Masters in Anthropology – Research Report

“Getting it off my chest”: Exploring the Lived Experiences of Breast Cancer Diagnosis and Treatment in Women of Reproductive Age

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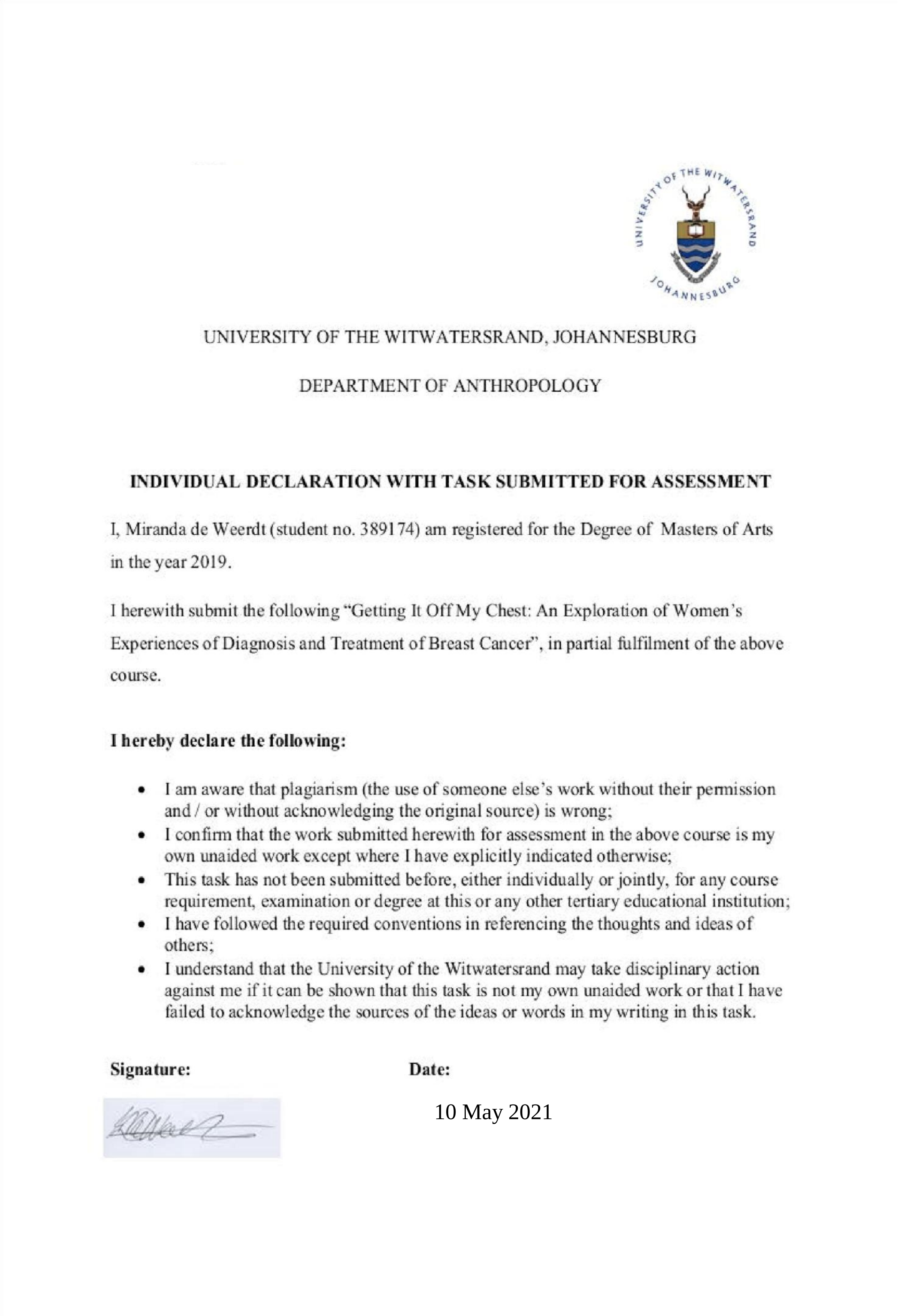

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

DEPARTMENT OF ANTHROPOLOGY

INDIVIDUAL DECLARATION WITH TASK SUBMITTED FOR ASSESSMENT

I, Miranda de Weerdt (student no. 389174) am registered for the Degree of Masters of Arts in the year 2019.

I herewith submit the following "Getting It Off My Chest: An Exploration of Women's Experiences of Diagnosis and Treatment of Breast Cancer", in partial fulfilment of the above course.

I hereby declare the following:

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- This task has not been submitted before, either individually or jointly, for any course requirement, examination or degree at this or any other tertiary educational institution;
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10 May 2021

Abstract

It is not easy being diagnosed and treated for breast cancer, as a diagnosis of breast cancer can cut to the very core of what it means to be a woman. In this study, I focused on the experiences of women of reproductive age who had been diagnosed and treated with breast cancer. After conducting interviews with 14 participants – including biomedical practitioners, members of various support-groups involved in guiding women through their journey, and women two to three years post breast cancer treatment – I was able to gain a better understanding of what Audrey Lorde meant by her expression ‘breast cancer warrior’. Common themes of these women’s interviews draws attention to delays in initial diagnosis premised on the age of the participants, the result of misconceptions, and perceptions of breast cancer in South Africa. Women’s journeys included diagnosis, treatment, adjuvant therapy, and how their experiences of these affected their lifestyles and their understanding of future life trajectories. To the extent that society places significant importance on outward appearance, women’s loss of identity due to alopecia and/or mastectomy, or their sense of narrative disruption, was significant in the overall experience. I also consider the role of various support systems in helping women come to terms with their new identity as survivors.

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Acknowledgements

Many times throughout this year I did not think this project would come to a conclusion. Only through the help of some amazing people was I able to complete this thesis. I would firstly like to thank my supervisors, Dr Caroline Coary Taylor and Professor Lenore Manderson, who dealt with my insecurities on various occasions. I especially thank Andrea Johnson and Molefi Makola in the Wits Department of Anthropology, who were my cheerleaders throughout this project, and believed in me, even at times when I didn't believe in myself. Thank you to my friends who read my work and provided much-needed guidance when I felt that I had nowhere to turn for help. My classmates were an amazing group, and if they did not always understand the nature my work, they were there when I needed them. Thank you to all members of the Department of Anthropology: you have taught me so much and I am indebted to you.

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Finally to the participants, Carol Benn and her team and the other biomedical staff who were willing to speak to me - you accepted me with open arms and readily discussed your experiences with me. I would like to thank Christine and other people from (i) the Breast Health Foundation and (ii) Look Good Feel Better with whom I consulted about their organisation's work and their experiences of breast cancer. Your stories have inflected my own journey in a way I will always value.

Chapter 1: Introduction

For women, a potential breast cancer diagnosis challenges both her sense of identity as a 'woman' and can challenge a hoped-for future as a partner, wife and mother. The word cancer elicits dread in everyone who is familiar with it. This is because a diagnosis of cancer as an illness, affects the predictability of bodily processes and life security. Western biomedicine has made enormous strides in describing biology of different cancers and developing appropriate ways of managing disease to maximise patient outcome. This is especially true for breast cancer: early diagnosis, treatment and effective care have significantly reduced the risk of early death.

However understanding the historical and contemporary social value of meaning of breasts could help to supplement biomedicine with the appropriate care designed for each woman's individual needs (Boyd 2015). Globally, breast cancer is the most commonly diagnosed cancer amongst women. It has been estimated that women in South Africa have a one-in-nine chance of developing this form of cancer (Lince-Deroche et al. 2017; Reddy et al. 2017). With early detection and prompt treatment following diagnosis, women have a good chance of long-term survival. Modern treatment for breast cancer offers far less external impact on the physical body, however as many women discover treatment following diagnosis does not always signify an end. Rather early treatment often anticipates continuing trauma (MacCann et al. 2010). Women may spend hours in biomedical spaces, their individual bodies objectified by investigation and examination into the causes and effects of their illness. This leads women into a discovery of what it means to be healthy and how health is understood following cancer treatment.

Large disparities in access to care persist in South Africa, as elsewhere in the world. These barriers reflect continuing socio-economic inequalities that derive from an historical context of "colonial subjection and apartheid disposition" (Coovadia, Jewkes Barron Sanders & McIntyre 2009: 817). These historical systems of oppression are responsible for differences in quality of healthcare provided to different socio-economic groups in South African society today. Delay in access to care may include exclusionary socio-economic factors (Lince-Deroche et al. 2017; Reddy et al. 2017), preference for alternative modes of care, and health system factors that influence quality of care, referral delay and delay in provision of surgical treatment, radiotherapy or chemotherapy (Lince-Deroche et al. 2017; Reddy et al. 2017).

Women may feel vulnerable to biomedical care due to language barriers or may prefer traditional healing to biomedical practices. Equally the cost of care may inhibit the use of Western biomedicine. Other historical factors such as racial and gender discrimination, migrant labour and forced changes in family life under colonialism and apartheid all affect access to clinics and hospitals (Coovadia et al. 2009). Cumulatively these factors impact access to Johannesburg's biomedical facilities. In addition, limitations of the South African healthcare system and service-delivery mechanisms prevent optimal timing and access to breast cancer management and treatment (Lince-Deroche et al. 2017; Reddy et al. 2017).

Specific barriers that prevent women from seeking breast cancer diagnosis and treatment include their theologically grounded beliefs and cultural influences as well as the interplay of these beliefs with biological, economic, geographic and psychosocial influences ever-present in their daily lives (Lince-Deroche et al. 2017; Reddy et al. 2017). These barriers are important, as any delay negatively impacts on possible survival (Reddy et al. 2017). In 2001, Vorobiof et al. (2017) describe the current situation of breast cancer in Johannesburg. They show that a disproportionate number of 'black'[1] women presented with locally advanced and metastatic disease and concluded that there was a significant correlation between "patient delay" and the categorisation of the cancer with regards to size, metastasis and the degree of lymph node involvement (Lince-Deroche et al. 2017). The stages of breast cancer (Stages 0-IV) can be differentiated according to the size and location of the tumour (lump), whether the cancer has metastasised to other areas, and how many lymph nodes are involved, if any. The larger the tumour, the more irregular the margins, and the more lymph nodes involved, the higher classification on the stage-scale. The stage- scale indicates the spread of the cancer, and so choice of treatment and likely prognosis.

Low- to middle-income countries are disproportionately disadvantaged, and more than 62% of breast cancer deaths worldwide occur in these countries (Lince-Deroche et al. 2017; Reddy et al. 2017). The availability of advanced medical technologies mainly in the global north drives many global health initiatives that attempt to export these technologies to the developing world (Burke & Mathews 2017). This was the case in the early years of the AIDS pandemic, where many countries in the global north manipulated their foreign policies to fund HIV/AIDS research in Africa (Simms 2007). In underdeveloped countries, resource shortages and lack of facilities limit the effective implementation of global guidelines and therapeutic

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[1] My use of 'black' and 'white' in this research report refers to the apartheid classificatory nomeculture

technologies to poorer populations both in the global north and in low- and middle- income countries (Burke & Mathews 2017). The consequential shortfalls play out differently in different settings, suggesting the need for research on local responses to cancer and the underlying political forces and structural variables that frame individual cancer patient experiences.

In June 2017, Dr Aaron Motsoaledi (South African Minister of Health), introduced the *Breast Cancer Control Policy* with the intent of “increasing early detection of breast cancer, treating breast cancer more effectively, and providing timely treatment and palliative care for invasive cancers” (Health 2017: 4). The policy was constructed to help bridge the gap between public and private breast cancer diagnosis and treatment to offer a universal standard of care across South Africa. As stated in the policy it was specifically designed on the basis of past case studies and data supplied by local biomedical practitioners (Cancer Control Policy 2017). An analysis of the policy helps to clarify the discourse of breast cancer and better understand various perceptions and misconceptions of breast cancer. It is important to note that in my study, 2015 -2016, the participants were diagnosed and treated before the *2017 Breast Cancer Control Policy*. The women selected for my study presented in this report were last treated in 2015 or 2016, as explained below (Chapter 3 page 18). Consequently, the policy was not immediately relevant to their experiences and my findings but a comparison between what is anticipated as a result of 2017 policy implementation and the perceptions of the participants in my study could help to reduce the gap experienced by women seeking care for breast cancer in South Africa.

Research Brief

> *How does the diagnosis and treatment processes of breast cancer affect the lives of women of reproductive age in contemporary urban South Africa?*

This research project aims to describe and analyse the impact of breast cancer diagnosis and treatment of women of reproductive age living in contemporary urban South Africa. I also self-reflexively draw on my experience of breast cancer diagnosis. In my research, I focus on three themes: (i) women’s perceptions and misconceptions of breast cancer, (ii) women’s life trajectories to date and as anticipated by them, and (iii) the effect of bodily changes on their female identity. I specifically investigate how the diagnosis and treatment of breast cancer affect a woman’s potential life-trajectory with respect to personal relationships, use of contraception and ideas about reproduction together with the (re)formation of individual and social identity. I seek to understand how each woman navigated the diagnostic and treatment procedures and the ways in which she navigated both the hospital and oncology clinic environments. I invited women to reflect on their life trajectory and explored how cancer diagnostic and treatment procedures impacted their everyday quality of life. As breast cancer treatment is traumatic (that is, usually with some surgery), it externalises changes that occur on the cellular level in the body.

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Chapter Outline

In the literature review (**Chapter 2**), I identify three core themes in the realm of lived experiences of women of reproductive age diagnosed and treated for breast cancer, perceptions and misconceptions of breast cancer in South Africa, the journey from diagnosis to treatment, and the way in which treatment choices affects each woman’s sense of herself.

I describe in my methods chapter (**Chapter 3**), how the participants in my research are women of reproductive age diagnosed and treated for breast cancer in 2015 and 2016. Medical ethical clearance was obtained from the University of the Witwatersrand. This influenced my access to potential participants as it allowed me access to Carol Benn’s patient files. I selected participants from the patient files who matched my study’s criteria and telephonically contacted them to inquire whether or not they might be willing to participate in my study. From the 15 women who were contacted, five were willing to speak to me. The other nine participants who participated were biomedical practitioners and/or members of support groups involved in the diagnosis of breast cancer.

I present and analyse my data via three analytical themes in Chapter 4, Chapter 5 and Chapter 6 of the research report. **Chapter 4** examines the role of public discourse and its influence on beliefs about breast cancer. Through an analysis of public health educational material in the form of pamphlets, I examined the discourse and ideology of breast cancer. By exploring participants’ own experiences, I examine social and cultural understanding of breast cancer. I offer a reflective analysis of the 2017 South African Breast Cancer Care Policy and compare past lived experiences of the women interviewed with more recent expected experiences suggested in the policy.

Chapter 5 describes and analyses the role of the social body in a biomedical environment. The experience of diagnosis and treatment in the selected public and private health system in my study differs among the participants. Thus, I examine women's accounts of their personal journeys from being a 'healthy' person to becoming a 'cancer patient' relative to a new embodiment of illness.

Chapter 6 examines how changes in the physical body influences each woman's self-identity that typically manifests in a change of identity from 'woman', 'mother', or 'wife' to 'cancer patient'. Each woman's individual experience of treatment is attendant upon a need to control a seemingly uncontrollable biological situation. This reflects a change in each individual's identity that speaks to a new seemingly fluid social status.

Chapter 2: Literature Review

Each woman's experience of breast cancer is different, as she navigates biomedical and socio-cultural spaces to regain control of her identity (Soffa 1994). The promotion of early detection as the best defense against breast cancer in popular media has brought to light the dichotomous nature of breast cancer in being a personal as well as a socio-cultural issue in society (Soffa 1994). According to the National Cancer Registry (2014) it was recorded that 9.78% of the number of new cases recorded were breast cancer in women of reproductive age. In contrast to 4.35% represented by men diagnosed with breast cancer. These figures further highlight the importance of understanding this dichotomous nature in which **a**nthropologists have an important role to play in the understanding of the barriers that prevent women from seeking diagnosis and/or treatment for breast cancer (Burke & Mathews 2017). The fear of diagnosis and treatment underlie many women's reluctance to present for care in the face of a very frank disease (Manderson 2018).

To experience an illness such as cancer is subjective, that is a subjective, that may be completely understood once experienced by an individual (Rosaldo 1993). In *Grief and a Headhunter's Rage*, the social anthropologist, Renato Rosaldo (1993, 2004) discusses how cultural forces of emotion originates from pathological experience. Rosaldo's research among the Ilongots of Northern Luzon, Philippines, particularly highlights a consideration of the subject's positionality in the field of social relations that enables an understanding of deeply personal disconcerting experience(s). He further argues that any interpretations made in the field are provisional and such interpretation(s) are made by situated subjects who are selectively willing to accept certain phenomena but not others. My research findings corroborate Rosaldo's claim with respect to breast cancers. This is due to the semantics significance of a single word e.g. cancer, that can signify the potential loss of an imagined future and the beginning of a journey in biomedical facilities in search of remission. Rosaldo (ibid) research further signals an individual's subjectivity via the interplay of the diagnostic experience and subsequent individual cancer treatment in such biomedical spaces enabling anthropologists to understand the discourse of breast cancer.

The discourse of breast cancer diagnosis and treatment is located in the idiosyncrasy of symbolic femininity. Conceptions of the female breasts is semantically complex in socio-cultural meaning and value(s). Breasts constitute every woman's body image on a personal, social and societal level such that the potential loss of a breast due to mastectomy threatens her identity in these each social spheres (Boyd 2015).

The Breast as Identity

Why does breast cancer have such an impact on women? Looking at the role of 'pop culture' and social media, the value and meaning of the female breast is socially constructed (Manderson Markovic & Quinn 2005). The female breast has both symbolic and functional meanings spanning different time, place and space. Breasts symbolize: self-esteem, body image, beauty, femininity and motherhood (Boyd 2015; Soffa 1994; Kaufert 1998). Breasts symbolize femininity, desire and sexuality while serving as a source of infant nourishment (Boyd 2015; Soffa 1994; Kaufert 1998). These multiple meanings and the cultural values of breast contribute to each woman's sense of herself (Boyd 2015; Soffa 1994; Kaufert 1998). Thus the loss of a breast has a significant psychological effect on a woman, engendering feelings of insecurity, inferiority and fear of becoming undesirable (Boyd 2015; Soffa 1994; Kaufert 1998). The removal of such a symbolically dense aspect of each woman's body to save her life may render her body dysfunctional as both a future mother and – at least in her own mind – as an undesirable sexual partner (Boyd 2015; Soffa 1994; Kaufert 1998).

The threat of a potential cancer diagnosis similar to any other personal or social crisis strips an individual of a sense of inability to control their own life and those of the people for whom they care (Manderson Markovic & Quinn 2005). Thus understanding the value and meaning of breast malignancy can assist health professionals to understand how any woman might react to breast cancer diagnosis and treatment, thereby enabling appropriate timely intervention to be implemented (Boyd 2015; Soffa 1994; Kaufert 1998). A woman's distress can result from her anxiety regarding recurrence, threats to her sexuality and/or social and professional roles. Each woman's everyday health, self-esteem, sexuality, relationships and social activities may all be affected by a diagnostic distress causing feelings of helpless and powerless (Boyd 2015; Soffa 1994; Kaufert 1998). These feelings are exacerbated by any delay in treatment caused by her fear or a belief that the diagnosis is unlikely to be breast cancer, given their youthful reproductive age. In South Africa many challenges are inherent in local healthcare systems for example inadequate government healthcare expenditure and shortage of skilled healthcare professionals.

Consequently South Africa's current healthcare policy focuses strongly on appropriate management of care in establishing localized community-based healthcare (Mbakile-Mahlanza Manderson Downing & Ponsford 2017). For all young women facing early breast cancer diagnosis, fertility needs to be prioritized. Today many healthcare professionals are preoccupied with short-term survival rather than a woman's biological and social future (van der Wiel 2013). It is important to note here, that van der Wiel's (2013) study focusing on a Johannesburg public healthcare facility found this to be the case. In contrast my retrospective study of women's oncology healthcare diagnosis and treatment focusses on two oncology centers – one public and one private. However, it is also true that in many instances young South African women do not consider the necessity of gaining knowledge about their fertility and the possible negation of future pregnancy relative to life-saving treatments (Peate et al. 2011).

Diagnosis and Treatment

Internationally and in South Africa breast cancer is the most common cancer in all demographics and the most common cause of cancer-related mortality (Lince-Deroche et al. 2017; Herbst 2017; Wray Markovic & Manderson 2007a). In an attempt to increase breast cancer awareness and prevention in contemporary South African discourse campaigns; promote early-screening and a healthy lifestyle (Lince-Deroche et al. 2017; Herbst 2017; Wray Markovic & Manderson 2007a). The availability and importance of breast cancer screening is widely publicized. However the lack of knowledge about breast cancer prevention, together with socio-economic and cultural barriers limit the participation of women from lower socio-economic backgrounds (Lince-Deroche et al. 2017; Herbst 2017; Wray Markovic & Manderson 2007a). South African biomedical practitioners Lince-Deroche and colleagues (2017), argue that breast self-examination plays a major role in the early detection of breast cancer. For example in an Egyptian study (2017) found that women who had practiced self-examination presented earlier and with smaller tumors than their counterparts who did not practice the self-examination. Whereas in low-to middle-income resource settings, the teaching of breast self-examination promotes breast awareness and supports general health education (Herbst 2017). Therefore, broader awareness-raising campaigns can complement individual-level interventions promoting greater awareness of breast conditions including cancer, the availability of healthcare, and reduce the stigmatization of woman suffering from cancer. Thus self-examination and clinical breast exams may successfully be used to explore the characteristics of palpable and/or impalpable breast lesion especially in young breasts tissue density that is often used to guide breast biopsy for diagnostic purposes (Bell & Ristovski-Slijepcevic 2015; Drageset et al. 2011; Al-Azri Al-Awisi & Al-Moundhri 2009).

Additionally ultrasounds have been shown to be as good as mammography in detecting invasive cancer, albeit with more false positives such that ultrasound technology can be a diagnostic alternative in resource poor-communities where mammograph equipment is often not available.

Currently increasing cancer incidence and improvement in earlier screening and treatment will continue to increase the number of patients needing long-term follow-up and lifelong surveillance for cancer recurrence (Bell & Ristovski-Slijepcevic 2015; Al-Azri Al-Awisi, & Al-Moundhri 2009). Formerly, Tamoxifen has been recommended to be taken for up to 5 years after treatment for women with hormone receptive breast cancer. However recently it is suggested that the Tamoxifen regime become lifelong so as to prevent cancer reoccurrence. In this biomedical model young women require careful tracking and health system follow-up that includes an annual mammogram, gynecological assessments and routine monitoring of bone density (Bell & Ristovski-Slijepcevic 2015; Drageset et al. 2011; Al-Azri Al-Awisi & Al-Moundhri 2009). A recent study by medical oncologist Rana and colleagues (2017) found that breast cancer diagnosis in young women of reproductive age is typically associated with a poorer prognosis. These researchers argue that poor prognosis may be associated with an inherently more aggressive microbiology which tends to be diagnosed at a more advanced stage (Rana et al. 2017). A result of this, is that the clinical care of young women diagnosed with breast cancer tends to be more complex than for older women with breast cancer (Rana et al. 2017). Although the constant monitoring is deemed necessary in a context of cancer, women who have navigated the cancer diagnosis and treatment journey often become victims of a punitive biomedical system. This reality necessitates social scientific research into understanding why women choose to or do not choose to seek treatment, or to end their annual screenings in a harsh biomedical environment.

Resources

At the time of diagnosis medical specialists look at the specific characteristics of a breast tumour to determine a treatment plan. In simple terms, these tumours may be categorized into two types according to the presence of hormone receptors on the surface of the cancer cells (Medrano et al. 2018). Young women with breast cancer usually present with hormone receptor positive- type cells. This can be successfully treated with hormonal therapy such as Tamoxifen or an aromatase inhibitor, in order to prevent hormones such as oestrogen and progestogen from attaching to the cancer cells and allowing them to grow (Medrano et al. 2018). Unfortunately by limiting these hormones in the blood, women of reproductive age more often than not risk going into early menopause (Medrano et al. 2018). As fertility-preservation treatment is becoming more and more popular, with treatments aimed to protect woman's future reproductive ability by offering fertility treatments such as gamete harvesting and freezing (Medrano et al. 2018). These fertility conservation options are now increasingly prevalent and so young cancer patients need to be aware that this life saving treatment will inhibit ovarian gamete stimulation (Medrano et al. 2018). Consequently insufficient knowledge combined with high treatment costs associated with hormonal breast cancer treatment often incurs decisional conflict that undermines the quality of cancer treatment decision making process. A study by Peate et al (2011) into the psychosocial effects of cancer treatment on life trajectories among young women with breast cancer suggests that timely targeted information regarding fertility preservation may increase in informed choice and reduce such decisional conflict. A Ruddy and colleagues (2014) study at Baston Massachusetts[2] Mayo Clinic found that important factors in fertility-related decision making and prompt referral to an experienced reproductive endocrinologist that included medical aid coverage or personal financial resources reduced patients – doctor decision making conflict.

In South Africa, the majority of the population do not have the resources medical aid cover or financial means to access quality health care, resulting in a large number of women being left without any fertility conservation treatment options due to impoverished socio-economic factors.

Breast cancer and life trajectory

Bodies as socially-constructed entities incorporating the mystical and sacred yet also the stigmatized and the freakish (Wray Markovic & Manderson 2007a). Individual people acquire an identity in relation to illness and developed a percept of normative difference from healthy people (Wray Markovic & Manderson 2007a). Young women of reproductive age diagnosed with breast cancer often experience unique physical and psychosocially constructed problematic issues (Rana et al. 2017). Although post-pubertal, menopausal and post-menopausal women experience similar physical and emotional issues in response to treatment, for example: nausea, vomiting, hair loss and an altered body image, post-pubertal women characteristically experience unique problems including premature menopause and infertility (Rana et al. 2017; Bell & Ristovski-Slijepcevic 2011; Peate et al. 2011). Regardless of individual response to treatment, women of any age diagnosed with breast cancer are primarily concerned with survival (van der Wiel 2013). Yet younger women faced with potential breast cancer procrastinate the diagnostic process due to fear

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[2] The Mayo Clinic in Massachusetts was closed in 2016, but when the research paper was published there were labs located in the city

of the unknown. This results in a significant lapse of time after the initial discovery of a breast lump and their initial diagnosis which may, in many cases, lead to the development of malignancy (Bell & Ristovski-Slijepcevic 2011; Peate et al. 2011). This is not to say, however, that the initial ‘lump’, however small, is not malignant, for in the case of cancer it is not the size that counts but rather deviation from a normative clinical margin.

Chapter 3: Methodology

This research project was to document the lived experience of women with breast cancer. As very little research has been conducted on the lived experience of cancer diagnosis among South African woman the research into their experiences of cancer opened up a conversation about spatial and temporal circumstances of urban South Africa breast cancer discourse. The study explores the experiences and understanding of the diagnosis and treatment of breast cancer in woman of reproductive age. To answer my research question, I focused on women of ‘reproductive age’ between 18 and 35, to allow consideration of salient ideas about fertility, motherhood and the life trajectory of the selected participants.

In order to recruit these female participants, two clinics were identified in the urban Johannesburg area - (i)’Millwood,’ a private clinic, and (ii) ‘St. Beatrice,’ a public clinic – both of which are under the administration of Professor Carol Benn breast cancer treatment specialist. Discrepancies between the public and the private facility enabled a comparative analysis of diagnostic and treatment experience among participants of different socio-economic backgrounds.

Additionally, collection of educational pamphlets on breast cancer from these Johannesburg clinics led me to investigate popular discourse and South African government policy relating to breast cancer diagnosis and treatment. This provided insight into the limited educational resources provided on breast cancer diagnosis in younger women and men. As the risk of breast cancer increases with age, resources for breast cancer patients in South Africa are prioritised for women over the age of 50.

The themes of perception and misconception about breast cancer are explored below (see page 28-35) in order to better understand the differing social and cultural perspectives of breast cancer in Johannesburg. The literature to date claims that mastectomies are the greatest threat to a woman's identity yet participants in this study ascertained alopecia and other side-effects of chemotherapy as significant factors influencing a woman's identity. A conceptual framework is developed using theory grounded in the findings of this research study. Participant's descriptions enabled an *emic* understanding of these lived experience of breast cancer diagnosis and treatment in urban Johannesburg.

Research Methods

Study participants include English and Afrikaans[3] speaking adult women of reproductive age (18-35 years) from any South African demographic group, diagnosed with breast cancer and were three years post treatment[4]. Treatments included chemotherapy, radiation and/or any surgical procedure. All participants received treatment at either Millwood Breast Care Clinic or St. Beatrice Breast Care Clinic. Participants who matched any of the following criteria were excluded from participating in the study:

- Women under the age of 18
- Women undergoing active treatment
- Women with impaired cognition
- Men

Professor Carol Benn approved the study. Access to the clinics and approval from the clinics were contingent on approval from the University of the Witwatersrand (Wits) Human Research Ethics Committee (Medical). I worked closely with Ms. Kyara Bergstrom (Head of Research) who had access to the patient file database for both clinics and granted me access to the information required for my selection of participants in this study. As I am a patient of Professor Benn, I am familiar with the biomedical environment navigated by individuals diagnosed with breast cancer. I did not conduct participant-observation research in the clinical environment since this was not possible for ethical reasons. My own cancer treatment experiences add a reflexive dimension to the research study.

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[3] Research interviews were conducted in English at the participants request

[4] Initially the criteria was stated at two years post treatment.

Once Wits ethics approval was granted, Ms. Bergstrom submitted applications to both clinics for ethical clearance to conduct the research. Once this approval was granted, potential participants who matched the selection criteria were approached by a staff member of Professor Benn's clinics, in accordance with the ethical requirements of Wits University Ethical committee (Medical). Through screening for possible participants, I was able to exclude participants based on their medical history, so that I did not invite and potentially distress women who had, for example, previous history of mental health problems.

I provided Professor Benn with a Research Information Sheet giving a synopsis of the research in plain English and Afrikaans, and my contact details that she could give to the identified participants. the staff person who contacted potential participants used my descriptive synopsis to explain the purpose study. The participants were then free to contact me if they were willing to participate.

I later interviewed voluntary participants either in their home or telephonically in order to find out about their lived experience of breast cancer diagnosis and treatment. I reflexively my own experience of breast cancer diagnosis and treatment in a Johannesburg public health system.

Fourteen participants were willing to be interviewed, with consent obtained through signing a Consent Form. The interviews extended over a period of three months and relied on the participants willingness to be open about the information they provided. Each interview was purpose specific to determine how each person's experience was linked to and reflected her pre-existing knowledge of breast cancer and her personal choices in navigating a sense-of-self premised on her knowledge and her own negotiation of breast cancer diagnosis and treatment.

I interviewed consenting participants both formally in semi-structured interview/interviews and informally in conversational interviews regarding their experience of breast cancer diagnosis and treatment. As I was interested in women's lived experiences, particularly of the cancer diagnostic and treatment processes, a qualitative research approach was used with an interview guideline drawing on appropriate academic literature and my experience with breast cancer diagnosis and treatment. The interview guideline helped me to encourage each woman to tell her story without prescribing what might be important to her. Rather, I aimed to allow them to tell *their* stories. Accordingly, a simple interview-guideline was constructed, composed of a list of questions that enabled me to facilitate and guide a reflexive semi-structured interview conversation. A potential follow-up interview was arranged, if needed, to gain further understanding of each woman's experience or to seek clarification. Interviews were intended to be conducted with participants at a location convenient for them, for example, either at their home or at one of the clinics in an empty counselling room or vacant office. Ideally, interviews should have been done in the clinical environment to enable participants to seek counselling if they so wished but for logistical reasons relative to where a participant lived most interviews were conducted telephonically. The fourteen interviews allowed for research saturation.

Participant overview

As noted above (page 17) this study's participants selected from two facilities, one private and one public, in Johannesburg. Given the type of sampling selection chosen, it was difficult to interview an equal amount of participants from the two facilities. A summary of the information collected is tabulated as captured in Table 1.

Table 1: Participant Information resize

Participant Information

	Name of participant	**Date of Birth**	**Date of Diagnosis**	**Treatment facility**	**Clinical Diagnosis**	**Type of Treatment**	**Family History of Breast Cancer**	**Children**
1	Susan	1984	05/07/08	public	Stage 3B; bi-phenotype carcinoma; ER 3+; PR 1+	Bilateral mastectomy	No	Yes
2	Alicia	1991	2016	public	Stage 3A (T3, N1,M0); invasive grade 3 mammary carcinoma NST; high grade ductal carcinoma in-situ; OR +, PR +, Her2 +	right hemi mastectomy and axillary sampeling. Bilateral breast reduction and reconstruction. Celtron trail for chemotherapy	No	Yes
3	Katherine	1984	2016	private	invasive gradell mammary carcinoma NST (duct carcinoma NOS); OR+, PR+, Her2-; positive ductal differentiation, positive for endolymphatic invasion, vascular, ar invasion; left breast BYRADS 6	Wire localisation prior to bilateral mastectomies and immediate reconstruction	No	No
4	Charlotte	1988	2016	private	BI-RADS 6 proven malignant; OR+. PR+; invasive grade III mammary carcinoma	Billateral goldilocks TE flap. Bilateral skin sparing mastectomy	No	Yes
5	Abigail	1987	2016	private	residual triple negative mammary carcinoma; invasive grade 3 mammary carcinoma NST; grade 3 ductal carcinoma; OR+; PR+	Wide local excisions and parenchymal flap. Unilateral reconstruction only. Chemotherapy	No	No
6	Jacky	1995	2013	Private	sarcoma, no infiltration of ducts or glands. OR-, PR-	No tissue or nipple sparing mastectomy of left breast, breast reduction and lift of right breast.	No	No
7	Christine	1985	2016	Private	Invasive grade 3 mammary carcinoma NST; high grade ductal carcinoma in-situ; OR +, PR +, Her2 +	Wide local excisions and parenchymal flap. Bilateral reconstruction only. Chemotherapy - Adriamycin	No	Yes

Field sites

St Beatrice Breast Care Clinic

The St. Beatrice Breast Care Clinic is unlike other governmental hospital departments. Instead of white or grey walls characteristic of most clinics, this clinic is painted in different shades of pink. The pink ribbon is used globally to symbolise breast cancer awareness, and throughout this clinic has pink walls and posters of courage and hope. Staff help guide the patients waiting to see Professor Benn. Professor Benn who prefers to be called Carol, is a lecturer at Wits University and in established the Breast Health Foundation.

Once one enters St. Beatrice Breast Care Clinic one become part of a larger support community that is often lost in private clinics. St. Beatrice Breast Care clinic waiting area starts filling up around 6am with women coming from as far as Witbank (now known as Emalahleni, some 138.3 kilometres from Johannesburg) either to see Carol for their first appointment, for a check-up, or to get results. Depending on the time of year, women wait for three to six weeks for their results in the public health system at the St. Beatrice's. The waiting area is clean and tidy, but one get tired of the pink especially if you have been waiting since six and the offices only open at 8am. The clinic is broken down into four sections of blue plastic chairs that are not very. The first waiting area is where one sits and wait for the patient file. It faces the eastern boundary wall of the second waiting area. This is where patients must pay for their visit to the doctor, prior to the consultation. Payment is dependent on average yearly income: a student who earns less than R15,000 a year pays R35. This entire area is a large L shape of chairs, with a small a reception counter. The offices of the different doctors are situated in front of waiting area three and along another L shape that borders the first three waiting areas. Once one has paid, you are moved from waiting area two to waiting area three, where Carol will direct you to different waiting areas, to see either a junior doctor for a check-up or to see a surgeon or to consult with Carol in her office.

A friendly female guard in a blue uniform greets you at the door. Her role is to get your identification number either from your South African ID or your St. Beatrice's Patient ID (which is written on a little blue outpatient card including your date of birth in the format DD/MM/YY). The guard writes down all these numbers in a file and hands the file over to one of the clerks. When the clerks start coming in, all dressed in blue pants and crisp pink golf shirts, they use the numbers in the file to collect the patients' files from the file room. Everyone sitting in the waiting area can see the file room just behind the reception desk, containing countless files of different colours. Once it is time for the clinic to officially open the names on the files are called out and your heart starts racing as you hope that your file has been found. On two separate occasions my file had been misplaced; once found in a cupboard with blank files waiting for patients to fill in their details. However, there was no point in complaining so I was forced to sit patiently waiting, watching people who arrived long after me enter the area to see a doctor. When you have received your file you move on to the next waiting area. You patiently wait for the lady with funky pink glasses and red lips to take your money and write you a slip. The whole process takes approximately two hours but after you have paid your money and been moved on to waiting area three, you feel the weight of the world lift.

At this point with file in hand, you sit in the section marked 'Waiting Area.' Carol, who is always dressed in pink, from a pink fleece lined jacket to her pink scrubs to her pink Crocs – she is never in any colour other than pink or white – will take your file, quickly skim it and move you to the appropriate waiting section. If you are undergoing chemotherapy or if you been biopsied, Carol will personally see you in her office to give you the results; otherwise, you will be seen by a junior doctor.

The atmosphere in St. Beatrice Clinic is very entertaining - you meet interesting people full of hope, offering words of encouragement or advice about treatment decisions. As a young student often very scared of results, older women would give me the most encouraging advice, from "Just think how skinny you will be for summer holidays after Chemo," or "Don't stress if you lose your hair, there are some very interesting wigs on the market, you will never have to look the same again."

Millwood Breast Cancer Clinic

The combination of the dust and perspiration caused by the heat outside made it nearly unbearable to work in the narrow storeroom located in the basement of Millwood hospital during the research. The Millwood Breast Cancer Clinic lies in the very heart of Millwood Private Hospital, situated on the outskirts of Johannesburg CBD. The vast size of the hospital is only realised as you start to navigate the maze of pale-yellow corridors to the basement where the clinic is tucked between the renal dialysis unit and pathology. This specific storeroom houses all the patient files from the Millwood Breast Care Clinic and it was amongst all these filing cabinets that I was able to find participants for my research study.

The clinic is enveloped by breast memorabilia ranging from artistic interpretations of breasts to pink couches and chandeliers. Each of the three examination rooms is decorated in a specific theme: glamour, the ocean and baobab trees. The clinic houses a wide range of specialists all working towards a common goal – breast healthcare and patient wellbeing. The space is always buzzing with either specialist doctors or auxiliary staff ensuring that all patients' needs are taken care off.

I had sat on one of these couches on my first visit to the clinic. I had just turned 23 and had discovered a large lump in my right breast. After consulting various biomedical specialists I was seeking the counsel of the Clinic Director and founder Professor Benn for answers about my growing lump. The room was quiet. This clinic was no more like any other doctor's rooms I had visited in my life. Yet a nervous energy filled the room as other patients waited to consult various specialists regarding their treatment of breast cancer. Patients mainly kept to themselves either preoccupied with a magazine provided by the clinic or mobile devices used to occupy them as they waited. As a young woman in my early twenties I was a ball of nervous energy and could only page through so many magazines before feeling frustrated. Unlike other medical appointments, those at the clinic could not be predicted, appointments were often delayed by hours due to emergency surgeries or consultations. To the left of the couch where I was seated there was a basket of knitting needles and wool for a recent charity drive to knit blankets for the homeless. I had picked up the needles to preoccupy myself as I waited to see Prof Benn. Hours had passed since my scheduled appointment and I desperately needed something to distract me. Eventually I was called into one of the consultation rooms and I met a tall blonde doctor clothed head to toe in pink. Her passion for her field was contagious and I felt at ease as she explained my diagnosis. From that point onwards I had to monitor for any signs of growth in my breasts. And so my journey with breast cancer started both in my personal life and my academic one.

Limitations to research

This research considers only a small sample of women affected by breast cancer, treated at one of two Johannesburg clinics. Cancer does not occur in isolation but affects families and whole communities as well. I did not take into consideration the effects of breast cancer treatment and diagnosis on the families and communities interacting with the study's participants and so my work is limited in this regard. The research is also limited in scope in its focus on only two clinics run and managed by the same medical professor. Additionally, as the participants in my study were treated during 2015 - 2016, the new 2017 South African Breast Cancer Policy had not yet been implemented. This policy changed certain procedures which provides for a more diverse treatment regime including cosmetic reconstructive surgery as well as fertility concerns.

To ensure accuracy of coding, I transcribed all the interview tapes verbatim and then manually assigned codes to discreet themes emerging in the interview data (Williams and Jeanetta 2015). My supervisors reviewed these codes and themes to ensure that they were a true representation of the participants' lived experiences. My supervisors and I met regularly to explore both the similarities and differences in themes so as to refine the visible codes.

Ethics

Ethical Approval

In November 2018 provisional approval was obtained by the medical authorities from each clinic on condition that the names of the clinics would be anonymised through the use of pseudonyms. Once provisional approval was obtained from the clinical field sites, full ethical approval was obtained from the Wits University Human Research Ethics Committee (Medical) in December 2018 (Appendix 1). Wits Human Research Ethics (Medical) forms required an in-depth description of the research I wished to carry out as well as the selection process whereby I would recruit and interview participants. Inclusive of proposed themes, to possible harm the study could cause participants, Wits Medical Ethics committee wanted to know every foreseeable methodological detail of the study. After completing this documentation, twenty-three copies were required to be submitted to the Wits Medical Ethics Research Committee on a date specified on the Wits website.

Due to not being able to recruit a sufficient number of participants under the initial study criteria, the selection criteria of 'two years post treatment' were expanded to three years. Revised ethical approval was requested and was received from the Wits Human Research Ethics Committee (Medical) in late January 2019 (Appendix 1).

Participants were contacted and asked to give consent for the audio-recording of their interviews which were only conducted in English as the participants felt comfortable being interviewed in this language medium. Once a participant had been interviewed, I verbatim transcribed it and saved on a secure flash drive. The data from each interview was summarised and saved onto an Excel document in order for me, guided by my supervisors, to identify correlations between the participants.

Research Saturation

This study uses a qualitative research methodology to gather sensitive data in order to allow for an emic understanding of the lived experiences of young women diagnosed breast cancer (Wray Markovic & Manderson 2007:1392). As noted in earlier publications this type of research can be cathartic for participants (Wray Markovic & Manderson 2007: 1392). However researchers often experienced stressful and traumatic events during this type of fieldwork (Wray Markovic & Manderson 2007: 1392). During the process of drafting a proposal to the writing-up of the research report, I experienced with various distressing psychosomatic symptoms including insomnia, nausea, headaches and tender breasts. The experience of exploring and recording the lived experiences of these young women took a toll on my body. As it was important to prevent burnout and to minimise recurring trauma for the study's participants and myself as the researcher, arrangements were made to provide counselling. The recollection of one's experience can be cathartic but also trigger emotional and occasionally traumatic experiences for participants in a study of this kind. This is the reason why, ideally, I would have liked to interview the participants in my study in a clinical environment providing professional counsellors who could have provided emotional help to them, if they needed or requested it. I had meetings with my supervisors at regular intervals for necessary debriefing sessions during my research.

Accuracy

I used an ethnographic approach of non-participant observation to collect the data. This enabled me to achieve data saturation and allowed me to develop grounded theory analysis in my research report, as the data provided by the participants allowed in-depth understanding of the young women's experiences.

The following measures were taken to ensure reliability and validity of the research data collected in the study.

Reliability in my research relates to the ‘truth value’ of participants’ narratives in response to my research questions, whereas validity refers to the accuracy and trustworthiness of my interview based research tool and the data findings of the research. As the research question examines the lived experience of young woman a weighting was placed on each answer to determine the subjectivity or objectivity of any and all responses (Murphy & Davidshofer 2004) as no response is incorrect. This allowed me to differentiate between my possible subjective bias and perceptions regarding women’s statements and expectations.

Chapter 4: Perceptions and Misconceptions of Breast Cancer

Don't worry, you're too young to have breast cancer [5]

BREAST CANCER RISK FACTORS [6]

All women are at risk of getting Breast Cancer, but you are at risk if you:
Breast Cancer is more common in women, but men can get breast cancer
A family history of breast cancer is a strong risk factor; the closer the relative the higher the risk
Breast Cancer is more common in older age groups, with the number of cases rising after 50 years of age
Have gone through menopause at a late stage

In this chapter I critically analyse the discourse surrounding breast cancer in the urban Johannesburg context. Many of the misconceptions discussed by the participants have grounding in information they received from different sources; for example, posters, pamphlets and educational material all available from various biomedical spaces in central Johannesburg **(see Appendix 7).** In order to understand discourse and ideology surrounding breast cancer in urban Johannesburg, this chapter critically evaluated the various materials available to the public in order to gain a better understanding of the perceptions and misconceptions people have of breast cancer.

Cultural perceptions of breast cancer

It was a busy Tuesday at the 'Millwood' cafe, the place is buzzing with the sound of conversation. I had arranged to meet with Jacky, the communications and marketing manager at the Breast Health Foundation (BHF), whom I got to know at their support meeting the previous month. The BHF is a non-profit organisation started in 2002 as part of a larger group of cancer associations all falling under the Cancer Alliance. The main objectives of the BHF are educating

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[5] This was the reassurance provided to me by a biomedical practitioner during my first sonar at a clinic in my area

[6] These risk factors are compiled from various educational pamphlets on breast cancer (see Appendix 7)

the public about breast cancer and breast healthcare, increasing awareness and helping to empower women as they navigate their way through diagnosis and treatment of breast cancer (The Breast Health Foundation: https://www.mybreast.org.za/). Jacky had personally gone through her own journey with breast cancer in her matric year (final year of secondary school). When I inquired about any perceptions or misconceptions she had come across, she answered:

> **Bras cause cancer. Cancer is a white woman's disease. Underarm deodorant causes cancer. Any cosmetic causes cancer. I've heard white people's food causes breast cancer. The microwave causes breast cancer. The electricity poles cause breast cancer. The size, colour, shape whatever of the bra causes breast cancer. Clothing, dirty bras, food and preservatives - what's in our food. Mammograms cause breast cancer. Taking a biopsy or opening a tumour up makes the cancer spread. You can't get cancer after you've had a mastectomy. You can't get cancer again. Chemotherapy will kill you. Cancer in the breast kills - that is a myth you don't need your breast (19/03/19)**

Jacky's observations reflect a reality that misunderstandings about cancer in South Africa are perceived and misperceived through the lens of 'racial classification' that structures the nature of contemporary South African Society. From her response five distinct themes can be isolated: (i) race, (ii) cosmetics, (iii) food, (iv) biomedical technology and cancer treatment procedures, and (v) myths about breasts and breast cancer. Much of the public health literature provided is only directed to a small demographic of the population. In order to better understand the experiences of young women diagnosed with and treated for breast cancer it is important to take into consideration the discourse surrounding breast cancer in Johannesburg. By critically analysing the literature available to the public, the perceptions and misconceptions surrounding breast cancer can be deconstructed.

Discourse and Ideology of Breast Cancer

In order to better understand breast cancer discourse in a South African perspective, I define 'discourse' as a productive force that inflects thoughts, ideas and identities in a given society (Foucault 2003). The French philosopher Michel Foucault (2003) suggests that discourse emerges out of social institutions – in the case of this research report the discourse of the South African public health sector – and is amplified by the media and politics in the spatial and temporal setting of a given location. In this chapter, a particular discourse provides a framework in which individuals living in Johannesburg structure and order their lives regarding their understanding of breast cancer. It is then this specific discourse on breast cancer that facilitates the development of biases and stereotypes in urban Johannesburg. Discourse is embedded in and emerges out of relations of power enabling those controlling institutions the power to formulate and control production of discourse, power and knowledge about, for example, knowledge of breast cancer provided to the general public (Foucault 2003). The literature provided by the South African public health sector on breast cancer typically focuses on a small demographic of the population based on a specific race and age of a patient, i.e. ‘older white women’. In so doing these institutions limit the set of diagnostic criteria by focusing only on this targeted demographic and excluding potential patients who do not meet these diagnostic criteria yet but are at risk of developing breast cancer in the future. The misconception of breast cancer in being perceptually restricted to an older ‘white woman’s’ disease reinforces the creation of a certain discourse on breast cancer in South Africa. This is then perceived and understood through the lens of ‘racial classification’ that is the foundation upon which South Africa society is built.

Consequently, the public health sector continues to limit the risk factors to certain demographics resulting in the discourse surrounding breast cancer excluding many individuals at risk, from treatment. This misconception is further perpetuated by the marginalisation of potential breast cancer patients via the focus of a particular demographic in the pamphlet literature provided to breast cancer patients in various Johannesburg biomedical environments. The majority of these pamphlets are written in English and use images of ‘older white’ women thus excluding other key demographics from its audience. Although the global figures recorded for breast cancer in pre-menopausal women and men are still relatively very small, one needs to consider how many cases go undocumented due to the lack of more comprehensive information regarding the risks of breast cancer in all demographics.

Breast cancer and cervical cancer are the leading causes of cancer related deaths in South Africa, accounting for over 38% of all cancers diagnosed in women (National Cancer Registry 2014). Yet these figures singularly focus on the gendered dimension of breast cancer. As previously stated, breast cancer is a disease affecting the growth rate of tissue cells in the breast; therefore, anyone with breast tissue – regardless of gender, race or age – may develop cancer of the breast. According to the National Cancer Registry in 2012, out of the 8203 newly diagnosed female breast cancer patients, 8.59 % were under the age of 39. In the same year there were 212 newly diagnosed male breast cancer patients of whom 6.6% were under the age of 39. In a subsequent

2014 report by the National Cancer registry, the figures rose to 8230 new breast cancer cases among women, with 9.78% being young women under the age of 39. There were also 184 cases of breast cancer reported in men, 4.35% being in men under the age of 39 (National Cancer Registry 2014). It is then surprising taking these figures into consideration that the South African Public Health sector focuses on levels of hormones (i.e. levels of oestrogen) rather than age or gender in its attempt.

This could contribute to the misconception introduced by my participant, Alicia – a young black woman diagnosed with cancer in her early twenties – that reflects the belief in her community that cancer is an older 'white person' disease, Alicia commented:

> **And you know us black people, some of the things we don't take them seriously… Even the time I told them I went to do the test for cancer, they were like, "No, that's for white people. You cannot have cancer. And you are still young to have cancer." (17/01/19)**

Alicia's description of her community's denial of the knowledge of a young black woman diagnosed with breast cancer, further reiterates the misconceptions noted by Jacky regarding the various race groups and age categories perceived to be at risk in South African society.

Breast cancer in young women

Most of the participants interviewed were unaware of the risk of breast cancer in pre-menopausal women (e.g. women aged between 18 and 35). This is not surprising as the information provided by the public health sector regarding the risk factors of breast cancer is specifically directed towards menopausal and postmenopausal women. If the information provided by the South African Public Health Sector limits breast cancer to older 'white' women, it was then not surprising that many of the participants interviewed, recollected the technicians telling them they had nothing to worry about. This could clearly be seen in Alicia's recollection of seeking treatment for a lump she found in her breast:

> **I went to the clinic on Wednesday, then when I got there, they told me that it's not cancer. I'm too young to have breast cancer and my breast hadn't changed. If I had cancer, my breasts were going to change. (17/01/19)**

For Alicia, like many of the other participants interviewed in my study, if they had listened to the biomedical practitioners who first conducted their clinical breast examinations, they might not be alive today. Fortunately, participants like Alicia, were able to use their agency to overcome a biomedical system that excluded them from a specific diagnosis based on misinformation. Significantly, it suggests that each woman has the ability to go against erroneous information provided by biomedical practitioners in seeking a second opinion. This shows that not every member of the population surrenders their agency when given a misconception influenced by biomedical opinions. Thus the situation with Alicia and the other participants draws attention to the question of agency amongst women seeking treatment in various Johannesburg biomedical spaces. Alicia and the other participants chose to go against popular discourse on breast cancer in search of a second opinion. This suggests that the discourse surrounding breast cancer is not entirely deterministic but rather is susceptible to change given the right circumstances. However the biomedical technicians in these participants' recollection are all implicated in the creation of a discourse which excludes young women from being diagnosed with breast cancer. This example, and many like it, clearly indicate that this discourse is not restricted to the general public but also affects the ideas and misperceptions of biomedical practitioners in the Johannesburg health system. These practitioners have come to believe that one of the diagnostic criteria for breast cancer is 'age'. As seen in Alicia's recollection, this technician unaware that young women could be at risk of breast cancer.

Breast cancer in men

Early in January 2019, my mother and I were settling down to watch her latest TV Drama obsession - an Afrikaans legal drama 'Fynskrif' (Fine Print)- following the legal cases pursued by a South African law firm while the partners and associates try to balance their professional and private lives (Botha 2018). On this particular Tuesday, one associate Corné Hannekom (Beer Adriaanse) unexpectedly finds a lump in his breast after completing push-ups. Later on in the episode he asks his colleague Ben (Neels van Jaarsvelf) about the lump and the audience gets a glimpse of the reddening of the areola and surrounding area. Concerned, Ben suggests he see a doctor, Corné responds "it is only a lump", to which Ben replies, "Exactly, why you should see a doctor!”. Later on in the episode when Corné confides to his girlfriend in a serious tone, “I have breast cancer”, she responds with laughter. She then says, “Are you serious?” and continues laughing. This sceptical trend continues as more people around the office find out about Corné’s breast cancer.

In this episode of ‘Fynskrif’ the display of amusement and mirth demonstrates popular misunderstandings and pervasive erroneous discourse associated around breast cancer. Ergo, breast cancer is perceived to be a female disease but the truth is as mentioned above anyone who has breast tissue, regardless of ‘gender’, can have breast cancer. To reiterate, in the information provided by the South African public health sector, the description of most diagnostic criteria is restricted to ‘older white women’. In none of the pamphlets that I collected during my 2019 research were men ever mentioned or even represented. There clearly is an urgent need for the revision of the discourse about breast cancer, beginning with the inclusion of men and pre-menopausal women in the diagnostic criteria.

Breast Cancer Policy

In June 2017, a ‘South African Breast Cancer Control Policy’ was introduced by Dr Aaron Motsoaledi, South African Minister of Health, in the hope of “increasing early detection of breast cancer, treating breast cancer more effectively, and providing timely treatment and palliative care for invasive cancers” (Breast Cancer Control Policy, 2017: 4). As the policy was devised through reflecting on past case studies and information supplied by South African biomedical practitioners, an analysis of the policy will be helpful in understanding the discourse of breast cancer and thus better reveal the origins of the erroneous perceptions and misconceptions of breast cancer. Jacky was the first person who I encountered who spoke about the benefits of a breast cancer control policy:

> **South Africa has a breast policy which is really really amazing and really really exciting that South Africa has a breast policy. Because it means that patients throughout the provinces of South Africa have to be treated according to the breast policy’s guidelines. They can’t be treated differently. In that policy it states that as South Africans and as educators we should be educating on self-breast examinations, if there is a problem, clinical breast examinations for screening and then only mammogram and ultrasound for diagnostics. (17/01/19)**

With further research into the construction and implementation of the 2017 South African Breast Cancer Control Policy it became clear that it was introduced to help bridge the gap between public and private breast cancer diagnosis and treatment in the hopes of offering a universal standard of care across South Africa. The criteria I used to select participants in 2015 - 2016 was limited to women who were two to three years post-treatment and thus they had not experienced the full effects of the 2017 policy. Yet a reflective analysis of this policy compared to the experiences of my participants enabled me to critically evaluate the policy in the contemporary South African context.

Given the nature of the discourse surrounding breast cancer it was surprising to find that one of the objectives: Objective 1 Standard 1.2, of the policy specifically mentions that all women attending a Primary Health Clinic “will be given opportunistic breast education including printed education material and taught breast self-examination” (Health, 2017:14). Yet most of the education material I collected in 2019 was only available in English and continues to portray ‘older white women’ on the pamphlets; thus continuing to help to propagate the misconception of breast cancer as an ‘older white woman’s’ disease. Most women attending the two Clinics in my study barely speak English. The pamphlets and booklets currently provided by the clinics are all in English and for someone who hardly speaks English and has no knowledge of biomedical technology, these pamphlets may be redundantly overwhelming to a newly diagnosed patient.

The policy still marginalises women under the age of 40 and men. For instance: Objective 1 Standard 1.1 states:

“Women over 40 years attending a Primary Health Clinic will have a clinical breast examination (Provider Initiated Screening Clinical Breast Exams (PISCBE)) biannually” (Health, 2017:14).

Yet given the rise in newly diagnosed breast cancer among women of reproductive age and men, public health policy should refocus its attention towards comprehensive education among all communities of the symptoms of breast cancer. Additionally given the cultural and social factors including stigma around breast cancer especially for men, more accurate educational programs should and could easily break down these barriers.

Conclusion

Chapter 4 has critically analysed the discourse of breast cancer in Johannesburg. It critically evaluated the misconceptions and misperceptions of a community's denial of the interview comments about breast cancer as mentioned by one Study participant. The discourse analysis of these misperceptions and misconceptions further considers mis-information regarding 'race', 'age' and 'gender' categories perceived to be at risk of breast cancer in South African society. Many of these misconceptions have grounding in biased information received inherent in different sources, for example: posters, pamphlets and educational material that were available in various Johannesburg biomedical centres (See Appendix 7). South African Department of Health educational material regarding breast cancer health awareness is typically written in English and specifically focuses on 'older white women' as the information provided exclusively points to the risk of developing breast cancer among 'white' women over the age of fifty years.

Chapter 4 evaluates the information provided in these pamphlets and found it seriously circumscribed in that the majority of them are written in English and use images of 'older white women' that excludes other key South African demographics from their audience. Although the figures recorded for pre-menopausal women, and men are still very small in comparison to those of the post-menopausal 'white women', one needs to consider as a matter of concern how many cases continue go undocumented due to a lack of proper information regarding the generalised risks of breast cancer. Along with the educational material, the Chapter 4 focuses on the invisibility of men with breast cancer in South African popular media. The incredulous reaction of the actors in a South African TV series regarding male breast cancer mimic those portrayed in TV series and movies in other countries; men who confided in partners or friends thus men are met with concerted disbelief and laughter. Finally, Chapter 4 analyses 2017 South African Breast Control Policy that was introduced in an attempt to universalise treatment in South Africa. It has been found that the policy still marginalises those who do not conform to South African risk factors criterion.

Chapter 5: Journey

From the moment an abnormality is discovered in breast tissue, one's life forever changes regardless of whether it is simply a fibroadenoma or a cancerous lump. In **Chapter 5** I focus on capturing others' stories by tracing the ethnographic (i.e. existential) journeys of young women from the discovery of an abnormality in their breast tissue, to diagnosis and subsequently the various treatments of breast cancer. Using a lived experience approach as a tool of analysis, **Chapter 5** traces the orientation of the self in different spatial and temporal environments in order to better understand an individual's journey from life before cancer, through diagnosis and treatment and finally to what it means to be in remission. This is done by comparing an example of an artistic film representation of a young woman's experience with breast cancer to those of young women in urban Johannesburg.

During the opening monologue of the 2006 film '*Why I Wore Lipstick To My Mastectomy'*, directed by American film and TV director Peter Werner, the protagonist Geralyn Lucas (Sarah Chalke) proclaims:

> **I wasn't really a red lipstick girl. I was more of a gloss girl. Gloss is safe. I felt like the women who wore red lipstick were more deserving than me… More powerful than me. But they aren't facing the life and death decision I am.**

This pragmatically realistic, but also charmingly witty movie touches on what it truly means to be a woman. The film based on Geralyn Lucas' autobiography – by the same name – recounts a young woman's experience with biomedicine, self-discovery and what it means to be alive when faced with a cancer diagnosis. In following Lucas' journey, the audience is able to enter into the world of a young woman diagnosed with cancer that takes them on an ethnographic expedition of how one young woman refused to allow her sense of self to be eclipsed by becoming a woman with breast cancer. Rather her prior identity enables the foundation of a new sense of self (Lock & Kaufert 1998). John Wynne (2010) uses the film to comment on the intersection of representation in ethnography both in artistic practice and in anthropological practice. He argues, "It aims to create a contemplative space in which the audience can think about the issues that underlie the work and in which my presence as an artist coexists with the otherness of the subject rather than either subsuming it or presenting it under the guise of objectivity." (pps. 63-64).

The autobiographical film, ‘*Why I Wore Lipstick to My Mastectomy*’ is the story of a woman, Geralyn Lucas who at the age of twenty-seven years thought she had it all until she found a lump that would throw her life, sense of identity and what she believed to be her successful existence into turmoil. The film’s sympathetic treatment of one woman’s experience provides a humorous take on Geralyn Lucas’s journey through breast cancer diagnosis, surgery and chemotherapy. In ‘*Why I Wore Lipstick To My Mastectomy*’, the young Lucas recounts certain milestones in her life journey such as – promising her cute husband to one of her girlfriends once she has passed on, meeting a taxi driver who has had surgery for testicular cancer who in recalling his experience says, “I dance better after this operation” and renames her plastic surgery reconstruction photos as “breast mug shots” after her mastectomy. Thus the film provides both a narrative and artistic representation of this young woman’s journey through an unexpected and unanticipated situation. This leaves a void of the intimate understanding of the embodied experiences of healing as experienced by young women diagnoses and treated for breast cancer.

Theoretical Framework

Breast cancer ‘sucks’ because it can cut at the very core of what it means to be a ‘woman’. In order for the experience of healing, diagnosis and treatment of breast cancer, to be understood – within a western biomedical paradigm – one needs to consider the context in which illness and healing arise. The socio-cultural imposed meanings of illness and healing, their categorisation and subsequent treatment are often established in socio-historical context. My findings suggest that this is especially prevalent in the case of breast cancer treatment in Johannesburg cancer treatment clinics and hospitals. Whilst a great deal of discourse has been explored in the field of biomedicine regarding breast cancer, very little inquiry has been conducted to date into the actual healing experience of young women (Csordas 1997, 3). Csordas’ phenomenological approach utilized in the lived experience of this leaves a void of intimate understanding of the embodied experiences of healing by young women diagosed and treated for breast cancer that the lived experience approach utilized in this research tries to fill.

According to Csordas (1997: 9) phenomenology is the study of consciousness as experienced from the first-person point of view in order to delve deeper into the way things are experienced in the world around us. Phenomenology provides us with a framework for an analysis of bodily experiences and senses in relation to illness. In this existential approach an individual’s bodily experiences may be analysed through exploration of their perceived and embodied engagement with their environment and social network that ultimately influences their understanding of the world around them. Csordas (ibid) argues that the purpose of using phenomenology for an analysis of breast cancer patients’ journeys, is to better understand the ‘self’ based on their ‘orientation’ with respect to self-awareness in different temporal and spatial circumstances, changing motivations and roles, as well as the influence of social norms on them. These experiences can be better understood in terms of perception and practice. These concept of ‘self’ does more than merely place individuals in temporal and spatial locatedness linking behaviour to an objective world but is also defined by this objective world in terms of one’s sociocultural circumstances. The aim here is to link perceptual process with social constraints and cultural meanings that add awareness and self-reflexivity. Using Csordas’ (ibid) structural hypothesis of phenomenology, which posits that an inherent power of correspondence or homology between symbolic acts and objects, metaphors or cosmological structures, thoughts, emotions, behaviour or diseases of those treated as the ‘other’ can be better understood. Since perception and practice are central to the self as a capacity for orientation, we can identify the locus of the self as identical with the locus of perception and practice (Csordas 1997: 9). In drawing on Csordas (1997), Chapter 5 focuses on the lived experiences of 5 women of various reproductive ages who have had individual a life experience from pre-diagnosis to understanding what it means to be ‘cancer-free’[7].

Life before cancer

In the movie, ‘*Why I Wore Lipstick To My Mastectomy*’, Lucas was an ambitious, highly organised newlywed with her life all planned out (Lee 2006), when she receives conflicting medical advice on treatment for her breast cancer – either a double mastectomy or a lumpectomy. Faced with this life altering decision, we see her heading to a strip club to ponder the power of the mammary gland. Like many of the participants interviewed in my study, Lucas did not expect to be diagnosed with breast cancer at such a young age. The concept of what it means to be ‘healthy’ is problematised especially when biomedical information delineates specific set of criteria for breast cancer risk. These conceptions of the embodiment regarding a ‘healthy’ or ‘unhealthy’ body brings into question ideas around what it truly means to be ‘healthy’ when faced with a diagnosis. As symptoms of breast cancer are rarely externalised the concept of

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[7] If there are no cancer cells found in the blood work of an individual for five consecutive years, they are considered ‘cancer-free’ or in remission.

‘health’ in society is highlighted in study participant Katherine’s perception of her own lifestyle before her diagnosis. She said:

> **I can tell you now, I was always a very healthy person. I always exercised, I always ate well, but I did it purely for a figure. I did it because I wanted to look good, I wanted to be able to wear my clothes and whatever! I’ve always enjoyed exercise but I thought I had to exercise so that I could eat certain things (18/01/19)**

Katherine was thirty-one when she found a lump in her left breast. There was no history of breast cancer in her family and although she knew about breast cancer and its risks from her past work experiences because she had sold breast cancer oncology medication for a big pharmaceutical company she did not think that the lump she found could be cancerous.

In the absence of a family history of cancer - which is considered a significant risk factor noted by South Africa’s Public Health system and literature – individuals often equate the absence of any external cancer symptoms to the lack of cellular abnormalities in their bodies. Thus this socially-constructed idea of a healthy body was what prevented them from seeking treatment earlier or participating in Breast Self-Examinations as a precaution. Synott (1993) states that the body is at the heart of our social lives and our sense of selves. Similar to Katherine, most of my participants perceived themselves as ‘healthy’, leading active lifestyles. This belief was reiterated by Abigail – who was diagnosed with Stage II invasive carcinoma – who before her diagnosis engaged in various physical activities. She claimed:

> **I was very fit; I had literally done a Fish River Canyon hike[8] probably a month before I was diagnosed. (26/01/19)**

Both Katherine and Abigail had a clear conceptual understanding of what it means to be ‘healthy’ in the specific social construction of bodies in contemporary urban Johannesburg. Finding out that this conceptualisation was misinformed on the discovery of abnormal lumps in their breasts, brought into question the concept of what it means to be ‘unhealthy’ or ‘abnormal’ leading to their re-questioning of the social body. The social body in this instance was taken from

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[8] The Fish River Canyon is located in the south of Namibia. It is the largest canyon in Africa

the heights of the mystical and sacred, to stigmatised and freakish with the discovery of the lumps (Synott 1993). Abigail recounted her astonishment at the discovery that she had cancer:

> **Cancer was something other people get not me. And there was no history of cancer in my family so it was an unexpected diagnosis. (26/01/19)**

Cancer sucks! It breaks at the boundaries of what the social body is normatively expected to be. Ultimately human beings are shaped by the perceptions of other people. With a potential diagnosis, the body becomes more tangible than the physical object – "a mere skeleton wrapped in muscles and stuffed with organs" **(**Moore 1998: 3) – it is believed to be, rather becoming a body as a subject. Understanding the experience of Abigail and Katherine as well as the other participants in my study allows anthropologists to traverse the boundaries between the 'self' and the 'other' as these are inter-related experiences in biomedicine – that which is the self and that which is the other are both embodied experiences and influence our understanding of 'healthy' and 'unhealthy' in social dimensions.

Diagnosis

Every woman dread hearing the words that Lucas heard after numerous people told her she was too young to have cancer,

> **I'm afraid the news isn't good. It's cancer. We can do everything we can to beat this. We have to wait for the final pathology but I'm sure you're a candidate for lumpectomy. It's a small scar, nothing to worry about and you'll be mostly unchanged (Werner 2006).**

Yet the message behind, "*Why I Wore Lipstick to My Mastectomy*" (Werner 2006), resonates with so many women because it tells the journey of one young woman's fight to keep her identity. An estimated one in eight women receives a diagnosis of breast cancer during their lifetimes (Lee 2006). The film – although funny – shares the message that you are never too young to have cancer. The power of the story encourages women to get examined and explore their treatment options. As a young woman watching this film for the first time, my experience could most accurately be described as that of a tourist. Watching this woman go through these very real experiences of breast cancer, prepared me for my own encounter with the disease a few years later. As Lucy Lippard states, "experience comes first and theory later, once we realise what we should be thinking." (Lippard in Waynne 2010). In the case of, "*Why I Wore Lipstick to My Mastectomy*", her statement rings true – theory (biomedical knowledge) does not come into play when you come face to face with a breast cancer diagnosis.

Patient Delay

With a potential cancer diagnosis, the social body is brought into question. Individuals are confronted with the interrogation and renegotiation of agency, gender and sexuality with the discovery of a malformation in their physical bodies (Manderson 2018). It is then not unlikely that given the very specific diagnostic criteria associated with breast cancer that young women often neglect symptoms such as abnormalities, for example discoloration of the areola, in their breasts. Given this every-day reality, patient-delay in treatment is not uncommon. And as is often the case, young women are frequently misdiagnosed with fibroadenomas - a common malformation in fibrous breast tissue found in young women - and only later after seeking a second opinion or follow-up appointments are the abnormalities correctly diagnosed. Abigail found a lump in her breast a month before her wedding. She initially sought treatment and the lump was diagnosed as a fibroadenoma. She recalled her experience:

> **The lump grew quite big, probably three times the size and he had said that I had to come back in six months, but I landed up going back in 8 months just because I googled stuff and I found that fibroadenoma can grow, it's not an issue so I wasn't really worried (26/01/19)**

Subsequently due to the rapid changes in the lump she returned to the radiologist for a follow-up scan. With the delay in diagnosis the abnormality was allowed to grow rapidly; changing the stage from I to II of diagnosis of the cancer. As Abigail went on to explain:

> **It was pretty much eight months between when I went for the scan. It was just a lump, between its growing to about 3 cm to a substantial tumour when I was diagnosed I was at Stage II (26/01/19)**

The barriers which kept Abigail from a seeking diagnosis were not constructed by geographic, social or historical contexts but rather through a public health system discourse formulated by the construction of knowledge based on misperceptions and misconceptions of breast cancer. These marginalised those who do not conform to the specific diagnostic criteria provided as educational material disseminated in South African Public Health literature.

The liminality of the diagnostic process[8]

Many of the participants in my study recount long periods of time between the diagnostic procedures and receiving a diagnosis. They speak of the stress and anxiety associated with the 'not knowing'. For some like Abigail, who was initially misdiagnosed with a fibroadenoma the initial diagnosis was a relief as she was able to continue with events planned in her life without the anxiety of being diagnosed with breast cancer. She commented:

> **In hindsight, I thought it was a miracle because being diagnosed with breast cancer during your honeymoon would not have been ideal. The timing was perfect because I had not been diagnosed yet (26/01/19)**

The concept of *rites des passage* was introduced by Arnold van Gennep (1968)[9] to describe the role of rituals in various spheres and phase-stages of lived social life in society. The concept of a *rite of passage* helps to mark the turning points - both biological and social - that social bodies experience through various stages of one's life. The different stages involved in the diagnosis of breast cancer are (i) the medical examination, (ii) the period of liminality in which the patient has not yet received their definitive diagnosis, (iii) the physical and symbolic removal of a social body out of the category of 'healthy' into a category of 'unhealthy' and need for treatment, and (iv) reintegration into society post-treatment. Considering cancer diagnosis and treatment, stage (ii) is a transitory stage which cannot yet be classified as 'unhealthy' because a diagnosis has not yet been received. This 'waiting for the confirmation of a possible diagnosis' period entailing the reclassification of the social body can best be described as a liminal '*betwixt and between'* phase. Abigail recounted this experience as:

> **It was a rough journey, the whole thing, not easy. Throughout the different stages you feel different things. I think initially it was probably the most difficult time because the feeling of shock and not knowing whether or not it spreads. So obviously when they diagnose you they have to do tests to determine whether it had spread (26/01/19)**

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[9] Arnold van Gennep (1968) introduced the concept of 'liminality' as a betwixt and between stage of being in a 'rite of passage' that involved an individual's movement through three stages – (i) separation, (ii) liminality, and (iii) re-integration into, for example, a process of initiation into adulthood or professionalization

The diagnostic process is tedious. It follows various clinical diagnostic processes from clinical breast examinations to biopsies to determine the nature of the abnormal cells. At this point in time individuals are left wanting and waiting for answers regarding their new social bodies. Only after a definitive diagnosis is obtained in step (iii) where the social body is reclassified as ‘unhealthy’ or ‘cancerous’.

Treatment

In a scene from the film ‘*Why I Wore Lipstick To My Mastectomy*’ the voice-over says, “I’d gone there to decide whether or not to have a mastectomy,” as Geralyn Lucas sits alone in a purple velvet booth and orders a beer. Pertinently, Geralyn says to a waitress,

> **“Isn’t it weird how women have the power to hypnotise men into a trance simply by taking off their tops.”**

This rhetorical question addressed to the waitress highlights just how important the physical body is to the formation of the social body. Each individual diagnosed with breast cancer receives a treatment program to match her specific diagnosis. A breast cancer diagnosis is saturated with terminology as each term can be deconstructed into various symbols and meanings. When asked about how women experience the treatment process Sarah an oncology nurse responded:

> **It depends on the person. It depends on the diagnosis – if it is just a lump, and it hasn’t advanced, it doesn’t include the lymph nodes – it is fairly easy to treat and go into remission. But if it is something like a metastatic cancer or an advanced cancer, then that person will technically never end their treatment because they will never completely get rid of the cancer. (12/03/19)**

Treatment is dependent upon the nature of the margins that characterises each lump. The size and shape of the abnormal mass of cells relate to the staging of the cancer. The breaching of boundaries such as those beyond the breast – involving lymph nodes or other organs – will affect the severity of the treatment. Treatment varies between lumpectomy to mastectomy – single or bilateral - chemotherapy and/or radiation. The purpose surrounding treatment is to remove the cancer cells as well as to limit the spread beyond the margins of the breast. The stage of the cancer - whether there is lymph involvement and the rate at which the cells are growing – all affect the type of treatment given. Ideally women are advised of their best options but often choose to give up their agency in the hope that the biomedical practitioner knows best. Most of the study's participants suggested that they often gave up their agency in order to reduce the anxiety caused by this process. Abigail speaks about the lack of control she had throughout the process:

> **The most stressful part of the whole thing was the surgery and deciding what to do - whether to go for a mastectomy or a lumpectomy. That was for me the worst. Everything before then was pre-planned, so you have your chemo pre-planned, and you have however many sessions as agreed upon. At the end of chemo, they decide on the type of surgery. (12/03/19)**

Cancer is defined by the uncontrollable growth of certain cells. Many individuals diagnosed often hold on to what they can control, to help maintain a certain level of sanity. Yet some try to hold on to certain aspects of their past lives. Abigail speaks of her love for exercise. During her treatment she recounts being adamant in continuing her exercise regime but did not expect the effects it had on her. She recounts:

> **I remember asking the doctor, 'Is it ok to go for a run when you are on chemo?' Because the chemo is quite hectic, and they have to monitor that it doesn't affect your heart. 'Will it be detrimental to my health? They said if you have the energy you are welcome to. I didn't understand at the time that I wouldn't have any energy to do the exercise. That was quite horrible, it wasn't great. (12/03/19)**

The interaction of the individual as 'self' and 'object' come into play at the intersection of treatment. Each treatment is tailored to an individual's needs - yet it affects the embodiment of the social body in similar ways. Individuals are no longer able to behave in predictable ways as they once had. The concept of agency is brought into question as individuals often feel overwhelmed by the diagnosis that they hand over the decision process to those they feel more experienced.

What now? Life Beyond Breast Cancer

The post-mastectomy phase of treatment of cancer for any young woman can be tumultuous as illustrated in Werner's (2006) film, '*Why I Wore Lipstick To My Mastectomy*', features Geralyn Lucas, as a once organised woman whose life is out of whack. Surrounded by several supportive individuals – from parents to husband to "composites of my group of girlfriends". The film chronologically portrays a woman undergoing chemotherapy; from vomiting, losing her hair yet never losing hope. The film speaks to the symbolism and power of breasts breast and how a disease that affects both the interior and exterior of one's body may diminish the fundamental identity of 'womanhood'. Ultimately a woman is more than a right breast, a glowing complexion, a head full of hair. Life is different after treatment and each individual needs to get used to a new 'normal'- the embodiment of a new social body. When confronted with this new identity of 'cancer patient', the oncology nurse Sarah, explained that it all depends on the type of diagnosis, noting:

> **So, the metastatic patients compared to the patients that are less advanced is very different. The patients that are less advanced and have gone into survivorship; it will depend on how long their treatments were and if they had gone through those stages. As well as other family drama that has hindered their progression through the stages. Sometimes the patient will enter treatment and they will still be angry, or they hadn't accepted it yet. It went so quickly, they had to have a mastectomy and they hadn't accepted it yet. So, I think it completely depends on the patients. (17/01/19)**

The participants interviewed in the study embraced their new 'normal' - incorporating their new 'cancerous' social body into the embodiment of social activist. They incorporate elements from their old selves into their new 'bodies'. As Susan recounted:

> **I am back exercising and back living healthily but because I know what it feels like to lie there and your body feels useless, and you are bed bound and you can't exercise and can't move your hands above your…**
> **I have been very lucky that the side effects of the Tamoxifen haven't been that bad, compared to what others experienced. (17/01/19)**

Susan's account speaks to the social nature of bodies. Many of the participants in the study view their new 'bodies' as extensions of their old selves. They feel that a positive outlook throughout their treatment helped them with their recovery and many of the women interviewed had taken the opportunity to become activists in their community. Alicia, who was marginalised in her community, due to cultural misconceptions regarding cancer, became an activist to help educate her community about the diagnosis and treatment of cancer. She explained:

> **I am so positive; I am even doing my third year in beauty therapy. I am helping people who have cancer. I'm even doing the wigs course because at the time I had cancer, there were no wigs available. (17/01/19)**

Jacky speaks of a similar experience and has submerged her life into the Breast Health Foundation in order to help other individuals with their journeys:

> **My life is so entrenched in the breast cancer community. My surgery and my diagnosis definitely changed me; it changed my perspective in life. (17/01/19)**

These accounts speak to the changing nature of the 'social body'. These women's bodies were categorised as 'unhealthy' yet they decided to take on the embodiment of the 'activist'. Providing guidance, support and education regarding premenopausal breast cancer diagnosis.

While some accepted the embodiment of the social activists, others had to come to terms with the loss of a potential social 'body'. Many women incorporate 'motherhood' into their life trajectories but certain cancer treatments have the possibility of stripping these women of potential 'motherhood'. In response to this, Prof Benn and her team often advise women of reproductive age to undergo fertility conservation before treatment regimens are initiated. In the South African context fertility treatment – specifically cryopreservation of sexual gametes or embryos – is expensive and not readily available in the public health system nor is it covered under medical aid. The participants who were already mothers were not concerned with their future fertility but those who were at risk – mainly Katherine and Abigail- were advised to seek advice from a fertility specialist before they started their chemotherapy regimens.

Both Katherine and Abigail were diagnosed with breast cancer before their weddings. When asked about their experience with fertility, Katherine commented:

> **They said because you were going on this pre-menopause stuff, freeze your eggs. And they made it sound so 'willy nilly', "You are young just go and freeze your eggs and everything will be fine." I think that was**

> **probably the worst part. We went to this fertility clinic, basically spent every cent we had and the two rounds of fertility didn't work even though they made it sound like this easy thing and they did all the tests, it should have been fine, but I just couldn't get any embryos, so we tried another round, spent a fortune. (18/01/19)**

The loss of her embodied 'motherhood' was worse for Katherine than the loss of her breasts. The social expectations of a newly married couple mixed with the potential loss of an essential part of her expected social identity negatively affected Katherine's experience as a new wife. Both Katherine and Abigail suggested that the loss of fertility was the worst part of their experience. Katherine continued by explaining how the decrease in fertility had changed in her imagined life trajectory affected her and with the hope that one day she and her husband might start a family:

> **That was the worst part, and they still say that there are women, so I was thirty-one, so once I have done the five years there is a chance that my body will go back to normal, and I will be able to still try and have kids. The difficulty is that you don't know what your ovaries are going to do, at that point you are in your late thirties, we didn't manage to freeze any eggs; I think that was for me the absolute worst. I didn't mind having boobs chopped off, I survived all of that, I was lucky at least I got to have reconstruction at least I didn't have to have chemo or radiation, but that whole thing was definitely the worst, especially because I had just got married right at the start of the treatment. (18/01/19)**

The understanding of the lived experience of the 'self' in relation to the object allows anthropologists to better understand how different processes in the biomedical sphere affects the social body of an individual. With this information health care practitioners are able to better understand these women's experiences and adjust treatment plans to overcome the barriers associated with the diagnosis and treatment of breast cancer.

Conclusion

The film, '*Why I Wore Lipstick To My Mastectomy*', pushes the boundaries of anthropological practice as ethnography and visual art is combined and portrayed on screen for ordinary everyday cinema going people. It allows an insight into the embodied experience of a young woman with breast cancer. This personal story of one young woman's account of diagnosis, treatment and self-reflection is delivered to the homes of strangers who thereby become informed of the consequences of such a disease. The movie communicates the intimate missive of one woman's experience to help educate others through her story much as is the case with the young women participants interviewed for this study. Geralyn Lucas had none of the diagnostic criteria specifically associated with breast cancer patients – as the diagnostic criteria is focused on family history of cancer and post-menopausal women – yet her recollection of becoming the ‘other’ resonates with my own experience in the biomedical environment as a young woman with breast cancer. The message informing the journeys experienced by these young women also allows for the dissemination of important existential knowledge that these individuals have shared through experiences – that is often lost in academic writing. The visual medium provides a mechanism through which information and knowledge is effectively transmitted, in such a way that art, film and science become readily accessible to ordinary people. Technology in this case is able to transcend spatial and temporal boundaries. Werner’s (2006) film, ‘*Why I Wore Lipstick To My Mastectomy*’, is able to take the audience in to a space that they may not have necessarily experienced but “provides a reflection of the received mythology of the other” (Wynne 2010:50). In this case, a person struggling with the diagnosis and treatment of breast cancer who in societal norms is not expected to undertake this journey.

Chapter 5 has drawn on an analysis of the film ‘*Why I Wore Lipstick To My Mastectomy*’ and the accounts of the participants in this study. In following Michael Tassig’s description of ethnography as the process of “telling other people’s stories – badly” (Wynne 2010, 50), this chapter draws on the analysis of ‘*Why I Wore Lipstick To My Mastectomy*’ and the personal accounts of five young women in focusing on telling others’ stories by tracing their ethnographic journeys through the discovery of an abnormality in their breast tissue, to diagnosis, and then the various treatments of breast cancer. Concepts of ‘illness’ and ‘unhealthy’ are understood as changes in the embodiment of the social ‘self’ from constructed conditions of ‘healthy’ and ‘normal’. The lived experience grounded in Csordas’ understanding of phenomenology was used as a tool of analysis as Chapter 5 traced the orientation of the ‘self’ in different spatial and temporal environments in order to better understand an individual’s journey from life before cancer, through diagnosis, to treatment, and finally to what it means to be in remission.

Chapter 6: “Just cut it off and be done with it”[10] Communication, control and circumvention of breast cancer in young women.

Introduction

It is a bright Saturday morning in October as I attended, “Life is Beautiful”, a special conference focused on the celebration of life and giving thanks to those who had walked the journey with cancer survivors. The conference venue is located in Constantia Kloof, close to my house. The venue was filled with biomedical practitioners, support groups, and personal cancer caregivers - all of whom had participated in the care of cancer patients as they travelled along their journey from diagnosis to remission. Before today my assumption had been that a breast cancer patient’s identity was only affected by the potential loss or loss of a breast. I had never considered the loss of hair to be a significant component of the physical embodiment of identity, because at the time of my own journey, I did not know whether or not I would lose my hair. One of the speakers at the conference, Lily, the founding member of ‘A Few Grey Hairs’, altered my entire perception of embodied identity and the potential changes to identity caused by the side effects of various cancer treatments through her own life story. Lily spoke about the predictability of our hair the way it could refuse to curl or becomes frizzy in humid weather, yet regardless of these frustrations as a woman we come to expect a certain amount of predictability from how our hair behaves – or ought to behave – in different circumstances. This is why alopecia, one of the significant side effects of chemotherapy – along with nausea and fatigue – is often feared amongst newly diagnosed women (Frith Harcourt & Fussell 2007). Hearing more and more women recount how the loss of their hair severely affected them, more than the loss of their body part, as it was easier to conceal the loss of a breast than the loss of hair, made me rethink my entire approach to the effects of altered aesthetics due to cancer treatment. In this chapter I focus on how these physical changes to a woman’s body during breast cancer treatment affects her sense of control in an uncontrollable situation.

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[10] Katherine recounts her response to the proposed treatment she received when she was first diagnosed in 2016

Compared to previous decades, women treated for breast cancer in the 21^{st} century usually show no external symptoms rather it is the various treatments used to fight the cancer cells are what significantly affect the physical appearance of women (Frith Harcourt & Fussell 2007). As a society a certain amount of emphasis is placed on the external appearance of women, it is then not surprising that cancer patients have to reconstitute their identities based on their new external appearance; whether it is the loss of a breast due to a mastectomy or the loss of hair due to alopecia.

Alopecia

Alopecia is the loss of hair due to chemotherapy. The accounts of the study's participants interviewed and those told by the ladies at the cancer conference were different; whereas some played down the effects of the loss of hair in relation to the potential loss of life - others were severely affected by the loss of any external body part. Charlotte recounted her own experience comparing the side effects of chemotherapy to her idea of what it meant to be a woman:

> **There are a lot of things you don't think of with chemo, the process of losing your hair, which wasn't too traumatic in the end. I think I had a moment where I freaked out and thought "Is this really happening?" But actually, you get over it and then you don't have hair. Then you go buy a wig or get nice little "doekies"[11] for your head or whatever. So that becomes less than an issue. (21/01/19)**

The initial loss of hair can be better explained as the loss of control. The loss of control perpetuated by a cancer diagnosis changes the social body from 'normal' or 'healthy' to that of 'cancer patient'. Many individuals, such as Charlotte, expressed a need to take control – even if it is something as simple as taking control of your external appearance. Although wigs are available in South Africa, the majority of wigs available in local shops are synthetic or made from Indian hair which is very expensive[12]. Thus for a breast cancer patient struggling to retain a sense of control over her own body, the sudden change in the texture or type of hair, can induce even more trauma and personal distress. Chemotherapy is known to severely affect the external appearance of patients inclusive of alopecia, sensitive skin, brittle and damaged nails (Frith,

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[11] 10 A headscarf

[12] Wigs made from Indian hair are very expensive

Harcourt & Fussell 2007). Organisations such as ‘A Few Grey Hairs’ have taken the initiative to ‘harvest’ the healthy hair from cancer patients before the effects of chemotherapy have taken its course. This is because the patient’s natural hair is only affected by chemotherapy ten days after the patient’s first chemotherapy treatment session. From this harvested hair, the company ‘A Few Grey Hairs’ creates wigs from the patient’s original hair or similar hair donated by other people. In this way the wig manufacturer endeavours to provide a breast cancer patient with a sense of control over her body in a situation that is otherwise experienced as completely devoid of self-control and personal dignity. The loss of control perpetuates the fear of a cancer diagnosis. The problem with commercially manufactured wigs currently available on the market are the varying textures in the hair used to make the wigs. As explained by Lily from ‘A Few Grey Hairs”:

> **Our hair makes us unique. We use it as a way to express our identity. If you suddenly lose it due to chemotherapy, you will feel like a part of you has been removed. That being said, a Caucasian woman is not used to dealing with Indian hair, so giving her a wig made from Indian hair is not going to help her ‘feel better’ in her new reality. (27/10/18)**

Lily’s explanation suggests that the control over narratives – whereby one chooses what information to share with whom – becomes crucial in the process of changing identities from ‘healthy’ to ‘unhealthy’. The use of wigs and other aesthetics to help control the narrative of a ‘cancer patient’ becomes more of a symbol of control than an actual aesthetic tool. In this research study, most women interviewed found the loss of hair more significant than the loss of a breast. The United Kingdom’s National Health Service provides a free wig for all patients who are likely to lose their hair as a result of chemotherapy treatment (Frith Harcourt & Fussell 2007). Currently South African medical aids do not provide funds for wigs and most women have to be satisfied with synthetic wigs or pay upwards of R18, 000 for a custom wig.

Frith, Harcourt & Fussell (2007) note that it is often suggested by oncologists that it is the side effects caused by chemotherapy that influences a patient’s identity more than the cancer itself. Alopecia was more feared than the lumpectomy or mastectomy. Alicia, another participant young woman in my study who is from a rural community outside of Johannesburg, recounted her community’s reaction to the change in external appearance:

> **They didn't know anything about cancer. So, my head was black and when I would walk past people, they would be like - “Hey you! Why are**

> **you like this? Why did you cut your hair? It doesn't suit you. You look ugly. (17/01/19)**

As a young woman in a community who didn't understand what she was going through, Alicia was marginalised by her external appearance as her external body symptoms were easier to understand than the concept of 'cancer' as a disease in her community. Consequently, the sudden change in her appearance, provoked negative comments from those around her who did not understand what she was going through. If she had not experienced these physical changes associated with chemotherapy, Alicia would have been able to control her narrative; in the sense with whom and in what way she would have shared her personal diagnosis of her cancer story.

The external physical embodiment of cancer, through the loss of hair or a breast, further perpetuates the loss of control that breast cancer patients feel. As the cells in their bodies grow uncontrollably, causing the cancer mass, the changes in their physical bodies, spreads through communities. At this point, they are no longer in control of their own narratives. Instead of slowly finding their way through this difficult time in their lives, they are forced to become the physical representation of a 'cancer patient'. Once this new identity is given to them by those around them, they are expected to behave in a certain manner. South African organisations such as 'Look Good Feel Better', use their contacts in the cosmetic industry to help women come to terms with these new identities and thus to take some personal control in what otherwise seems to be an uncontrollable situation. Christine, who has taken up the role of program director at 'Look Good Feel Better', commented on her own experience:

> **After my first meeting, I decided to own my narrative. Where I used to never leave the house without my wig, I decided to embrace my new altered appearance. (03/04/19)**

Organisations with South Africa such as 'Look Good Feel Better' and 'A Few Grey Hairs' have made it their goal to help people diagnosed with cancer and undergoing treatment to embrace their new 'normal'. They try to help women to find a new identity in a horrible situation, whether it is as a 'cancer patient' or alternatively a cancer 'warrior', with the aim of helping them gain back control of their personal narratives.

Breast cancer can cut at the very nature of what it means to be a woman - whether it is breasts or hair. A breast cancer patient’s physical appearance will be altered with treatments that are aimed at saving their lives. Younger women, such as Jacky – a participant mentioned in **Chapter 5** (see pages 36-47) – who were diagnosed at a time in their lives where they are expected to find their identity at the end of high school, sometimes find these bodily changes due to breast cancer treatment harder to cope with due to socio-environmental factors. As Jacky recounts:

> **So, I was diagnosed at the beginning of my matric year and it was a very big shock. It all happened very quickly, because we wanted to get it done before my school year started. And it was great because they tried to organise an immediate reconstruction – so that I wouldn’t wake up flat chested. It was decided that I wasn’t going to tell my fellow school mates exactly what was going on. Boys in high school are already only thinking about boobs, so how are they going to take this? I didn’t want to, so I just told everyone that I was getting a dangerous lump removed. Which was the truth, it just wasn’t the whole truth. So, I had my mastectomy and immediate reconstruction. (19/03/19)**

From Jacky’s account, it can be argued that the reactions from the young woman’s community play a significant role in the development of identities even new identities. Jacky decided to take control of her narrative by limiting the information she shared with those around her. The choice of immediate reconstruction after her mastectomy helped preserve her identity as a young woman, as well as helped to limit the external changes people associate with cancer patients. With this control, she was able to work on the formation of her new identity without the negative influences of other people’s comments, as was seen in Alicia’s account.

Conclusion

Throughout **Chapter 6** the external changes associated with breast cancer have been discussed. What seems more traumatically devastating for young women diagnosed with breast cancer than the changes in the physical body due to the loss of a breast or hair is the loss of control over their own body that individual women experienced. The fewer the external manifestations of their cancer the more these young women were able to construct a new narrative of their new identity at their own pace. Whereas those who exhibited more visible physical changes were often left feeling marginalised due to the negative comments or influences of those around them. With the help of organisations such as ‘Look Good Feel Better’ and ‘A Few Grey Hairs’, cancer patients in South Africa are able to limit these visible changes and take control of that which they can control. With this control, whether it is the sharing of information or the reassurance that hair will behave as expected, these individuals are able to create new identities from damaged ones.

Chapter 7 Conclusion

This research report aims to conduct an exploration of the impact on the lived experience of breast cancer diagnosis and treatment on women of reproductive age living in contemporary Johannesburg. Three main themes were identified in the study’s findings and discussed in separate chapters. The themes were organised into the following chapters: **Chapter 4**: perceptions and misconceptions of breast cancer in urban Johannesburg, (ii) **Chapter 5**: women’s life trajectories as explored through their individual journey from diagnosis to post treatment, and (iii) **Chapter 6**: the effects of the altered body on the identity of a woman. This study specifically focused on investigating how the diagnosis and treatment of breast cancer affected a woman’s life trajectory with respect to personal relationships, family planning, and the re-formation of individual and social identities throughout the three chapters. The research seeks to understand how each woman navigated the diagnostic and treatment procedures, how she was able to navigate the hospital and oncology environments, and how this may affected her life trajectory. In essence, the study explores how cancer diagnostic and treatment procedures impact the everyday quality of life.

Chapter 4 focuses on the perceptions and misconceptions surrounding breast cancer in the broader discourse of cancer in Johannesburg. Information was collected from participants as well as public health educational pamphlets distributed at both field sites. It was found that the discourse of breast cancer in South Africa is viewed through a (i) ‘racially structured lens’, and (ii) often people perceived breast cancer in both age and gendered terms in that breast cancer is perceived as a disease associated with ‘older white women’. Thus, the nature of South African discourse around cancer influences health seeking behaviour amongst young women and ‘black’ women as they are excluded from the diagnostic criteria for breast cancer. Some participants in my study suggested their delay in seeking a diagnosis was influenced by this discourse and the diagnostic criteria. A critical analysis was conducted on recent South African Breast Cancer Care Policy (2017), in order to evaluate the changes in current biomedical spaces in South Africa as the policy aims to distribute a universal standard of care throughout South Africa. The policy was not relevant in the experience of the participants interviewed in my 20150-2016 research, yet it was interesting to see that the diagnostic criteria in the policy marginalises men and young women from breast cancer diagnosis. It is important to note that this policy still has not been implemented as discussed by the policy.

Chapter 5 uses the analysis of the film, '*Why I Wore Lipstick To My Mastectomy*', to help gain further insight into the embodied experience of a young woman with breast cancer. This personal story of one young woman's personal account of diagnosis, treatment and self-reflection was similar to the experiences of the participants interviewed in this study. The movie is able to communicate the intimate missive of one woman's experience to help educate others through her story much as is the case with the young women participants interviewed for this research report. Both the interviews and the movie helped to provide further insight into the experiences of these women as well as allowed for the dissemination of important existential knowledge that these individuals have shared through experiences. In following Michael Tassig's description of ethnography as the process of "telling other people's stories- badly" (Wynne 2010:50) this chapter was able to explore concepts of 'illness' and 'unhealthy' that were understood as changes in the embodiment of the social self from states of 'healthy' and 'normal'. Csordas' understanding of phenomenology helped with the understanding of an analysis of the lived experience of young woman diagnosed and treated for breast cancer. This particular framework was used to trace the orientation of the self in different spatial and temporal environments in order to better understand an individual's journey from life before cancer, through diagnosis, treatment, and finally to what it means to be in remission.

Chapter 6 explores how an individual's identity is broken, changed and re-created as a result of the physical changes in appearance. Young women diagnosed with breast cancer told stories of how the loss of control due to the changes in the physical body were experienced and how they navigated these changes. The fewer the external manifestations of their cancer the more these young women were able to construct a new narrative of their new identity at their own pace. In contradiction those who exhibited more visible physical changes were often left feeling marginalised due to the negative comments or influences of those around them. With the help of organisations such as 'Look Good Feel Better' and 'A Few Grey Hairs', cancer patients in South Africa are able to limit these visible changes and take control of that which they can control. With this control, whether it is the sharing of information or the reassurance that hair will behave as expected, these individuals are able to create new identities from damaged ones.

The findings in this study helps to extend understandings of the experiences of women of reproductive age with the diagnosis and treatment of breast cancer in the social, economic, and spatial and temporal context of Johannesburg. It is highlighted that although a new 2017 ‘South African Public Health Breast Cancer Policy’ has been implemented, the needs of young women in the context of this research report are still neglected. Educational material provided by Public Health needs to be updated to include risk factors for young women and men. It was shown that there is a clear ‘racially’ constructed discourse surrounding breast cancer in contemporary urban Johannesburg context. Thus, there continues to be a need to focus on comprehensively educating various communities and biomedical health practitioners on the ‘race’, ‘age’, and ‘gender’ inclusive nature of breast cancer.

Bibliography

Films

Pretorius, L., director. (2018). “Fynskrif” Season 1 Episode 7. 2018. Cape Town, South Africa: KykNet. Showmax, Accessed: 23/04/2019. URL:https://www.showmax.com/eng/tvseries/0i7rof69fynskrif.

Werner, P., director.(2006). “Why I Wore Lipstick to My Mastectomy”. 2006. New York: Lifetime, 2018.” Accessed on: 11/04/18. URL: https://www.youtube.com/watch?v=ha7jMcg3Xx4.

Literature

Al-Azri, M., Al-Awisi, H., & Al-Moundhri, M.(2009). “Coping With a Diagnosis of Breast Cancer-Literature Review and Implications for Developing Countries.” In: The Breast Journal, 15 (6): 615-22. URL: https://doi.org/10.1111/j.1524-4741.2009.00812.x.

Bell, K. & Ristovski-Slijepcevic, S.(2011). “Metastatic Cancer and Mothering: Being a Mother in the Face of a Contracted Future.” In: Medical Anthropology, Cross-Cultural Studies in Health and Illness, 30 (6): 629-49.

Bell, K. & Ristovski-Slijepcevic, S.(2015). “Communicating ‘Evidence’: Lifestyle, Cancer, and the Promise of a Disease-Free Future.” Medical Anthropology Quarterly 29 (2): 216-36.

Boyd, C. (2015). “Breast Cancer: The Value and Meaning of Breasts.” Cancer Forum. Accessed: 31 May 2018 11:

Burke, N. and Mathews, H.(2017). “Returning to Earth: Setting a Global Agenda for the Anthropology of Cancer.” Medical Anthropology, Cross-Cultural Studies in Health and Illness, 36 (3): 179-86.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D.(2009). “The Health and Health

System of South Africa: Historical Roots of Current Public Health Challenges”. Lancet 374: 817834.

Csordas, T.J.(1997). “The Sacred Self: A Cultural Phenomenology of Charismatic Healing”, 1-56. Berkley: University of California Press.

Drageset, S., Lindstrøm, T.C., Giske, T., & Underlid, K.(2011). “Being in Suspense: Women’s Experiences Awaiting Breast Cancer Surgery.” In: Journal of Advanced Nursing 67 (9): 1941-51. URL: https://doi.org/10.1111/j.1365- 2648.2011.05638.x.

Foucault, M.(1977). “Discipline and Punish: The Birth of the Prison.” New York :Pantheon Books.

Frith, H., Harcourt, D., & Fussell, A.(2007). “Anticipating an altered appearance: women undergoing chemotherapy treatment for breast cancer.” In: European Journal of Oncology Nursing 11 (5), pp. 385–391. URL: https://www.ejoncologynursing.com/article/S1462-3889(07)00054- 3/fulltext.

Health, National Department of (2017). “Breast Cancer Control Policy.” In: accessed: 19/03/10]. URL: http://www.health.gov.za/index.php/2014-08-15-12-53-24?download=2533:breastcancer-policy.

Herbst, M.C. (2017). “Fact Sheet on Breast Cancer.” In: Cancer Association of South Africa (CANSA)(Fact Sheet). URL: http://www.cansa.org.za/files/2017/08/Fact-Sheet-Breast-Cancer-in- Women-NCR-2012-web-August-2017.pdf.

Kaufert, P.A. (1998). “Women’s Resistance and the Breast Cancer Movement.” In: New York: Cambridge University Press. Chap. In Pragmatic Women and Body Politics, edited by Margret Lock and Patricia A. Kaufert, pp. 287–309.

Lee, F.R. (2006). “Fighting Cancer With Sass and Gloss.” In: The New York Times, October 23, 2006. URL: http://www.nytimes.com/2006/10/23/arts/television/23luca.html.

Lince-Deroche, N., Rayne, S., van Rensburg, C., Benn, C., Masuku, S., & Holele, P.(2017). “Breast Cancer in South Africa: Developing an Affordable and Achievable Plan to Improve Detection and Survival.” In: In South African Health Review 2017, 20th ed., Durban, South Africa: Health Systems Trust. Pp. 181–188.

Lorde, A. (1980). The Cancer Journals. San Francisco: Aunt Lute Books.

Manderson, L. (2018). “Cancer Singular. Unpublished paper presented at Cancer in Context: Clinical, Organizational and Psychosocial Perspectives on the Cancer Course, 1-11. Middelfart, Denmark.”

Manderson, L., Markovic, M., & Quinn, M. (2005). “Like Roulette: Australian Women’s Explanations of Gynecological Cancer.” In: Social Science & Medicine 61.2, pp. 323–332. URL: https://doi.org/10.1016/j.socscimed.2004.11.052.

Mbakile-Mahlanza, L., Manderson, L., Downing, M., & Ponford, J. (2017). “Family caregiving of individuals with Traumatic Brain Injury in Botswana.” Disability and Rehabilitation 39(6), Pp. 559–567. DOI: DOI:10.3109/09638288. 2016.1152605.

Murphy, K. R., & Davidshofer (2004). Psychological Testing: Principles and Applications. 6th ed. New Jersey: Pearson Prentice Hall.

Peate, M., Meiser, B., Friedlander, M., Zorbas, H., Rovelli, S., Sansom-Daly, U., Sangster, J., Hadzi-Pavlovic, D., & Hickey, M. (2011). “It’s Now or Never: Fertility-Related Knowledge, Decision-Making Preferences, and Treatment Intentions in Young Women With Breast Cancer- An Australian Fertility Decision Aid Collaborative Group Study.” Journal of Clinical Oncology 29(13), pp. 1670–1677. URL: https://doi.org/10.1200/JCO.2010.31.2462.

Punam, R., Ratcliffe, J., Sussman, J., Forbes, M., Levine, M., & Hodgson, N.(2017). “Young Women with Breast Cancer: Needs and Experience”. Edited by Udo Schumacher. Cogent Medicine 4(1). URL: https://doi.org/10.1080/2331205X.2017. 1278836.

Reddy, P., Ebrahim, S., Singh, B., Ramklass, S., & Buccimazza, I. (2017). “Breast Cancer and HIV: A South African Perspective and a Critical Review of the Literature.” South African Journal of Surgery 55(1), pp. 10–15.

Registry, National Cancer (2014). “Cancer in South Africa 2014 Full Report.” Accessed: 19/03/19. URL: http://www.nicd.ac.za/wp-content/uploads/2017/03/2014-NCR-tables-1.pdf.

Rosaldo, R. (1993). “Grief and a Headhunter’s Rage” in *Culture and Truth: The Remaking of Social Analysis.* London: Taylor & Francis.

Ruddy, K.J., Gelber, S.I., Tamimi, R.M., Ginsburg, E.S., Schapira, L., Come, S.E., Borges, V.F., Meyer, M.E., & Partridge, H.(2014). “Prospective Study of Fertility Concerns and Preservation Strategies in Young Women with Breast Cancer.” Journal of Clinical Oncology 32(11), pp. 1151–1156. URL: https://doi.org/10.1200/JCO.2013.52.8877.

Simms, C. (2007). “The World Bank and sub-Saharan Africa’s HIV/AIDS crisis.” CMAJ 176(12), pp. 1728–1730. URL: https://doi.org/10/1503/cmaj.061661.

Soffa, V. M. (1994). “The journey beyond breast cancer: From the personal to the political.” Rochester Vermont: Healing Arts Press. pp. 11–19.

Synnott, A. (1993). The Body Social: Symbolism, Self And Society. New York: Routledge.

Van derWiel, R. (2013). "I am happy with one": Re-evaluating the relationship between gender, breast-cancer surgery, and survival.” Agenda, 27(4), pp. 55-64. DOI: 10.1080/10130950.2013.855526

Williams, F. and Jeanetta, S.C. (2015). “Lived Experiences of Breast Cancer Survivors After Diagnosis, Treatment and Beyond: Qualitative Study.” Health Expectations 19, pp. 631–642. URL: https://doi.org/10.1111/hex.12372.

Wray, N., Markovic, M., & Manderson, L. (2007a). “Discourses of Normality and Difference: Responses to Diagnosis and Treatment of Gynecological Cancer of Australian Women.” Social Science & Medicine 64(11), pp. 2260–2271.

URL: https://doi.org/10.1016/j.socscimed.2007.02.034.

Wray, N., Markovic, M., & Manderson, L. (2007b). “Researcher Saturation: The Impact of Data Triangulation and Intensive-Research Practices on The Researcher and Qualitative Research Process.” Qualitative Health Research, 17(10) pp. 1392–1402.

Appendixes

1. **Ethical approval**
2. **Information sheet**
3. **Participant request sheet**
4. **Request to be interviewed**
5. **Request to be recorded**
6. **Interview guidelines**
7. **Pamphlets**