared as she believed that the ancestors had called all of us at home and that she was the only person who was brave enough to respond to her calling to become a sangoma. So she came into my ward and before she could even reach my bed to greet me she took out her bushy tail, which she believed had powers and started chasing away evil spirits and calling our ancestors.

So I just lay there in disbelief and she continued to tell me that the only way I was going to be saved is if I accept the calling and she initiates me to being a sangoma.

The case of Dimphoe was not unique. Each story that I heard had its own unique features, but the end results or proposed solution was often training to become a sangoma because the survivors were chosen by their ancestors. There was, however, a particular case where the survivor knew of a family member that had gone through the initiation and a year later was diagnosed with stage 3 cancer that took her life only days after visiting the doctor. Such examples caused some of the participants to reconsider their ‘calling’, as they believed that the initiators may have lied about their calling if they could sense the participant had strong ancestors. This is one of the reasons Dimphoe did not accept her calling.

The above narratives on the influence of African traditional beliefs amongst the young women confirms Grix’s argument where he states that social construction occurs through the interaction of individuals and “does not exist independently of individuals’ knowledge of the world” (Grix, 2004, p. 83). Through their socialisation, the young women were exposed to traditional worship which has influenced their understanding of illness. This influence was also seen in the young women’s spiritual and religious beliefs. Some shared that their religious beliefs compelled them to seek traditional health assistance instead of going to the clinics and doctors. Having been born into a very strict and traditional Shembe family, Zethu was also forced to consult a healer after being ill with an undiagnosable disease. Zethu claimed that her family had refused to take her to any specialist as they felt it would be a waste of money since she had dropped out of a traditional initiation school.

Ngesikhathi ngiqala ukugula umama wamane wacaabanga ukuthi ingoba ngeqa ekuthwaseni ngalokhoke amadlozi ayengiphendukele. Ngahanjiswa kudokotela owayesebenza laphezulu [esho ekhomba]. Udokotela wenza nje amatesi amubalwa wase wanginika amaphilisi ama-antibiotics wathi angibuye emva lkwezinsuku ezimbalwa. Umama wamane wabona ukuthi lento engiphethe shuthi ayibonakali wathi angiphindele emthwasweni. Ngempela ngaphindela noma ngingathandanga. Ngesikhathi ngikhona ngabona ukuthi izinhlungu zazinyukela. Ngaxoxa phela ngezinhlungu engangizizwa awu umama wasemthwasweni mangihlanginisela amakhambi,. Uyazi njalo mangikhale ngikunyuka kwezinhlungu wayemane awenze ubabe kakhulu umuthi. Ngabanenhlanhla nje yokuvakashelwa udade wethu owangiphokaukuthi sithi ukushaywa umoya naye. Shuthi wangibona ngisakhumulile wabona ukuthi laselinjani ibele lami wase wangiphoka ukuba siye emtholampilo. Ilaphoke engathola khona usizo.

Weh when I started being ill my mother assumed that it was the ancestors who were angry with me. As a result, I was taken to a general doctor who works up the road [points to the surgery direction]. The doctor did basic tests and gave me antibiotics and asked me to return after a few days as he thought I had an allergy reaction of some sort. So my mother interpreted this as not a diagnosable illness and commanded me to go back to the initiation house. Which I involuntarily did. While there I realised that that pains were persisting. Upon sharing the pain and describing how I felt was happening in my body, the initiator felt I needed a stronger concoction. The stronger the pain the more bitter the concoction was. I was fortunate to have been visited by my younger sister who had forced me to take a break and go to town with her. While preparing she saw me naked and saw my breasts and insisted that we were to go to a local clinic. This is where I was diagnosed.

The measures taken in an attempt at ‘spiritual healing’ were similar for Nosizwe.

The challenge with us Blacks is that we do not like to accept reality. Rather, we always want to assume that someone did something to us. This was the case for me. My dad being born from a polygamous family so he always thinks his father’s first wife is doing things to us. As a result, he makes us take concoctions to cleanse us every month. So when I started feeling ill, he took me to BabBhungane [sangoma’s name] who without even looking at me assumed that I had been bewitched. He even suggested I was attacked in a dream that’s why I did not even see or feel the pain. Well, to cut the long story short, I was sick for more than three months before I could see a doctor.

Nosizwe: Iheeee weNoks [rises up, walks around the whole focus group venue clapping, chanting and crying tears] you are blessed if you come from a strong Christian family! You see where I come from, you cough... you have been bewitched... you have diarrhoea you have been bewitched and because the clinic is far BabMayeni is the only person you go to for medical assistance. I was taken to him and he thought I had strong ancestors that were fighting over me.

Me: Fighting over you? Please explain to me. Please treat me like a child in grade one because I am really interested in understanding what you went through.

Nosizwe: Yes BabMayeni thought I should first please ancestors by slaughtering four goats for the paternal and two for the maternal. Then finally my father slaughtered another goat to welcome me into his family. So that’s exactly what happened and I ended up with five goat wrist bangles. It was believed that I would get better after the ceremony, which took the whole weekend.

Me: Did your health improve?

Nosizwe: Not at all. In fact, after the ceremony, I got worse, I developed a lump that looked like an abscess I would squeeze it every day and it’s very painful but I never gave up and I continued steaming my body as BabMayeni had suggested but still nothing came out of it.

Me: Sounds like a great deal of pain

Nosizwe: Yes, it was very painful my father eventually bought plasters for abscess since he thought BabMayeni's medication was cleansing me from the inside and the dirt collected itself and looked like an abscess. In fact, he believed it was the ancestors that were helping to collect the dirt and the process of squeezing it out was the ancestor's way of relieving me from the pain.

Me: Hmmm

Nosizwe: So as you can see how much pain I went through. To top it all I got weak and my father took me back to BabMayeni who claimed that I was improving since both my breasts had an abscess. My father only realized I was getting worse once he found me unconscious in my bedroom that was when he decided to drive through the night to bring me to my mother's family as he thought our whole house was infected with a spell.

Me: That's how you moved from Stanger to Durban

Nosizwe: Yes Nokwanda that's how I was saved from BabMayeni. After moving here I was taken to Prince Mshiyeni Memorial Hospital where the doctors were very angry at my dad as they felt he had wasted time with all the traditional medicine instead of taking me to a hospital.

Me: Mmm...

Nosizwe: All sorts of tests were done and they even took me for X-rays. I think there were about four doctors who were with me on that day and they really helped. My dad was just sitting there helplessly. And did I mention that he had brought incense and all? Yes, he brought it to the hospital. The security guard escorted him out because they feared that he was going to burn down the hospital. He had it in an ashtray. Can you imagine? Once I was better I was sent home but I refused to go back to Stanger because I knew my dad was going to take me back to that man so I asked to stay with my mother's family. Three weeks later I went to visit my father and I felt better as I had already started going to cancer counselling which was organised by my cousins.

Me: Was the counselling part of Sinothando?

Nosizwe: Yes it was. Since then I have understood the importance of seeking medical assistance against traditional medicine. I'm not saying BabMayeni's effort were useless, but it would have been so much better if I had gone to a hospital instead of my father convincing me that I had been bewitched. But hey, that's what you get from being a young African woman. You don't get to make decisions and you don't really have a voice you always have to listen to what the men think even if it affects you directly as was the case with me.

Not all participants expressed dissatisfaction with consulting traditional and spiritual healers. Some, like Thina, shared their satisfaction with the process. She claimed that the consultations

she had with her healer were very profitable as even the medical doctors were happy with her healing progress.

Sisi I have always believed in the afterlife. I believed that my ancestors are always guarding and guiding me. I worshiped them before cancer and I continue worshipping them today. I grew in a family that believed in slaughtering cattle and dedicating all achievements and reporting all misfortunes to my late parents. So when I got sick, I had to consult them for guidance. I burnt incense and requested that they reveal themselves when I see the traditional doctor the next day and they did. As I entered his consultation room, he stood up and went to umsamo which is a room or a part of a room where ancestral spirits are believed to be. It is in this place that he was able to connect with my ancestors and even see what was bothering me.

Similar to Thina, Mpilonhle also had a positive outcome from following her only surviving family member's advice. She shared that she was not a person who believed in ancestors or the idea of a God. Rather, she claimed to have been a 'carefree soul that had given up the 'higher being' since they "all had failed her by not protecting her family from the cancer gene". Despite her previous feelings she was grateful to the "old lady who helped her when she least expected it".

Njengomuntu obengenandaba nonkulunkulu nokunye nje manje ngizizwa nginokubonaga mangibacabanga bobabili ngoba ngibona ukuthi kokubili kwangihlenga ngezikhathi zobunzima, ngezikhathi zekhensa. Okwangithusa kakhulu indlela izinto ezenzeka ngayo. Yazi uaunti wasola ukuthi name senginalesisifo wakhuluma nomuntu owasiza umama walula impilo yakhe ngoba phela odokotela base bemukalelile ukuthi unezinyanga eziwu 3 emhlabeni. Umama waphila isikhathi engingaphezu kwezinyanga eziwu7 ngenxa yamakhambi alowamama. Ngenxa yalokhu ngase ngimethemba lomama.

Being a person who had zero respect and care for the dead and God, I feel very grateful to both, as I believe they were with me and both forces protected me from the dreadful power of cancer. What was more interesting to me was how everything happened. You know as soon as my aunt suspected that I had cancer she spoke to the women who helped my mother and prolonged her life, even when she was told she only had less than three months to live. My mother lived for about seven months because of the old lady so I guess that was the reason I sort of had faith in her powers.

From the information that was shared by Mpilonhle, I gathered that while some believed that traditional medicine was an easier and less painful form of treatment, it also had some negative consequences. According to both Mpilonhle and Thandeka, the process of healing was time-consuming, but they felt this part of the process of their healing was a different experience compared to what they went through in the government hospitals. Dimphoe believed that the

process was successful because she was not new to pleasing and appeasing ancestors. On the contrary, Mpilonhle believed that it was her late maternal family that protected her and guided the 'old lady' throughout the process.

In remembering the process of traditional healing, Thandeka shared that her traditional healer had asked her to buy four candles. The candles were to be bought on different days and in different shops. This is how she shared her experience:

Thandeka: I was told to buy four candles, from different shops. So I went around Isiphingo and looked at the candles. They were to be red, blue, black and yellow. The instruction was for the candles not to be packed or carried in the same packet or bag. And so it took me four consecutive days to collect all four. I also had to get three chickens. One black, one white and one brown. These cost me a lot of money, but I prepared to buy everything that would please the healer since he was instructed by my ancestors. Nokwanda but it was hard. I had to do much to please the ancestors. I mean I had to have my body cut with a razor which left even more marks on me. The areas that were cut were used as an entry point for the medication. I don't know how to explain this, but he took the herbal mixtures which were more like a paste and applied them on my body. It was itchy and burning. He did this for a week while I stayed in his house. He also instructed me to steam my body while lighting the four candles and I used the feathers from the white chicken while bathing. This process, while some may think it's a lot easier than being at the hospital, was very hard for me as I fear pain and I did not like the taste of any of the medication that he gave me. He also gave me a powder that was made of ashes. This powder was to protect me from pain and any evil spirit.

Me: It sounds like you spent a lot of time with your traditional doctor.

Thandeka: Yes I did. I spent time with him before I went to the clinic for a checkup and I spent three days at his house once the date for the operation was set. He recommended this as he felt the need to protect from the evil spirits that are all over the hospital

Me: What sort of challenges did you as a woman experience while following his orders and taking his medication?

Thandeka: The idea of not being home did not settle well and having to endure the pains of being cut with a razor was also problematic. I also did not like how I ended up with scars, especially on my face. It was so bad that even people who did not know me well knew I had a problem and a spiritual one for that matter since I had obviously been consulting a traditional doctor. Let me not even dwell on the chickens and having to swallow its blood. It was horrible, but I endured it and I would not trade my tradition and culture for anything.

Some of the challenges that women went through in the process of their healing have been described. These processes were all fuelled by the women's hunger for survival and the pressure from their respective families and friends. Regardless of the processes they engaged in, the young Black women seemed content with their treatment choices, and most especially those who consulted traditional healers were proud of having engaged with African mediation. While it was argued that seeing a traditional healer did not necessarily mean they were more African than others, they argued that they are happy to have accepted the support of their loved ones and that the role of traditional healers was important as they felt closer to their ancestors.

6.3 Beliefs and medicine

Health related choices are influenced by spiritual and traditional beliefs. Such beliefs may be restrictive on the types of medication that its followers can use. Rumun (2014, p. 37) stated that "the religious beliefs of the people result in many health care beliefs and practices which are significantly different based on the person's religion". As a result, people's treatment choices are limited to what is considered to be correct by their religious and traditional beliefs. Consider the following narrative:

Yazi kwaku nzima ukugculisa umyeni wami ukuthi indlela yokwenza izinto ngokwendlela yemadlovu iyona eyayingilungele. Yazi ngangihlala enqenqemeni lombhede ngizame ukumtshengisa ukuthi iyona ndlela engangiyazi futhi ngikhuliswe ngayo. Kodwa ke ngamuchazela ukuthi abanye abantu babebulalwa ukungawahloniphi amadlozi abo ngesikhathi bebiona odokotela. Wayengayizwa lendaba kodwa ke ngaqhubeka namadlozi ami ngoba ngangifuna ukuphila

It wasn't easy convincing my husband that the traditional route was the best option since he believed in alternative medicine. You know I would sit at the edge of our bed and try to explain to him why I thought we should continue with the herbs and stuff. But he was never convinced. Even when I explained to him how women and people, in general, were dying due to not seeking pleasing their ancestors while seeking medical assistance. But he still said no. But I continued because I believed in my ancestors. [Thandaza]

While I was heartbroken when he left me because I was not pregnant with his 'Uzwile' I now understand that he did what he believed was best. And as the holy book says it all worked out for the best. I mean, if I had continued and married him I would have had to convert to his religion. I would be a Jehovah's Witness. So do you know what that means? Do you know Noks [sounds rather shattered and has glassy eyes, she quickly dries her eyes as our eyes meet] Noks, I don't think I would be alive. Especially since I have had more than 5 litres of blood infused. [Thina]

The above narratives are examples of the influence of traditional and spiritual beliefs. Thandaza and Thina's spiritual and religious beliefs were different from their male partners. This affected their relationships as it was important for the young women to honour their own beliefs. Thina also shared that separating from her partner of many years was painful but she believes 'it was part of God's plan' as she feels she would not have been able to undergo blood infusion (which she required) if she had converted to her partner's religious beliefs.

I was rather confused about the relationship between religion and blood transfusion. Upon delving deeper into literature, I realised that for years, some patients have denied themselves several operations due to their religious inclinations. What also transpired from the literature was that family members at times were responsible for such decisions. During a focus group interview, a number of participants attested to this some even going to the extent of instructing doctors to not allow certain family members to visit them.

I am one of the people who switched between religions. You know I had been a Witness [member of Jehovah's Witness church] for all my life and one day while visiting a friend's church I learned of the disadvantage of being a Witness. At first, I thought the pastor was misinformed after all charismatic pastors are known for their negative attitude towards the so-called mainline churches. So when I got home, I started going through my church notes and searching for supporting Bible verses and I realized that it was all there. The pastor was correct if one reads with a charismatic mentality, but he was also incorrect when one goes deep into the Bible and its meaning. This left me confused. I continued with the church, but I never found closure in that regard... Well, until I was diagnosed and I learned that I may need to get blood should I need it during any of the operations. That's where my faith was seriously challenged and I decided not to fill in that I am a Jehovah's Witness. Instead, I wrote that I am Christian and that I accepted any means of saving my life. Yes, even if it meant someone donated an organ or blood to me. [Nontobeko]

Two other participants shared how they had also been victims of religious doctrines. According to Ziphoe, the greatest challenge about her religion was that she was only allowed to use holy water was that blessed by her church bishop. She shared that when she started feeling pains and discomfort, she discussed her issue with her bishop's assistant whose role was to evaluate the importance prior to seeking the bishop's prayer and assistance.

You know I wanted to ask the bishop to lay hands on me, but as always I had to go via Reverend Themba who dismissed my problem before I could even finish. His judgment was that the matter was not too important and that just five litres of holy water were going to lessen my pain and heal me. He also reminded me that the bishop was busy with really ill patients, but assured me that the water was freshly prayed for hence I

would be healed much easily. So, that night I drank a cup of holy water and used another cup to rinse the painful areas which were around my nipple, shoulder and back. After a week the pain was still there, but I still could not see the bishop plus I could not go to the clinic just in case a member of the church saw me.

Ziphoe belonged to a fairly new church that was formed by her bishop and his wife. She claimed that the church believed in water and in seeking ancestors. The experience and understanding of the young women in terms of their spiritual beliefs indicates that human beings perceive social circumstances using their own interpretations. Some African women sought traditional healers while others believed that religious interventions could cure them from the illness. This illustrates the influence of interpretation which allows for “the complex world of lived experience from the point of view of those who live it.” (Schwandt, 1994) cited in Andrade (2009, p. 43).

6.4 Conclusion

Traditional and spiritual beliefs play a vital role in the well-being of people, including most of the young Black African women in this study. Religious-cultural beliefs influenced their socialisation and inevitably, their socio-cultural beliefs about the body and health. This is what impacted on their construction and interpretation of their health-related beliefs. This resulted in consulting traditional medical practitioners who gave them concoctions and comforted their anxieties. This chapter also reported on the spiritual interventions of illness which also served to provide hope for the young women. This chapter has shown the measures that were taken by the young women with respect to their treatment options. It further discussed the influence of culture and religion in making decisions. Through the above narratives, one can deduce that for this group of survivors, belonging to a particular faith or having a form of belief in ancestors or ‘higher beings’ as discussed by participants, enables patients to have faith and a more positive attitude towards their healing process. Lastly, this chapter has offered narratives that revealed the influence of religious beliefs in their cancer journeys.

CHAPTER 7: INTIMACY AFTER BREAST CANCER: YOUNG BLACK WOMEN AND THEIR STORIES OF INTIMACIES

7.1 Introduction

Breast cancer treatment affects women in many different ways, hair loss and breast reconstruction being some of the common side effects of the treatment. For young women, premature menopause is one of the greatest concerns before and after breast cancer treatment. Premature menopause leads to loss of fertility which can be challenging and difficult to accept for young women. During this phase, these young Black women experience a number of uncomfortable conditions and illnesses which may include night sweats, hot flushes and weight gain. While there are options for breast conservation and reconstruction which in a sense give women a new sense of control over their treatment and are quite successful in helping women feel comfortable with their bodies again, intimate relationships cannot be easily negotiated after surviving breast cancer. This chapter discusses the participants' intimate relationships before and after surgery. It discusses the changes caused by surgery and accounts for the measures used by women in attempts to renegotiate their sexuality.

7.2 My intimate relationships *before* cancer

Intimacy is an important yet sensitive issue to discuss with women, especially those who are recovering from breast cancer treatment. Previous studies have reported on the hardships that women are confronted with from the day they are diagnosed with cancer. Zimmermann (2015) argued that "cancer diagnosis imposes significant emotional distress on a substantial proportion of patients and their partners". Kurowecki and Fergus (2013) described the negative effects of cancer treatment mentioning that couples often experience extreme difficulties especially if the woman experiences sexual dysfunction and loss of fertility. Holmberg, cited in Kurowecki and Fergus (2013), argued that relationship failures often occur at the beginning of the cancer treatment when women find it difficult to manage their depression and side effects.

Thors, Broeckel and Jacobson (2001) claimed that many patients were reluctant to share their sexual difficulties with health care providers. This was the case also for the women who took part in this study. The young Black African women who participated in this study were

uncomfortable with expressing their experiences, especially during individual interviews. My rather petite body may have made me look younger and perhaps not 'sexually experienced'. Most of the participants requested that I skip the intimacy questions during interviews but were not shy to discuss their experiences once they were in a group environment. 'Hanging-out' with participants also gave me the advantage to discuss some of the issues that affected the women during their cancer days.

Zibuyile was the first participant that was open about her experience. At the baby shower which she had organised, there were a number of games and questions which involved sharing of sexual experiences which led to conceiving. Fortunately, the shower was held six months after I had given birth to my daughter, so I was able to participate fully. Once the word 'sex' was mentioned, all the women started laughing and pretending to be shy until Zibuyile decided to share about her intimate relationship before being diagnosed.

Aike sihleli noGuy that I had been dating for about 6 months. Ay umtanomuntu angithelele iwayini abeke namagrebhisi namabhiskidanyana lawa abelungulu adliwa noCheese... ya labo chadder nton nton. Ay yimi lo ngiphuza iwayini ngiliqede eglasini ngisho ngithele elinye lapho uGuy ubhizi nje uyangibrasha amathanga yonkinto igrand. Hee ai angazi kwenzakalani kodwa ngazizwa sengithi 'baby do we have protection' waphendula wathi 'yes ofcourse I do'. Ay yaqhubekake inkonzo. Enmpeleni into eyangi-charma indlela angibotobotoza ngayo amabele. Weh mame ngabamanzi same time ngathi ukudrayisa ngabona ukuthi ayikho lento weh ngaliphonsa ithawula kanti angazi ukuthi uGuy lo uzimisele udle nekhambi khona ngizobamba. Ay, that's the day I conceived my son who was stillborn.

And so we were sitting with this guy, well my boyfriend and we had been dating for 6 months. So he poured wine for me and he also served me grapes and those funny white biscuits that are served with cheese. And so there I was sipping wine till I finished the first glass and I moved on to the next. At that moment my boyfriend busy brushing my thighs everything was going well. I'm not sure what happened but I remember saying 'baby do we have protection?' he replied and said 'of course I do'. And so we continue. You can imagine the rest. What really caught me was the way he held me and the way he was brushing my thighs and breasts. I got wet same time. I tried to play hard to get at that time but I realized that I was pushing myself so I gave up and gave in. Little did I know that my boyfriend had used a traditional mixture that was to give him stamina so I could conceive my son who was stillborn.

This was the first time I heard about her pregnancy and her child not being born alive. We had had a number of conversations on WhatsApp and Facebook but she had never been open about this experience. She later revealed that she had not intended sharing her but considering that it would have been her son's birth week, she felt it was necessary to share it with her close friends

in memory of him. In continuing to gather stories relating to intimacy I was fortunate to visit Phiwe who I had met through one of the social gatherings organized by Sinothando.

I'm a married woman so this topic makes me uncomfortable but because I trust you I'll let you into my world...

My husband was the first man to ever touch me (engage in sexual intercourse) so he knows me very well. He taught me how to do everything so I can say that when it comes to sex he's my guru. Now I used to be very sexually active. My husband and I got married when we were only 23 so you can imagine. So after a year of dating, I fell pregnant and we had to get married. I was the type who initiated sex even when he didn't want but I would blackmail him by saying I'll get someone else or something like that (she rolls her eyes and laughs while clapping my hand). Used to easily get wet. My husband would touch me and I would be turned on. You would swear I was a porn star (laughs again but this time ends up getting tearful)

Noks I believe I was satisfying my husband until I started feeling weak and he noticed it. This turned our relationship sour as he first thought I was cheating on him. Somehow he thought I was no longer interested in engaging with him so there could only be one explanation. I was cheating. Instead of asking me directly he decided that we should see a marriage counsellor 'for the sake of ensuring that our relationship is still healthy'. So we went. The counselor's office was close to the Gateway shopping centre. So she asks... what's brings you guys to see me today. And I just stared at him as he replied 'my wife and I are having problems but I didn't want to confront her on my own so I thought we should come here and see if you can help us'. He got me confused. Like what problems were we having? What led to those problems? Why didn't he sit me down as his wife and ask me if he wanted to ask anything? I was furious as you can imagine. I was also disappointed at him. So the counsellor asked what was the matter and he said 'I think my wife is cheating'. I just sat there hoping the couch would swallow me up. He continued and said 'I have been trying to touch her for the past five weeks and she has not allowed me to have her, now my wife, the woman I married never said no to she was always willing to have me satisfy her. But lately, she has been hostile'.

To my surprise, the counsellor had removed her glasses and was looking at me in shock and disgust. More like I had disappointed her. Well, I explained that I was just not in the mood for sex in the past weeks but I was not cheating.

Being a woman, it was somewhat difficult not to reflect on the issue but I had to continuously remind myself that I was a researcher and I had to reserve my feelings and refrain from commenting on the participants' experiences. As she continued sharing her story, I realised how much this incident had hurt her and was still hurting her. In the process of recalling the ordeal, she became emotional and often cried while I requested that reserve the topic for another day. But she preferred to continue with her story. She continued to share that after the marriage

counselling session, their relationship experienced more hardships which she feels she can never forget as her husband was convinced she was having an affair. She further shared that this led to stress and depression as her husband had even told her family that she was no longer performing her duties, hence he was also thinking of having another relationship and he wanted their permission. She shared that she was admitted to hospital for stress and headaches after this incident.

Noks ngagcina sengilala esbhedlela ngoba phela ngase ngiwumuntu omuntu yonke indawo. Ngangi bukelwa phansi nje nasemphakathini. Ngesinye isikhathi ngangifisa sengabe bekukhona noma icamera ezotshengisa umyeni wami ukuthi ngangimsulwa. Ukuthi ngangisigcinile isithembiso sokungaphingi. Ngangifuna angithembe nkosiyami.kodwa nje kwakusobala ukuthi wayecabanga izinto ezimbi ngami ngoba nje wayenga funu kuzwa lutho nkosi yami. Yazi ngisho nomalume bami batshelwa. Babengifonela basho ukuthi akuve ngibaphoxile ngokuhlulwa ukubamba umendo nokujabulisa umyeni wami. Yazi kwaze kwafika lapho eletha khona owesifazane emzini wethu ukuthi ngimubone. Kwangiphula inhliziyo lokhu ngoba phela kwakukhona nendodazi yethu ngaze ngaqamba amanga ngathi losisi obefikile uwumngani kababa wakhe ngoba ngingazi ngempela ukuthi ngizothini, ngizosimisa kanjani lesisimo. Ayi ngike ngathwala nkosiyami.

Noks I ended up being admitted because I was now seen as a bad person. I was being looked down upon. My uncles called me a disgrace. Sometimes I wish my husband would have had a camera to see where I was and who I was with because he clearly thought negatively about me. He even introduced the woman who was to satisfy his manhood to me and our daughter. This was very hard as I had to explain to my daughter that the last was his friend that he worked with. It was hard.

The challenge that I immediately realised among the women was their lack of voice when it came to their relationships. All seven women who were willing to share their intimacy stories found it difficult to share their lack of sexual interest with their partners. Phiwe felt that this was because she was embarrassed and she feared that her husband might not be able to understand what she was feeling at that time. I also gathered that women who were not married found it even more difficult to deal with the changes in their sexual appetite as they felt they were disappointing their partners and that their partners could easily replace them with women who were willing to take care of their sexual needs. Consider the following excerpt from Sisanda:

Noks you may not know how it feels but it hurts. You know we used to have a good intimate relationship I think we both knew how to satisfy each other. We were so sure about our relationship and he always told me that he would never be involved in a serious relationship with a woman that did not satisfy him in bed. So I always made

sure that I gave him what he wanted. Fortunately, I never used to get periods on a monthly basis so we could have sex almost anytime he wanted to. But I always feared for our future. I mean, I was never sure whether he wanted me or my body. So, like the other participants I experienced vaginal dryness long before I was diagnosed. I knew that in my monthly shopping I had to get lubricant but I did not tell him. Just before we started I would pretend as if I needed to use the toilet and I would go and lubricate myself and be ready for him.

The fear of disappointing sexual partners led women such as Asanda to find ways of ‘normalising the situation’. Dimphoe’s experience is another example of how women felt the need to satisfy their sexual partners. She, amongst other challenges, experienced vaginal dryness which the clinic nurse thought was normal for women aged between 30 and 40 as ‘it was their bodies preparing them for menopause’. She further added that while she did not fully understand what the nurse said, she felt embarrassed to ask again as the nurse gave her the impression that it was normal yet she was not feeling normal. Nompilo experienced something similar. According to her story, her partner complained of her dryness and accused her of being no longer attracted to her. To her partner, being sexually attracted meant the ability to get wet during sexual intercourse.

Aibo ubhuti eqala ukungizwa ukuthi ngomile wakhuluma uwaya waya nje. Into engangingayizwa nakahle. Waze wangisola ngokungamuthandi. Kwangithusa k lokhu ngoba phela ngangimthanda. Waze wathi ngenza sengathi akangichazi. Naliokhu kwaxaka ngoba phela ngangingeke ngihlale naye engasangichazi. Ngangimthanda ngakho konke futhi ngizama ukuntshengisa. Kwathi nangesikhathi sengigula ngazama ukumunika uthanda. Ngangicabanga ukuthi ngempela ngaphuma embanjweni yakhe. Kodwa angiqondi ukuthi indaba acabanga ukuthi ngomile ngaphansi ngenxa yokungamuthandi. Ubani nje olingana name owayengenza lowomsangano? Owayenganqaba ucansi?

Noks the first time he realised that I was dry he made a big fuss about it. Even accused me of not loving him or even being attracted to him. I was shocked. I mean this is a guy that I had loved all my life and I was so sure that he was my better half and he accused me of not loving him just because my body decided not to release fluids. Like what the hell was that? Which woman in her early 30s could have said no to sex?

Me: How was your sexual relationship before that?

Nompilo: It was good, at least that what I thought. He knew what I liked and he satisfied me. I did not have any problems in terms of my sexual relationship.

Me: When did you start feeling differently?

Nompilo: It was like two weeks after I found out. The doctor had told that I may be much stressed which could affect my libido as my brain was under pressure. When he told me I just laughed because it did not make much sense but I soon understood what he meant.

Me: What changes did you experience and how did you feel about them

Nompilo: It began with a fever like feeling so I thought I needed Med Lemon and after taking it for two consecutive days I decided to go to the clinic as I remembered that the doctor had advised me not to self-medicate so I went there and the clinic sister didn't think it was much of deal as she thought my body was preparing itself for menopause and besides she said it could have been the side effects of antibiotics... but of course being Black I had to find more information the African way.

Me: What do you mean by 'the African Way'?

Nompilo: kalokhu I am human and I am Black so nje I had to see ukuthi ogogo nomkhulu bathini kulesisimo aibo phela bekungenzeka ukuthi umnakwethu ubesengifakele isichitho ukuze ubhuti angangizwa kahle ebusuku so I had to check.

I am only human and I am Black and so I had to go and see what my ancestors were going to say about my condition. It could had been a matter of my competitor (boyfriend's other girlfriend or sexual partner) having used muti on my boyfriend to make our sexual relationship less enjoyable for him

Me: Were you worried about that?

Nompilo: Of course I was. I mean which woman would not have cared about losing a man that she loves because some witch decided to come between them. I had witnessed a number of women losing against whichever their partners because of this so I did not want to be a victim. I had to check then protect myself spell was directed to them and possibly send back to that witch.

Me: What was the outcome of your consultation, if you don't mind me asking?

Nompilo: It was positive because nothing had happened there was no spell sent in my direction so I was relieved but of course I had to get a second opinion so my friend took me to her healer also revealed that he did not see anything negative coming my way. He gave me a bottle of herbs that I was to heat up and drink for three days and something like an ointment which was to make me more desirable to my partner

Me: Was the ointment helpful?

Nompilo: Maybe I don't know I mean I only saw him once after that and it was only on my second day of drinking the herbs so I don't know maybe I sabotaged my chance by sleeping with him too soon but the old man has done wonders for my friend so I think it would have worked. Maybe that's he tried to see me even when I was in the hospital maybe it helped by drawing him to me.

The idea of using traditional means to prevent the changes in terms of sexual relations was highlighted during interviews when participants shared their experiences. Some even went to the extent of sharing if it was not for their traditional healers they would have lost all their possessions and people that mattered to them. The role and beliefs in traditional healers has been discussed in Chapter 5. It is worth reiterating that for the young Black women who believed in traditional healing, the traditional healers were consulted whenever they experienced problems with physical and even social circumstances. Hence, when it came to relationship insecurities, the women wanted to find immediate solutions and guidance from ancestors. This was achieved by some of the women as they believed that the herbs they received from their healers and spiritualist was able to mend their relationships.

Nontando was another survivor who shared of her insecurities due to her inability to satisfy her partner. She felt that her lack of interest in sex was problematic in her relationship and she was too embarrassed to share her experience with the doctor she was seeing on a bimonthly basis.

You know once you lack in sexual pleasure you can't help but wonder if your partner has picked up the vibes. You keep thinking if he won't be fed up with you and get someone for the night and besides it's not like you are married so he doesn't have to explain anything. This is what used to bother me the most as he was always out and about and just did not have any time for me. At the end, I learned that he was indeed cheating and that he was even considering marrying the woman he was with. I mean he could have told me. I would have been hurt but not as much as I was once I learned from my cousin that my Mr. Right was in a serious relationship with someone else.

The above is an example of several insecurities that were cited by the unmarried women who were in relationships. According to Nontando, the fact that she was not married and that her ancestors had not blessed her relationship, made it difficult for her to seek their guidance when she started experiencing difficulties:

You know if I had been married I would have easily burned incense or even asked our families to intervene on the matter. But because we were not spiritually and traditionally joined through lobolo and the other ceremonies, I had to do all I could to keep him. So this is why I had to consider leaving him when I heard that he was in another serious relationship. We Black women understand that a man is never yours until you are traditionally married through the process of lobola.

The above excerpt introduces another dynamic of Black African people, the payment of lobolo (bridewealth in the form of cows). This was reported by Phiwe as being unique to African women as it brought together the living and dead families which were to protect the

relationships and families that were formulated through the process of young women. Due to the protection from ancestors, Nontando felt she was not capable of mending her relationship especially when her health began to deteriorate due to cancer.

Zibuyile is amongst several women who also claimed to have lost their partner long before the relationship was ended by a mutual agreement. While they had initially claimed to be in ‘good’ and ‘stable’ relationships prior to their diagnoses, I later learned that her relationship was heavily affected by medical conditions as mentioned by Zimmerman (2015) in his report. Thina was one of the women who thought her lumpy breasts were a sign of pregnancy and that this sign had led to great excitement between her and her late partner but she revealed that her relationship “came to a standstill once she was diagnosed”. During the second focus group, she was more open about her relationship and the challenges she faced.

As much as I go around telling people that I had a perfect relationship we had our bad days or rather bad nights as my partner would be OK with me until we had to go to bed. Inkonzo yasekameleni yamande yangathandeka [our sexual relationship because the least favourite thing about our relationship] after he said he thought it was a sin for us to engage in sex before my biopsy. He fooled around with me and started telling me how sex would affect my hormones and how the doctors may not find anything wrong with me because I would have had sex the night before. Sure I sort of understood but a part of me was disappointed as I felt I was being cheated of my last chance to fall pregnant. I had been trying for years with no luck.

Thandeka who looked rather confused asked Thina the following question:

Thina ukube izinto zaziphambene nje kube nguwe ozwa kuthiwa umuntu wakho wayezoya kobona noma udokotela wamazinyo eyokhipha izinyo wawuzofuna ukulala naye? Wawuzofuna ukwenza ucansi naye? Umucabuza? Ngiyabanga nje ukuthi wayephatheke kabi ethukile ngale nto eyayenzeka kuwe. Futhi hlampe wayekusabela nje nkosi yami ukuthi uzoba sezinhlungwini. Angikholwa nje ukuthi kwase kuwukuphela kothando lokho kodwa ngathi wazithukele nje.

Thina, if the roles were reversed and you heard that your partner was to see a doctor even a dentist to extract his tooth would you have wanted to sleep with him? Would you have wanted to make love to him and kiss him? I'm sure he was feeling down and even scared of what you were about to go through but I do not believe it was because he was falling out of love.

Nontobeko then shared her views:

Kodwa Thina, ucabanga ukuthi lokhu okwenzela phakathi kwakho nomuntu kwakunzima, mina ngibona ukuthi wayewumuntu onozwelo. Owami ntombi

wayengaunderstandi nje efuna la ukwenza ucansi noma seengigula. Uma ngingazizwa sengathi ngingalwenza wayemane athi shuthi ngiyamjolela ngoba phela wayengaqondi ukuthi yini sengihlezi ngiseclinikhi noma kadokotela. Ngoba phela ngase ngihleli ngiya kodokotela bese bengidlulisela esbhedlela. Wake wacela ukuthingimuchazele ukuthi ngifike ngenzeni ebhedlela, ngempela ngichaze. Have kanti ngiyaziqhatha, kusukela lapho umuntu wathi mina ngihamba ngitshengisa abantu umziba wami, amaAsset akhe. Yazi angiqondanga nje ukuthi wayekushiswa yini lokhu lokhu kodwa ngokuhamba kwesikhath ngaqonda ukuthi naye ubenokwesaba ukuthi kuzokwenzakalani ngami Kanye nobudlwelane bethu futhi ke ngathi wayesaba kakhulu kwezocaansi.

Thina love, I think what you had with your partner was real at least he was understanding. Mine did not even understand my diagnosis and he demanded that we made love. In fact when I said I was not feeling up to it he accused me of cheating as he did not understand why I was always at the clinic or talking about my doctor, once he asked me to explain what happened during my clinic and hospitals visits, the matter became worse and started accusing me of showing 'his assets' to the doctor. I did not understand why he said that but I later realized that he too was feeling the pressure and he feared the outcome of our sexual relationship.

The above excerpt is evidence of the vulnerability of young Black African women once they were affected by sexuality related challenges. The above also indicates that women, regardless of their medical status, wish to be loved and cared for. Following their sexual problems, women began to question their femininity as they felt they were no longer seen as sexual beings by their sexual partners. Those who were in casual relationships felt their experiences were harder as they could not consult their ancestors for guidance. However, the case of Phiwe who was married when her husband accused her of infidelity, indicated that even married couples experienced hardships once there were difficulties in their sexual relationships.

7.3 Fertility issues

Fertility is arguably important amongst many categories of women. Kurowecki and Fergus (2013) discussed the important for women to be able to reproduce as the majority of the men get married for the sake of continuing their family name. While some women are naturally infertile, studies have indicated that when a woman enters the African home, she is expected to have a child as soon as possible. Young Black women in the study were very confident of their sexuality and ability to reproduce prior to cancer. Some shared that they already had children and some were preparing to conceive. These were issues that were very emotional for the participants as they felt cancer robbed them of their opportunities of becoming mothers and possibly, of marriage. Zibuyile had never had the chance to conceive after she lost her son who

as a still birth. She shared that her partner was from a very traditional family which made conceiving very important to her.

Love, where I come from, being a mother is a must. My partner's family did not really like me because they believed that I was on contraceptives as I had not fallen pregnant after three years of a relationship. So they made a plot for my partner to leave me. Fortunately, I conceived during those months and that led to them seeing that I have never had a problem. Now Noks, and am sure my fellow survivors will attest to this, it's not nice to have people talking about you saying these negative things as you feel less of a woman. You feel like a failure since you already know that you are expected to fall pregnant. So it happened with me. It was believed that I was useless there were even thoughts and rumours that since my partner loves me and does not want to leave me then he should find someone else.

A similar story was later shared by Thina who also felt that her partner's family was negative towards her as she did not conceive after many years. She even went for medical consultations and counselling as she felt the need to prove to her partner's family that she was not the reason she was not conceiving.

Ngangazi vele ukuthi abangithandi kodwa ngangingacabangi ukuthi sengaze bengicbangele ukuthi ngiyimnyumba, angizali owadlisa indoda ethemba ukuthi iyodela ikhaya inamathele kuye. Ngangithanda futhi ngifisa ukuba nomndeneni naye kodwa ngangingenje ngenze leyonto, ngimudlise. Ukuze ngibavale imilomo ngahamba ngayokwenza amaTest abuya sisi etshengisa ukuthi anginayo inkinga.

Heaaaa I wanted to close their big mouths and prove that I am not infertile as they were calling me inyumba (an infertile woman) who had bewitched her partner in hope that he would neglect them and focus only her. This was not nice and I would cry about this. So I showed them the results as my doctor told me that there was nothing wrong with me.

Both Zibuyile and Thina shared that cancer was an 'unnecessary addition to their problems'. This they shared as they had been struggling to conceive for a number of years and while Zibuyile succeeded once, her son had passed away. They shared that when they learned of the possible effects of cancer and its treatment, they feared for their chances of conceiving and their hopes of being married 'became zero'. Mandisa's case was different as she was already raising her child when she learned that she had cancer. Even though this was the case she shared that she was still scared as she feared that she would not be able to conceive again. Samantha, on the other hand, shared that while she received the utmost support from her husband and family, she feared for her position in his life as she was under pressure to conceive after getting married.

I know some think I have it easy just because my husband and his family are supportive but I don't I have had insecurities and I still have them. I sometimes think of how one day a woman can show up with a child and claim that it is my husband's I would not be able to do anything about it. I mean he may love me and support me but this does not mean he will not want to have an heir. I do fear that he might just end up sleeping with any woman for the sake of impregnating her. I won't blame him since the doctors told him we cannot have any children.

The other participants had a rather favourable picture of Samantha's relationship and had shared that they wished they had met someone like Samantha's husband. Someone who would have taken them to galas and given her all the support she needed. Zibuyile stood up and clapped her hands in disbelief saying:

Samantha, please don't get me wrong, but I am relieved. I appreciate the fact that you shared your story because I have been thinking about the wonderful life that you live. A life that doesn't sound Black at all. I mean look at you, you have a fancy job and car and even a husband that is waiting for you outside. I do not believe that a woman like you even cares about children. Do you? I mean you have it all. And you look young in fact I feel that you look like 26 or something. I honestly thought you had it all but what you shared has given me hope as I now realise that I am not alone. Since I learned that I would never be able to have children I have always looked down upon myself and this has led to insecurity issues. I don't really understand why but I am very insecure as I too think that someday my partner will find someone else who will satisfy his dream of being a father.

The issue of infertility was mostly cited with regard to family instability. In most cases, the participants cited their insecurities in their relationships and not so much their wish to become parents. This led me to question if they felt cancer and its treatment affected their longing to become mothers or their roles as wives and suitable partners. Samantha was eager to answer this question:

OK, I will be dead honest with you. I have always dreamt of being a mother. I wanted it so bad that I did not hesitate to marry my husband. However, we both had dreams and ambitions which led us to try and wait until we were finally secure to have a baby. So in focusing on our careers, we drew even closer together and I sort of chose loving and satisfying my husband over being a mother. After visiting his older brother and his family I realised that my husband was incomplete as he seemed to love playing uncle with his nieces but I quickly distanced this thought as I felt I was just overthinking. So when he introduced the 'growing the family' topic I wasn't really surprised but it got to me as I felt I was not ready to share him with the baby. But once he shared that nothing would make him happier than being a dad I wanted to give him a child. Again,

I was not really looking forward to being a mother. I wanted to be a good wife who satisfied her husband so I wanted to conceive.

Samantha's story served as an ice breaker for the group and more participants raised their hands to share their stories:

I also want, to be honest, and say I wanted to conceive so badly for my partner and not myself. Yes, I did long to become a mother before meeting my late partner but once I met him I was so in love that all the love and energy I thought had reserved for my child I gave to him. I gave him my all. I think that's the reason I was so hurt when he said being intimate before my appointment at the hospital was a sin. I think having a child would have brought us even closer and it would not have given him a chance to cheat like he once did since he would have known that he had a wife and daughter waiting for him. [Thina]

Zibuyile was another participant who felt strongly about the issue of putting her partner first and in satisfying the 'potential wife profile' as she carefully worded it.

Like I have already shared, my partner's family thought I was on contraceptives or something as I had fertility issues since nothing came through for a good three years. I also overheard a conversation between my partner and one of his siblings where they were discussing if he should pay bridewealth for me. His sibling was fast to say no as I had not given him an heir. The sibling even suggested that I may not even be fertile as in his family 'no one had shot blanks'. This really got to me. I mean I wanted to live up to my name. I wanted my father's cows to be returned... I mean I wanted my father to gain something through me. So I wanted to have a child for the sake of keeping the relationship and of being his wife.

The above are challenges that the survivors faced before and after their cancer journeys with respect to their intimate relationships. This chapter has discussed issues relating to the survivor's insecurities in their relationships, paying particular attention to the unmarried participants such as Zibuyile who took measures to secure their relationships. From the above chapter, one can deduce that for this group of young Black women, fertility was considered important as it secured their marriages and romantic relationships.

7.4 Conclusion

The above excerpts indicate the strong need of expanding families for young Black African women. For example, Zibuyile strongly believed that her inability to conceive after cancer treatment was one of the reasons she could no longer fulfil her father's wish for her. This implies that for some young African women marriage is linked to family pride and is a means

of upholding the parents' name. Also due to their sociocultural beliefs, the young women often felt defeated when they found out there they could not produce an heir for their partners. Again, the case of Zibuyile is an example of this as her partner's family were questioning her fertility even before she experienced the treatment's side effects. Infertility is a major negative effect of cancer treatment. Though infertility may be relatively common amongst all women, this chapter has discussed this challenge specifically from the perspective of young Black African women.

CHAPTER 8: MY PERFECTED BLACK AFRICAN BODY

8.1 Introduction

This chapter draws attention to the constructions that young Black African women use to describe and discuss their womanhood post treatment. It also looks at how women reintegrate themselves into society and how they identify with other women in their respective societies and cultures. In an attempt to better understand how the survivor's lives have been affected by cancer, four survivors were requested to write short letters to their younger selves. This was a methodological technique to acquire an insight into the women's youthful years and what they wish they had known about the sociocultural construction their own bodies (this method is also discussed in the second chapter of this thesis).

This chapter begins with a short poem that was written and recited by a survivor in one of the focus groups.

8.2 The African body

Mzimba wami
Ngingayini ngaphendle kwakho?
Nsuku zonke ngilala ngivuke nawe. Awukaze ungishiye.
Abaningi bakhulume kabi ngawe basho lukhu nalokhuya kodwa awuzange ungishiye.
Ngiyavuma angikuphathanga kahle esikhathini esidlulile,
Nginikelengawe kubantu abangazange bakuphathe ngedlela
Kodwa wena wama nami. Noma odokotela sebethu unesifo wamanani
Baningi bebekugxeka bathi umubi ngaze ngakholwa
Kodwa namhlanje ngithi wena uwumzimba wami ngiyazuqhenya ngawe
Nawe singene la okuthiwa akungenwa khona saphuma la kuthiwa akuphumeki khona
Ngiyaziqhenya ngawe mzimba wami.

My body
What would I be without you?
Every day I sleep and wake up with you. You have never left me.
Many people have said a lot of negative things about you
and I but you have never left me.
I admit to mistreating you in the past
I gave you away to people who did not treat you well
But you never left me. Even when doctors said you have a disease
you did not leave me.
Some called you ugly and I believed them
But today I want to remind you that you are my body and I am proud of you
We experience the worst but you never once failed me
Even cancer was not enough to break the relationship we have
I am proud to have you as my body. [Sisanda]

Sisanda shared that she had written this poem to celebrate her 29th birthday, a birthday that she had feared she would not see. Fellow survivors applauded and started thinking of all the challenges that their bodies had encountered and survived. The poem introduces this chapter on the personal challenges that were experienced by young women when they realised and learned of their bodily changes. The changes challenged their prior knowledge of being an African women. This poem deconstructs the women's construction and function of the body. It embraces the body's potential in relationships and in the individual women as they learned to reconstruct their femininity after the bodies they were socialised to embrace had now become different.

8.3 Letter to my younger self

In reflecting on the challenges they had overcome, some women mentioned that there were things that they wished they knew when they were younger. The young Black African women believed that such knowledge could have protected them from believing only in physical appearance; rather, they would have learned to appreciate their inner personalities and femininity from a young age.

Letter from Mpho to her younger self:

It's been four years and I have been meaning to tell You a few things that I believe you need to hear. I'm not sure if I am now doing this for myself or for You. I know I have neglected You for so long and you probably think I am not serious but I am. I feel I need to be honest with you because You are very important to me.

Amongst the number of things I have realised was the fact that I have not been kind to you. I have emotionally abused You and neglected you. I have not given You much attention and while I have known You all my life, it feels like I have just met You. I guess we can say it took losing my breasts to love and appreciate You.

Looking back I realise just how much I have not embraced Your colour, Your Blackness. Yes there is so much richness in Your Africanism. Richness comes not from the popularity that I have always wished for You but in you identifying with the African soil.

I remember when I only 12 and I had started high school. I was popular in my community and at school and you did well. You unconsciously represented your people, your Black African people. I entered beauty pageants and I was crowned Miss Rainbow because I was known for my bubbly personality. In all this, I only concentrated on my appearance not so much my inner beauty. To think You have been with me all these years and stood by me, never giving up on my weaknesses and on the days I would feel down. I have been blessed with so much. Even when I starved You for weeks only drinking water and Oros juice You never gave up on me. I am grateful.

I know you have been taking so much medication. You probably think it's because I have never appreciated Your true beauty. I feel this is true. I feel I owe You so much explanation that I cannot even begin to explain.

If I could go back to being 12 I would begin by greeting you every morning. Giving You healthy meals at least three times a day. I would stop trying to change the way You look and concentrate on keeping You happy and energised. I would enter beauty pageants for the sake of showing off Your African beauty and not to spite other women. I would only date one guy at a time and make you wait for the guy that appreciates You and

does not touch You to prove a point to his friends. I would encourage You to think positively and to always look for better solutions. I would change so much, stop living for now as if You were depreciating. Rather, I would treat you like a house which appreciates. I would ensure that Your value increases every day.

I would have also breastfed my daughter which could have minimised my chances of having cancer. Instead of listening to my then partner who was convinced that breastfeeding changes the breast size and appearance.

I would also find suitable bras and garments that are risk-free just to ensure that You are risk-free. I would live to pamper and protect you all the days of my life.

In all this, I would constantly remind You of the importance of being You, of appreciating your culture and heritage. I would ensure that you love and appreciate every spiritual lesson that You have been taught from your Sunday school days. Lastly, I would teach You that being a Black woman is nothing that has to be taught to You, rather its who You are. All the lessons and examples that have been demonstrated to You. Continue uplifting the African flag never forgetting that our beauty lies not in our appearance but in our faith in beings that can no longer be seen as it is through them that we make sense of our lives.

I love You.

Me.

The above letter by Mpho to her younger self illustrates that illness leads to the need for social support. The letter begins rather regretful of the past experiences and it later begins to delve into issues regarding being a Black African women. Mpho revealed that while she had initially seen her Africanism as nothing to be proud of, her experience with cancer has taught her otherwise. Through her letter, we learn of the importance of loving and appreciating not only the African body but the African mind as well. She believed it offered young women richness and that through embracing the sociocultural matrix that constructed her African identity, her younger self would be able to embrace the physical challenges that it might endure in the future.

Letter from Thandeka to her younger self

Letter entitled: Reflections

Dear Self,

Haha, where do I even begin? There is so much I wish to share with you today. Don't even know if this is appropriate or if you will believe any of the things I am about to say. Anyways...

Do you remember when you were young and I used to always look at you in the mirror in disgust and ask you why you didn't have a bigger butt, bigger breasts, taller in length and brighter teeth like all the cute girls at school? I remember you used to cry within me and refuse to believe me. Instead, you would always want to read and listen to stories of people who had disabilities. Such stories always made you feel better as you always saw yourself in a better condition. Well. Fifteen years later I would like to apologise. I swear you were right. You and mom and all the motivational speakers' notes you used to read and listen to were correct and I was wrong. If this was an exam I would have gotten an 'F'. I am truly sorry. Not only am I sorry but I also wish to tell you a few things that I have realised in the past five years.

Firstly. I love you. Yes, you. You may be surprised to hear these words from someone who has considered to do anything and everything to change you in the past but truth is, I really do love you.

Secondly, I am sorry. Sorry for never defending you whenever other girls and sometimes guys would say negative things about you and I should smile or laugh while you cried inside me and sometimes screamed to get my attention. I am truly sorry Self. If I could I would hug you tightly and apologize in person but for now, this is the best I can do. Please find it in your glorious heart to forgive me.

I am also sorry for the days I starved you. The days I forced you to take weight loss pills and all sorts of chemicals that would change your shape. Even for the days, I spent at the gym not for the sake of keeping you fit but in an attempt of getting you to lose weight. Again I am sorry.

Thirdly, and I probably should have begun with this as I feel it was my harshest and most inconsiderate thing I ever did to you. Well, I am sorry for the weeks and months I

squeezed tissues and pantyhose to increase the size of your breasts. Those days I thought breasts were all that women needed to boost their confidence. But today as I sit here with tears flowing endlessly I would like you to know that I love your breasts the way they were. I believe that were perfect for you. They may not have been as big as our best friend's but they were enough to nourish your son who breastfed exclusively for a year. Your breasts have healed your son's infections and even eczema. Now I have heard of the wonder of the world and don't get me wrong you had your own faults and at times you would ache a few days before our monthly periods but you did not give up on me.

Remember those days when I would wear big tops just so I could hide. I'm sure you noticed how all the beautiful girls would wear nice tight tops just so they could show off their 34 D cup breasts and all I would do with you was to wear anything and everything that could cover you so I would not be noticed as the girl who had small breasts.

I hope you haven't forgotten all these incidents as they have made you who you are today. They have shaped every part of your being and I now celebrate everything about you. I know this may come as a surprise since you are still mourning the loss of your breast, hair and even the eyebrows that never grew again. You are probably wondering what is there to love since you are now incomplete. You have lost some of the parts that made you attractive and feminine. But I want to assure you that to me you are even more attractive. You are even more beautiful. To me, you are everything and more.

I see you blushing. I love you are you like this. Blushing. Not because someone has complimented your smile or even your looks but today you are blushing as you realise that I have found true beauty in you. You now see that I realise my mistakes and I am doing all I can to keep you fit. My life is now about keeping you in shape so you can be proud of yourself and be confident. I love you. You are perfect. The world will always see you as imperfect especially now that you are boobless. But to me, your beauty has increased. You have blossomed. You have grown a boob in your brain. Ha ha ha. Yes, I believe you have. I mean how else would I have learned to love and appreciate you.

I so wish I knew back then what I know now. I wish I appreciated you more. I wish you could teach the future generations what you have taught me now.

May you live long to see another women who will be even more loving and confident than me.

Love,

The Better Woman You have Created.

The above letter makes reference to *bigger butt, bigger breasts, taller in length* which from the information gathered and documented in the third chapter of this study alludes to African assets. Hence, one is led to assume that in writing this letter Thandeka was advising her younger self against the popular belief that she and other participants have shared about body image. In the third chapter, this study described how young African women aspired to maintain certain body features as they believed that these features represented their uniqueness as Africans and that such features were found to be attractive by Black African men. Having described the importance of marriage within the Black African socioculture and religious beliefs, this study concluded by arguing that even after invasive breast cancer treatment, young women still wished to identify themselves as sexual beings with an ideal body image as African queens. Through her letter, Mpho unconsciously encouraged her younger self to reconstruct her ideologies of beauty and a positive body image.

Letter from Zee to her younger self

Letter to me: Baby Zee

Dear Zee,

You should thank a lady called Nokwanda for I do not think would have bothered to do this. Yes, I see the need to do this because it seems like closure. You know I have never been a cry baby but I will do my best to say everything that has always been in my heart.

Firstly, Black girl you are beautiful. With your flaws and all.

There is and there has never been anything wrong with you have always been everyone's favourite that why grandma named you Ntandokazi. The only name I have ever heard of that suggests that you are a favourite. You are a special Black girl.

You may wonder why I keep calling you Black girl but I have my reasons and they are based on what happened in the past. How I have tried to change you. From changing my African accent to always tweezing my bushy eyebrows to painting my lips and to always wearing an oversized bra just to make it seem as if my breasts were bigger. Without a doubt, this added volume to my appearance. I turned heads of every boy in high school but not even one of them is still with me or even contacts me to check on how you are doing. Even worse there have been days in the past where I wish I could contact at least one of them to transport me for my consultations but I have never because I have been too ashamed of the fact that I was fake. Now they will see the naked me. The real me. The real Black girl that is no longer a yellow bone that has lost all power and confidence when it comes to me. The Black girl that no longer has boobs to attract men.

Remember that guy, yes that one whom I loved so much and could not wait to get married to. The one who bought me lingerie for valentines and took me to his fancy home in Chesterville. Yes, the first guy we ever truly fell for. The one I gave up my virginity for. Yes, Charles. Remember the day we met him and he smiled and walked away with his wife who looked like me in high school? Yes, that's the guy I am really sorry for introducing you to. He promised you the world but was unable to at least give you a centimetre of your heart. One he learned about your abscess and the pains you had on your armpits, he ran away. I think he even changed his number because he knew my friends were going to contact him. I guess he also believed that I was infected with HIV, Lord knows who and where because I was always faithful to him. Anyways let's get back to the point of this letter.

Black girl you are a cancer survivor and not an HIV survivor understand the two. You need to remain positive and always know that your appearance is not who you really are. What is more important is the person within you. Like your inner beauty. I know you probably thinking 'oh here comes Zee again with her so called wisdom' but I am being serious. You are one of a kind and I know of many women who went through chemo and never came back. But you Ntandokazi, you made it. You came back. You hardly look the same with your new skin colour and fake breast and fake nails but I would not change anything about you. I mean I know I used to blame you about Charles but looking at it now I realise just how little I knew about you and your strength. I mean in varsity our friends used to drop out of school and stay at home just because they

broke up with their boyfriends but you have remained strong even when everybody thought you had HIV and even family members did not want to be with you.

I am so proud of you Black girl. If I could I would tell you every day and assure you that you are so much better than you were. And if I could go back in time and change anything about the experiences we have gone through I wouldn't because I have realised through counselling and being part of Sinothando that I have been going through emotional growth and that I am the best to have ever existed. All this has happened to me because I am strong and I can do a lot of things with God of course.

I hope I get to live longer to experience even more challenges and growth. I hope you will always remind me how far we have come. I hope you will be strong to advise the future generations who may go through cancer, to advise them and remind them that cancer cannot be avoided like HIV but you can live through it without hesitations. So long as you remember what is important. And that is loving and appreciating yourself even when everything has turned sour and you no longer look and feel the same.

Remain strong and don't forget that while your changes may have caused some people to leave you, better people have entered your life and none of them are interested in your outward appearance but they all live each day to learn something new from you. So Black girl continue loving yourself and stop looking back for you are loved enough already.

Letter from Amanda to her younger self

Letter to the 18 year old me

Today you turned 18, you became legal. You can now make your own decisions. You can even go to the bottle store congratulations.

I have seen you grow and mature. I have seen you fail and pull yourself up again. I have seen you soaking your pillow with tears but I have not yet seen you respecting and appreciating your body the way you should. You last had a good body exercise at the age of 16, since then you have been up and down chasing after guys and trying to please everyone. I have even heard your thoughts contemplating how you will get tattoos on your breasts and neck. You have been saving for the past three months just so you can

afford to get inked next Friday without the parents' consent. Of course, your dad has tried to stop you from piercing your belly, nose, and tongue and you have never forgotten to tell him that this is your body and that their responsibility as parents is to fund anything you want to do all the times as you did not ask to be born. You are their full financial responsibility.

Guess what you are right. You have full authority over your body but oh but!!! You do not think beyond today. If you did you would be wondering how your parents would feel should you get infections from all the fake jewellery you keep adding on your body?

You know I have seen and heard of people being ill and some even dying due to illness. I guess this doesn't really matter because your mom and dad have shielded you from the realities of life. Maybe if they had taken you Port Shepstone with them when your aunt died of TB you would much deeper respect for life instead of going about life in any way. You have been so reckless and the company that you keep is no different. I fear for you. I fear that someday you will wake up with the parents you disrespect gone and you will realise just how lonely life can get when you have no one you to give love to. You have been advised a number of times to take better care of yourself. Your mom had even had to get you on a contraception pill because she fears that the lifestyle you lead may lead you to unplanned pregnancy. I bet you had no idea what those vitamins from your mother's friendly nurse are for. Well, they are contraceptives. If your mother could she would also buy you condoms just so you do not get sexually transmitted diseases. I so wish I you could read this letter so you will make wise decisions now so you can be a better in future. A person that your parents can be proud of and a person whose past you will not be ashamed of sharing about.

But I understand. I am now 36 years old and I fully understand why your parents were so concerned about you. Why they are already trying to save you from yourself. Please listen to everything that they say. You don't have to believe much of it but through listening to them you will be able to learn and find yourself. You will realise what is important and what is not. You may be wondering why your mother is forever checking your breasts and timing your weight gain and loss as well as your appetite. Well, it's because she has learned a lot through losing friends and family members through a number of diseases and what she's mainly doing now is to try and protect you from

getting sick. Hope you now understand why she is so straight and why she said no to the Mozambique trip that you were planning with your friends.

Have you realized how much your family spends on food? How much they buy food that is considered to be healthy. How they have always forced you to eat dried fruits instead of chips and all the other sweet things. Yes, it's because they care for you and they understand that you only have a chance in life. Just last week you asked your parents for a new set of underwear and your mother bought you five sets from Woolworths. Instead of appreciating all they got for you, you complained and said you would rather get cash and money. How I wish you did not return the sets she got you. Who knows maybe they could have saved your breasts. Maybe they would have been so comfortable that your breasts would have been saved from cancer. Who knows....?

I will leave it here for I do not wish to sound like a preacher to you.

I love you.

Similar to the letter by Mpho to her younger self, the above two letters make specific reference to young Black African women. However, the letters speak to the younger self from the perspective of self-respect which can be considered as an important aspect of the Black African culture. All four letters make reference to self-love and respect indicating that this is a quality that was lacking for the young women. Also, the younger women were encouraged to be respectful which in a sense proposes and prepares them for the challenges that they may encounter in the future. It is arguable that the young Black African women would have achieved a different form of social identity should they had been mindful of the issues that have been highlighted as important in their letters. Similarly, Deaux (1996) asserted that each person has many different identities and attributes linked to gender, ethnicity, professional status, weight, parental status and these have an impact on self-concept. The above letters are examples of the fluidity of the young women's identity.

8.4 Conclusion

In reading the letters that participants wrote to their younger selves and listening to the poem entitled 'My body', I realised that after losing their African assets, the young Black African women needed to reconstruct and interpret the idea of having an ideal body image. Through the letters, we begin to see that the older women had achieved a different sense of identity, one

that included loving and respecting their bodies even when they were no longer 'ideal'. Having learned of what is believed to be the ideal African body for young women and in deconstructing the above letters, one may argue that losing African assets, reconstructed the manner in which the ideal body was known and understood by the women after having gone through cancer and its evasive treatment.

CHAPTER 9: CONCLUSION

9.1 Introduction

This chapter reviews the fundamental findings and arguments of the study illustrating that the study successfully achieved its primary objectives which were to:

1. To determine a sociocultural understanding of reconstructive breast surgery for young Black women
2. To determine the relationship between breasts and sexuality for young Black women.

The discussions in this chapter also reiterate issues pertaining to the young women's understanding of their bodies prior to cancer and its treatment, family and spirituality related challenges in choosing treatment and the women's understanding of their sexuality and body image as breast cancer survivors. Particularly, this chapter also discusses the challenges I experienced in constructing and conducting this highly qualitative study. Finally, the chapter discusses the contributions of the study by summarising findings related to its key questions.

9.2 Summary of findings

The study provided a contemporary contextualisation of the challenges that young Black African women face once they are diagnosed with breast cancer. It focused particularly on young Black women between 24 and 40 years living in Durban, South Africa. Using the interpretative paradigm and social construction theory, this study analysed the young women's understanding of their bodies as African assets before and after breast surgery. The study revealed that young women understand their sense of self and sexuality differently after undergoing invasive breast cancer treatment. Due to limited knowledge, most of the women discovered their cancer status at a late stage which limited their breast conserving treatment options. As result, all the women who were sampled had had a single or double mastectomy. The findings resulted in these women experiencing challenges as they attempted to renegotiate their self-image as their physical appearance and especially their breasts, were shaped differently compared with their peers.

During the course of this research, young Black African women revealed that prior to being diagnosed with cancer they possessed a sense of confidence and self-worth. While this may be

true for some women, the participants of this study illustrated that this self-worth was linked to their African assets which they believed were important as they made them attractive to Black African men. This was mainly constructed by their sociocultural upbringing, which emphasised maintaining body features such as a plump body to be considered as a sexy and desirable young woman. The young Black women also shared that they had been content with their body images and especially with their breasts which they highlighted as the main sense of attraction when it came to romantic relationships. These women described themselves as African queens possessing African assets prior to experiencing side effects of treatment. Chapter 4 of this study described African assets as body features that the survivors considered being unique to Black Africans. These included having big and sexy breasts, plump bodies, round stomachs, big breasts, full and muscular buttocks and muscular legs as opposed to thin legs which they referred to as 'toothpicks'. These bodily features, while not unique to women, were said to qualify Black African women as 'African queens' and were features that African men found irresistibly attractive. This led young women to interpreting their beauty based on their physical attributes and believing that women who fitted the 'African queen profile' were most likely to receive marriage proposals.

In an attempt to understand the women's construction and their sexuality prior to being diagnosed, this study revealed that it was possessing features such as these that made the young Black women feel sexy and able to attract men. While this did not mean that the women who did not possess the so-called African assets were not considered marriage material, the participants mentioned they felt the men that they were intimately involved with preferred women with bodies with these assets. Hence, in interpreting their sense of identity as beautiful and sexually attractive beings, the young women used the wider African society's construction of beauty. Also, the women were conscious of their role (which included being married and procreating) within the Black African cultural matrix; as a result, they pursued measures to maintain their role in society. This was evident in the women's attempt to maintain their fertility through traditional medicine.

Bodily changes due to cancer were said to be traumatic for the young Black women. All participants shared how they were dissatisfied with the outcome of their treatment. The treatment was said to have had a very negative impact on the women's appearance often leaving them with a poor sense of self.

Apart from altering physical appearance, cancer treatment led to women losing their ideal body images and sense of sexuality. The following were some of the generic yet differently constructed changes that the women felt strongly about:

- Breast surgery – removal of one or both breasts,
- Loss of hair,
- Menopause, and
- Depression.

From the above, it appears that women were concerned about the physical changes that they experienced. While such experiences often are discussed in relation to body image, much concern and focus was also placed on how the changes affected the women's sexual relationships. The physical and emotional changes that were experienced by women were not uniquely Black, meaning that they were universal challenges that affected most cancer victims. However, what made the case of Black African women unique was the construction and interpretation of the perceived side effects. The majority of the women and their families first thought their illnesses were due to the ancestors wanting to be appeased. Also, most of the women sought traditional health care and spiritual intervention which indicates that they were socialised into believing in higher beings.

Emotional changes were also discussed as women revealed that they felt stressed and depressed by the changes and pain from the cancer. For many, this stress manifested as depression. Loss of hair was also cited as having had a traumatic impact as to some, hair was part of their pride and it added to their African beauty. Some women had initially taken their hair for granted, but for all hair loss due to chemotherapy had a negative effect on how they perceived themselves as women. One participant first started losing her hair while her daughter was playing with it, which depressed her as she felt she had not considered how her daughter would feel. Also, the issue of hair loss brought about unfavourable memories for the young Black African women as some were led to recall of their unfavourable childhood experiences of haircuts due to death of a family member. Most importantly, hair loss meant that the young women's illnesses were exposed to their communities. Cancer treatment had an unfavourable impact on young Black African women as it challenged their body image and sexuality.

Losing one or more African assets (big breasts, fuller and muscular buttocks and muscular legs) led to the young Black women to lose their sense of body image and confidence. This study

revealed that their confidence was heavily reliant on how society and especially their sexual partners appreciated their bodies. Hence, the young women socially identified with each other. Thus, these women devised means of re-enhancing their self-worth after treatment. Some resorted to wearing wigs and using make-up accessories to disguise their losses. Even though some had not appreciated this artificial look, they felt it was a viable option as they did not want to draw attention to themselves. Renegotiating their romantic and sexual lives was said to have been problematic for the survivors as the treatment had led to a low sex drive and sometimes vaginal dryness. These unfavourable changes led to some of the partners assuming that the women had lost interest in their relationships and marriages. For one woman, she felt her value had depreciated as her husband had gone to the extent of openly replacing her with another woman as he felt she was no longer interested in him. What is also worth noting is that some women experienced sex-related changes prior to starting treatment as their sex drive had decreased. Also, the women complained of receiving limited support from 'Western' health practitioners during this challenging time. Women shared that the nurses' responses towards their sexuality concerns were usually based on the assumption that the symptoms that the women were presenting and complaining of were very common amongst women, regardless of their health challenges. The women felt their cases were not properly looked into and the women were also not psychologically prepared to deal with infertility.

All the women attempted to renegotiate their sexuality. During the process of collecting data for Chapter 8, I discovered that the young women's interpretation of being sexual beings and being attractive had been redefined. The women, while they had initially shared that their appearances made them feel like African queens and that they felt very sexy and of marriage material, changed and showed a certain level of maturity towards the end of this study. In the eighth chapter, this study reported on the changes in how women defined and understood the term 'African assets'. In this, women shared that while they no longer considered themselves to be sexy and as African queens, they were confident with their new mental spaces. This meant that they were proud to be survivors and were able to appreciate their current body image and lifestyles. They had learned to appreciate themselves and especially their bodies even more. As seen in the opening poem that was written and recited at the beginning of a group discussion, this study's participants had a greater sense of ownership of their bodies after the treatment and its side effects. What is also to be noted with respect to some of these women was their positive attitude towards their lives after cancer. 'Renegotiation' was not limited to enhancing their beauty; they were also proud of having overcome life-changing challenges.

Sociocultural expectations played a major role in how these young Black women understood themselves as individuals, partners and family members. As part of their socialisation, women were led to believe that ‘real’ women could be seen through their appearance, through their African assets. This ideology was said to be exclusive to Black women as they were believed to be different from other races. Also, participants shared a common understanding of how Black men chose their partners, with African assets as paramount as Black men were looking for African queens. Having African assets was therefore seen as a sociocultural advantage as women who possessed them were believed to be at an advantage in terms of marriage prospects.

The influence of social and religious culture also appeared in understanding illness. Some of the women shared that their families accused them of being bewitched especially since cancer was an illness that only presented itself externally after having spread inside the body. This study learned that some women had even assumed that it was their partner's mistresses that had bewitched them when they are started having sexual problems. In their individual stories and experiences, women indicated that they consulted with prophets and traditional doctors with the aim of understanding their illness and what was causing it. Even the participants who had a working knowledge of cancer and its effects shared that they had consulted traditional healers and spiritualists for a better explanation of the possible causes of their illness. Some consulted with traditional doctors before seeking professional health assistance. This often led to women believing that they had been bewitched or that their illnesses were the work of their ancestors who were required to be appeased or who had called the women to become traditional healers. For the majority who were influenced by friends and family members to seek traditional assistance, diagnoses occurred at a late stage, often when women had reached stage 2. The belief in witchcraft was also considered as an influence of culture in this study as women could not explain their circumstances without saying ‘that is how it has always been done in my family’ or ‘that is how it is done in my culture’. This influenced how women cooperatively constructed and interpreted their self-images after treatment.

In this study, self-image was beyond the external appearance of women and was linked to women saw themselves in all aspects of their lives. This included their appearances and mentalities that defined them as women. In renegotiating their images of self, this study also witnessed the role of cultural identity and sociocultural expectations in how women chose to conduct themselves. In reporting on the challenges of having to hide their bald heads, this study learned that wearing head wraps was not ideal for some participants as they were not used to hiding their hair. Women who were married shared that they were compelled by their culture

to always have their heads covered as it was considered as a sign of respect. This cultural practice was said to have relieved some of the survivors from having to explain to their in-laws about their treatment's side effects. Collectively, women associated their symptoms and diagnoses with their culture and traditions. The cultural matrix played an influential role in the women's understanding of their self-image, body image and as women in society.

Fertility is essential for young Black African women; it was regarded as an important sign of their femininity. Some women shared that their partners would only consider marrying them after they had proven to be fertile. As described in Chapter 3, some women had initially mistaken breast cancer symptoms for pregnancy symptoms. This led to mixed feelings, but in all the participants infertility brought about by the cancer treatment later was experienced with great difficulty.

The participants tried to improve their fertility chances in different ways including traditional healers, holy water and prayers by their church bishops. The pressure that was placed on women to conceive was very evident. Pregnancy was not only important for the married women in the study; having a child was also seen as an important stage in a pre-marital relationship as some women believed that through pregnancy (and proving they were fertile), their partners would make a marriage related commitment.

The topic of menopause was also discussed by the women with some originally misinterpreting symptoms for normal fever. Ultimately menopause, brought about often by cancer treatment, leads to infertility. Women who were initially eager to become mothers at the beginning of the study shared that they later realised the disadvantages of conceiving after cancer and were concerned their children could carry the cancer gene. The issue of having no breasts was also problematic in terms of pregnancy after treatment.

In this study, a sociocultural understanding of reconstructive surgery for young Black women was also developed. Discussions on reconstructive surgery and treatment played a role in understanding how women understood their bodies and sexuality before and after surgery. Body images were significantly affected by treatment and surgery. It was evident that there was a significant relationship between breasts and sexuality for young Black women. They shared experiences of feeling sexy and being treated as African queens, and the important role of the breast in romantic relationships was evident.

9.3 Contributions of study

At the beginning of this study, it was mentioned that there is very limited literature concerning Black African women. Available studies have focused on other ethnicities; these include Christie, Meyerowitz and Maly (2010), Martínez-Ramos (2009), Jacobson, Workman and Kronenberg (2000). These studies having limited inclusion of the topic pertaining to how young Black women renegotiate their sexualities after cancer. While there is a rich pool of studies pertaining to cancer as a whole which focuses on treatment and its effects, there was little dedicated to young Black women. Even on the topic of sexuality, young Black women's views have not been represented. This led to difficulty in comparing other studies and with the women's experiences in this study but it also served to make this study's contribution more appreciable.

This study's first academic input can be linked to its focus on Black women. Choosing Black women was a conscious decision which was led by my own observations and interpretations on how Black women understand their bodies. To provide a unique contribution, I felt the need to focus on Black women specifically. Through the literature review, I realised that breast cancer not only affects women's appearances but their sexuality also comes into question. Hence, it was important to uncover the relationship between breasts and body image for women who were historically known not to hide their breasts, especially for cultural ceremonies. It was interesting therefore to explore how young Black women understand and feel about their bodies when their breasts are no longer part of them. In this aspect, I believe this research has made a significant contribution. Topics concerning sexuality and body image are popular within the anthropology of the body discourse (Maksimowski, 2012 and Anderson-Fye, 2012). However, there is limited representation of Black African women who have undergone breast cancer treatment.

The study has also explored the role of traditional beliefs in engaging with illness. While this was not the main objective of this study, it clearly contributed to the uniqueness of experiences that are shared by Black African women. In listening to the women attesting to how they looked for guidance from their ancestors, this study deduced that in general, ancestor worship is important as are the powers of traditional healers for Black African women. This was found to be unique when compared to the majority of patients in other studies who only used western medicine to find answers and healing for their illnesses. This study therefore also makes a

valuable and unique contribution to anthropological studies which consider the role of culture in understanding illness.

By strictly focusing on women who are breast cancer survivors, this study was able to explore in detail the link between body image and sexuality for young women. As there are already libraries of research comparing men and women's experiences in health, this study prioritised women. While it may have enriched this study to discuss the experiences of men with partners who are breast cancer survivors, it may have diverted the focus from the women's understanding of their bodies and sexualities to how their partners feel about their reconstructed bodies and personalities. Hence, through this study Black women alone were given an opportunity to express themselves.

This study focused on how women understand their bodies and sexualities before and after cancer treatment. It emphasized and prioritised women's perceptions over the researcher's. In reading and summarising the research gaps that were revealed through collecting and reporting on this research, I have developed three major recommendations which I believe would make a healthy contribution to understanding challenges faced by women with respect to breast cancer.

The findings of this study revealed that there are a number of topics and demographics that need further attention in the study of women. This study sample was limited to women aged between 24 to 40 years. In looking for potential young Black African women to recruit, I realised that the majority of cancer victims were aged between 40 and 65. It was assumed this particular age group of women would not have had the same collective interest in their body image due to their age, yet they expressed their disappointment when they learned that they could not participate. There were also potential participants younger than 24 years old.

Also, in conducting this study I realised that studies concerning diseases such as cancer should not be limited to certain cities. A group beyond the province of KwaZulu-Natal could have shared the experiences of women who believed in a greater number of cultural and traditional belief systems. The findings of this study also revealed that it would benefit the discipline of anthropology and enrich the anthropological discourse to engage further with this topic of the sociocultural and traditional beliefs of women. There is also room for studies that focus on the influence and impact of traditional medicine in dealing with infertility for women who experience premature menopause. This theme resonated extensively in this study but due to time constraints, I could not probe it fully.

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Appendices

Appendix 1: Interview Questions

1. What is your understanding of an ideal body? Sexy body? _____

2. What is your understanding of women as sexual beings? _____

3. What is the function of breasts in a woman's body? _____

4. Do you think this function differs according to 'race' and age? Please explain. _____

5. Some people regard breasts as a sign of womanhood, do you agree? Please support your answer. _____

6. Do you think there is a link between breasts and sexuality? Please support your answer

7. What is your understanding of breast cancer? _____

8. How old were you when you were diagnosed with breast cancer? _____

9. Who was the first person you told about your illness? _____

10. How did your family respond to your illness? _____

11. Did the diagnosis affect your relationship with other women? _____

12. Were you in a relationship when you were diagnosed? If yes, at what stage did you share the news with your partner? _____

13. How did your partner respond? _____

14. Can you describe your body image prior to being diagnosed with breast cancer? _____

15. What cancer treatment did you undergo? _____

16. What has been the impact of the treatment and breast construction surgery? _____

17. Can you describe your body image after treatment? _____

18. How has your body image been affected through the treatment and or surgery? _____

19. How do you think society sees you now that you are on remission? _____

20. Has the impact of treatment made you more or less of what society calls a 'women'? _____

21. What measures have you taken to reaffirm your body image? _____

22. Do you consider yourself as a sexual being? _____

23. How can women reaffirm their sexuality after breast cancer treatment? _____

24. Do you have children? _____

25. Has breast cancer and its treatment changed your perceptions about motherhood? _____

Thank you

Appendix 2: Focus group interview

1. What is your understanding of an ideal body?
2. What is your understanding of women as sexual beings?
3. What is the function of breasts in a woman's body?
4. How has breast cancer affected your life?
5. How has breast cancer affected your 'sexual-self'?
6. What has been the greatest challenge in dealing with breast cancer?
7. How did you decide on the treatment and surgery? Who assisted you with this decision?
8. Has your romantic relationship been affected by your diagnosis and surgery?
9. How do you think your partner feels about your body after surgery?
10. How do you feel about women having children after surgery?
11. How has breast cancer and its treatment changed your understanding of your body and value as a woman?

Appendix 3: Informed consent (isiZulu)

Usuku:

Sawubona

Igama lami nginguNokwanda Nzuza, ngivela eUniversity of KwaZulu-Natal, kwaAnthropology. Ngitholakala ku-yoliswanzuza@gmail.com.

Uyamenywa ukuna ube ingxenye yocwaningo olumayelana nesifo momdlavuzo webele, ukubukeka komzimba Kanye nezindaba eziphathelene nocansi. Lolucwaningo lizobhekana nezingqinamba abesifazane ababhekana nazo emva kokuhlinzwa amabele ngenxa yomdlavuzo. Lolucwaningo luqonde ukuba nabantu abangu15 abayinxenye yeSinothando. Uma uzibandakanya uzocelwa ukuba uphendule imibuzo futhi uvakashelwe yini. Lolucwaningo luzothatha unyaka owoyithile, uzocelwa ukuba ube ingxenye kuze kube sekupheleni.

Lolucwaningo lungase lubeke encupheni futhi lungehli kahle kwezinye izimo njengoba kuzomele ukhulume mayelane nokugula kwakho. Ngiyathemba ukuthi luzokunika ithuba lokuxoxa ngezingqinamba owabhekana nazo futhi uthole ukusizakala uma uzwa abanye bexoxa ngezinto abadlule kuzo.

lolucwangingo lugunyazwe i UKZN Humanities and Social Sciences Research Ethics Committee

Uma kukhona inkinga onayo ongabashayela kulezizinombolo ezingezansi.

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

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Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Ukuzibandakanye kulolucwaningo kumakhala ngakho ungayeka uma ungazizwa kahle noma ungakuphenduli ongazizwa kahle ngakho. Imininingwane yakho angeke inikwe abanye abantu. Igama lakho lizoshintshwa ngenhloso yokukuvikela.

Angeke uzuze imali ngalolucwaningo. Kuzohlenganyelwa ezindaweni eziseduze nawe.

ISIVUMELWANO

Mina _____ ngiyazibandakanya kucwaningo olubizwa ngokuthi 'Renegotiating body image and sexuality after surviving breast cancer: Narratives of Young Black African Women' esenziwa nguNokwanda Nzuza.

Ngियाqonda ngalolucwaningo

Nginikiwe ithuba lokuphendula imibuzo ngagculiseka.

Ngiyavuma ukuthi ngiyazibandakanya mahhala futhi ngियाqonda ukuthhi ngingayeka noma inini.

Ngazisiwe ngemikomele etholakala kulolucwaningo.

Ngiyazi ukuthi uma nginemibuzo kumele ngishayele: yoliswanzuza@gmail.com

Uma nginemibuzo ngingaashayela laba abangezansi

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Email: HSSREC@ukzn.ac.za

Ngiyabuma lokhu okulandelayo:

Ukuqoshwa kwengxoxo yami ngedwa yebo/cha

Ukuqoshwa kwevidiyo yebo/cha

Ukusetshenziswa kwezithombe zami yebo/cha

Signature of Participant

usuku

Signature of Witness
(Where applicable)

usuku

Signature of Translator
(Where applicable)

usuku

Appendix 4: Informed consent (English)

Dear Potential Participant

My name is Nokwanda Nzuza from the University of KwaZulu Natal, Anthropology department. My contact details are as follows: email- yoliswanzuza@gmail.com.

You are being invited to consider participating in a study that involves research on breast cancer, body image and sexuality. The aim and purpose of this research is to investigate the challenges that young women are faced with as they attempt to reaffirm their body image and their sexuality having undergone breast cancer treatment. The study is expected to enroll 15 participants who are part of Sinothando support group meetings. It will involve the following procedures: individual interviews, visitations and focus groups. The duration of your participation if you choose to enroll and remain in the study is expected to be one full year.

The study may involve the following risks and/or discomforts: individual sharing of health journey and group meetings with other survivors. We hope that the study will give you the opportunity to share your experiences with other survivors and enable you to learn from their health journeys.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee

In the event of any problems or concerns/questions you may contact the researcher at (provide contact details) or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

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Email: HSSREC@ukzn.ac.za

Participation in this study is voluntary, you may, at any stage, withdraw from this interview or choose not to answer any of the questions that you may not be comfortable with. For the purpose of this research study your comments will be anonymous unless you request that your personal information be revealed and used. I will make all possible efforts to preserve confidentiality including using pseudonyms and arranging a secure place for data storage. Information gathered through this study may be published in academic journals and presented orally. But here too your confidentiality will be maintained.

Lastly, you will not incur any costs during this study. All interviews and focus groups will be conducted in accessible venues.

CONSENT

I _____ have been informed about the study entitled ‘Renegotiating body image and sexuality after surviving breast cancer: Narratives of Young Black African Women’ by Nokwanda Nzuza.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at yoliswanzuza@gmail.com

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

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Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Additional consent, where applicable

I hereby provide consent to:

Audio-record my interview / focus group discussion YES / NO

Video-record my interview / focus group discussion YES / NO

Use of my photographs for research purposes YES / NO

Signature of Participant

Date

Signature of Witness

Date

(Where applicable)

Signature of Translator

Date

(Where applicable)