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Unravelling stereotype, unanticipated sociality: Breast cancer treatment at a public healthcare facility in post-apartheid Johannesburg

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This dissertation submitted in partial fulfillment of the requirements for the degree of Master of Arts, by coursework and dissertation (part-time).

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Declaration:

I declare that this is my own unaided work. It is being submitted for the requirements of the degree of Master of Art in Anthropology, at the University of the Witwatersrand, Johannesburg. It has not been submitted for any degree or examination at any other university.

…….

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21/04/2013

Dedication:

This dissertation is dedicated to my late father, Berend van der Wiel, who was endlessly proud of his children's achievements, most especially the academic ones.

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Abstract

This dissertation presents an ethnographic account of a socially diverse, public breast cancer clinic in Johannesburg. The findings of this qualitative research radically challenge the unproblematised and overdetermined use of the categories of race and gender in existing literature concerning this disease. The growing breast cancer epidemic in South Africa affects all demographic categories of women including young women. Yet, previous research frames this as a racialised and gendered crisis. Black women have been depicted as ignorant "problem patients" who resist biomedical treatment, and all women are described as having a particular relationship to their breasted bodies and a deep fear of mastectomy. Departing from these stereotypes, this ethnography reveals unanticipated data showing, firstly, that race, class, age and level of education did not determine women's relationship to breast cancer and biomedicine. Secondly, socially diverse women commonly experienced breast cancer as a life-threatening disease that evoked confrontation with existential concerns regarding suffering, death, family, and faith. Due to these commonalities, an intimate and powerful sociality existed amongst women at this clinic. Thirdly, within this sociality, women accepted mastectomy as a necessity in creating a healthy body. Breastlessness was normalised and women generally were reluctant of breast reconstruction, thus destabilising the conceptual relationship between breasts and gender. This dissertation's deconstruction of the use of hegemonic social categories is a significant intervention in a context where these categories are often viewed as absolute determinants of social and health phenomena, and therefore prompts more nuanced approaches to understanding experiences of illness in post-apartheid South Africa.

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Chapter One – (Up)Setting the scene: An introduction

A bluish-purple mound of flesh erupting through the skin – the photograph of the large cancerous breast of a black woman filled the screen of Dr Heather's cell-phone. Next - less alarming, but more puzzling - Heather showed me photograph of a tiny bone. "Who puts a chicken bone in a breast?" she asked incredulously, and explained how this had been surgically removed this from a black patient's breast. The patient had sworn that she did not know how the bone came to be in her flesh, but the doctors presumed it was placed there by a *sangoma* to cure the woman's breast disease.

This was my initial exposure to the explicit details of the breast cancer crisis in South Africa. It was my first visit to the Helen Joseph Breast Care Centre (HJBCC), in Johannesburg, to meet with Heather, a senior surgeon there. She was eager that I, as a student of anthropology, investigate the ways in which patients at the centre understood breast cancer and its treatment. For example, finding the answers to questions, such as why women chose to use traditional medicine to treat cancer. Or, why women "presented late" for medical care – such as the patient whose huge, painful-looking malignancy I had just seen a photo of.

After speaking about her experiences of and concerns about breast cancer amongst South African women, Heather introduced me to Joan, a black breast cancer survivor. She worked as a counsellor at the HJBCC providing patients with emotional support and basic information about breast cancer and treatment. The senior doctors at HJBCC collaborated with the management of an organisation called Association for Breast Cancer (ABC) to employ five counsellors.

Talking with Joan, I asked very few questions, she simply forthrightly told me about her work. My sense was that Joan thought I - as a white, university student - wanted to know specifically about black women and breast cancer. "Our people" was a phrase she used often, stating, for example, that "our people" have little education about breast cancer – its symptoms and the necessity for its early treatment. She was also vehement that traditional African healers who claimed that they could cure cancer were frauds - that there were some diseases that only medical doctors could cure.

From this initial foray into the world of breast cancer, and from studying existing academic literature about this disease in South Africa, a particular picture – one-dimensional, as I would later realise – was painted of women's relationship to this disease and its treatment. In this picture, women's ideas and actions relating to

breast cancer were determined by race, class, and "culture". Black women were considered most likely to have a mistrust of biomedicine, and believe that cancer was a "white disease". So-called coloured, Indian and white women did not feature prominently in this picture. Therefore by omission these groups of women appeared as patients who were compliant with treatments, and who had more knowledge of cancer. However, women generally were described as being devastated that they should have a breast surgically removed in the course of cancer treatment. Black women were reported to avoid medical treatment, for a fear of mastectomy. With this image in mind, what I actually experienced during fieldwork at the HJBCC, and in other locales, was unexpected.

I undertook several months of participant-observation fieldwork at the HJBCC, observing doctor-patient consultations, counselling sessions, and spent hours conversing with patients, with medical staff, and with counsellors. Due to its location – near to the city centre, suburbs, and townships – the HJBCC was a socially diverse environment. At the centre, there were patients of varying ages, incomes, beliefs, education, and skin tones. Unlike other life-threatening diseases affecting South African women – for example, HIV/AIDS and cervical cancer – breast cancer affects a more demographically diverse range of women. Therefore the nature of this illness and along with it the specific clinical context of the HJBCC, offered a fairly uncommon opportunity to examine the experiences that different kinds of South African women have of the same disease. This revealed significant findings about the inadequacy of previous breast cancer research, as well as the flaws of using social categories as unproblematised and overdetermined tools of analysis to explain illness in South Africa more generally.

My fieldwork revealed that social categories, specifically race and gender, did not operate as anticipated in affecting women's experience of breast cancer. Firstly, I encountered women who unravelled the existing stereotypes of South African breast cancer sufferers. Categories of race, class, age or religion did not correspond neatly with women's knowledge of breast cancer or their relationship to biomedical treatment. Also unanticipated was, secondly, the intimate social interactions between demographically dissimilar patients and counsellors, which took place in the counselling room and waiting areas of the HJBCC. In these interactions it was strikingly clear that when diagnosed with breast cancer, a life-threatening illness, many different women confronted similar, "human" existential concerns regarding death, suffering, family and religious faith. This sociality and these existential worries powerfully underline the limitations of using social categories to frame analysis of illness experience. The third unanticipated finding was that most patients accepted mastectomy as a dimension of ensuring future health, and many rejected the opportunity to

surgically reconstruct a prior, breasted body. This indicates that the relationship between gender and breasted bodies is not a simple as presumed, and points to the instability of the category of gender and to the malleable materiality of “womanly” bodies.

These three ethnographic insights indicate that the racialised and gendered notions of health behaviour that pervade previous breast cancer research would not be satisfactory in explaining my findings. In medical humanities the apartheid racial categories - black, coloured, white and Indian – are often retained because they are categorisations that still remain socially relevant, despite their problematic nature as reflecting ideological construction rather than biological or even social reality (Wood et al. 1997:283). These categories are retained in this dissertation more specifically to contrast my qualitative findings with those of existing breast cancer research, which has relied heavily on these categories to analyse breast cancer in South Africa. In particular, this is helpful to reflect the inadequacy of simplistic racial category to qualitatively interpret the social aspects of breast cancer within the intimate, clinical context of the HJBCC. I am not advocating a post-racial approach in understanding breast cancer in post-apartheid South Africa. It is not possible to suggest that race, class, age or linguistic comprehension made no difference to patients’ navigation of public healthcare, or to how they managed their lives as breast cancer patients outside of the HJBCC. However, it is necessary to depart from current research that applies social categories, in an over-determined fashion, to explain patients’ ideas and actions relating the breast cancer.

As an introduction, the present chapter aims to set the scene of my ethnography, and also serves as a beginning in upsetting present ideas about the social aspects of breast cancer. This chapter firstly discusses the breast cancer crisis in South Africa, as well as reviews the small amount of existing literature about social aspects breast cancer in South Africa – including the need for increased qualitative insight into this crisis to create a more fully developed picture of this disease in the post-apartheid context. Applying literature from medical anthropology, sociology, history and social theory, the existing research is contextualised and critiqued. This contextualisation leads into a discussion of the significance of a qualitative approach to examining the breast cancer crisis in South Africa, particularly in the socially diverse HJBCC, which is introduced in more detail along with a description of the methodological processes. Lastly, a chapter outline charts the way forward for this ethnography.

Cancer crisis

Breast cancer has a long-recorded history. Due to the externality of breasts and breast tumours – as compared to other forms of malignancies – the relationship between this disease and death has long been known (Olson 2002:1 & 10). Today, not only is breast cancer globally the most common cancer amongst women, it is also the cancer that kills the highest number of women (Globocan 2008). Far from being a disease of the world's wealthier women, increasing numbers of women are afflicted by this form cancer in the global south (Coughlin and Ekwueme 2009:315). Today, women in places classified as middle- and lower-income countries, although at slightly less risk of developing breast cancer, are significantly more likely to die of breast cancer than women in the higher-income countries (Coughlin and Ekwueme 2009:315; Dalal et al. 2011:10; Parker et al. 2009:686).

There is a nexus of causal relationships behind this fact, but in order to explain this it is necessary to give a brief medical description of the biological workings of breast cancer, drawing on Benn and Pantonowitz (2007), the Cancer Association of South Africa (2012) and the World Health Organisation (2007).

Cancer is the result of abnormal cell behaviour and uncontrolled cell growth leading to a malignancy that destroys surrounding tissues. Although the exact cause of breast cancer is not fully understood by medical scientists, there are several known risk factors for developing this disease: sedentary lifestyle, being overweight or obese, a diet high in fat, high alcohol consumption, early menarche, having no pregnancy or having a first pregnancy after the age of 35 years, certain genetic factors, aging, hormone replacement therapy for extended periods of time, and exposure to carcinogens[1]. There are several different types of breast cancer – different because of the tissues in which the cancer arises, for example, ductal carcinoma or lobular carcinoma. While cancer in the breast itself is not deadly, if left undiagnosed and untreated this disease can be fatal as breast cancer cells can metastasize and spread into surrounding axilla lymph nodes, and beyond into bone, lungs, liver, skin or brain. Hence, early detection and early treatment are crucial to decreasing breast cancer mortality rates. Women are generally encouraged to perform a breast self-

1 Although, according to Benn and Pantonowitz (2007:6,47) 60% of women who are diagnosed with breast cancer do not have any of these risk factors.

examination every month and to have clinical breast exams performed by a health practitioner as a routine medical check-up, with women over 40 years of age ideally having a mammogram every 2-3 years.

Growing numbers of women will develop this disease, as more and more women in the so-called developing world, such as in Africa, have longer lives, urbanise and are exposed to a "western" lifestyle – with less physical labour, fewer births, and greater disposable income and with it access to a diet high in meat products and fat, harmful alcohol consumption – and with it more risk factors of breast cancer(Akarolo-Anthony et al. 2010:2; Dalal et al. 2011:10; Parkin et al. 2008:683; Walker et al. 2004:82; Day et al. 2011:205). A more western, less impoverished life increases chances of cancer, yet medical cancer care is very poor in most African health systems, and many women are unable to easily access screening programmes or appropriate medical care (Igene 2008; Maree et al. 2012:2; Wadler et al. 2011:1; Yip et al. 2011:14). Furthermore, many African women are reportedly not aware of the danger of breast cancer (Dye et al. 2010:578; Kelland 2012). Women may first seek the help of traditional healers for their symptoms before visiting a clinic or hospital (Ajekigbe 1991; Dye et al. 2010:578; Mdondolo et al. 2003; Yip et al. 2011:S14). These factors combined result in many African women seeking medical help for breast cancer once it has advanced to Stage III or IV – when it has moved beyond the breast and its nearby lymph-nodes making it difficult to treat particularly in resource-scarce settings (Coughlin and Ekwueme 2009:315; Dalal et al. 2011:10; Dye et al. 2010:578; Maree and Wright 2010:2; Parkin et al. 2008:686). In addition, it appears that women of African descent – in Africa and in North America – are at a higher risk of developing more aggressive breast cancer at younger ages than women of Asian or European descent (Parkin et al. 2008:686; Walker et al. 2004:83). Yet, this phenomenon has not been satisfactorily explained by social or genetic factors and still remains a biosocial mystery, as such (Happe 2006).

Writing about cancer treatment in Botswana, anthropologist Julie Livingston (2012:8) has stated that "the tide of cancer is rising steadily across Africa" and "cancer is a critical face of African health *after* ARVs" (8) (emphasis in original). Until recently the gravity of the global incidence of cancer had not been fully appreciated, particularly the phenomenal increase in cancer incidence in middle- and low-income countries, where this disease has been eclipsed by other pressing health concerns, largely related to communicable disease (Farmer et al. 2010:1187; Kelland 2012). This neglect of cancer has not only been a result of pragmatic issues. It has also been overlooked as "conceptual impossibility" (Livingston 2012:33) because cancer has been framed as disease of modernity, while Africa has been framed as a continent of contagious sicknesses (Lock and Nguyen 2010:174). Yet, cancer is a leading cause of death across the world, and it is estimated that

approximately two-thirds to three-quarters of the people who die of cancer are located in countries classified and middle- and low- income (Farmer et al. 2010:1186; The Lancet 2011:1605; WHO 2007:3; WHO n.d.). Since 2005 the World Health Organisation (WHO) has placed a number of resolutions and strategies to address the impact of cancer especially in developing countries, and in 2011 the United Nations (UN) held its first high-level meeting regarding non-communicable diseases (NCDs), including cancer(Day et al. 2011:199; Thom 2011; UN 2011a; UN 2011b; WHO 2005; WHO 2007; WHO 2008). Largely the WHO and UN actions, as well as those of smaller groups, have been to encourage national governments to improve education about, prevention and screening of cancers, as well learning from or extending on strategies implemented in addressing the AIDS pandemic(Coughlin and Ekwueme 2009:316; Farmer et al. 2010; The Lancet 2011)[2].

The South African government and National Department of Health (NDoH) have not until recently recognised or addressed the impending cancer catastrophe. Increasing numbers of South Africans are developing this disease, it is the fourth leading cause of death in the country, causing the deaths of approximately 7% South Africans (DoH 2012:4; Singh 2011:1; WHO 2011). However, the statistics of cancer in South Africa affected by underreporting of cancer cases, and Albrecht (Albrecht 2006:38) estimates this figure to be closer to 20%. With an overwhelming disease burden[3] the complex impact of cancer has largely been overlooked in South Africa (Thom 2011; Singh 2011:1). Yet with the increased roll-out of anti-retroviral medicines the country will have an aging population, non-communicable diseases will become more prevalent and a larger burden on an already dysfunctional state health system(Mayosi et al. 2009:936; Mayosi et al. 2012:2032)

Non-governmental organisations, such as Association for Breast Cancer have shouldered much of the responsibility of spreading awareness about breast cancer, and increasing access to screening services and offering support to cancer sufferers. Such organisations spend much of their time raising funds, a lot of it from private companies (including international cosmetics companies that support breast cancer awareness globally) (Malan n.d.; Campaign 4 Cancer n.d.).

2 African medical cancer care accounts for 0.2% of global spending on cancer treatment.

3 South Africa has the highest disease burden amongst middle-income countries. It is beleaguered by a quadruple disease burden of – HIV and tuberculosis; chronic illnesses or NCDs; injury and violence; and maternal and child morbidity and mortality (Mayosi et al. 2012:2030; Coovadia et al. 2009:820). This disease burden is contributed to by both diseases of poverty, including malnutrition, as well as so-called diseases of development, for example, diabetes.

Regarding treatment, South Africa's public health service is not adequate to cope with existing and future cancer patients, particularly in that oncology care is only available in urban centres. From journalistic accounts as well as from conversations in the field, it is apparent unrepaired radiotherapy machines and shortages of medications have disrupted the treatment of many cancer patients in the public healthcare system (Malan n.d.; Stassen 2012). However, South Africa – as an upper middle-income country - has relatively plentiful medical resources, at least in urban areas, as compared other African countries (Besada and Ermakov 2008; Farmer et al. 2010; Harris et al. 2003; Kelland 2012; Livingston 2012)[4].

However, since starting my research process into cancer in 2011, there appears to be a significant shift in publicity about cancer generally, and attitudes towards cancer. On World Cancer Day, 4 February 2013, a variety of organisations publicised their goal to increase awareness of cancer and dispel myths about cancer. There are also a number of advocacy groups, such as Campaign for Cancer, that are pushing for cancer to become a national priority. They claim that a lack of access to information and treatment for cancer are a human rights issue that need addressing.

In 2012-2013 the Minister of Health, Aaron Motsoaledi, established a National Advisory Committee on the Prevention and Control of Cancer (DoH 2012; NDoH 2013). In response the UN special meeting on NCDs, the National Department of Health established a series of targets to better manage NCDs. These targets relate to preventative measures such as decreasing intake of tobacco, alcohol and salt, and screening for cervical and prostate cancers as part of primary healthcare– with no mention of breast cancer, however (Day et al 2011:199; Mayosi et al. 2012:2034) .

Importantly, in 2011 the NDoH resolved to revitalise the National Cancer Registry (NCR 2012), which has been defunct for the last decade (Malan n.d.; NDoH 2013; Singh 2011)[5]. The NCR is the national body to which health professionals are required to submit data regarding cancer cases they diagnose and treat. The NCR is

4 Farmer et al. 2010 report that Africa's medical cancer care amounts to 0.2% of the global costs of treating cancer.

5 According journalists accounts the collapse of the NCR is related to a fear amongst medical practitioners that reporting patient details could be legally problematic (Malan n.d.)

intended to be an authoritative source of statistics to determine the extent of incidence of various cancers, and the resources needed to treat them. However, NCR statistics having been based on pathological records and not a population-based register, and therefore are considered notoriously inaccurate (Albrecht 2006:3; Day et al; 2011:205; Singh 2011; Vorobiof et al.2001). Medical researcher Albrecht (Albrecht 2006:3) has earnestly stated that "we really do not know for sure what the real incidence of cancer in South Africa is".

Nonetheless, in 2012 the NCR published the (underreported) cancer statistics of 2004 (NCR 2012). In South Africa, according to these latest statistics, breast cancer is the most common cancer amongst women. Breast cancer represents one in every five female cancer cases, which is a rate slightly higher than that of cervical cancer. One in 29 women will develop breast cancer[6]. According to the registry, white women are most likely to develop breast, and black women more likely to develop cervical cancer.

South African women's risk of developing breast cancer according to National Cancer Registry 2012	
All women	1 in 29
Black women	1 in 53
Coloured women	1 in 17
Asian (Indian) women	1 in 20
White women	1 in 14

Statistics reported according the race categories, interpreting statistics prompts an analysis of how or why cancer is more prevalent in some groups as compared to others – whether explained as genetic or social. However, it is important to remember, as Albrecht (2006:3) suggests, that cases of cancer amongst black people are most underreported. Additionally, medical doctors involved in treating breast cancer are far more pessimistic about the real incidence of breast cancer amongst South African women, with Benn and Pantanowitz (2007:45) reporting that one in nine women will suffer from breast cancer. Professor Ruff, well-

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According to Benn and Pantonowitz (2007:39) males make up between 0.7% to 10 of breast cancer patients.

known oncologist at Charlotte Maxeke Hospital, has stated the following in relation to breast cancer statistics – "We don't really know what we are doing because the cancer data are so bad in this country" (Bateman 2008:836).

A crisis of representation: Literature review

Existing research: Problem patients

In addition to the statistical uncertainties, there is a limited academic literature about breast cancer in South Africa that is not techno-medical. This refers to literature that is not about the technical, medical, scientific intricacies of cancer and treatment, but rather that concern socially-related factors – about patient behaviours, and knowledge about breast cancer. The non-technical research that does exist is largely quantitative, mostly written by medical professionals.

According to this research, breast cancer rates are increasing amongst all South Africa women, but particularly among black women (Doyal and Hoffman 2009; Hacking et al1984; Hoffman and Cooper 1996; Jones 2011; Maree and Wright 2010; Maree et al. 2012; Matatiele and Van den Heever 2008; Mdondolo et al. 2003; Mosavel et al. 2010; Mugivhi et al 2009; Pegoraro et al. 1985; Pillay 2002; Vorobiof et al 2001; Wadler et al. 2011; Walker et al. 1984; Walker et al.2004). This is seen to be related to increasing urbanisation and the increased health risks associated with a more "western" lifestyle. The research generally concerns "late presentation" and "non-compliance", or lack of health awareness amongst breast cancer patients, in which these are contrasted between apartheid-style racial groupings. This literature does discuss in brief that structural issues have affected black women's access to medical facilities and information. However, this literature tends to provide over-simplified explanations of social life and patient behaviour. Authors depict black women as "problem patients", have little awareness of breast cancer and who after failed attempts at being cured through traditional African healing, "present late" for biomedical treatment when their cancer is at a late stage, increasing their chances of cancer-related mortality[7].

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Furthermore, Wright (1996) and Jones (2010), note that many black women do not make autonomous healthcare decisions. Instead women have what Wright (1996:1542) terms a "treatment management group", constituted largely of older family members, who depending on their beliefs, might encourage.

Similarly to international literature, South African women, and especially black women, are portrayed as fearful of mastectomy, "presenting late" with symptoms of breast cancer, because this disease affects a part of the body that is enmeshed with ideas about womanhood and attractiveness (Benn and Pantanowitz 2007; Hoffman and Cooper 1996; Cooper and Mullin 2001; Jones 2011; Mdondolo et al.2003)[8]. This research, particularly suggests that black women fear mastectomy because this may result in a rejection by community or male partners.

Contextualising existing research: Problem concepts

Not only is breast cancer a health crisis in South Africa, it appears that this illness suffers from a crisis of representation. Quantitatively - breast cancer research is uncertain. Qualitatively, this research is lacking significant in-depth understandings of South African's relationship to this disease – particularly as existing non-medical research relies heavily on some anthropologically problematic concepts in order to describe social life.

In existing breast cancer research, there are some rare points amongst the data that indicate a more considered approach to research in post-apartheid South Africa, and these will be highlighted specifically throughout the remaining chapters. However, previous research and its focus on the racialised problem patient has predominantly been riddled with problematic concepts and modes of analysis. Particularly problematic has been the overreliance on race as a meaningful classification in analysing the ideas and actions of breast cancer patients. Also of concern is the evidence of discursive legacy in which black people, black women in particular, are portrayed as "other" trapped by "tradition". Below is a literature review that provides a historic and discursive contextualisation of the breast cancer research described in brief above. This serves as a precursor to the proceeding chapters, which will discuss parts of this history in more depth when critiquing specific aspects of breast cancer research in relation to ethnographic data.

Through processes of European colonisation, Africans have come to be imagined by the global north as embodying unchanging culture (Mamdani 1996). Early anthropologists themselves had a role to play in the conceptualisation of a magically-oriented, exotic "other" (Good 1994:25). Likewise the spread of early

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Many non-academic sources, such as South African newspapers, also promulgate this idea that breast surgery is detrimental to women (for example: (Bhengu 2001; Foster 2007).

biomedicine in the colonial world established non-modern people as having unmodern beliefs and customs about healing, from which they needed saving by medical information and intervention (Comaroff and Comaroff 1997; Digby 2006). Through such medical practice and discourse, various race groups in South Africa were established as innately physically and psychologically different from one another (Digby 2006:186; Saethre and Stadler 2009:278).

Historians and public health specialists have traced such ideology in the machinations of apartheid, which resulted in the segregated healthcare for South Africans and the segregated training of nurses and doctors (Burns 1998; Burns 2004; Coovadia et al. 2009; Digby 2006; Horwitz 2009; Noble 2009). These scholars have noted that by the 1980s there were 14 separate health departments serving various homelands and race groups, with the per capita budget for the healthcare of black South Africans was roughly a quarter of that of whites, and less than half that provided for Indians and coloureds. Not only were various race groups treated in separate facilities by different doctors, but different categories of South Africans suffered from and died from different diseases. For example, the black population was far more adversely affected by infectious disease, and had a lower life expectancy. Despite the desegregation of healthcare since 1990, and a massive expansion of primary healthcare, this trend is still prevalent today – especially with regards to HIV/AIDS and tuberculosis.

Similarly, the dismantling of the apartheid medical system has not meant the erasing of a problematic medical practice or rhetoric (MacLeod and Durrheim 2002; Saethre and Stadler 2009). Dissembling apartheid structures did not vanquish racialised and racist discourse that had historically constructed South Africans as delineated groups of race, culture, tradition – with some as being positioned as more biomedically rational and compliant than others. This is particularly evident in the rhetoric about HIV/AIDS in Africa has perpetuated myths and stereotypes regarding African sexuality and patriarchy. Hence, following on from the trajectory of colonial conceptualisations black people have continued to be cast as a category of cultural, racial, traditional "other" (Bibeau and Pedersen 2002; Livingston 2012; Saethre and Stadler 2009). The influence of this history, as discussed further in Chapter One, can be seen in existing breast cancer literature, which centres around the "exotic" beliefs and practices of black. Subsequently, "What remains tacit and hidden (as opposed to audible and visible) is the normalized absent trace of 'whiteness' " (MacLeod and Durrheim 2002:796).

Concurrently to the developing and dismantling of apartheid healthcare, was the establishment of a "women centred" medicine to treat breast cancer patients. During the latter half of the twentieth century women rose to prominence in several ways that have had an impact on breast cancer treatment. Feminists played a role in critiquing biomedicine as a technocratic extension of an oppressive patriarchal system that trivalised women's subjective experiences of their bodies (Boston Women's Health Book Collective 1998; Joralemon 1999; Kaufert 1998; Lock and Nguyen 2010:70; Lorber and Moore 2002; Lupton 2003; Martin 1989; Sherwin 1996). Also, since the 1970s increasing numbers of female medical doctors have been trained, and many became specifically involved in "women's health" (Riska 2010:390; Riska and Wegar 1993). As a result, there was a growing opposition to paternalistic medical practice that had dispensed urgent, radical mastectomies removing breast tissue, lymph nodes and muscle heedless of women's wishes for their bodies (Olson 2002; Klawiter 2004; Klawiter 2005; Lorde 1997; Young 1990). In addressing these past surgical insensitivies, more conservative breast surgeries and as well as reconstructive surgery have been incorporated into breast cancer treatment. As a result of this history, a new global discourse has emerged regarding "wholeness" and "femininity" – a form of prescriptive "two breasted" feminism (Potts 2000:8–9). As will be elaborated in Chapter Four, this has characterised women generally as attaching a particular value to their breasts.

Beyond the development of this new medical practice, is that fact the breast cancer in the public sphere is an extremely gendered disease. A number of feminist commentators have criticised the heteronormativity and "pink kitsch" (Jain 2007:504) of breast cancer awareness campaigns and fundraising efforts (see for example (see for example, Ehrenreich 2001; Rubin and Tanenbaum 2011). This, along with a medical practice of two-breasted feminism, functions to conceptually entrench the indivisibility of breasts - as part of the sexed body – and gender – in the form of a certain kind of heterosexual femininity.

Moreover, breast cancer research has characterised black women as culturally prohibited from having a mastectomy, for fear of rejection from communities and intimate partners. This research reflects a history in which black women's bodies have been seen as moulded by "culture" and "tradition". Throughout the twentieth century in South Africa, and Africa more broadly, black women's bodies have been of particular medical and social concern. This has resulted in much research and intervention focused on the reproductive and sexual health of black women, in particular, fertility, teenage pregnancy, transactional sex, sexual violence, domestic abuse, and sexually transmitted disease – especially HIV/AIDS (Burns 2004; Coovadia et al. 2009; Hassim 2009; Haysom 2012; Mbali and Mthembu 2012; Mkhwanazi 2011; Wood et al. 1997). Some of this research and these interventions have depicted black women stereotypically as disempowered victims of

a conservative, masculinist society, in which they have been expected to "conform impeccably to narrow stereotypes of femininity" (Hassim 2009:70). Previous breast cancer literature has been influenced by, and reproduces, this stereotype in that it represents black women as a category of women trapped in a traditional society in which they fear that losing a breast through mastectomy will result in losing her femininity and with it her male partner, as well as potentially her economic support.

Research significance

This dissertation is significant in addressing the representational crisis of breast cancer that has been noted above. Firstly, this research contributes to an as-of-yet under-researched subject, therefore adding to a emergent body of knowledge about a significant disease in Africa and South Africa. Anthropologist, Susan Reynolds Whyte, and historian-ethnographer Julie Livingston, emphasise that there has been a dearth of social science investigation into chronic illness conditions, including cancer, in Africa. They call for a scholarship that recognises African health problems, beyond the infectious. Whyte also emphases that because of the longevity of the experience of chronic illness, and as well as the ongoing medical monitoring of conditions, such illnesses have a significant social aspect that should be examined. Parkin et al (2008:691) Dalal et al (2011:12), and Lodge and Corbex (2011) suggest that breast cancer in Africa generally needs better monitoring. In addition, Coughlin and Ekwuene (2009:317), suggest that more research be undertaken to understand the behavioural aspects of the control and prevention of breast cancer in Africa. Regarding South Africa, Albrecht (2006:5) suggests that "cancer research…has reached a dangerously low level and needs a substantial boost". Pillay (2002:105) and Maree et al (2010:195) concur that there is a need for research regarding the knowledge that South African women, of various racial categories or "cultures", have of breast cancer, and what their health-seeking behaviours they have regarding this disease. Additionally, while there is a substantial literature of the relationship between gender, breast cancer and mastectomy in Europe and North America, there is scarce in-depth investigation of how women of the global south experience their bodies and what they think about their breasts. Therefore this ethnographic study goes some way in to giving a "boost" to research investigating social or "behavioural" aspects of cancer research in the South African context.

Anthropologist-psychiatrist, Dein (2003), suggests that the anthropological study of human relationships to biomedical healthcare are especially vital, as human behaviour, constantly in flux, is elusive to quantitative approaches and a biomedical lens – which relies on simplistic social categories. Hence, secondly, through its qualitative approach to breast cancer research, this dissertation addresses the crisis of racialised and

gendered analysis in current literature. From a general ethnographic reading of a public healthcare context in which socially diverse women were treated, my analysis will extend to include women of all racial groups, giving a more balanced understanding of South African women's experiences of breast cancer. This is in contrast to previous research, which has focused overwhelmingly on the beliefs and actions of black women only, therefore unable to see beyond stereotype, and unable to acknowledge the existence of sociality, and commonality.

Furthermore, this ethnography presents a shift from much medical humanities scholarship in South Africa, which places significant emphasis on the social categories and backgrounds, of individuals experiencing a particular disease. Unlike HIV/AIDS and cervical cancer, breast cancer is a life-threatening disease that affects a diverse range of women, who are treated alongside one another in the HJBCC. By looking specifically at this illness, therefore, this study is able to compare the experiences demographically different women have of the life-changing and life-threatening illness.

As previously mentioned, South Africa appears to be experiencing a watershed moment with regards to the social and governmental importance accorded to cancer – the National Department of Health, advocacy groups are increasing efforts to extend information and treatment of cancers. Therefore, this ethnography, is socially relevant and reflects aspects of this changing cancer landscape.

Ethnographic processes

Fieldwork context

The ethnographic fieldwork for this dissertation took place at the Helen Joseph Breast Care Centre in Auckland Park, Johannesburg. I conducted preliminary fieldwork at the HJBCC in July and December of 2011. I began my fieldwork in earnest from the end of January 2011 until the beginning of June 2012.

A prominent landmark, Helen Joseph Hospital has been named after a stalwart of the struggle against apartheid. It is an academic hospital where nurses and doctors are trained, and where medical research is conducted – for example, at the well-known Themba-Lethu HIV/AIDS unit. However, the hospital as a whole has over recent years – like many other state hospitals – featured several times in the news regarding allegations of mismanagement, lack of resources, patient neglect and security problems (Mail & Guardian Staff Reporter 2008; Rawoot n.d.; SAPA 2012; Thakrudin 2012). Much of the hospital was in a grimy and

dilapidated state – from broken glass and litter scattered across the parking lot, to potholes in the hospital floor, to shortages of surgical supplies and medications[9].

A group of medical students training at the hospital told me that the Breast Care Centre was "like private" – meaning like a private medical facility. "You can just see it when you come in here", they said. The Breast Care Centre is a well-kept island of pleasantness amidst the rest of the hospital complex. In the HJBCC, by contrast, dustbins were regularly emptied, the large, beige, floor tiles sparkled, the dusky-pink walls were relatively recently painted, and there were rows of clean, upholstered chairs. Also, as Elsie, the centre's cleaner, proudly professed, the toilets in the centre did not stink, unlike those in the other parts of the hospital. Waiting for hours in the clinic, patients made good use of the two well-stocked vending machines, and could catch up on reruns of popular soap-operas on the two wall-mounted televisions.

The HJBCC was established in 2006 as a specialist unit in the Helen Joseph Hospital. Senior doctors tried to maintain some spatial and operational independence from the hospital itself. Counsellors at the centre, frequently reassured patients saying for breast cancer treatment "here, we are the best", and is regarded as one of Gauteng's top public health specialist facilities (Mail & Guardian Staff Reporter 2007). The two senior surgeons of the HJBCC, Dr Susie Owen and Dr Heather Ballantyne, were women with impressive credentials. On several occasions, Dr Susie spoke to patients and to me about her and Dr Heather's commitment to providing quality healthcare to all South African women. Additionally, their invitation for me to make the HJBCC my fieldwork site is evidence of their commitment to expanding breast cancer research.

As a state medical facility, the HJBCC is open to the general public, for the screening of and treatment of breast disease, according to a sliding scale for payments. At the time of my fieldwork fees for a doctor's consultation ranged from R0 for pensioners to R183 for patients with a medical aid[10].

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9 The Public Affairs Research Institute, an academic research body, in January 2013 become involved in an international action team to establish some form of intervention in operation of the hospital (PARI n.d.).

10 During the time of my fieldwork consultations were charged at R35.00 for unemployed patients; R110.00 for employed patients without medical aid; and R183 for patients with medical aid. Mammograms, for example, cost R35.00; R145.00 and R323.00 for the respective patient categories. Surgeries were free of charge aside from a R45.00 fee to open a patient file for surgery. These fees are remarkably inexpensive compared to private practice.

On Wednesdays specialist surgeons, registrars, medical interns[11] ran a "clinic" and consulted with roughly 30 to 80 "new" patients[12] who visited the clinic for breast cancer screening or for medical advice regarding symptoms of breast disease. Thursdays were without doubt the busiest day at the Breast Care Centre as approximately 70 to 180 "follow-up" patients returned to collect mammogram, sonar and biopsy results, and consult with the doctors, including plastic surgeons regarding breast reconstruction. At the HJBCC, The vast majority of patients were women, each week there are only one or two men treated at the HJBCC[13]. Therefore due to the limitations of my research my focus is solely on women patients, and therefore the use of "patients" is to denote women patients.

The centre often appeared chaotic because of the volume of patients, and the number of clinic processes from collecting files, making payments, collecting test results to booking surgeries. Doctors often shouted out instructions to anxious and confused patients unsure of what to wait for and where to wait for it. As a "walk-in" or "open clinic" public facility, women may come to the clinic without an appointment and without a referral from another medical practitioner. However, this meant that women usually waited for between three and seven hours before consulting a doctor, or having surgical wounds dressed by nurses. Toddlers, friends, and concerned-looking husbands accompanied some patients to the clinic. The majority of women visited the clinic alone. Women would sit quietly and patiently for hours, doing little except moving up one chair at a time in their queues, perhaps reading the information in their patient files, sending text messages. However, women often engaged in small talk with those seated around them, regardless of age or race.

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11 Usually two surgical registrars, and about four to six interns worked in the BCC for a three month "rotation". Often on Thursdays groups of fifth-year medical students would observe senior doctors during consultations.

12 Dr Heather explained to me that the clinic is at its busiest from August - women's month – into October – as breast cancer awareness month – through to December when the clinic closes for approximately three weeks over the festive season. The winter months conversely are the least busy.

13 According to Benn and Pantonowitz (2007:39) males make up between 0.7% to 10% of breast cancer patients.

Patients who were diagnosed with breast cancer were referred for oncology treatment at Charlotte Maxeke Hospital[14], in Parktown about seven kilometres from the HJBCC. To undergo breast surgery women become in-patients in the breast ward, at the rear of the breast centre, where a shortage of linen and crockery, for example, serves as a reminder that the HJBCC, like other public facilities, has a shortage of many rudimentary supplies.

Generally, breast cancer treatment involved chemotherapy, and the surgical removal of tumour(s) and surrounding breast tissue, and also affected lymph nodes. Larger or more aggressive tumours are treated with chemotherapy, before surgery. If a patient had a partial mastectomy (lumpectomy) – removing some rather than all of a breast's tissue – she would also have radiotherapy (radiation) on the remaining breast tissue. Women may also have radiotherapy at the site of lymph node removal. Many varieties of breast cancer develop in response to estrogen levels in the body, therefore many women would also be advised to take Tamoxifen for five years after initial treatment, to suppress estrogen production and prevent cancer recurrence[15].

The women who came to the HJBCC were a diverse group. Teenage girls to women in their eighties visited the clinic with benign conditions such as non-specific breast pain or cysts, to a variety of breast cancers of ranging degrees of severity. A portion of the patients had no symptoms of breast disease and were present at the clinic for routine breast cancer screening.

The HJBCC draws a racially and economically diverse group of patients. This is related to the fact that the HJBCC is a specialist unit meaning it serves patients from a wide area, who may be referred there from various medical facilities. The HJBCC also draws a socially diverse range of women because of its proximity to the Johannesburg city centre, to townships to the south and west of the city, to fairly affluent as well as well lower-middle class suburbs. Racially, HJBCC patients are fairly representative of the South African population –

14 Previously known as the Johannesburg General Hospital, still colloquially known as the "Jo'burg Gen" or "Johannesburg Hospital".

15 Some breast cancer patients test positive for the oncogene HER2 and may be prescribed Herceptin, a form of immuno-therapy ((Benn and Pantanowitz 2007:66).

although with a larger percentage of coloured patients than the national population. This is most likely related to the fact that Helen Joseph Hospital is nearby to many areas such as Crosby, Mayfair, and Bosmont, formerly classified as coloured areas during the Apartheid era.

Most patients at the HJBCC come from central and southern Gauteng Province. The clinic's reputation for medical excellence attracts people from further afield in South Africa, including Eastern Cape and Western Cape. During my time at the clinic I also met several women from Zimbabwe and one woman from the Democratic Republic of the Congo. They explained that they found it impossible to get cancer treatment in their home countries, and learnt about the HJBCC through kin who live and work in South Africa.

A large portion of patients are referred to the centre by doctors at other state hospitals and clinics around Gauteng. Doctors in the private healthcare sector refer to the HJBCC patients who need surgery or oncology treatment, but who have no, or limited, medical aid to cover these[16]. Some women who I spoke to had found out about the centre through the media and community awareness events, particularly during October – breast cancer awareness month. Other women heard about the clinic by word of mouth, for example, they may have been encouraged to visit the clinic by a breast cancer survivor.

Senior doctors of HJBCC co-ordinate with the Association for Breast Cancer (ABC) to women diagnosed with breast cancer with emotional support, and some basic information about their treatment. Five black, breast-cancer survivors, employed by the ABC, worked as counsellors at the HJBCC. They worked from the "Counselling Room" approximately 20-24 square metres. Mostly a counsellor chatted to patients about their diagnosis, treatment and its side effects in full view and within earshot of others in the room, with other counsellors adding to the conversation where they felt it helpful. Patients were often counselled in pairs,

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From my research, membership to medical insurance, and lack of medical insurance was related to class and employment – there were a racial mixture of women who had insurance and women who did not. Although undoubtedly black women were less likely to have insurance. This goes some way in unsettling the recent discussion of healthcare in South Africa regarding the possibility of a National Health Insurance system. Such discussion crudely racialise access to health care assuming few black people have medical aid and few white people do not. Also discussions regarding NHI tend to overshadow the extent to which uninsured people pay "out of pocket" for healthcare.

Some women claimed to have had medical aid in previous years but could no longer afford it, or lost private medical benefits when they were retrenched. A number of patients explained that they had consulted private doctors, at their own or their children's expense, but when it became clear that they would need surgery or oncology treatment had to use the public health system.

sometimes groups of three, sometimes along with family members, and with doctors walking in and out of the room freely.

Methodology

The bulk of my fieldwork took place in the HJBCC on Wednesdays and Thursdays – "clinic days". On these days I observed encounters between doctors and patients, between counsellors and patients, and amongst patients. I observed patients' consultations with doctors in consultations rooms and the centre generally. I observed counsellors interactions with patients in the counselling room and the within the rest of the centre. I spent untold, and uncomfortable, hours speaking with patients, individually or in groups, while they waited in line as I crouched next their chairs or leaned against walls so as not to take up a precious seat in the often slow-moving queues. Over the months of my fieldwork I spent several "visitors' hours" in the breast ward at the HJBCC visiting women whom I got to know well, before their breast surgeries. Additionally, I spent some Monday and Tuesday mornings at the HJBCC, to spend time with patients receiving post-operative wound care.

With the counsellors, my fieldwork was the most participatory. I often volunteered or was asked, to go into the hospital itself to the mammography unit to make photocopies of the contents of patients' files[17]. Accompanying patients, showing them the way to the mammogram unit, and the laboratory office or from doctors' room to counselling room, also became one of my duties. In addition, I assisted counsellors in handing out sandwiches and fruit-juices donated to the centre by a charity organisation. Furthermore, I shared many an hour with them waiting for breast cancer patients to make their way through clinic processes and on to the counselling room, often sharing jokes and leftovers.

The bulk of my ethnographic research was participant-observation, which many of my interlocutors had decided was "a nice job, just talking to people". Additionally, I also interviewed ten women, for between one and four hours, with eight interviews taking place in women's homes, or offices outside of the HJBCC. I interviewed four of the five counsellors, two of the management team of ABC, two medically-trained women from a cancer support organisation in Soweto, one HJBCC patient whom I met after her treatment at the time

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Later a photocopy machine was installed in the counselling room, which improved the efficiency of the counsellors' work and shortened the wait patients had for having their referral administration seen to.

of her breast reconstruction, and one volunteer who helped counsellors and doctors at the HJBCC with patient support and redesigning HJBCC's administrative processes. In this dissertation I have used quotation marks to indicate the direct speech of my interlocutors. These quotations were taken from interview transcriptions, or from fieldwork notes. I acknowledge that direct speech taken fieldwork notes may therefore not be entirely verbatim, but I have attempted as best as possible to recreate the exact phrases used.

Although I was acquainted with countless patients, this dissertation is based most substantially of the experiences of fifteen patients in particular. I spent many hours getting to know these women while they waited in queues at the HJBCC, and by and large spent time with these fifteen women over several days at the HJBCC, and generally accompanied them on during at least one medical consultation. From the length of, depth of and number of the conversations I had with most patients, it did not appear necessary to interview them formally. Women were not bothered that I intruded on their time waiting and on their consultations and counselling or that our conversations were not confidential because they mostly took place in a public area in the HJBCC. Some patients seemed happy to meet with me away from the HJBCC. However, a few seemed somewhat reluctant for me to meet them outside of the HJBCC and impose on their private time. This further influenced by decision not to pursue interviews with patients outside of the HJBCC environment.

Originally I intended on meeting "new" patients on Wednesdays and then accompanying them through diagnosis and treatment. However, as my fieldwork unfolded I met women more haphazardly and thus became acquainted with patients at varying points in their diagnostic and treatment journeys. However, women regardless of their point in this journey expressed similar opinions and ideas therefore I am satisfied that this element of heterogeneity amongst patients has not significantly impacted my findings.

During my fieldwork, I was armed with information pamphlets and consent forms, and also had posters on display in the centre that explained my purpose as a student there. On these posters and forms was my politely worded request for women to grant me permission to talk with them and to accompany them around the centre, and that they would be represented anonymously in my final report.

A smile and a sympathetic ear proved powerful in convincing almost all patients I approached to allow me to intrude on their healthcare experiences in a busy place where many of them felt anxious and alone while waiting. Several patients commented that they enjoyed my company during the long, boring and nerve racking hours in the HJBCC. While I obtained permission from patients whose counselling session I observed,

and these sessions are those included in this ethnography, I was privy to numerous surrounding conversations. Given the open and sometimes chaotic character of the counselling room, patients were almost always unbothered by my presence and my purpose. I tried not to intrude on counselling, I never sat between patient and counsellor, and did not take massive volumes of notes during a session.

I had ad hoc conversations with the busy medical staff at the HJBCC to ask permission to observe them. In general doctors, interns and radiographers seemed very nonchalant about my presence, my observations and questions[18]. This trend may have been related to the fact that Helen Joseph Hospital is a teaching hospital were people in training frequently observe others. At the start of my research, I spoke to counsellors to explain my presence at the clinic and distributed information pamphlets amongst them. At most times, they seemed eager to show and explain their work to me because of my interest in breast cancer, which was an important part of their lives as they draw on their experiences of this disease as part of their work.

Although gaining rapport with interlocutors was easy, fieldwork with the counsellors highlighted a hitch in my fieldwork – my lack of language proficiency. Many counselling sessions took place in English – often because it was the only mutually understandable language between counsellor and patient(s). However, counsellors also frequently spoke to patients in isiZulu, Sesotho, occasionally Venda or Tsonga, with much of the terminology being in English. Thus with these English words and my *very* rudimentary knowledge of isiZulu I was occasionally able to follow the non-English explanations. On many occasions, senior counsellor, Joan, would unprompted translate in brief the contents of conversations. At other times I would ask counsellors to translate the explanations of other counsellors speaking, or counsellors would give me a summary of what they had explained in a speech.

Undoubtedly this affected the nuance of ethnographic data I was able to gather. Nonetheless, from the variety of patients I became well acquainted with, women's illness understandings and experiences were not necessary closely aligned to race, class and home language. Frequently diverse women expressed similar reluctances and motivations towards cancer treatment. Therefore, I have worked from the assumption that this linguistic challenge was not detrimental to my research.

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18 Nurses were the only people who seemed dubious about my fieldwork. When I explained to a group of nurses about my project a few were concerned that information about them might end up being published in the news.

Also, perhaps surprisingly, my age, race and language abilities, as well as my status as a non-breast cancer sufferer, rarely stood in the way of developing relationships with demographically diverse women. In the HJBCC, I was white, women in her late 20s, who was not a staff member or a patient, and who was younger than most patients. Therefore, I was a somewhat unusual individual in this context. Yet, as I have noted previously, patients were largely eager for an audience for their accounts of their illness.

Additionally, an important factor of my research is that in the time available for fieldwork I was not able to follow every one of my interlocutors through their treatments. I am not able to say with absolute certainly that every women I spoke to did go through with her treatment, after stating that she would so. However, of the fifteen patients whose stories I have drawn upon, I witnessed that eleven of them did comply with doctors' advice to go through surgery and chemotherapy. I was not able to ascertain the stage of patients' cancers when they first visited the HJBCC. This was because doctors did not share this information with patients. Thus, I cannot provide quantitative date regarding "late presentation" of breast cancer.

Lastly, there were aspects of my fieldwork that informed my research, but that are not discussed explicitly in this report. These were: support group meetings offered by ABC outside of the Breast Care Centre; three "community education" sessions conducted by ABC counsellors at community clinics around Gauteng; one ABC cancer education event at a Soweto High School; casual conversations with nurses, registrars, radiologists and radiographers; visits to the mammography unit with patients, including observing biopsy procedures; visiting the operating theatres at Helen Joseph Hospital to observe the more technical aspects of surgeons' work; attending the iThemba Walkathon in Johannesburg, October 2012.

Ethical considerations

With permission, I have retained the name of the HJBCC because the location of this facility, and as affiliated to the Helen Joseph Hospital, is relevant to my research findings, particularly regarding social diversity and commonalities between socially diverse women. All other names - of people and organisations - are pseudonyms. I have omitted any detail that would obviously identity a doctor, counsellor or patient.

To obtain ethical approval[19] for this research I had to prove that there was sufficient psychological support for patients involved in my study – through the counsellors, as well as the availability of a psychologist at the hospital. During my fieldwork there was only one patient, who over time because of various life circumstances, seemed to become psychologically unstable. I chose to slowly discontinue my ethnographic research with her. She was in consultation with counsellors, and both a psychologist and a psychiatrist at Helen Joseph Hospital, and therefore I felt that she was taking up the necessary support.

With the support of the senior doctors at the HJBCC, obtaining ethical approval from the hospital's management and the Wits ethics committee was relatively simple. While the doctor's may have extended an invitation to me to do research in the centre, they were uninvolved in any of my methodological choices, or in the focus of my findings. Therefore their invitation has not compromised my research.

Chapter outline

The proceeding chapter, *Demographic dilemma: Unravelling stereotype*, begins by tracking the genealogy of the trope of black "problem patient" in relation to colonial and apartheid history, and how this trope has developed a narrow racialised and classed framing of the breast cancer crisis in South Africa. Thereafter the biographical accounts of five women's experience of breast cancer and treatment at the Helen Joseph Breast Care Centre are introduced. These accounts serve as an introduction to demographically diverse clinical context in post-apartheid Johannesburg, and therefore includes the findings regarding women of hegemonic social groups, who have thus far been elided in research. The ideas and actions of these five, socially dissimilar, patients are unanticipated in relation to existing research. This demonstrates the inadequacy of seeing social category, in particular race, as determinant of women's relationship to illness and biomedicine – in particular, determinant of "late presentation", "non-compliance", or a reliance on non-biomedical healing modalities. Furthermore, presenting the comments of doctors and management of the Association for Breast Cancer, illustrates that while discourse regarding the black problem patient is still pervasive in the HJBCC, there is also some recognition in medical and counselling practice that this stereotype is not as stable as it has been represented in existing research.

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19 Ethical approval obtained from Human Research Ethics Committee (Non-Medical) – reference number H111127, and also from the Human Research Ethics Committee (Medical) – reference number M111134.

Further unexpected findings are described in Chapter Three, *Shifting to sociality: Recognising common existential experience.* This chapter discusses how the physical space of the HJBCC, including the counselling room, as well as a common experience breast cancer diagnosis establish a sociality between socially diverse patients. In this sociality women's existential confrontation with breast cancer exposes commonalities between socially diverse patients. These commonalities reveal similar "human" concerns relating to suffering and death, and the importance of religious faith, family, and biomedicine. This existential significance of breast cancer, and the impact it has on women's widespread compliance with biomedical treatment, unsettles previous analysis of breast cancer, which supposes that different categories of women have divergent illness experiences. Furthermore, the notion that breast cancer is perceived as a "white disease", is challenged as patients commonly viewed breast cancer as an affliction of modern life and lifestyle.

Chapter Four, *Mastectomy and mortality: The malleability of the breasted body* undermines the stereotype that women resist and fear of mastectomy as an assault on the embodiment of womanliness, particularly for black women who are viewed as trapped by patriarchy and traditional notions of femininity. In contrast, ethnographic data from the HJBCC show that gender and race did not operate as expected in relation to breasted bodies and biomedicine. Black women did not have a distinctive relationship to their breasts that as compared to other women. In the sociality of the HJBCC, this was manifested through women's common acceptance of mastectomy as important to surviving a life-threatening disease, their normalisation of breastlessness, and a widespread reluctance towards reconstructive surgery. These findings cast doubt on the relationship between mastectomy, gender and race. This provokes a contemplation of the manner in which breast cancer, breast surgery and women's post-mastectomy bodies reveal the malleability of bodies, and conceptually unhinges gender from breasts, as components of a natural, sexed body.

Concluding this dissertation is *Alternative treatment: Challenging the tyranny of social category*. In this fifth and final chapter, I articulate how the arguments presented in the previous chapters work together to challenge the powerful, but problematic, discourse about breast cancer, and the unproblematised, overdetermined use of social categories, particularly of "race" and "gender". This chapter closes with the proposition that more care must to be taken when relying on such hegemonic categories to explain illness experiences in post-apartheid South Africa, and thus prompts more nuanced approaches to understanding of health and illness in future anthropology.

Chapter Two - Demographic dilemma: Unravelling stereotype

After reading one of my earlier papers about the problematic nature of existing breast cancer research, Dr Heather gave a very pithy summation of the situation. Heather was a senior doctor at the Helen Joseph Breast Clinic, and she contended that simply because suburban house-wives might take vitamins to cure cancer did not mean this was not "culture". Aptly and succinctly, she stated that assuming that only black patients had culture and a reliance on herbal medicines that might affect their decision to go through medical breast cancer treatment was "just racist". As far as she – as a medical professional – was concerned, "quackery", regardless of its form, was simply "quackery".

Heather's comments highlight four concerns that underpin this chapter. Firstly, existing literature connects culture, tradition and belief to statistics of "late presentation" and treatment "non-compliance" in such a way that paint black women as exceptional patients. Secondly, in constructing this stereotype there is an absence of discussion about women who are not members of the problem population. As a result, thirdly, there is a lack of recognition that women of hegemonic categories may also challenge biomedical treatment, or delay treatment. Fourthly, unlike existing medical discourse, in practice medical professionals and counsellors acknowledge that women's perceptions of cancer and its treatment are not necessarily determined by the social categories that they belong to.

This chapter addresses these concerns, initially, by tracing the history of the problematic breast cancer patient in South Africa, in relation to anthropological critique of the creation of the "other" through medical discourse. Thereafter the biographical accounts of the experiences of five patients at the Helen Joseph Breast Care Centre are presented. Significantly, these include the introduction of findings regarding categories of women who have thus far been absent in research, and who therefore by omission have been characterized as model patients. These accounts, as a qualitative examination of subjective experiences of individual patients, challenge existing stereotypes of largely quantitative findings. Additionally, the manner in which the racialised trope of the problem patient is both reproduced and brought into question by Association for Breast Cancer and by HJBCC doctors will be described. Through the presentation of this ethnographic evidence this chapter erodes existing stereotypes, and highlights the inadequacy of an overreliance on social categories of race, class, and culture, in studying illness experience in post-apartheid South Africa is highlighted. Hence, rather than positioning one demographic group as problematic in treating breast cancer, the dilemma is

rather the employment of demographic classifications to represent complex illness experience in post-apartheid South Africa.

Construction of a problem

Existing literature exploits ideas of social difference in evaluating the breast cancer crisis in South Africa. Below is an account of how this literature creates a stereotype of the problem, black, breast cancer patient, as well as a critical discussion regarding the problematic nature of this trope, and the discursive history from which it arises.

Within the small body of existing breast cancer literature in South Africa, later articles always reference earlier articles. There has therefore been a cycling and recycling of information – racialised statistics, as well as information regarding "culture", which has been used to explain the quantitative data. Authors frequently resort to an evaluation of the breast cancer crisis through racial statistics. The statistical data, and accompanying explanations of "culture", that Vorobiof et al (2001) provide, are referred to in most of the literature published subsequently (Doyal and Hoffman 2009; Dye et al. 2010; Maree and Wright 2010; Matatiele and Van den Heever 2008; Mugivhi et al. 2009; Walker et al. 2004) and taken as definitive, expert opinion of breast cancer in South Africa. Therefore I take this work as exemplary of the problematic nature of existing research.

Vorobiof et al provide statistics of the breast cancer crisis in terms of black and non-black patients (See Fig. 1, page 32). Drawing from statistics from 1970-1997, they highlight that black patients have an almost 80% chance of seeking medical help when they have developed Stage III or IV breast cancer, when this disease becomes more difficult to treat, and is more likely to be fatal.

The positioning of black in opposition to non-black (white, Indian, coloured), suggests that there is something particular about black women's relationship to breast cancer and its treatment[20]. Statistics represented through racial groupings prompt an interpretation that suggests that membership of a group is socially

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Indian and coloured women are rarely mentioned in literature. Pegararo et al (1985) suggest that Indian women as seeking medical help when there cancer is at an early or intermediate stage, in Hacking et al (1984) and Pegararo (1985) coloured patients are positioned similarly to black women, as "presenting late".

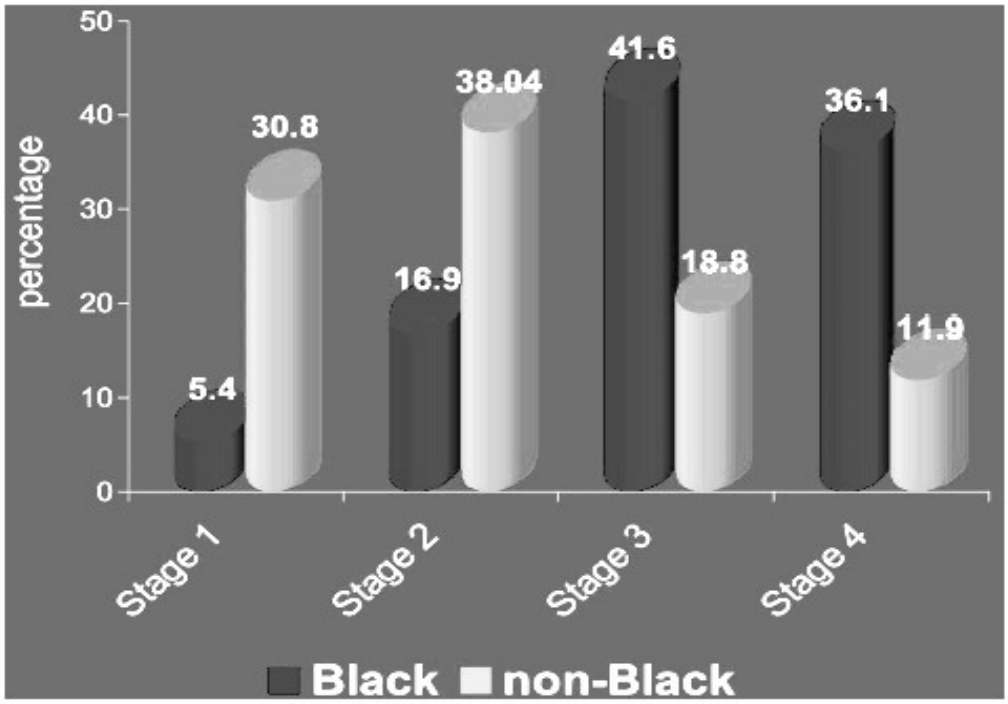

Fig 1. Presentation of breast cancer by stages.

(Taken from Vorobiof et al. 2001:126S)

significant in determining health behaviour. This is particularly so because complementing statistics there are comments about the behaviour of only one racial group – black patients. For example, below is an excerpt from Vorobiof et al. (2001:127S)

> "…many patients delay in searching medical help or avoid treatment. This is attributed to lack of access to oncology facilities but also to cultural and educational attitudes… Traditionally, black patients seek a cause for illness within the framework of indigenous beliefs… Many patients believed that a special witchcraft cause their cancer, and, therefore, their first priority was to reverse the sorcery…Black patients living in the milieu of an urban community, with exposure to Western medical standards of care and where there are fewer tribal ties, may have the necessary freedom of action and choice to obtain available medical attention."

The actual research supporting ideas of Vorobiof et al. (and by extension the others whom quote these ideas) are troubling. These authors speak authoritatively of the social world of black patients. However, this data

comes from a study conducted in 1988[21], and the work of Wright (1997)[22] who studied ten black breast cancer patients at a Cape Town hospital.

Furthermore, the work of Vorobiof et al. highlights a number of problematic ideas, which run throughout the existing literature. As in Vorobiof et al., throughout other research terms such as "belief", "tradition", "cultural and educational attitudes" are used in reference to black women. Older literature such as that of Perogaro et al. (1985:801) distinctly connects race, as absolute category, to behaviour. They state, for example, that "discrepancies in presentation may be attributable to differing cultural and educational attitudes to breast disease in various races". More recent research introduces a more diverse set of terms and ideas, to extrapolate more comprehensively why membership of a racial group would affect women's relationship to breast cancer and treatment. Thus lack of breast cancer knowledge, "late stage of presentation", and a suspicion of and resistance to biomedical treatment are associated with the following categories of women, for example: "poor and uneducated"(Foster 2007: no page number); "working class or unemployed ... having significant ties with the rural areas, with limited years of formal schooling , and with some understanding of traditional African healing systems" (Wright 1997:1540) "rural", "disadvantaged" (Vorobiof et al. 2001:127S); "lower-levels of education", not "acculturated", and "older" (Pillay 2002:112) .This extended vocabulary could arguably have been put in place, in the post-apartheid context, to give more qualification and nuance to the racialised and racist reading of the breast cancer crisis within medical discourse. However, these terms still operate to truncate and polarise the South African social world.

While race is now accompanied by or replaced by terms such as "culture", the prejudice behind racialised accounts of medical and social live are not erased (Bibeau and Pedersen 2002; Sharp and Vally 2009). Regarding the South African context, Erasmus (2008:172) suggests that through the ideology and enactment of apartheid, race does not merely reference different physical appearance. Rather race has become inseparable from difference in language, culture, social associations, class, and area of residence. Writing about the discourse of culture in accounts of the HIV pandemic in South Africa, Saethre and Stadler

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21 Hacking A, Gudgeon A, Lubelwana K: 1988. "Breast cancer in Xhosa women, a management challenge". *CME* 6:57-62. I was unable to source either a hardcopy or electronic copy of this article.

22 In much breast cancer literature, the work of Wright (1997) is referenced, independently of the Vorobiof et al article.

(2009:277), suggest terms such as culture and tradition act as "homologues" for race, and that therefore phenotype denotes the social. Macleod and Durrheim (2002) discuss the problematic racialisation of teenage pregnancy in South Africa. They suggest that in this extended vocabulary regarding medical and social "problems", tradition, culture and beliefs and actions becomes racialised, particularly because these terms are only used to describe black people as different and exotic. Thus this breadth of terminology ranging from "tradition" to "tribal" can be seen as variations on a theme that creates and delineates a black "other".

Countless social scientists have commented on the troublesome nature of the categories of race, culture, belief, religion, ethnicity, tradition when used in health research (for example, Bradby 2012; Briggs 2005; Chavez et al. 1995; Dein 2003; Das and Das 2007; DiGiacomo 1999; Lock and Nguyen 2010; Kleinman and Benson 2006; Rouse 2010; Taylor 2003; Volpp 2000; Wilce 2009). They have remarked that the manner in which these terms are employed by many doctors, public health specialists, policy makers, and psychologists reifies, essentialises, and homogenises large groups of people who are positioned as "other" to hegemonic social groups. In understanding health behaviour, such terms disallow for individual agency, idiosyncracy, and divergence within groups, which are instead painted as monolithic. Terminology of "other" then instantiate a deterministic logic that implies that membership to a group becomes a "cultural script" (Das and Das 2007:92) or a powerful fate (Taylor 2003) that dictates actions and understandings. Hence, Lock and Nguyen (2010:8) argue that terms such as "culture" have undergone a process of "medicalization", additionally Briggs (2005:276) suggests that "culture" has become "pathologized". In the world of quantitative, medical research race, class, tradition, culture are frequently viewed as a decontextualised and depoliticised risk factor (DiGiacomo 1999)[23].

Existing literature about breast cancer in South Africa, as illustrated in the above quote from Vorobiof et al. does mention to some extent mention historical political and economic context that has affected women's access to information and to health services. All authors give some acknowledgement that a lack of access to healthcare information, and healthcare particularly in rural areas, may prevent poor women from taking part in screening practices and seeking appropriate and early treatment for symptoms (Doyal and Hoffman 2009:457; Jones 2011:v; Maree et al 2012:5; Mugivhi et al. 2009:42; Pillay 2002:105; Vorobiof et al.

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Although, tradition and culture can be viewed as a protective factor (DiGiacomo 1999:445). As seen in the work of Walker et al (2004) who suggests that "African" women in KwaZulu-Natal return to tradition "prudent" lifestyle – low-fat diet, high-birth rate, first birth at a young age, physical exertion – as preventative measures against breast cancer.

2001:125S; Wadler et al. 2011; Walker et al. 2004:2). Additionally, as seen in Vorobiof et al, as quoted above, existing breast cancer literature does occasionally mention a brief subclause to indicate that their presumptions of social life do not apply to all black women (Wright 1997:1543). Although, the manner in which this is accomplished, for example, in reference to "tribal ties" are cause for anthropological concern. Overall, authors of this research have not contextualised or politicised the historical contingencies of their research discourse and frameworks of analysis. A lack of qualitative investigation has meant that problematic invocations of cultural, racial, and rural "other" are an unquestioned preoccupation in analysis. As a result "social categories that are based on historical and ideological representations become naturalized and accepted as fact" (Saethre and Stadler 2009:288). Biomedical science and its discourse are rendered a "culture of not culture" (Taylor 2003:161), as politically and culturally neutral (Lupton 1999:52). Yet terms such as "culture" and "race", are not neutral (Pon 2009:60; Wilce 2009:957). They are the products of colonial and apartheid political and economic processes, and scientific projects.

Thus far, existing breast cancer research has not acknowledged the role of history in the incarnation of the "problem patient" – a black woman who does not seek out breast cancer treatment, resists and delays medical treatment, and preferred traditional healing practices because of race, tradition, culture, beliefs and poverty. The imagining of this subject is only possible because of a particular past.

Foucault's (1979) exegesis of the category of the homosexual is helpful to consider in relation to the trope of the black problem patient. He emphasises that through a particular scientific project of knowledge-making over the nineteenth century that sexual practice of various individuals is constituted as a subjectivity. The medicalisation of these practices resulted in a category of individuals who were seen to have a specific essence, an internal nature. There are parallels between the constitution of the category deviant homosexual and the category of superstitious, ignorant African. During much the same era, also through a project of modern "governmentality"(2006), the beliefs and practices of Africans become objects of knowledge for colonial authorities, missionaries, and medical pracitioners (Joralemon 1999:90; Comaroff and Comaroff 1997) This instantiated a "new specification of individuals" (Foucault 1979:42–43), a new subject – poor, black, dependant on traditional healing, ignorant of biomedicine, carriers of infectious disease – and as such, a challenge to biomedical and political agenda. This subject has through colonial and apartheid history been positioned as innately "other", as the discourse relating race, culture and disease reinforced "conceptual boundaries" between race groups (Saethre and Stadler 2009:278). Once such concepts become "objectified" in literature, they take on life of their own and become forms of discursive rationale.

Although, as Livingston (2012:33) has stated, cancer as an African crisis has been a "conceptual impossibility" because it is a continent conceived of as a place of hunger and infection, converse to a so-called developed world. However, emerging discourse about cancer as a new African epidemic has continued to rely on a discursive history of invoking blackness, culture, traditional, and Africanness, as problematic to biomedical salvation from disease. Afflicted by a non-infectious disease, black breast cancer sufferers have still been made to fit the trope of unmodern African patient.

Saethre and Stadler (2009:279) and Macleod and Durrheim (2002:797), suggest that colonial and apartheid notions of development, and difference remain insidious. Desegregating healthcare within a democratic South Africa has not removed the centrality and gravity, and segregationalist qualities, of terms such as race, culture and tradition. As evident in existing breast cancer literature, these modes of thinking and speaking live on the medical and socio-medical literature.

A colonial aetiology that views social category as causing the behaviour of individual cancer patients is conceptually problematic in and of itself. This more so given that during my fieldwork I – unexpectedly – very rarely came across black women who approximated the problem patient. Prior analytical frameworks of breast cancer research are inadequate in interpreting illness experience in post-apartheid South Africa. The problematic nature of such analysis is accentuated further when contrasted to qualitative data collected in the socially diverse space of the HJBCC.

Unravelling stereotype

At the HJBCC, specialist unit some women arrived before the sunrise, others strolled as late at 10am. Many women disembarked from minibus taxis outside the hospital gates, others were dropped off by family members driving *skoroskoro*s. Some women drove in their own cars to the grungy parking lot outside the hospital. At the centre, waiting in line, there were elderly women in wheelchairs, mothers with toddlers, and sometimes even teenagers in school uniforms. A number of women spoke English to the clerks at the front desk, others spoke IsiZulu, some slurred from the effects of a stroke. There are women in heels and painted nails seated next to women veiled in *burkas*. Many of the women I spoke to at HJBCC were not formally employed, and most of the older patients were pensioners, some of whom spent their days looking after their grandchildren or participating in church activities. Numerous women were self-employed, through selling baked goods, beauty products, handmade crafts, and even through designing clothes, and teaching horse-

riding. Those women who were employed earned a range of different salaries from a variety of jobs - in the tourist industry, domestic work, manufacturing sector, administration, finance sector, and education. As a public specialist clinic, the HJBCC drew a demographically diverse group of patients from a wide area across Gauteng, especially from the nearby city centre, townships, and suburbs. Racially, HJBCC patients are fairly representative of the South African population.

In this fieldwork context, it soon became clear that the patients whom I met did not mirror the one-dimensional stereotypes formed in existing literature. To begin with, this literature did not reflect in any depth the subjective accounts of black women – such as, Zinhle and Virginia – who sought out biomedical help, despite structural challenges and "belief".

Zinhle, was a "hip", slender, black young woman most often wearing "skinny jeans" and bright earrings. When she came to the Helen Joseph Breast Care Centre she was 33 years old[24], and was diagnosed with stage III invasive ductal carcinoma[25]. Her cancer had affected the shape and structure of her breast and had spread to her lymph nodes. She eagerly showed me on her cellphone a photograph of her small breasts, taken at around the time she first came to the HJBCC. The photo showed that across her entire left breast just above the nipple was a line of indented flesh. Pointing to this, Zinhle said- "I look like I had an op there, but I didn't".

Initially Zinhle's case seems a typical one, which would place her into the large percentage of black women that have been reported as "presenting late". However, Zinhle said that for three years before going the breast care centre she had visited to Laratong hospital because she had a small lump in her breast. She was prescribed tablets for three years before being referred to the specialist unit at Helen Joseph Hospital. Zinhle has been through 6 cycles of chemotherapy over six months, each time travelling about 50 kilometres from the far west rand to Charlotte Maxeke hospital in Parktown. The return journey no mean feat after

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24 As in the case with Zinhle, I generally was able to ascertain from patients their ages, or approximate ages. However, there are a small number of patients whose ages I have estimated.

25 This is a breast cancer that develops in the ducts, grows and invades surrounding breast tissues (Benn and Pantanowitz 2007:101). Very few patients at the HJBCC knew their specific type of cancer they had, or the hormone receptivity of their cancer, for example. However, I accompanied Zinhle to a follow-up consultation where Dr Heather read aloud from Zinhle's file the type of cancer she had.

chemotherapy. She has had her breast and lymph nodes removed, and been through a course of radiotherapy. Motivated by her own experience she is passionate to become a breast cancer educator on the West Rand.

Zinhle's "late presentation" of symptoms of the HJBCC, most certainly was not related to a denial of her symptoms or an avoidance of biomedical treatment. Her challenges were evidence of the structural inequalities that many South African women face is accessing appropriate care. Her story in particular is indicative of a healthcare system that is not responsive to a rise in aggressive breast cancers in young women, particularly young black women. She is not the only women I met whose treatment was delayed by medical practitioners. Some women were prescribed ointments or painkillers on presenting signs of breast cancer at community clinics.

Furthermore, Zinhle's commitment to treatment is unquestionable, especially given the distances she travelled. Undergoing chemotherapy is incredibly unpleasant in most public healthcare centres in South Africa, because of the lack of adequate anti-nausea medications to manage the terrible side effects that patients experience. May conversations with Zinhle were haphazard over two chaotic Thursdays, and I was not able to confirm if she travelled by taxi to chemotherapy – as she did to visit the HJBCC. But nonetheless, several other black women I spoke to travelled by mini-bus taxi to and from chemotherapy sessions, carrying a plastic bag with them for when, or in case, they vomited while in transit.

Statistical analysis relating stage of presentation and patient race decontextualises and depoliticises the experiences of such women. In the case Zinhle, a commitment to biomedical treatment, despite late of presentation, would not be represented in such a one-dimensional analysis.

Similar to Zinhle's commitment to biomedical treatment, was Virginia's trust in chemotherapy and surgery. Virginia, however, could far more easily be cast as a stereotypical black, problem patient – her race, age, class, traditions and beliefs could be read as risk factors. Virginia was a 67-year-old black women, she had a rural upbringing but had lived in Soweto for decades. Virginia said that some time since her hysterectomy a year prior, a lump had started to develop in her breast. Subsequently her children paid for her to see private medical specialists. Upon seeing her mammogram results these doctors referred Virginia to Helen Joseph Breast Care Centre where she could get free treatment as a pensioner. Virginia had anticipated immediate surgery, and was shocked that she would need six months of oncology treatment before an operation.

Nonetheless Virginia said the following to me before beginning her treatment: “You must do what you need to, to live. You must not be scared. Otherwise what? – you will die”. She persevered through six months of chemotherapy which left her grumpy and in discomfort. Her were gums sore, her tongue black and swollen. But committed to her medical treatment, Virginia said she forced herself to eat to keep her strength up for her subsequent surgery. At the time of her mastectomy, she fully intended to visit her oncology doctor for follow up appointments every three months.

Virginia described herself as a “fortune teller”- a traditional diviner, and spoke for hours about her devotion to both the ancestors and the Jesus Christ and about her elaborate regiments of prayer and fasting. She relied on prayer to get through chemotherapy, especially the long, trying days at Charlotte Maxeke oncology unit. “Toor” – witchcraft - was what Virginia said had caused illness. Although on another occasion, she had mentioned to another patient that cancer can be caused by smoking cigarettes and drinking alcohol, and that she was confused because she had done neither or these.

From the existing literature, Virginia’s idea that witchcraft might be the cause of her illness might be anticipated. However, her reproduction of contemporary biomedical explanations of cancer as relating to carcinogens is unanticipated. Additionally her perseverance to undergo a demanding biomedical treatment was not expected, given her “otherness” - her race, age, class and level of formal education. However, as anthropologists, such as Dein (2003), and Das and Das (2007), DiGiacomo (1999) have suggested, regarding health there is no mechanical correlation between action and explanation. In various contexts in the global south, anthropologists have reported that people who believe in the witchcraft or spiritual causation of illness, will usually take up the opportunity to access good biomedical healthcare (Farmer 1999; Staples 2012) Additionally, Mugivhi et al (2009) conducted a questionnaire amongst (healthy) black women in Limpopo Province. This study found that vast majority of women indicated that for breast cancer their first preference would be medical care – regardless of their spiritual beliefs, or level of education.

The biographical accounts presented thus far are not anecdotal stories. There are countless other ethnographic data that I could have picked from – for example, a black domestic worker undergoing breast cancer screening, who had told her white employer to have a painful breast lump seen to at the HJBCC. Or, another example, were members of the Zion Christian Church, notorious for a reliance on faith healing and a rejection of biomedicine, who visited the clinic for breast cancer screening or treatment. Yes, this ethnography

portrays the experiences of women who had voluntarily presented themselves for at a medical facility in a large urban centre. However, the existing literature - which creates the stereotype of problem black patient – is almost entirely derived from data gathered at urban medical facilities[26]. This gives credence to the argument that the black problem patient is an object of knowledge born from influenced by discourse and scientific projects of colonial and apartheid eras, that reach from past into the present. This reiterates that this conceptualisation of the black problem patient-subject is not an adequate device to use to represented the nuanced world of breast cancer treatment in post-apartheid Johannesburg

Addressing the normalised absence

It is only the ideas and actions of black problem patients that are highlighted in existing South African research on breast cancer. The beliefs and behaviours of other categories of women have not been accounted for. This skewed research thus suggests that black women patients have a particularly unusual relationship to breast cancer. This scenario is related a global trend in health literature that constructs culture as a characteristic of "other", and casts membership of a hegemonic group as normative (Chavez et al. 1995; MacLeod and Durrheim 2002; Volpp 2000). Also, as Macleod and Durrhem (MacLeod and Durrheim 2002), would propose, this scenario is influenced by traces of racist and segregationalist apartheid discourse. Lastly, this scenario arises from a dearth of qualitative interpretations of breast cancer experiences in South Africa.

Research about breast cancer in South Africa, produces the expectation that white women, Indian women, coloured women, urban women, wealthy women, women with higher levels of formal education do not have "cultural beliefs" "interpretations", or "attitudes". Certainly, there is no evidence presented that suggests that these might cause such women to challenge the hegemony of biomedicine. Macleod and Durrheim (2002:796) would term this a "normalized absence", that defines "non-black" women in opposition to the problem patient. This absent group of women are by omission stereotyped as rational, modern, treatment-compliant patients. With this in mind, there is an intriguing contrast between Virginia and the description Lynley below.

26 Mugivhi et al. (2007), Pillay (2002) and Mdondolo et al. (2003) collected at least a portion of their data in rural settings.

A white teacher in her late 50s, Lynley delayed having breast cancer treatment for more than a year after being diagnosed with four cancerous breast lumps at the Breast Care Centre at the end of 2010. After receiving her diagnosis, Lynley had left Gauteng Province for a few months and had not thought that it was particularly important to get medical treatment. She confessed that she had not been aware that breast cancer could cause death if it metastasized and claimed that she had not received a phone call to confirm a date to begin chemotherapy. Joan, one of the most senior counsellors at HJBCC, checked through her paperwork from that year and stated with certainty that Lynley had been phoned.

After her consultation with Lynley, Dr Heather, a senior surgeon at the HJBCC, told me that she was astonished by this pateint. As a returning patient she did not display the usual sheepishness or fear that women apparently do when returning to the clinic after refusing treatment when it is first advised. Indeed, when I spoke to Lynley in the counselling room that quiet afternoon she was calm, and spoke casually about her condition or the prospect of chemotherapy. She had, on the advice of colleagues and from information available the internet, tried several different diets. These diets involved consuming large quantities of – watermelon, papaya, asparagus, cayenne pepper, cinnamon, turmeric, and saffron. She believed that if these foods could not cure cancer they could at least stop the cancer from growing. When her tumours broke through her skin in two places she thought that this was a positive sign that "all the muck was coming out". She then went to nurses at her local private pharmacy to have her wounds tended. As a result of the nurses' persistent protestations, Lynley eventually returned to the centre to have treatment.

Virginia anticipated and accepted doctor's directives. Lynley, a well-educated white women, showed a surprising lack of knowledge about cancer, and a nonchalance about her treatment and the symptoms of a spreading cancer. Lynley, relied, solely, on herbal medicines and folk remedies to cure her of a life-threatening illness. This is a choice or practice typically associated with the stereotype of older, black women.

Likewise, Raheemah, a 50 year old Indian women placed a lot of faith in non-biomedical, herbal cures. As mentioned, Indian women, in South Africa although rarely discussed are presented in a similar light to that of white women – compliant and aware patients. Raheemah, was a Muslim mother of four children. As a young woman she had worked as a technician in a pathology laboratory. Over several conversations while waiting at the Breast Care Centre, she explained to me that it was "God's will" that she had inadvertently felt in one of her breasts a lump, which Dr Susie termed marshmallow-sized. Her husband, a business owner, had paid for

her to visit a private doctor for a mammogram. Not having medical insurance the doctor referred Raheemah to HJBCC.

She anxiously divulged that she had considered not returning to the HJBCC to have breast surgery. Thereafter she hesitated, again, to then undergo chemotherapy. One of her nephews had encouraged her but to use a range of herbal medicines that, together with a strictly sugar-free diet, were meant to cure cancer and were less harmful than “poisonous” chemotherapy. She had mentioned this to Dr Susie who had shown her a picture of a woman who had “left her cancer - and the breast was all rotten”. Raheemah apprehensively went ahead to have chemotherapy. Nonetheless, she described herself as a religious woman who believed in the power of prayer, and she also drank what she called blessed, “prayer water” to rid herself of cancer. Also, Raheemah established her own vegetable garden and drank large amounts of juiced vegetables, especially beetroot as she had been told that this would “cut the cancer by half”.

Although she finally did comply with doctors’ orders, Raheemah, did not follow the “cultural script” (Das and Das, 2007:92) that a scientifically educated, relatively wealthy, and Indian woman should not resist medical processes in favour of herbal medicines. The kinds of reluctance that Raheemah shows towards biomedicine are not associated with the stereotype of “non-black” breast cancer patients in South Africa.Speaking about the “social life of medicines” Whyte et al (2002:75) suggest that there is an increasing “first world” scepticism challenging the power of the biomedical industry, and objecting to the side effects of modern medicines. Such scepticism is evident in Raheemah’s fear of chemotherapy as poison, and in Barbara’s theory that a cure for cancer existed but that was not publicised because of a money-making conspiracy in pharmaceutical industry.

Barbara was a well-travelled, well-read white woman of 65 years, and had worked in the media industry for many years. She was sceptical of biomedicine and believed that spiritual healing might be cure for her of breast cancer. A “spiritualist” was how Barbara described herself. Barbara irregularly went for mammograms, paying “out of pocket” for private healthcare. She sought medical advice after experiencing a short sharp pain in her breast, which she explained was “a warning by a spirit”. After being diagnosed with breast cancer, Barbara initially resisted going through with biomedical treatment. She preferred first trying what she termed “quantum healing” or “absent healing” where healing energy is transferred psychically from one human to another in a separate location. She had consulted such a healer to ease painful muscles after a fall, and was satisfied with the results.

During my interview with her, she recalled the consultation when she told Dr Susie that she wanted to first give quantum healing a chance before agreeing to chemotherapy and surgery –

> "She [Dr Susie] said I will give you three months to do this. I said I don't need three months. I said if it's going to happen it's going to happen rather rapidly. I said six weeks is all I'm giving it. I don't want to be silly".

After working with her quantum healer for six weeks, Barbara underwent another mammogram. It showed that the new tumours had subsequently grown in her breast. Thereafter she decided to undergo chemotherapy, mastectomy, radiation and breast reconstruction surgery.

The five biographical accounts presented unsettle previous approaches that related women's experiences of breast cancer to social categories, and that cast black patients as the only women whom may have ideas that would make them reluctant to rely on biomedicine. The stories of Zinhle and Virginia, destabilise the stereotype of black problem patient. Additionally the accounts of Lynley, Raheemah and Barbara highlight the imprudent absence of research regarding "non-black" breast cancer patients, and the misleading stereotype this had unwittingly created of such patients.

Grounded practice

Examining the comments and actions of patients provides substance for creating a less one-dimensional depiction of breast cancer. Likewise, it has been important to consider the insights of doctors and the management and counsellors of the Association for Breast Cancer, in relation to existing academic research.

Globally, much cancer literature promotes the idea of incorporating or tolerating for "traditional" and "alternative" healing into cancer treatment (for example, Coss et al 1998; Hart et al 2011). In literature regarding breast cancer in South Africa, only "traditional" healing is mentioned, for example that healers should be co-opted to refer patients displaying symptoms of breast cancer to medical specialists (Foster 2007; Steyn and Muller 2000; Vorobiof et al 2001:127S). "Alternative" therapies - supposedly non-African, non-biomedical practices such as reiki or homeopathy are not mentioned at all. This indicates something of a myopic obsession with reading only African as cultural. This therefore denies the reality that women in South Africa, such as those introduced in this chapter, rely on or contemplate more than biomedicine and/or traditional African medicine.

In practice, at the HJBCC, there is a more nuanced recognition that non-biomedical explanations of health and desire for non-biomedical healing are present amongst diverse women. Mpho and Silvia, of the Association for Breast Cancer management team, mentioned this during an interview in their head office. Mpho, a gregarious, black, breast cancer survivor in her late 50s, explained the mission of the ABC in the following way. An important aim of the organisation was to get rid of the "myths" that black people have about cancer – for example, that it could only be cured by traditional medicines and rituals. She explained how the ABC encouraged black women to do whatever rituals they felt necessary, but after chemotherapy. Silvia, a formidable, efficient, white, breast cancer survivor in her early 40s, added that ABC had to persuade white women also not to rely only alternative therapies. She added that "there are a few people, and this is not just in the white community, people *in general* that gravitate towards a holistic belief system that will cure them". This conversation suggested that the women of ABC felt that the patients' decisions to receive medical care was not related to beliefs and healing practices of black people specifically, but also amongst white women, and wealthy women. Therefore the work that ABC management and counsellors undertook was to encourage "people *in general"* to go through chemotherapy and surgery.

Similarly, in clinical practice at HJBCC the influence of the trope of the black, cancer patient was apparent. For example, white doctors suggested to black patients that their families in rural areas would try to convince them that biomedical treatment was inappropriate for their illness[27]. Yet, doctors seemed also to have recognise that wealth, education and whiteness did not always correspond with an acceptance of biomedicine or information about breast cancer. Dr Heather, for instance, sometimes spoke with scorn about "suburban" women who challenged biomedical treatment of cancer, claiming the efficacy unusual healing methods, such as "frequency healing".

The comments of counsellors and doctors are perhaps reminiscent of what Livingston (2012:25) would term "grounded practices occurring within a particular infrastructural, social and epidemiological setting, rather than as a therapeutic ideal or model emerging out of cutting-edge research". Livingston speaks about grounded practice in relation to the local practices of oncology, that take into account contingencies that are

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During my fieldwork, although I observed consultations with black intern doctors dealing with patients with less serious diseases, I was not able to observe the black registrar surgeon consulting with breast cancer patients.

not present in northern therapeutics, for example. However, the concept of grounded practice is a useful one with regards to the HJBCC, where senior doctors are well aware of prominent socio-medical research, of Vorobiof et al., for example. In the HJBCC, medical practice did reproduce the discourse of a stereotypical problem patient, a model that is created and recreated in such literature. However, there was also a sensitivity to a more nuanced context in which there were plural conceptualisations of cancer and its treatment, which could result in diverse patients challenging biomedicine. (Although as the following chapter will indicate, these challenges were most often short-lived.)

Doctors and ABC management both reaffirm the stereotype of problem patient as well as destabilise the powerful racialisation of this category. This destabilisation is through ascribing to socially diverse women the qualities of the stereotypical "other" – in particular the characteristic of a preference for non-medical healing, and resistance to biomedical treatment – to women of a variety of social categories. In a sense, in this grounded practice, all patients are suspected of having the potential to become problem patients with seemingly irrational beliefs and practices. While this is problematic as it creates an oversimplified dichotomy between biomedicine, as hegemonic, and all other modalities of healing and causal explanations of cancer. Nonetheless, in the HJBCC, the extension of problem patientness across demographic categories highlights that the trope of black problem patient is a decontextualised category that cannot aptly reflect the social reality of post-apartheid South Africa.

Exposing the dilemma

Zinhle, Virginia, Lynley, Raheemah and Barbara are not exceptions to the rule. They are not a minority of extraordinary women who are exceptions to the racialised propositions of existing literature about breast cancer in South Africa. Instead the experiences of these particular HJBCC patients indicate that we should take exception to existing research itself. The framing of the breast cancer crisis as a dilemma regarding a specific social group, is the product of a long, prejudiced history. By contextualising the dilemma of problem patient currently at play in existing literature, and introducing novel ethnographic findings of the subjective experiences of women, this chapter has argued that the demographic dilemma lies in seeing illness experience as contingent upon social categories, such as age, class, and race. Through examining the stories of categories of women who would have been absent in prior research, it is possible to challenge the assertion that blackness, poverty, and African tradition – as monolithic categories - determine the actions of black women, casting them as the only group of women who may show a reluctance towards biomedicine. Giving a meaningful anthropological account of breast cancer treatment at the HJBCC therefore requires a more

nuanced approach. The proceeding chapter will continue the erode the logic of existing research by arguing that the entrenchment of social difference within this research is incongruous with women's shared experiences of life-threatening illness.

Chapter Three - Shifting to sociality: Recognising common existential experience

Women's lives changed at the Helen Joseph Breast Care Centre. Regardless of what jobs they had or did not have, whether they were illiterate or they had a degree, whether they relied on Jesus, Allah, *amadlozi*, or crystals – a portion of the patients at this centre were diagnosed with cancer. Irrespective of the hormone receptivity of their cancer, or the size of their tumours - they became breast cancer patients. Their lives changed. They faced choices about medical treatment, and about life and suffering.

Current literature on breast cancer in South Africa suggests that women of different racial categories at the HJBCC would have a different relationship to this disease. From this literature, what would be especially anticipated, is that the black women would have a dramatically higher risk of being "problem patients". These patients would live with their symptoms for months or years before seeking help, and resist medical treatment. Therefore, in this context, black women would particularly need to be persuaded to undergo oncology and surgery by the peer counsellors at the centre.

From the biographical descriptions in Chapter Two, it is clear that this stereotype is not adequate in assessing women's experience of breast cancer. This chapter continues this argument by presenting ethnographic evidence of unanticipated intimate interactions amongst patients and counsellors that challenge the notion of the problem patient, and challenge the pervasive notion that responses to breast cancer are racially determined. Observations of counselling practice at the HJBCC reveal that women from various social categories need some encouragement to undergo biomedical treatment. The support and encouragement that counsellors offered patients, and that patients gave to one another, revealed several crucial commonalities amongst breast cancer patients. These commonalities related to the experience of cancer as evoking strong responses regarding a fear of suffering, a motivation to live, and faith in biomedicine and in god. These commonalities were the foundation of counselling practice and relationships amongst patients, which created an environment that nurtured compliance with medical treatment, such that compliance itself was a commonality. Existing breast cancer literature, relies on an analytical framework in which different categories of women are positioned as having different experiences of the same disease. This chapter suggests that such a framework cannot concede the life-altering effects of breast cancer diagnosis, and that various women may have similarities in their response to this diagnosis, including a perception of cancer as disease of modernity and not "white disease".

Counselling practice

The Association for Breast Cancer is a non-governmental organisation dedicated to spreading awareness about the disease and supporting women with the disease. Doctors at the HJBCC, recognising the need to provide counselling and information to patients, collaborated with the ABC to arrange a counselling service for patients.

The service at was more than an ancillary nicety offered to patients diagnosed with breast cancer[28]. It is a core component of the centre's processes. There were five, black counsellors who are breast cancer survivors. They were responsible for administrative functions, such as co-ordinating patient's transfer to the oncology centre at the Charlotte Maxeke Hospital, and following up with patients throughout treatment so as to make sure they felt supported and were not "lost in the system", and did not "default" from treatment. However, primarily counsellors provided information and emotional support to patients. This was an especially important job in the HJBCC, where doctors had a large number of patients to see to, and frequently experienced a "language barrier" between themselves and their patients. Between them, counsellors spoke a number of South African languages – IsiZulu, Sesotho, Tshivenda, Xitsonga, and English. Undeniably they were effective in translating information between doctors who speak only or mostly English and some black patients at the HJBCC.

The counsellors were located in a room, approximately 20-24 square metres[29]. It was windowless and stuffy – particularly for the menopausal. Inside it were two brown couches, three white "pleather" chairs, several stools, a fan, and a cupboard packed with breast cancer pamphlets and counsellors' handbags. The room was often crowded with the five counsellors, patients and their loved ones, anxiously awaiting counselling or

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28 According to the Patient Rights Charter, all patients have a right to information about their illness and treatment, and people diagnosed with cancer, specifically, have a right to access counselling (DoH n.d.). However, often doctors are overworked and there exist significant language barriers between healthcare provider and patient (Beck 2001; Walker et al. 2004), meaning that these rights are not necessarily met in many healthcare facilities.

29 During the latter part of my fieldwork, the counselling room was moved to a larger, breezier room. However, the bulk of my participant-observation took place in the older room.

eager to have their chemotherapy administration seen to, and also me and my notebook. Although there were many teary conversations in this room, generally it was a convivial space where socially diverse women spoke candidly about their life's experiences, gave religious advice, discussed diets and bus routes, complained about employers and even joked about sexual matters. Counselling, to a large extent, was a fairly public affair. Mostly counsellors chatted to patients about their diagnosis, treatment and its side effects in full view and within earshot of others in the room. Other counsellors added to the conversation where they felt it helpful. Patients were often counselled in pairs, sometimes groups of three, with an amalgam of languages, always involving English medical terminologies. Doctors walked in and out of the room freely, introducing worried patients to counsellors as "women who have been through this".

Technically the support offered within the Breast Care Centre is a peer-counselling service – meaning the counsellors were peers to the patients because they themselves were breast cancer sufferers. Only one counsellor had any formal training in counselling and another of the counsellors had medical training as a nurse's aide. Otherwise, none of the counsellors had any medical background or any formal assessment or certification of their knowledge of medical information regarding breast cancer and its treatment regimes[30]. Being "survivors", as counsellors described themselves, was a crucial criterion for being hired. Another was being black. This related to the fact that these counsellors also fulfil community education roles, in which they were expected to do public speaking in so-called indigenous South African languages. This also then related to the fact that speaking indigenous languages would enable counsellors to perform the important task of linguistically translating biomedical information for some black women, who consulted with English-speaking doctors.

As peer counsellors, the women fall into the category of community health worker, common-place in South Africa today. Globally, there has been an upsurge in the use of community health workers since the 1990s (Bekker et al. 2006; Steven Robins 2009; Schneider et al 2008). This was largely a response of the World Health Organisation, individual nation-states and NGOs to growing HIV and tuberculosis infections, mostly in developing countries. Community health workers have various names – lay counsellors, peer counsellors, treatment buddies, adherence counsellors. They function largely to disperse lay knowledge about diseases,

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Before beginning their work, as training, new counselors would "shadow" more-experienced counselors for about month, and would read some basic literature on breast cancer.

create a link between medical professionals and lay people, assist patients with psycho-social problems, and to ensure adherence to medical treatment regimes.

In the existing research on breast cancer in South Africa, "culturally congruent" peer-counselling and health education is touted as a means to address the breast cancer crisis, framed as a racialised, classed and "cultured" crisis (Jones 2010:89-90; Mdondolo et al. 2003; Wadler 2011). The logic behind such culturally congruent intervention is illustrated by Wadler (2011:4), who proposing that black peer educators in South Africa to address breast cancer crisis:

> "CHWs [community health workers] because of their grounding in the community, are uniquely prepared to understand and acknowledge local beliefs or "myths" and provide information about causes of the disease, which could help to destigmatize breast cancer. Women are more likely to engage with CHWs from their own communities, who understand and respect their beliefs and concerns and have earned their trust."

Community in contemporary South Africa often operates as a synonym for "poor" and "black". As Thornton and Ramphele (1988) have explained, in South Africa, the term "community" is often employed as a substitute term for racial group – particularly black people as the target of some form of intervention. Thus, Wadler et al., for example, illustrate the manner in which cultural congruency is associated only with category of "other" as black community, and the need to overcome associated "beliefs" and "myths" of the "other" (Chavez et al. 1995; DiGiacomo 1999; MacLeod and Durrheim 2002). According to this logic membership to the same social category is purported to convey a legitimacy to the information delivered by peer-counsellors.

The ABC's organisation of the practice of the counselling at the HJBCC may not necessarily be a direct response to such literature. Yet this counselling work is a manifestation of contemporary practice and discourse regarding peer counselling and culturally congruent counselling[31]. Mpho, an amiable member of the management team and a black, breast cancer survivor, emphasised the importance of similarity and congruency when explaining to me the work that the ABC does. She elaborated that "there are still people in

31 The "community education" projects that the ABC run are further evidence of a relationship to discourse regarding cultural congruency, as the black counselors work as "community educators" in community clinics in poor, black neighbourhoods across Gauteng. However, given the limitations of this dissertation there is not opportunity to discuss these projects at length.

the black communities who say breast cancer - it is a white women's disease. Pah! So if there is a [black] survivor, an educator - I am sure my skin does convince. And I have been through it [breast cancer]". She implied that the race of a breast cancer survivor illustrated that this is an illness of black women, and in order for black women to survive this illness they needed medical treatment.

Both a senior doctor at the centre, and a member of the management at the ABC explained to me that is was important that a woman newly-diagnosed with breast cancer was matched up with a survivor of the same "demographic". They explained that demographic referred to age, language and culture. As discussed in Chapter Two, in contemporary South Africa language and culture can be "homologues" for race (Erasmus 2008; MacLeod and Durrheim 2002; Saethre and Stadler 2009). Although it was unclear to me whether when talking about demographic similarity the doctor and the management were talking about the ABC's support network, outside of the centre – or whether they were talking about the counselling offered in the centre itself. Nonetheless their statements are perhaps evidence of the influence of the "culturally congruency" phenomenon.

From the contemporary milieu of cultural congruency, comments by ABC management, and the selection of counsellors at the HJBCC, I read the nuance that in this clinical scenario black patients especially need persuading to adhere to medical treatment. Perhaps further evidence of this was that there was no Afrikaans counsellor at the HJBCC. This despite the fact that a large portion of the patients that is draws were Afrikaans-speaking white and coloured women from the surrounding areas. Counsellors Dawn and Joan spoke about their anxieties that they were inept at counselling Afrikaans-speaking patients in English.

From my fieldwork observations – which I have shared thus far, and those I will present below - it emerged that in this socially diverse clinical environment women's attitudes, understandings and actions cannot necessarily be neatly predicted by their complexions. Many women who were not black needed counselling and persuasion to adhere to medical treatment. Counsellors spoke to women who, as illustrated thus far, had a variety of opinions regarding biomedicine, and cancer causation. Women also had extremely varied reactions to their cancer diagnosis – from tears, to shock and confusion, to anger. Dressed in t-shirts advertising breast cancer awareness, and equipped with their personal experiences the counsellors managed to find common ground with patients, regardless of difference. The case of Antoinette and Letta is one such example.

Antoinette was a 39-year-old, Afrikaans-speaking, white woman from the Vaal area, south of Johannesburg, where she ran her own small business. The day that I first met Antoinette she had travelled, the only white woman, on patient transport from Sebokeng Hospital in the "township" area of Sebokeng to the HJBCC. Doctors at HJBCC were trying to arrange a mammogram and biopsy for Antoinette on the same day as her visit. They were anxious to conduct tests, and start her on chemotherapy as her cancer had spread and broken through to the skin.

Antoinette was counselled by Letta, an IsiZulu-speaking black counsellor in her 40s. Letta had an unassuming, sweet manner and unending amounts of patience. It was a quiet afternoon at the clinic and the two women stood in the waiting area in front of the counselling room, speaking openly, in English, about Antoinette's worries. During the session Antoinette, trying her best to explain her fears – anxiously clutched a tissue and sobbed. She was distraught that the HJBCC doctors had told her that she should have chemotherapy before surgery. A doctor at Sebokeng Hospital had told she should have surgery first. Counsellors, regardless of what could be perceived as substantial differences between themselves and the patients, made a concerted effort to relate their situation to that of the patient. Letta explained the Antoinette about her own treatment dilemmas. Letta was already booked in for breast surgery at East Rand Hospital. But she transferred to the HJBCC to be treated by specialists – who also directed her to chemotherapy first.

In addition, Antoinette was concerned about undergoing chemotherapy because her mother died of advanced breast cancer, even though she had had chemotherapy (at a late stage). Antoinette was scared that chemotherapy would not work for her, and said she was terrified that she would die of breast cancer. In reply to such concerns counsellors always raised the weighty argument that medical treatment, despite its side-effects was necessary in order to live. The counsellors used their own existence as evidence of this. Letta confidently gave Antoinette the following reasoning - "You won't die, your mother was old, you are young, and are strong you will make it. Why are you crying when I am standing here a living testament. All the counsellors here are survivors. There is no need to be scared. You must be strong for your family".

Letta explained that a surgeon could "make another breast" for Antoinette after her mastectomy. Like many patients I observed, Antoinette disregarded the mention of breast reconstruction, saying instead "at this moment my greatest concern is survival". Counselling was often physically intimate, and by the end of this particular conversation, Letta and Antoinette's faces were about twenty centimetres apart. Antoinette was no longer sobbing, but was nodding, reassured, at Letta's authoritative advice.

The practice of counselling frequently involved earnest conversations between counsellors and patient, who together confronted the issue that treatment would be the best way to survive. As in the scenario involving Letta and Antoinette, counsellors repeatedly showed a non-medical authority to be able tell patients that they would be “okay” or “fine”, or they “will live”. Reflecting Letta’s sentiments, well-known sociologist Frank (1997:140) would suggest, within counselling practice there are “Illness stories told by bodies themselves the living testimony”. “Living testimony” is a phrased echoed in Letta’s sentiments as she established herself as experiential expert to coax Antoinette to go for chemotherapy.

However, counselling also involved practical advice, regarding life and living. The passage below, illustrates how Dawn, related her financial and familial difficulties to those of the patients who she counselled. It was a chaotic Thursday in the Breast Care Centre, the counselling room was crowded with women waiting for counselling, or waiting for the details about the start of their chemotherapy at Charlotte Maxeke Hospital. Two patients, both in their 50s, sat together on one of the brown couches. Magda was a white, Afrikaans-speaking, Christian from a small town in North West Province. Gloria was a calm, reserved Muslim woman. Their counsellor, Dawn, a kind-hearted, slightly absent-minded black women in her late 50s, sat on a chair facing the couch.

The three women’s legs touched. The intimacy of the conversation was heightened by the physical comfort the counsellor offered as Dawn touched the patients on the arm as a comforting gesture. Magda tearfully explained that she was a widow, and was worried that if she went through chemotherapy she would not be able to work and earn money. Sharing her own experiences with the patients, Dawn reassured Magda explaining that she was a widow with two children when she went through breast cancer treatment. She boldly said that by being strong she managed to go to work, and God helped her. God would help Magda too. Furthermore, counsellors and patients often establish common ground in prayer and a belief in the divine – regardless of religious affiliation. This common ground encourages patients that with some divine help they will survive breast cancer. So during this counselling session, the three women, all agreed confidently, nodding and encouraging each other, saying that God would help them through this time in their lives. Dawn went on to explain the side effects of chemotherapy, including hair loss. She mentioned that Magda would get a wig to wear to work. Magda shyly pointed to Gloria’s headscarf saying that she could get one of those. Gloria sweetly replied, yes, that she wore the headscarf because of her religion, so she even through chemotherapy she would just keep wearing it.

Beyond the counselling room, similar interactions also took place between patients. Demographically diverse women who were diagnosed with cancer at the same time, or went through chemotherapy or surgery at the same time form tight bonds. They shared hugs, cell phone numbers, life stories, fears and frustrations. They encouraged one another to go through treatment and said that they were praying for each other's health. The queues where post-surgery patients waited for hours to have their dressings seen to was an extremely common place for socially diverse patients to chat and share stories. Those women who had been through chemotherapy would often speak to patients who were about to embark on this stage of treatment regime, warning them of the ghastly side effects. Patients would share their experiential expertise of cancer and treatment with other patients, in a similar fashion to the counsellors, thereby creating a form of extended counselling.

The extended counselling that was manifest amongst different patients, is reminiscent of Livingston's (2012:78) concept of "vernacular oncology". She uses this term to explain social interactions and experiential learning that takes place amongst patients receiving oncology treatment. She describes this process as one that "merges language, techno-scientific practice, and embodied experience". This merging process can be seen in the accounts of counsellors, and in patient interactions, such as the one depicted below.

Aside from the medical treatment itself, patients also advise each other about what to expect of their personal treatment at the oncology unit at Charlotte Maxeke Hospital, such as the conversation between Yashika and Charlotte. One Monday morning, the HJBCC was empty except for a queue of about ten women outside the "dressings" room to have their post-surgical wounds and their wound dressings tended to. Charlotte and Yashika, two women who I got to know well during the course of the fieldwork, sat next to one another exchanging stories for over an hour. Yashika was an Indian woman in her 40s, she wore a colourful bandana over her bald head. She had chemotherapy before her surgery. Charlotte was a retired, white woman in her mid-60s and had just had surgery and was to begin chemotherapy soon. Yashika gave her no-holds-barred account of chemotherapy and of the oncology unit. It was filthy, and patients jumped the queues in the morning to have blood tests. Yashika explained briefly that the doctors used blood tests, and weighed a patient, to see how much chemo to give her. She complained that it took hours to wait for test results before seeing an oncologist. Sometimes processes took so long patients would have to return the next day for their consultation and treatment. Also, Yashika spoke about how awfully rude she found the medical staff there, and told Charlotte how best to survive this. That patients should just put their heads down, shut

their mouths and hope that they did not come into the firing line of the nursing staff, some of whom verbally berated cancer patients. Yashika also explained that she only suffered from nausea about two or three days after having a session of chemotherapy, and how this was different for everybody as some women felt sick almost immediately. She also had home remedies that she learnt of from her colleagues. She passed this information onto Charlotte, for example, that eating ginger biscuits and drinking ginger beer lessened nausea.

The space of the HJBCC, and the time patients spent there, affected the potential for a breast cancer sociality, and for the transmission of "vernacular oncology". The nature of treatment at HJBCC means that patients will return to the HJBCC several times. Women visited the clinic for the following purposes, for example - a first appointment, for a mammogram and biopsy, for follow-up appointment when diagnosed, for booking surgery, having surgical wounds tended to, and to obtain "repeat scripts" for hormone therapy. Klawiter (2005:7), a sociological expert on the development of the breast cancer movement in the USA and globally, highlights that contemporary breast cancer treatment involves many medical processes over an extended time. She calls this a "breast cancer continuum". Little et al (1998:1493) speak of cancer treatment as an "iterative" process within a clinical context. The nature of the "open clinic" environment at the HJBCC, means that women wait in long queues for hours when visiting the centre. Thus during the iterative process, or continuum, patients meet other patients – often meeting the same women over, and over. This means, as illustrated above, that patients who are going through the same medical processes at the same time encourage each other through treatment. Patients who had been through a process, prepare and advise other women entering into this particular process. Women often also encountered counsellors several times during the continuum of treatment.

At the HJBCC, counselling practice was deliberately designed to connect patients and counsellors, as prior patients. Klawiter (2000; 2004; 2005) argues that breast cancer support groups, regardless of their form, literally open up a time and space in which women relate to one another, therefore the experience of medical processes and anxieties about illness are less individualised. The practice of counselling, and the counselling room as a space in this Johannesburg hospital context, materially create a space for sociality. This is especially so given the fact that counselling is public, in that patients were counselled together in one room. Patients meet other patients there, and they meet multiple counsellors who contribute to one another's counselling sessions.

Yet, beyond the material reality of the HJBCC, there were other factors that influenced the potential for breast cancer sociality in the HJBCC. The personal experience of breast cancer, as a life-threatening illness, brought to the surface many reactions that are common amongst socially diverse women. The circulation of experiential expertise was a significant part of the sociality that existed amongst patients and counsellors at the HJBCC. Experience of the side effects of treatments, and the frustrations of public healthcare, were shared as warning and preparation for women yet to go through these processes. However, the candid experiential expertise would have little credence were it not for women's shared ideas regarding the importance of surviving cancer, and the power of biomedicine.

Cancer and commonality - Life, faith, family

Within the breast cancer sociality amongst patients and counsellors at the HJBCC, the following commonalities were distinguishable – a fear of suffering through treatment; a motivation to live particularly to live for family; religious faith; and faith in biomedicine. These commonalities arose in the ethnographic detail given thus far in this chapter as well as Chapter Two. Below is more detailed analysis of how these commonalities arose in conversation, and how they were utilised by counsellors and patients to encourage compliance with cancer treatment.

Medical anthropologists and sociologists have examined the relationships that may arise amongst people that share medical conditions. Whyte (2009) suggests that there have been two dominant trends in understanding the formation of identity and subjectivity in relation to health – firstly, biosociality, and secondly, politics of identity and social organisation. Rabinow (1999), Rose and Novas (2008), and Petryna (2002), for example, present the concept of biosociality, influenced heavily by Foucault's (2005) theory of biopower. Biosociality refers to the manner in which people who share the same medical condition development a connectedness, although geographically dispersed. This biosocial connectedness is specifically related to increasing lay exposure to biomedical knowledge of genetics and epigenetics, and also to the expansion of advocacy initiatives involving pharmaceutical industries, research institutes and the state. According to Whyte (2009), a politics of identity schema examines rights-based social movements demanding recognition and access to resources, for a group identified by a medical condition, such as, the disabled.

I propose that biosociality is not suitable in understanding the social world of HJBCC. The meaningful relationships amongst women at the HJBCC were not a biosociality in the sense that the vast majority of women, regardless of social context, did not have sophisticated information about their condition, biomedical

science, or have any involvement in advocacy initiatives, which relied on such information. A rights-based approach to being a breast cancer patient, demanding recognition or resources, although somewhat evident in cancer world in South Africa, was certainly was not at the heart of patient's common experiences at the HJBCC. Rather relationships amongst women were constituted by confrontation with disease that produced a field of response, particularly existential responses to cancer. Whyte suggests that nuanced ethnography, rather than assuming a connection between health and identity, assess the relationship between health and subjectivity. Therefore, the remainder of this chapter draws on literature that does not dismiss the "democratising" effects of increasing dispersal of bioscientific knowledge, or the increase in rights-based NGOs. However, this literature focuses more considerably on intimate social interactions and subjective experiences of people experiencing the same disease.

Regarding breast cancer specifically, there is qualitative evidence to suggest that illness can create meaningful community, one that is not reliant on extensive knowledge of bioscience or identity politics. Mathews (2000), conducted an ethnographic study of a racially and class diverse breast cancer support group in the U.S.A. She argues that common illness experiences took on heightened importance when coping with a life-threatening illness, with a long difficult to understand treatments. Under these circumstances, women cast aside various differences. Regarding the Bay Area in California, Klawiter (2005:15) has demonstrated the prolonged role of the cancer patient within the continuum of breast cancer treatment, accompanied by an increase in support structures for patients, has "challenged the structural barriers that separated women with breast cancer". The HJBCC context seems to mirror Mathews' and Klawiter's arguments.

In the HJBCC, becoming a breast cancer patient, or as Livingston (2012:78) might suggest - the "instantiation" of a cancer patient, induced similar contemplations of mortality amongst women who are of different categories of race, class, age, or religion. Speaking of the experience of cancer diagnosis and treatment, Little et al (1998:1489) suggest the following: "In our daily activities we live with existential phenomena which are transparent to us… cancer, as life-threatening illness, brings to the fore existential issues for many people". They add that confronting this illness creates a "cancer patientness" that disrupts everyday life, creating a consciousness of existential matters. Observations of the social world of the HJBCC suggest that breast cancer diagnosis prompts a confrontation with issues of suffering, death and life.

Women rarely spoke about their reluctance towards breast cancer surgery, as I will discuss in Chapter Four. Chemotherapy, however, was a potent subject. It struck absolute terror into the hearts of patients. This aspect

of treatment, because of the suffering it induced through its side effects, undoubtedly inspired women's strongest feelings of reluctance toward biomedicine. "Chemo is terrible" was a phrase I heard, verbatim, with great regularity from counsellors in interviews and in counselling sessions, and in conversations between patients. Livingstone (2012:93) and Frank (1997:173) highlight that oncology is a paradoxical medicine, one which harms and heals. Frank explains that oncology may therefore be construed as torture.

Nonetheless, counsellors used their powers of persuasion as experiential experts to convince patients that chemotherapy is a "twin" with surgery, and that with this pairing of treatments women would "survive" - like the counsellors themselves. While women were afraid of suffering through the side effects of chemotherapy, they were persuaded that this was a necessary evil in order not to suffer metastatic cancer and death. Letta told me how she would emphasise to patients that "they cannot run away from cancer, that if they don't have treatment they will die".

Despite women's horror at the prospect of chemotherapy, other phrases I heard in relation to the hardships of cancer treatment, was "it's my life" and "you must do what you can to survive". This is echoed in the stories of women in Chapter One. For example, Virginia, stated – "You do what you must do, to live". Antoinette, for example, emphasised that "survival" was a key concern, although she feared the prospect of treatment. In an interview, Dineo, one of the younger, more reserved counsellors, told me how she nearly gave up chemotherapy because it was so incredibly physically hard to endure. But she explained:

> "I said you know what, I have to go and finish this chemo – it's my life...Chemo is a terrible treatment. Chemo is not good, but you have to be patient. And you have to say – you know what I have to take this because of my life".

Frank (1997:29) suggests that when facing illness and death, people make self-conscious decisions that may differ substantially from their opinions and presumed choices before an existential experience. Counsellors and patients alike are adept at forcing patients to face up to potentially fatal consequences of avoiding chemotherapy, thereby changing reluctances patients had to this treatment, before they became cancer patients. This is particularly the case with women, such as Antoinette, whose experiential knowledge of cancer, chemotherapy and death that was in opposition to that of the counsellors. Women who had friends, aunts, mothers or sisters who had been through chemotherapy (at a late stage) and died from metastatic breast cancer were the patients that counsellors found were some of the most reluctant to undergo

chemotherapy. These women display what Fosket (2000:30) would regard as “bifurcated consciousness” where their knowledge of lived experiences contradicted the biomedical information pressed upon them in the Breast Care Centre context. For these women, chemotherapy was not a necessary evil, it was just a stage of suffering before death. In this case, as illustrated in the counselling session between Antoinette and Letta, the counsellors use themselves as “living testimony” arguing for the importance of biomedicine. Similarly, Dineo explained the way in which counsellors viewed their survival as a resource to successfully influence patients in their counselling practice:

> “When you tell them I am a survivor and stuff like that... Maybe they see you look nice, you didn’t die. Because when you say you have a cancer, people think you’re going to die...That is why they tell them these days we have a treatment – chemotherapy and radiation... And if you speak to the people they understand.”

At times counsellors were faced with patients extremely reluctant to go through treatment, and who declared that they were prepared to die. Little et al (1998:1487) mention that not everyone has a sense of pressing existential crisis when diagnosed as a cancer patient. In these rare scenarios counsellors shifted from using themselves as proof of the effectiveness of treatment, to giving more forthright opinions regarding death and suffering. (In a manner that perhaps doctors would not have been be able to). Joan often regaled me with stories while catching up on paperwork when the counselling room was not too busy. She told me one day of how she had managed to persuade a reluctant elderly patients to undergo treatment, even though the woman had claimed she were not scared of dying. Joan had told them: “You can’t just pray and god will take you peacefully in the night, you will suffer. The cancer will eat you little bit, little bit. God does not just take people like that. Your breast will be rotten”. Counsellors, particularly Joan were very proud of their persuasion of the more reluctant patients.

Another of these responses, relating to a common motivation to live – was the motivation specifically to live for family. For example, as Letta advised Antoinette in their counselling session – “you must be strong for your family”. Dineo in elaborating on her decision to continue with the gruelling course of chemotherapy also highlighted the relationship between life and family. “It’s my life. I have to stand up. For my baby … my baby was two years.” In another instance, Ntombazana, a very elegant and well-spoken counsellor, one day convinced a grouchy Afrikaans women in her late 60s to go through with chemotherapy, because of this invocation of the importance of family. This patient came into the counselling room in a rage. She was upset

because she felt her children had forced into having a mastectomy, and no one was going to convince her to go through chemotherapy. She was happy to die rather than go through treatment. The patient's daughter was patronisingly telling her mother that all would be fine, and that all the counsellors had managed to go through the treatment and had survived. The patient was not to be swayed. Joan flatly told the patient that she had "problems", that she should consider seeing the social worker at the hospital. Ntombazana chose a different tack. She spoke calmly and encouragingly to the patient explaining that she was "too young to die, your family still needs you". Ntombazana found out that she and the patient lived in a similar area, about sixty kilometres away from the HJBCC. Joking with the patient, she said "ag, we can catch a ride together to the hospital". The patient left the HJBCC having given her details to Joan to book chemotherapy for her.

Throughout this discussion so far, it is clear that counsellors endorse biomedicine as providing powerful treatments for cancer. However, similar sentiments are widespread amongst patients. Related to the motivation amongst HJBCC patients to survive breast cancer, was a corresponding, common faith in biomedicine as giving them the best chance of survival. Little et al. (1998:1487) argue that because of the seriousness of cancer, part of "cancer patientness" is often a surrender to a medical system. Many women stated that although they might consider, for example, prayer or herbal remedies, as an important part of getting well, that they would not be "stupid" enough not to comply with medical treatment. Barbara, who attempted quantum healing to cure her breast cancer said "I certainly don't want to die just because of this belief, it [the quantum healing] might not work this time... If I am not healed, obviously I will go and see a doctor, I am not stupid." Dorcas and Esther were two fervently religious, black women who sought help at the centre because of they were worried about the lumps in their breasts. Ultimately neither woman was diagnosed with breast cancer. Yet in conversation with me about prayer and healing, Dorcas from the Zion Christian Church said emphatically that religion was not enough, "others [who rely only on prayer] die, you *must* come to the clinic". Esther, a domestic worker, who attended an evangelical church told me "God will take care of you - but you must take care of yourself."

This combination of faith in the divine and faith in biomedicine was pervasive in counselling practice, as well as the "extended counselling" of patient sociality at the Breast Care Centre. As visible in the counselling encounter with Dawn, Magda and Gloria – counsellors frequently encourage patients to pray as well as explaining the benefits of medical treatment. On another occasion, to give one example, Dawn told a male patient that he should pray to god to "take this devil away" – meaning his cancer. Simultaneously she and Joan were explaining to this man why he needed to take his medication.

I cannot recall an instance when a patient resisted the mention of the power of prayer. Many patients – whether Christian, Hindu, Muslim, or spiritualist – agreed whole-heartedly with the counsellors about the power of the divine to help recovery from cancer and chemotherapy. Some patients would talk about cancer as a curse from Satan, while the counsellors told me that some patients thought their cancer was god's punishment for their sin. Diane a coloured women, who was zealous, evangelical Christian, claimed that breast cancer was Satan targeting women. While these pluralistic explanations healing were commonplace, a complete rejection of biomedical treatment in preference for only a faith-based healing was not treated lightly by counsellors. When Rose, a 60-year-old, suburban, coloured women playfully admitted that she considered attending a friend's church for faith healing rather than choosing chemotherapy, Joan very seriously told her "please please, this is a chronic disease. We all pray, but you must get your treatment".

From all of the above ethnographic detail, it is pertinent to note that a racialised framework that pigeon-holes patients into race groups attributes behaviours to them, ignores common experiences of different categories of women who experience breast cancer. This framework denies the importance of illness experience, the manner in which a diagnosis instantiates common profound responses, what could be termed "human" responses, to a confrontation with mortality. Livingston (2012:x) has pertinently stated:

> "Cancer, like biomedicine itself, is neither an exclusively African problem, nor a particularly Western one. The problems of pain, death, illness, disfigurement, and care … are basic human ones."

In the HJBCC, these basic human commonalities act in conjunction with the breast cancer continuum to generate a powerful breast cancer sociality. From my observations of patients' comments in counselling, as well as their actions in going through treatment, indicated that this sociality was almost always successful in turning women's reluctances into motivations as women complied with treatment. This sociality, amongst diverse women, impacts patient's subjective experiences of breast cancer and their approach to treatment in such a way that this sociality produces another commonality – that of compliance with medical treatment. In viewing breast cancer patients strictly as objects of social category, the existence of these commonalities and the significant effects of these on the compliance-creating sociality remain unacknowledged.

This sociality undermines the logic of cultural congruency that posits that only certain kinds of women – the stereotype of black problem patients - need counselling services or provision of information. Furthermore, the HJBCC sociality erodes the logic of cultural congruency, which suggests that counsellor and patient must both

be members of the same a particular community or culture in order for counselling to be effective. As evident in the HJBCC sociality - women's experience of cancer as an existential concern, as well as interactions with counsellors as "living testimony" of the importance of biomedicine are extremely powerful and persuasive across barriers of race, class, language, religion and age. The important dimension of counselling practice in HJBCC is a congruency of cancer experience, not similarity of social category. Perhaps Mpho's rational about counselling and education being that "skin colour does convince", in the context of the HJBCC, is overshadowed instead by the importance of the "I have been through it".

From "white disease" to modern threat

Within the breast cancer sociality at HJBCC, there were plural explanations about the development of cancer, especially as being related to religious causes. Within the sociality was a notable omission in women's explanations of cancer, and in their becoming cancer patients. There was relatively little reference to the idea of breast cancer as a "white women's disease", which is suggested in existing literature (Amusa and Besada 2005; Beck 2000:92; Kopane 2013; Maree and Wright 2010:191). During my fieldwork, two women did specifically mention this – Mpho of the ABC management team, Ntombazana a counsellor at HJBCC. When these women explained their work, they described that amongst black people there was a common "myth" of breast cancer a "white disease". While in the HJBCC, I overheard two conversations in which black women expressed their surprise at their diagnosis because of they had previously thought this. Undoubtedly, being a white women with an inept grasp of indigenous South African languages, would have affected how often I encountered these ideas about cancer.

However, while taking this into account, much more prevalent amongst socially diverse women was a common understanding of cancer as a modern illness, rather than a racialised illness. Observing social interactions in the HJBCC, it was clear that women were shocked and worried at the vast number of women who had cancer. Their awe was in response to the amount of patients at the HJBCC, especially young women patients, and also to their knowledge of friends, family and colleagues with diagnosed with cancer. Frequently, women – of a variety of races, and classes - would comment that cancer was not nearly as prevalent in their parents' generation. They would relate cancer to modern life - particularly diet, stress and pollution. For example, Ivy an elderly, unemployed black woman from Soweto said authoritatively that "nice food is killing us". This was a reference to fried foods and sweets, and she explained that she had started to eat more "leafy greens". Contrary to prevailing ideas regarding African perceptions of cancer as relating to

race, the sociality of the HJBCC highlighted that women commonly experienced cancer as a mortal confrontation with modernity.

Kleinman (1988:20–21) and Sontag (1979:14, 62, 19-70) have described such explanations as being a commonplace western responses to cancer as an unintended, side effect of modernity. Yet, to repeat Livingston's (2012:x) words, "Cancer, like biomedicine itself, is neither an exclusively African problem, nor a particularly Western one". Modernity and biosocial effects of urbanisation and "western" lifestyle in increasing risk factors for developing cancer – are not particularly western, nor particularly African. Neither, it seems, are people's perceptions of their common existential vulnerability to modern life, and their attempts to explain the causes and prevalence of this disease, both of which was difficult for any lay-person to comprehend.

Limits to sociality

The descriptions of counselling and patient interactions thus far reveal a number of scenarios in which patients who are reluctant to undergo treatment, listened to counsellors' experiential expertise and them decided to accept the logic of biomedicine as being crucial to survive. In these scenarios, counsellors were mostly calm and accepting of patients' concerns. They listened patiently to women's different explanations of the cause of their cancer, and other remedies they thought would be beneficial. However, counsellors did not spare their disapproval of patients who persistently challenged the narrative regarding biomedicine as necessary to avoid suffering and death and to survive, such as the counsellors had.

This scenario described below involved two women, who according to existing literature may be conceived of as possible problem patients whose "traditions" and "culture" might challenge clinical treatments. However, only one woman felt the ire of the counsellors.

It was an early Thursday afternoon when a black breast cancer patient, in approximately her early 50s, was directed to a couch in the counselling room by Dr Heather. The patient abruptly left the room after an extremely brief, terse conversation with counsellors. I was not able to even take note of this interaction because it happened so quickly. Counsellors then complained that the patient was stubborn and that she had been there three times over the last three months during which time she had previously refused treatment. Palesa, a cancer survivor and a friend of the counsellors, was making a social call at the HJBCC that day. Regarding the incident, she said with contempt "this African nonsense, all these big African traditions".

Making a cutting motion across her wrist, Joan said – “you see, she has these”. She was referring to bracelets of red and white beads– often worn by traditional African healers and those going through traditional healing. Joan added that the patient “probably wanted traditional treatment”. This was one of the only times I saw Joan truly frustrated and irate with a patient.

Meanwhile, Letta had spent about twenty minutes talking to the patient in a quite spot, of unoccupied chairs in the waiting area. Thereafter Letta came to me in the counselling room and told me that in order to be a counsellor at the Breast Care Centre you needed “a lot of heart”. This was so that you could listen to a patient even when they did not want to go through treatment and “they are talking nonsense”. Letta’s patience and persistence must have made a difference because the following week the woman returned to book her treatment.

However, later this same Thursday afternoon, a friendly patient sat down on one of the white “pleather” seats in the counselling room. Along with a bright “Brazil” football shirt, she wore countless beaded necklaces, bracelets and anklets. I talked with her briefly and found out she had a “small operation” on her breast a few years prior she had received mammograms every year. She explained that this particular year the doctors said that she had a cancerous lump in her breast. She was at the counselling room to arrange for chemotherapy at Charlotte Maxeke oncology unit. Before I could find out more about the woman, Dawn began to counselling her. Suddenly the patient was overcome by a sort of frantic hiccupping-sneezing-burping action. She stood up and disappeared from the counselling room as the sounds emanating from her grew louder and louder.

The counsellors remained seated, seemingly unperturbed. I presumed that this woman – because of the beaded items she wore – was involved in some way with traditional healing, and presumed that the sneezing was related to the manifestation of ancestral spirits. I asked the counsellors what they thought had happened. They replied that woman was alright, Joan said “it is just the ancestors, her ancestors were coming up”.

Both these black patients had displayed conspicuous evidence of their involvement in African traditional healing. The second patient even more so. Yet the counsellors calmly tolerated the dramatic display of this women’s ancestors “coming up”. This woman had previously been through biomedical treatment, and had not in the counselling room challenged the need to go through medical treatment. The first patient, however, had outright, on several occasions, persistently challenged the counsellors’ and doctors’ advice that surgery and chemotherapy were necessary for her to live. Many patients at the HJBCC questioned treatment, showed

reluctance towards it or criticised the doctors. But this patient had done more than that. She resisted the counsellors repeated advice, and delayed her treatment. The sociality of breast cancer at the HJBCC allowed for plural explanations of disease and plural healing practices. Counsellors were tolerant towards women who spoke of quantum healing, cutting sugar out of their diets, or doing "traditional African" ceremonies. Importantly, this was only if women *also* accepted the need for biomedical treatment in order to overcome breast cancer and live. Otherwise patients were condescendingly cast as "talking nonsense", and "being stupid".

There were limits to the sociality of breast cancer patients at the HJBCC. The limits were determined not by race, class, religion, age, or "big African traditions". The limits of sociality were determined by perceptions women had about the relationship between their illness, death, and biomedicine, and the acceptance of counsellors as "living testimony" of this relationship.

Furthermore, recognising the limits of breast cancer sociality at the HJBCC also reveals the limitations of the logic of cultural congruency. The incidence described above contrasts significantly from the portrayal of Wadler et al (2011) - of women of the same culture or race being respectful of beliefs and trustful relationships amongst women of the same social group. In the context of the HJBCC, the notion that sharing membership to social category is automatically grounds for trust and commonality is shattered. Instead, being a breast cancer patient with a specific conviction in the power of biomedicine, and recognising the counsellors as "living testimony" – becomes the important congruency, a common ground amongst otherwise socially diverse women.

It is important to acknowledge that the counsellors' and patients' faith in biomedicine, is one that could be discussed further in relation to a "modernist" imagining of science as infallible salvation, despite medical science's inability to successfully prevent or cure cancer (Frank 1997; Livingston 2012; Kleinman 1988). Also with regards to my findings I could elaborate further on the problematic invocations of "survivorship". A multitude of commentators have cautioned against a trope that represses less attractive aspects of cancer experience, particularly to precariousness of remission (Ehrenreich 2001; Frank 1997; Jain 2007; Kaiser 2008; Lorde 1997; Mathews 2000). However, given the scope of this dissertation, the significance of the data presented is that it serves to uncover an aspect of breast cancer – common perceptions of suffering, and mortality – that has not before been explored in research about this disease amongst South African women.

Bearing witness to the "human"

Medical anthropologist, Browner (1999) has warned against the "medicalisation" of anthropology in accepting disease categories as "natural community", rather than a group of people dispersed within a wider population. Whyte (2009:13), has cautioned an overemphasis that shared medical conditions are identity creating, as this can "essentialize, fragment, and decontexualise what is really only part of life".

Heeding the warnings of Whyte and Browner, it is unwise to disregard that breast cancer patients at the HJBCC, as socially dissimilar women, had to navigate a public healthcare environment and manage other arenas of their lives. Differences of circumstance, often related to race and class, made a significante impact on these women's experiences of breast cancer. These differences meant that a middle-class, Indian women drove herself to Charlotte Maxeke Hospital, and "talked" her way into the pathology unit to get her overdue test results. A white woman could afford to see her local, private doctor for emergency care for an infected surgery scar. A large number of black women used public transport to travel home after chemotherapy. Many white, Indian, and coloured women in the HJBCC Breast Ward felt that because of their race they were victimised by some of the black nurses who mistreat patients. A counsellor visited the home of a black woman to convince her husband of the value of chemotherapy, which could be followed by "traditional rituals".

I am by no means advocating a post-racial interpretation of women's experience of breast cancer, or an analysis that decontextualises or essentialises cancer as social category. Indeed, the experience of cancer does not trigger the same intensity of concern about life, family or faith in biomedicine amongst all women. Nuance is required in understanding the making of a cancer subjectivity within the clinical context. However, a fundamental concern of this ethnography has been to represent, the as-of-yet unacknowledged intimate, subjective, existential experiences of breast cancer patients. Doing so has exposes the flaw of an overdetermined reading of social circumstance as determining women's relationship to illness and biomedicine. Predominantly amongst the demographically dissimilar women HJBCC patients, diagnosis and medical procedures instantiated a common field of response. In the sociality of the HJBCC, women's similar, human responses to the existential challenges that cancer evoked were significant in steering patients' thoughts and actions regarding their treatment – more significant than race, class, age or cultural category. Although Thompson's (2004:350) comments below are in reference to the shortfalls of a psychologically oriented analysis of cancer diagnosis, her words are nonetheless appropriate.

> "Suffering, living a threatened life, needs to be explored. Yet, over and over language falls short as traditional notions of nomenclature or classification somehow diminish the gravity and particularity of what is witnessed."

Collecting qualitative data, at a clinical site that provided care for a range of women in post-apartheid Johannesburg, yielded unanticipated results. Observing the sociality amongst breast cancer patients shed light on the existential gravity of being diagnosed with cancer, and therefore this is an important shift away from previous approaches that analysed breast cancer through nomenclature and classifications external to the experience of this illness.

Chapter Four – Mastectomy and mortality: The malleability of the breasted body

At a busy Thursday clinic, Dr Susie – a middle-aged, white, senior surgeon at the HJBCC – strode from consultation room to the counselling room. In her wake were two short black women, one of them was elderly and looked disgruntled. Susie enthusiastically told me – "this is a fascinating case for you, this woman is about 80 years old, with Paget's disease[32] [a form of breast cancer] and needs to be operated on. But look at her, look at the face she pulls when I mention the idea". Susie physically steered the elderly woman toward me, who - as soon as she was aware of the doctor looking at her, expecting something of her - gave a toothless hiss in my direction - as if on demand. "Look", said Susie pointing at the patient, who again dutifully screwed up her face and hissed at me. Startled by this, I began to feel as if this patient was being displayed like a circus animal, and wondered what the reason was for this bizarre show.

Susie led the patient and her companion, and myself, into the crowded and close counselling room. The two women sat down one of the large brown couches. I found myself a place to sit on a small stool on the opposite side of the room. Setting down the patients on the desk Susie said to Joan, the most experienced of the counsellors that "I will kiss you on the nose if you manage to get the patient to go through surgery".

As is common practice at the BCC, the counsellors gave advice collaboratively, moving in and out of conversations with multiple patients. Together they explained that they have all had mastectomies and that it is "okay" to have this operation done. An elderly white woman in the counselling room took an interest in this patient's dilemma. She said that the surgery it is not a problem, and lifted up her blouse and pointed to her chest, where she was missing a breast. The elderly black patient looked overwhelmed and disgusted. Eventually the quiet, younger woman explained that she was a granddaughter of the patient. She then turned her body to her grandmother and started to use a form of simple sign language. This was when we all realise for the first time that the patient was deaf and could not speak clearly. Evidently the encouraging explanations that the doctor and gregarious women of the counselling room had offered up had not been heard by the disconcerted patient. The granddaughter managed to indicate to her grandmother that she would be asleep when the surgeons operated on her, she would not feel pain. She did this by wincing and making a cutting

32 Paget's disease is a condition that affects the skin of the nipple, and signifies an underlying breast cancer (Benn and Pantonowitz, 2007: 105).

motion across her breast. She then shook her head as if to say no, and then closed her eyes and relaxed her neck, to indicate sleep. Through another series of efficient hand movements, the granddaughter indicated why the whole breast needed to be removed and not only the visibly affected area.

Five weeks later, again on a busy Thursday, this elderly patient was wandering casually around the clinic in her nightgown and slippers. She was clearly an in-patient of the breast ward having a walkabout. Susie spotted her and touched her affectionately saying, “this patient is top of the class!”. The woman had been through her surgery.

In this scenario, the doctor’s conviction that this patient was furious about and resistant to undergoing a mastectomy is evidence of a powerful and pervasive medical and academic presumption regarding women’s, and particularly black women’s, relationships to breasts as markers of womanliness. Much contemporary literature and medical practice emphasises that breast surgery, as treatment for breast cancer, is a traumatic experience for a patient as the removal of the breast disrupts a woman’s sense of gendered-self. Thus some women may refuse surgical procedures. This elderly women’s clinical narrative, however, was not the exemplary case of fear of or the non-compliance to mastectomy that Dr Susie had initially thought. More striking is the fact that during my fieldwork I did not witness any such case of a woman refusing to have breast surgery for her cancer.

In this chapter, I present observations from the HJBCC that problematise the assumed relationship between gender and breasts, as well as the assumed intersection of race and gender as categorical determinants of women’s relationship to breast surgery. In the face of life-threatening illness, women’s concern for the preservation and reconstruction of a gendered body is neither monolithic nor ubiquitous. I discuss women’s non-reluctance of mastectomy and reluctance towards reconstruction, as indicating that breast cancer patients are more concerned with surviving cancer and chemotherapy, than defending or retaining a female embodiedness. Thus proving that women, commonly, do not value their breasts in the ways that contemporary discourse and medical practice suggest. Also this indicates, similarly to Chapter Two, that membership in standard social categories, including that of “women”, does not determine patients’ experiences of breast cancer. Rather, being a breast cancer patient and becoming a post-mastectomy body, is an experience that changes women’s relationship with and experience of their bodies. It is also an experience that inserts a malleability into the conceptual association between women and breasts, thereby bringing to the fore the instability of gender performance and the sexed body.

Medical practice and the "monovocal"

Since the 1980s there has been an abundance of literature written about breast cancer as a gendered disease. As discussed in Chapter One, from the 1970s and the development of the women's health movement and growing numbers of female medical doctors, breast cancer and mastectomy have become a feminist concern (Boston Women's Health Book Collective 1998; Joralemon 1999; Kaufert 1998; Lock and Nguyen 2010:70; Lorber and Moore 2002; Lupton 2003; Martin 1989; Sherwin 1996). In particular, activists in North America have challenged past medical practice and how male doctors had paternalistically dispensed urgent radical, mastectomies (Olson 2002; Klawiter 2004; Klawiter 2004; Klawiter 2005; Lorde 1997; Young 1990). Historically these surgeries had been performed with little concern for the debilitating physical effects of these operations, as a radical mastectomy removed not only a breast, or breasts, but also chest muscle and axilla lymph nodes, which are located in the armpit. These, often unnecessarily aggressive, surgeries left women with limited motion, the terrible discomfort lymphedema[33] , and sometimes sepsis.

"Chop it off, chop it off, chop it off" – is how Dr Susie at the HJBCC described the attitude and method that South African surgeons adopted in the past when dealing with breast cancer patients. She explained to me that surgeons had been predominantly men, that they were paternalistic, authoritative. Additionally these men uniformly used radical mastectomy – an outdated model for treating patients that took no heed of a patient's stage of cancer, or her personal wishes regarding her body. Susie explained that the starting point on her journey to becoming a prominent breast surgeon was when she worked at a large public hospital. There she saw the faces of women diagnosed with breast cancer, lined up for wholesale radical mastectomies. She had thought – "there must be another way". She investigated the methods of doctors abroad and found that, particularly in Europe, more conservative breast surgeries were performed in tandem with oncology treatments. This multidisciplinary medical approach had been successful in reducing breast cancer mortality rates.

This history, including that of Dr Susie's ambitions for women's healthcare in South Africa, has had a substantial effect on the operation of the HJBCC, and the surgeries that patients may receive. At the time of

33 Lymphedema is swelling caused by insufficient drainage of lymph fluid, in post-mastectomy patients swelling of the arm is related to the removal of axilla lymph nodes in and around the armpit (Benn and Pantanowitz 2007:102).

my fieldwork at the HJBCC, the two resident specialist surgeons were women. Many of the training registrars and interns were also women. Depending on the severity of their cancer, patients at the centre have full mastectomies – removal of the breast, sometimes including affected lymph nodes in the armpit. These may be skin sparing-mastectomies, which allow for an implant to be inserted and the entire breast reconstructed. Some patients have partial mastectomies, also known as lumpectomies. This procedure is the removal of only the tumour and a margin of surrounding tissue. Surgeries are always combined with chemotherapy, and/or radiotherapy and/or hormone therapy[34]. Depending on their treatment, patients were offered breast reconstruction – to be done either at the time of their breast cancer surgery, or subsequent to radiotherapy. This offer of reconstruction seems remarkable in a public healthcare where there is a scarcity of resources and doctors are expected to see a large volume of patients. In South Africa, the Helen Joseph Breast Care Centre may be more patient-oriented than other facilities, and therefore more exceptional in its sensitivity to the relationship between breasts, gender, and self-esteem. Nonetheless, the operation of this clinic is indicative of worldwide trends in medical practice regarding breast cancer.

Feminist commentators have been critical of the apparently self-evident relationship between breasts and gender, and healthy body image. For instance, Young (1990) and Olsen (2002) reveal that over the latter half of the twentieth century breasts have increasingly been fetishised and objectified, certainly in westernised contexts, as an unintended consequence of the sexual revolution. Subsequently, feminists disagree about whether bodily practices relating to breasts, for example, breast enlargement are evidence of women's oppression or opportunities for women to exert agency (R Parker 2010; Wolf 1990). Specifically relating to breast cancer, feminists argue that the medical establishment's promotion of breast prostheses and breast reconstruction for breast cancer sufferers is harmful (Jain 2007; Kaufert 1998; Rubin and Tanenbaum 2011; Sandell 2008; Sherwin 1996). They argue that this medical new practice reproduces normative heterosexist and sexist attitudes regarding women's desire to conform the "male gaze", and in so doing disguise the presence of breast cancer in society. Jain (2007:506) argues that "the relentless hyper- and heterosexualization of the disease results in something of a recursive process through which gender is produced and policed". Therefore in the allegedly "gender-sensitive" approach to breast cancer treatment, the possibilities of breastlessness , or variations on the gendered body have been limited, given the

34 Patients who have partial mastectomies are always referred for radiotherapy. Patients whose cancers are estrogen receptive, will be advised to follow a course of Tamoxifen, a hormone therapy, for five years after surgery and chemotherapy.

development of a "two breasted feminism" (Potts 2000:8–9). Furthermore, there have been no comprehensive studies that can verify the long-term psychological benefits of breast reconstruction (Rubin and Tanenbaum 2011:3).

Sandell (2008:326) explains, however, that these kinds of critical approaches to gender and breasts are currently eclispsed by a more powerful "monovocal" breast cancer discourse and medical practice. Large numbers of medical practitioners, public health professionals and social scientists, including psychologists, have written authoritatively about mastectomy as having destructive effects on a woman's sense of self, femininity, womanliness, sexuality, attractiveness (Ajekigbe 1991; Amusa and Sakato 2005; Benn and Pantanowitz 2007; Foster 2007; Hoffman and Cooper 1996; Manderson 1999; Mdondolo et al 2003; Piot-Ziegler et al. 2010; Remennick 2006; Rowland et al. 2000).The quotes below, from South African researchers, give further indication of the degree to which, and the certainty with which, breast cancer surgery is painted locally as socially and psychologically detrimental to women.

> *"*To most women, the diagnosis of breast cancer is devastating. Quite apart from the horror one experiences at having a malignant disease, the added anxiety of possibly losing a breast, and therefore one's so-called 'femininity', is a crippling experience" (Hoffman and Cooper 1996:111).

> "Early detection and treatment could help avoiding a [full/radical] mastectomy which could destroy a woman's dignity" (Mdondolo et al. 2003:no page number).

> "A big problem following mastectomy is the cosmetic deformity, with its associated psychosexual morbidity" (Benn and Pantanowitz 2007:77).

So-called minority groups or women of colour, poor African women, and women with little formal education are in particular perceived of as avoiding medical treatment, for example, for fear that their communities or romantic partners may reject them (Ajekigbe 1991; Cooper and Mullin 2001:52; Coughlin and Ekwueme 2009; Errico and Rowden 2006; Gerend and Pai 2008; Remennick 2006). Regarding South Africa, Mdondolo et al (2003), for example, suggested that mastectomy is for "traditional", rural black women an attack on womanliness and therefore prohibits women from getting medical help at clinics and hospitals. A white co-ordinator of and organisation that provides breast cancer support suggested that "poor or uneducated" women do not seek treatment because of "cultural taboos" and fears that they will lose their husbands if they have mastectomies (in Foster, 2007, no page number).

It is fair to say that in the South African literature regarding mastectomy there are two different, although intertwined, conceptualisations of breastlessness and gender. The first is a western fetishisation of breasts and hence the importance of breasts to the self-image of women – as related to the "male gaze". In addition, there is a conceptualisation of an apparently traditional African view of breasts as important to womanliness and maintaining heterosexual relationships - in the context of an intolerant patriarchy. This second conceptualisation, supplements the stereotype of black women problem patient as discussed in Chapter Two. Not only is this stereotypical patient seen as having troublesome traditional beliefs that challenge biomedicine, but also as having "cultural taboos" about having a breast surgically removed.

Beyond assuming that all women have a fundamental attachment to their breasts, literature establishes the notion that women who are black, poor, traditional and with little formal education, have a different relationship to their bodies and to breast cancer, as compared to other women. Therefore, as discussed in prior chapters, current research suggests that different categories of women in South Africa have divergent experiences of the same disease, and divergent experiences of their bodies.

Beyond mastectomy

My findings at the Helen Joseph Breast Care Centre sit uneasily in relation to the "monovocal" discourse, regarding breasts, gender, race, and non-compliance with medical treatment. As the introductory scenario concerning the deaf women begins to indicate – patients' relationships with breast surgery are perhaps not as universal as might be assumed. However, what was apparent in my ethnographic research was an absence of comments regarding mastectomy as traumatic, which was evidence of a non-reluctance towards surgery. As evident in Chapter Two many of the conversations between counsellors and patients were centred round persuading a patient to go through with chemotherapy. Of the numerous counselling sessions that I observed, almost none of them concerned convincing a reluctant patient to go through surgery. Of the socially diverse women whom I knew well, and was able to follow through the course of their breast cancer treatment, all complied with doctors' recommendations for mastectomy. In this group of women, there was no exemplary case of non-compliance because of fear of losing a breast. They were preoccupied instead with ensuring a life beyond breast cancer.

Rather than being reluctant, fearful and depressed about surgery that would affect a highly-gendered part of their bodies, some patients were in fact eager to have tumours removed. This was the case with Virginia a

black, 67-year-old mother of seven children, traditional healer, and avid Christian. She arrived with a small overnight bag, on her first visit to the Breast Care Centre. She was ready for the doctors to book her into the ward and operate on her immediately, upon seeing her mammogram she had with her that had been taken previously by private radiologists. Unfortunately for Virginia, she had to wait to have a biopsy to confirm a cancer diagnosis, and followed by chemotherapy, and only thereafter surgery.

HJBCC doctors also recommended that Antoinette have chemotherapy before surgery, which bewildered her initially. “I should just have it cut off” - were her words to me about her reluctance to have chemotherapy first. Antoinette was a 39-year-old white woman, she spoke vehemently about having their cancer surgically removed. She explained that she would feel much better if her breast and her cancer was removed, and said that when previously discussing this with her husband he had said “why not just cut it off, get it off”.

Not all patients I was acquainted with were quite as eager as Antoinette and Virginia to have breast removal surgery. Nonetheless, overwhelmingly, while counselled newly diagnosed patients were unconcerned about, or dismissive of breast surgery. Indeed at the moment of diagnosis breast surgery might not seem particularly horrifying if women believe that they are facing their mortality, and six months of suffering through chemotherapy. Little et al (1998) and Thompson (2007) suggest that cancer diagnosis induces a confrontation with existential concerns, that may suspend normal relationships to life and living. Within this experience, being a person with an illness takes on heightened importance that may overwhelm ideas previously held about womanly bodies and about breasts. Breast cancer diagnosis was not merely a confrontation with death. The palpable and sometimes visible abnormalities of the breast, once diagnosed as cancer, may have made some women feel that their breast was a site of life-threatening trouble. Therefore, Antoinette’s panic to have her breast removed is not surprising.

Frank (1997:32) offers the following insight regarding embodied illness and suffering - “During illness, people who have *been* bodies have distinctive problems *continuing* to be bodies, particularly continuing to be the same sorts of bodies they have been” (emphasis in original). He adds that “The flesh cannot be denied… people interpret their bodies and make choices” (Frank 1997:28). Evidently, in the HJBCC, particularly in the space of the counselling room, through a non-reluctance toward mastectomy, women demonstrated their choice to put their faith in biomedical treatment to remake a healthy body, albeit with less breast tissue. Contrary to existing literature, they were mostly resigned to the fact that they would not be able to continue to be same the kinds of bodies. Becoming a different kind of body was crucial to living beyond breast cancer.

Rubin and Tanenbaum (2011), suggest that in studying breast cancer it is less problematic to concentrate predominantly on the physical outcomes of breast cancer surgery, and look to easy cosmetic solutions to rectify these outcomes. They argue that in doing so more substantial existential issues concerning this disease are overlooked. In the context of the HJBCC, looking at existential issues and at patients' overwhelming concern with surviving this unpredictable disease, casts doubt on the relationship between mastectomy, race and non-compliance. Hoffman and Cooper (1996:111), as quoted earlier in this chapter, suggested that for South African women the loss of a breast was a devastation "aside" from having life-threatening cancer itself. I suggest that the loss of a breast is not absolutely devastating precisely because of the mortal concerns patients have regarding cancer.

Patients' comments regarding reconstructive surgery emphasised this further, as most of them were not captured by the possibility of remaking the breasted aspects of the bodies they had been before being diagnosed with cancer. The justification for offering of breast reconstruction as part of breast cancer treatment, is largely that women should be able to reconstruct the kinds of breasted bodies they had been before their diagnosis, and hence repair any psychological damage resulting from the corporeal side effects of mastectomy. Despite this practice and powerful discourse, there is a small body of literature that indicates that a majority of breast cancer patients do not choose to have reconstructive breast surgery (for example, Heliopoulos 2012:15; Ness 2011:24; Rubin and Tanenbaum 2011:3; Sandell 2008:339).

At the time of breast cancer diagnosis, the bulk of my interlocutors at the HJBCC dismissed breast reconstruction. Many do not speak of it at all. Others spoke of it flippantly, as an unnecessary procedure. Similarly to a non-reluctance to mastectomy, these comments may be related to the daunting nature of diagnosis and the concern with life and death. However, patients disregard breast reconstruction even sometime after treatment, including mastectomies, and the presumed destruction of their womanly bodies. The statements below by breast cancer sufferers regarding reconstruction and the mastectomy-affected body are thus in contrast to the "monovocal" mastectomy literature cited prior.

> "I am 60, I don't need these reconstructed boobs – what for? If my husband doesn't like me he can go somewhere else" (Rose, a 60 year old coloured woman from a suburb on the East Rand at the time of her breast cancer diagnosis).

> "I do not want reconstruction, I am old what do I want that for" (Marie, a 70-year-old coloured woman, after her mastectomy).

Some might suggest that older breast cancer sufferers may be less affected by the idea of having a breast or breasts removed, as they may not be looking for sexual partners, or sexual attractiveness may of less concern for them. Therefore it might seem less remarkable that I heard numerous older women making statements similar to that of Rose and Marie. However, the counsellors, years after their breast removal, and after several years of remission, display an ease with breastlessness and a rejection of breast reconstruction. None of the five black women who worked at HJBCC as counsellors had chosen surgery to remake their breasts. These women were relatively young – between 35 and 61 years old – with the youngest three women being either married or engaged to men. (The older two women were widows). My interactions with Dineo and Letta, two of the younger counsellors, illustrated how for some women having one breast was ordinary, not something which they wanted to "correct".

When I asked Letta if she had considered reconstructive surgery, she replied, "Ha, I don't think about it. I am happy with one. It is better this prosthesis, to just put something inside your bra". Dineo expressed her ease with only having one breast, saying that she mostly forgot that she had only one breast. She went on to tell me about her humorous experience at a sports day. Laughing, she explained that she had forgotten that she was wearing a prosthesis, and that while she was running it popped out unexpectedly.

Women's widespread disinterest in breast reconstructive surgery is a reflection that remaking a breasted body that approximates to a prior self was not as important as ridding a body of cancer. Although there is significant evidence that breasts were not that important to women facing existential concerns relating to their illness, there may be other facets that relate to women's reluctance to take up reconstruction. The counsellor, Letta, dismissed the idea of reconstruction saying that she was comfortable with her body as it was. However, she added "another operation – I don't want to get the pain". Reconstructive surgery, as I will discuss shortly, is a serious operation, that causes much pain, and can put a patient's health at risk. Furthermore, if women are employed, and/or if they have dependents whom need their everyday assistance around the home – breast reconstructive surgery would demand that these women give up these responsibilities for a period to have surgery, and recuperate thereafter. These factors could additionally dissuade women from reconstructing a two-breasted body, especially if they have exhausted their sick-leave or lost income going through chemotherapy. However, if breasts were as important to women's sense of

bodily integrity, or if they felt their post-mastectomy bodies were deformed, as existing research suggests, it would be expected that more patients would speak benefits of reconstructive surgery. More women would be willing to undergo these procedures despite the pain or inconvenience, as opposed to seeing them as superfluous to their treatment experience.

Furthermore, HJBCC patients and counsellors would speak more enthusiastically about reconstructive surgery if they were especially concerned that two-breasted body was important to remaining womanly, sexually attractive and important, particularly for black women, to sustain heterosexual relationships. From my observations this was not the case at all, rather women spoke about the importance of having a partner who loved them despite having one or no breasts. Dineo, for example, often spoke adoringly of her husband, and during my interview with her she revealed the following about her mastectomy and her relationship:

> "He stuck with me. Ai, I love that man... my darling, he support me every step of the way… I was like - this man can leave me with the one breast. But here, it's my husband now. We married, everything." She giggled and added "He forget I have one breast".

An incident in the counselling room also went some way in explaining what counsellors thought about love and women who had breast removal surgery. It was a quite afternoon when Dr Sergio, a registrar surgeon, led into the room a patient, Dorah, who needed to be referred to Charlotte Maxeke Hospital for chemotherapy. She had already undergone a mastectomy, and she seemed sad and listless. There were no other patients to attend to in the room, and all the counsellors engaged in a short and animated discussion with this woman. Although, I could not follow the conversation – a mixture of IsiZulu and Sesotho – I was aware that the words "love" and "men" were said a good many times. Joan turned to me and asked if I knew what they had told this patient. Joan was a widow, she was proud that her husband had supported throughout her treatment. From this fact, I guessed that the counsellors had told Dorah that there are men that love women who have had breast cancer and surgery. Joan said that I was correct and explained that this patient had complained to them that after her operation she was feeling miserable because she believed she would not find a man to love her. Then in a bold and bossy tone, Joan proclaimed to all in the room that a woman who has had breast cancer can find a man to love her "the way she is". She did not sympathise with Dorah about having one breast, and she did not promote breast reconstruction as a remedy to what this woman perceived of as an embodiment of romantic dilemma and loneliness. Joan instead advocated that women who had suffered

breast cancer, and have one or both breasts removed, had a right to be loved and to maintain or to establish new intimate relationships[35].

Not only did counsellors discursively normalise being without one or both breasts, but through their physical bodies they also made ordinary the process of becoming a new sort of body. They often agreed with patients that chemotherapy was a terrible ordeal. Yet they did not converse with patients about the painfulness, physical or psychological, of surgery. Rather, if counsellors did speak about mastectomy, they normalised not having one or either breasts. When I had met Joan for the first time she displayed to me, completely unprompted, her mastectomy scar as well as her remaining breast. Counsellors showed their own scars and prostheses almost as didactic devices to attempt to normalise breastlessness for newly diagnosed patients (or in my case as an interested anthropology student). The session between Antoinette and her counsellor, Letta, was not uncommon. During this particular session, Letta patted her soft prosthesis and said "I don't have one breast, so what, you will live". She pulled down the neckline of her top, and showed her mastectomy scar. She added that, if Antoinette wanted, there are plastic surgeons that could reconstruct her breast. Like most other patients, Antoinette disregarded the mention of breast reconstruction and said "at this moment my greatest concern is survival". In a context where women were troubled by their illness and the prospects of suffering and death, the bodies of the counsellors became "living testimony" (Frank 1997:140). Their conversations with patients, persuading and guiding them through treatment, were stories of "a memory now written into tissues" (Frank 1997:165).

Aside from the testimonies and displays of counsellors, in the broader sociality, and throughout the space of the HJBCC, variations of breastedness or breastlessness were made ordinary. The physical nature of breast cancer diagnosis and treatment, and the physical presence or absence of breasts was not hidden in HJBCC. Waiting in queues to see doctors or nurses some post-mastectomy patients wore loose-fitting blouses or scarves covering their altered bosom. Frequently similar patients waited with their breastlessness conspicuous underneath their clothes. Both in doctors' consulting rooms and in the counselling room, women's bodies were exposed - healthy breasts, breasts with cancerous lumps, inflamed breasts, a few breasts remade with silicon, and some breasts rebuilt from bodily tissue. Of course, there were also many

35 With the quantity of information I garnered in the field it would be difficult for me to say to in what ways and to what extent women's romantic relationships are affected by mastectomy. Also, all the women that I knew well at the HJBCC were ostensibly heterosexual, and therefore cannot comment on the affect breastlessness may have had on lesbian relationships.

partially or completely flat chests - spaces were breasts had once been[36]. The feminist, breast-cancer activist Audre Lorde (1997), claimed that women should not be afraid to show the effects of breast cancer and treatment of a gendered body. That in doing so women who had suffered from breast cancer would be visible to each other, and could carve for themselves a community. Lorde would have approved of the way in which breastless bodies were a part of the HJBCC sociality.

Reconstructing appearances

In 2011, South African writer and director Thandi Brewer showed off a "daring dress", at the South African Film and Television awards. A woman with a mastectomy scar and no reconstruction, Brewer's dress deliberately exposed her scar to make people aware of breast cancer and prove, as she said, "You are more than just their boobs" (Makhubele n.d.:3). To my knowledge this is a fairly unusual occasion, and that generally South African women do not advocate breast cancer awareness or force society to confront this disease by exhibiting the effects of treatment on their bodies[37].

Mastectomy scars and breastlessness are normalised in the sociality of the HJBCC. Yet, this centre is surely a relatively easy place for women to be visibly breastless, or one-breasted, as they are amidst a community of other women whose breasted bodies have been or will be affected by mastectomy. While in the HJBCC women might not appear particularly self-conscious about being breastless, it is difficult to assess how these same women might feel or act at work, at home, when shopping for clothes or in sexually intimate moments.

Thus far, the stories I have shared indicate women's comfort with *embodying* a breastless body. Yet, the counsellors Letta and Dineo reveals, breast prostheses were a part of daily life. In the long term, certainly outside the clinic space and outside of their homes, most women tried to construct for themselves a normatively womanly body after their cancer treatment. This suggests that women are, at some level,

36 The exposure of women's bodies to me was a situation that I found ethically challenging – not because women were necessarily modest or shy about exposing their chests in this clinical setting, but because my body was not exposed to my interlocutors, it was an interaction that was not reciprocal.

37 This is in contrast to the USA, for example, where artists, models and occasionally protestors, have exposed their chests and the scars of breast surgery in order to promote awareness and visibility of breast cancer (for example see Jain 2009).

concerned with the *appearance* of being symmetrically breasted. Therefore there is some "gender policing" of everyday appearances, if not necessarily in the make-up of the actual flesh of the body. From women's conversations and counselling, mastectomy might not have been a particularly traumatic procedure that deterred them from complying with biomedical treatment. It is something, nonetheless, that outside of the breast cancer world many of them concealed. When asked, counsellors would advise patients on appearing two-breasted – that silicon prostheses were available for R50 each from an organisation based at Charlotte Maxeke Hospital[38], or that a pair of pantihose or a shoulder pad made for a good, soft prosthesis.

Certainly the women I met at the HJBCC, were not as radical as Thandi Brewer, and Audre Lorde would have been dismayed that the exposure of the breastless body did not extend beyond the context of the HJBCC. However, the conviction that "you are more than just your boobs", did still underscore the actions and reactions diverse women at the HJBCC had regarding mastectomy and reconstruction. Women commonly prioritised a healthy body, and rejecting the idea that to have a male partner they needed to have two breasts to be accepted and loved by partners.

Nevertheless, while many women remained breastless in the flesh, so to speak, a small minority of the HJBCC patients whom I knew, decided to have their breasts surgically reconstructed, wanting to have two breasts, and to try to approximate the kinds of breasted bodies they had been before their diagnosis and treatment. Historian, Gilman (1999), suggests that surgery has become the ultimate tool in remaking the self as socially "passable" body. The following comments from Mbali, Barbara, and Virginia suggest that they viewed surgery as an important tool in making themselves "passable", as sexually attractive women, with symmetrical appearance.

Mbali was an elegant and fashionable young black woman in her 30s. We met at a breast cancer support group meeting where she candidly explained her breast cancer treatment – chemotherapy and a mastectomy. After just a short conversation it was clear that Mbali was anxious to have reconstructive surgery, her motivation being that she was unmarried and could not imagine a man wanting to marry a woman with only one breast. Mbali felt her attractiveness was related to having two breasts, a sentiment often reported in current breast cancer research.

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38 From the information I could gather, the cost of the prosthesis was subsidised.

Barbara expressed similar concerns to Mbali, but explained that she moved through a range of reactions towards breast surgery. Barbara was a single, 65-year-old, white woman who initially attempted to cure her cancer with "quantum healing". This was to avoid chemotherapy and a mastectomy. But after this healing failed, Barbara began oncology treatment. At this stage, Barbara recalled that she was horrified that none of the counsellors at HJBCC had reconstructive surgeries. But she said that over the course of chemotherapy she "had time to get used the idea that it [the mastectomy] was going to happen. Didn't worry me in the least… hadn't discussed reconstruction or anything [with Dr Susie] at that stage. I just wanted to stay alive, you know. Boob was gone - but it was not as much of a shock as I thought it was going to be. Most odd, most odd."

When I first met Barbara, it had been more than a year since her mastectomy, and she had recently been through a "tramflap" operation. This is an intricate and lengthy operation performed by plastic surgeons who transfer a "flap" of abdominal skin and fatty tissue to the site of the mastectomy and build a breast from the patient's own flesh. Barbara had said that she wanted a breast that was "still me". She told me that having breast reconstruction, and having breasts, was an important part of a relationship – to be being physically attractive and whole. Barbara later mentioned a physic reading had indicated that a long-lost love would re-enter her life later that year.

Virginia, unlike Barbara and Mbali, did not make any mention of sexual attractiveness, but rather stated her concern about her symmetrical appearance. It was the day Virginia got the results of her biopsy, and was diagnosed with breast cancer. During the consultation, Dr Sergio, a polite and thorough registrar, said "you can live without the breast, you don't need it to live". He explained in detail how she would first go for chemotherapy, a mastectomy and the radiotherapy. He then quickly added "afterwards you will meet with the plastic surgeons and they will discuss the options for reconstructing a breast, making a new breast". Later, on that day she asked me to confirm that surgeons could make her a new breast. Virginia said, "they must, I can't have just one breast, what am I going to do with this" and motioned to her large, healthy breast.

Mbali, Barbara and Virginia considered or chose breast reconstruction surgery of their own volition. Their reasons for doing so – reconstructing a sexually attractive, and symmetrical body – is anticipated within the predominant discourse regarding mastectomy and reconstruction. However, in HJBCC this was not necessarily that case with all patients who underwent breast reconstruction surgery.

Writing about women and cosmetic surgery, the health sociologist Parker (2010), has argued that in debating breast surgery, feminists seldom take cognisance of the interactions women have with medical practitioners. She notes, that these practitioners are powerful agents with their own socially-contingent ideas regarding gender, breasts and bodies. Listening to patients' accounts of interactions in the HJBCC setting, reveals that women's decisions about surgery, were not solely their own. Virginia's doctor made available information regarding the possibility of breast reconstruction, which Virginia saw an answer to her anxiety about an assymetrical breastless body. However, there were doctors who were much more prescriptive about reconstructive plastic surgery. From the cases of Fatima and Jeanie, for example, the HJBCC is arguably a place where doctors are powerful agents who reinforce trends that overemphasise the relationship between breasts and "whole" gendered body.

Fatima, an Indian woman in her early 60s, had a partial mastectomy removing a small tumour, and a margin of surrounding breast tissue. Simultaneously she underwent a breast reduction of the other breast. Doctors had recommended this aesthetic surgery so that her breasts would appear more symmetrical after the surgery. Fatima was very unsure and anxious about making decisions about her treatment, especially as her husband had recently passed away from cancer. She had initially contemplated a full mastectomy. Her doctor, however, had said that she should not decide to have a full mastectomy as she could not anticipate the way it would feel "not to have anything there". Fatima spent over a week in the breast ward, miserable, while she recovered from a severe post-surgery infection in the healthy breast that was reduced. Even weeks after she had recovered, she sorely regretted the reduction and vowed that she would never let anyone "cut on healthy skin again".

It is clear that Fatima regretted her decision to have a partial mastectomy and breast reduction, under the advice of doctors who felt that they psychologically benefitting patients by offering them their version of aesthetic health. Jeanie a slight, white women in her late 50s also felt pressurised by doctors to remake her breast. In 2010, she went through breast cancer treatment, and significant health complications – including, pneumonia and "chemo burn", a chemical burn of the skin and underlying tissue when chemotherapy is administered incorrectly. Over the weeks that I spent time with Jeanie, she frequently spoke with dread about these experiences, and while she appreciated the work of the doctor's at HJBCC and at Charlotte Maxeke, she would have preferred a life that did not involve long waits at hospitals, and regular check-ups and tests.

In late 2011, Jeanie was advised by HJBCC surgeons to reconstruct her breast that had been removed by mastectomy, saying it would be "better" for her than wearing a prosthesis. After several logistical hiccups at the hospital, Jeanie eventually went through surgery to insert a tissue-expander prosthesis beneath her skin. Over the next several months, this prosthesis would be injected with saline to expand the skin. Thereafter, a permanent prosthesis would be surgically inserted. Jeanie experienced a post-operative wound infection. She had to have fluid drained from the surgical site, and had to wait several weeks for this infection to clear, before the plastic surgeons could start the process of tissue expansion. Once she had recovered, Jeanie still told me in hushed tones "I wish I had never opened my mouth to say yes"- to having reconstructive surgery.

Through her qualitative research, Parker (Parker 2010:86) discovered that cosmetic surgeons frequently feel they are thoughtfully providing an important psychological therapy to their patients. Through his Brazilian ethnographies, Edmonds (Edmonds 2008:153) has argued that "aesthetic health" is a powerful aspect of modern medicine that connects cosmetic concerns and physiological health. Certainly, in the HJBCC context, breast cancer treatment combines the cosmetic and the physiological within medical practitioners, perhaps paternalistic, notions of psychological care. Through the contemporary practice of an ostensibly "gender-sensitive" treatment, doctors may in fact medicalise breastedness. This process reproduces a paternalistic medical approach to treating breast cancer, which may not necessarily take the wishes of women patients into consideration. Therefore, biomedicine again reproduces a tension between oppressiveness and granting women the opportunity to enact agency over configuring a new body – a tension that feminists have frequently noted (Lupton 2003:142).

Malleability

The gender stereotype that posits that women fear or resist the surgical treatment of breast cancer because of the affect this has on the gendered body is inaccurate. At the Helen Joseph Breast Care Centre, a commonality amongst socially diverse women was a non-reluctance towards mastectomy. Women's concerns were overwhelmed instead with the possibility of death, and with enduring six months of chemotherapy. Although many of them, in a variety of ways, did reconstruct breasted bodies, or conceal breastless chests – there was no clear trend amongst my interlocutors, as to which categories of women would choose reconstruction or prostheses, and which would not. Black women did not have a distinctive relationship with their breasts, nor with breast cancer. As in Chapter Two, evidence thus points to a shared cancer experience that related to existential concerns. Women's experience of breast cancer and its treatment did not correspond to their membership to particular racial, class or age categories. Therefore, this reveals the need

to insert malleability into the conceptual relationship between gender, race and health. However, this chapter has revealed a mutability beyond even this.

Breasts are not synonymous with health, as breast cancer clearly demonstrates. Equally, breasts are also not synonymous with women. As post-structuralist feminist, Butler (1990; 2006) has highlighted the "performativity" of the gendered body, and has drawn attention to the haziness of the relationship between the gender performance and the materiality of the sexed body. At the HJBCC, the actions patients take regarding mastectomy and reconstructive surgery – as destroying and creating breasts – embody and highlight this haziness. Furthermore, women's engagement with biotechnologies to construct healthy bodies, and their use of surgical implants or external prostheses, perhaps allude to a form of cyborg. The cyborg, as discussed by Haraway (1991), deconstructs conceptualisations of bodies as natural and of "woman" as essentialised and naturalised category. This theorisation of the cyborg generally erodes the kinds of dichotomies – such as woman/man, sex/gender, nature/culture – that underlie everyday life, including medical practice and discourse. Women's experiences of breast cancer and surgery make bare the malleability in these dichotomies and the malleability between the material "natural" body and the performance and appearance of gender. This is indeed a malleability that they exploit to try to ensure their health, and to remove breasts as existential vulnerabilities of the "kinds of bodies" they were when diagnosed with life-threatening illness. Patients' discourse and decisions belie the logic of existing breast cancer research that views social category as essentialised and as determinant of illness experience. In addition, the discourse and decisions of these women indicate the potential of illness and biomedicine to enact the "postgender", or at very least the potential to function as some sort of "gender trouble".

The "post-human" ideas of Butler and Haraway may sit in tension to the emphasis previously placed on "human" commonalities, particularly in Chapter Two. However, these feminist theorists are – like human, existential experience – useful in contemplating how "naturalised", "objectified" social categories, such "race" or "gender", are inadequate tools to explain the ways in which women experience breast cancer as a particular kind of disease, life-threatening and body-altering.

Chapter Five – Alternative treatment: Challenging the tyranny of social category

Social categories, particularly those of "race" and "gender", have been ill used in understanding the social realities of breast cancer in South Africa. These classifications have taken on an objectivity and rationality that is divorced from reality, neglecting the nuance and the malleability of individuals' embodied, subjective experiences of illness. Categories have been treated conceptually as the determinants of illness experience. This concluding chapter reiterates how the particularity of breast cancer and of the Helen Joseph Breast Care Centre have revealed the shortcomings of prior research and analysis. I also articulate how the approaches I have used in this dissertation challenge the powerful, yet problematic, discourse about this disease. This is followed by a brief description of the changing cancer landscape in South Africa, and how this too may demonstrate the inadequacies of previous modes of analysis in understanding the contemporary cancer world. To conclude I propose that the evidence and arguments presented in this dissertation may be helpful in prompting future investigations that problematise social categories so as to provide more nuanced representations of illness experiences in post-apartheid South Africa.

Breast cancer is a disease that affects a demographically diverse range of women. Unlike HIV/AIDS or cervical cancer, for example, its medical aetiology is not linked to contagion, or to the vulnerabilities of poor, black women in a gender-unequal society. Furthermore breast cancer is an expensive disease to treat biomedically. Only women with exceptionally comprehensive medical insurance are not treated in public healthcare centres. The Helen Joseph Breast Care Centre, as an urban facility in Johannesburg, is located as a nexus between city, township and suburb. Overall these factors result in the socially diverse environment of HJBCC. Given the nature of this disease, its treatment, and the structure of post-apartheid healthcare, breast cancer and the HJBCC are uniquely placed to reflect the inadequacies of conceptualising the breast cancer crisis only in terms of hegemonic social categories.

This ethnography has thus far exposed racial and gendered categorisation to be problematic in and of itself because these categories parade as neutral fact representing reality, rather than being contextualised as the objects of discursive history involving colonialism, sexism, and paternalistic medical practice. In South Africa the existence of the trope of the black "problem patient", as well as the development of "gender-sensitive" medical practice, has lead – perhaps inevitably – to the racialised and gendered framing of the breast cancer epidemic. The critique offered in this dissertation has not aimed to ignore that there are, and have been, South African women who have rejecting medical treatment instead relying on *umuthi*, or that there are, and

have been, patients who fear breast surgery. This critique proposes that these are not the only responses, nor the predominant responses, that women have to breast cancer and its treatment, in a post-apartheid urban context. Moreover, these purported responses are reported and recycled in what are mostly quantitative analyses, which do not rightly have authority to declare these as *the* relationships women have to breast cancer and to biomedicine.

It might be anticipated that an anthropological analysis of illness experience, such as this dissertation, would find the social commentary offered in quantitative, medically-oriented research to be problematic. As with breast cancer literature, the complicatedness of human experience of ill-health is evaded by quantitatively designating patients, their ideas and actions, into demographic groupings (noted for example in, Das and Das 2007; Dein 2003, DiGiacomo 1999). It might be anticipated that anthropologists, would instead see social categories as overarching contingencies determining access to health information and healthcare, and determining susceptibility of disease. All of which are significant. Yet, in the case of breast cancer treatment at the HJBCC, even such analysis is limited, and therefore is also not entirely adequate in explaining my unanticipated findings. Stressing category and context in social science emphasises divisions amongst South Africans (Macleod and Durrheim 2002: Saethre and Stadler 2009). This may be to the detriment of understanding other facets of illness, for example: the potential of the experience of illness itself to alter subjectivity; the "human" confrontation with the existential dilemma of cancer diagnosis; or similar experiences of the malleability of a gendered body. These facets were indeed evident during my participant observation, and have formed an important part of this dissertation, which therefore differs in nature from some other anthropological analysis.

Therefore, the following is a reiteration of how the arguments of the preceding chapters have worked to undermine the tyranny and hegemony of social category in understanding life-threatening disease within the intimacy of the HJBCC. In Chapter Two, this dissertation exposed the troubling discursive history of the "problem patient" and the "normalised absence". The biographical accounts of patients unsettled hegemonic categories as inadequate to reflect post-apartheid Johannesburg, where classifications of race, class and gender belie vast diversity within these classifications. Chapter Three discussed the limitations of relying on social category to explain experiences of breast cancer, emphasising the need move beyond difference to be able to acknowledge commonalities amongst sufferers of this disease. In particular to recognise the "human" existential experiences and the sociality they enact. It is important to note that the HJBCC, as a space removed from everyday aspects of women's lives, could be seen as a liminal space therefore fostering social

connections between diverse women. However, part of the common experiences of breast cancer amongst HJBCC patients, is precisely the experience of the same public healthcare. This is a part of the shared social fabric of post-apartheid South Africa.

Lastly, in Chapter Four I argued that, in particular, the category of gender – as imagined in relationship to womanly, breasted bodies – is tenuous. Unfortunately, there has been no room to expand this ethnography to consider the manner in which a small group of HJBCC patients elected bilateral mastectomy to create healthy bodies. But also to create completely breastless bodies, which they simply find pragmatically easier in everyday life. The decisions of this small group of women further indicate the manner in which women consciously embrace biomedical technologies and the malleability of their bodies, in such ways that further upset the relationship between gender and breasts. Overall, the findings from the HJBCC regarding breast surgery highlight the opportunity for further qualitative research about how women in the global south relate to and experience their breasts and breastlessness.

The discussion of common, "human" fears of suffering through chemotherapy or death, and embracing mastectomy as crucial to ensuring a healthy body may sit a little uncomfortably next to the feminist discussions, of the construction of gender and the sexed flesh. However, these different forms of contemplation have served the same purpose of attempting to find alternative conceptual approaches that more appropriately represent an intimate, social world of breast cancer treatment in contemporary Johannesburg.

In addition to understanding the ethnographic accounts of a breast cancer within a particular clinical context, it is important in closing off this dissertation to briefly consider broader social discourses and practices regarding this disease. Thus reflecting on how these may also play a role in undermining the powerful racialised and gendered interpretations of cancer in South Africa. Regarding breast cancer, Klawiter (2004: 866) suggests:

> "If there were ever a time when the social construction of disease and the social structuring of illness could be understood by limiting one's focus to the institutions of science and medicine and the social relations of class, race, gender, etc., that time has surely passed. We need frameworks that recognise the multiplicity of practices and institutions shaping the social structuring of disease and illness experience"

As discussed previously, the cancer landscape in South Africa is changing swiftly as cancer is becoming of greater importance to the government, and in society generally. This has resulted in the wider dispersal of biomedical information and treatments, and the rapid expansion of support structures for cancer patients. This evidently impacts women's experiences of breast cancer as seen in the following snippet of ethnographic data, and in recent statistical findings.

"Nowadays everything is about cancer", Busisiwe informed me. As a qualified nurse, she worked for the Soweto branch of a national cancer organisation that managed wide-scale awareness campaigns and fundraising. She believed that in her line of work "people are understanding about cancer" and "people have no excuse for not hearing or knowing about cancer". In the past health campaigns always focussed on HIV/AIDS, and hence people are generally aware of this illness, she explained, but now cancer was in the spotlight. Certainly Busisiwe's ideas are reflected in the data from the HJBCC that show that women are familiar with contemporary biomedical explanations of cancer as being related to the risk factors of modern life, and the fact that very few patients explained cancer as a "white disease". This undermines previous propositions that knowledge of cancer and perceptions of the importance of biomedical treatment correlated directly with social classifications, such as race, class, age and "culture".

Furthermore, in the late stages of writing this dissertation I came across an article by Bateman (December 2012), the news editor of the prominent South African Medical Journal. He presented statistical data from the Batho Pele Breast Unit at Chris Hani Baragwanath Hospital, in Soweto. These data indicate that the rate of breast cancer patients coming for treatment with Stage I and II cancer has almost doubled, from 29.7% to 54,6%, from 2006-2007 to 2011-2012. The statistics are not presented as relating to any racial categories, but are celebrated as a positive sign that increasing numbers of South African women, generally, have been exposed to breast cancer awareness campaigns, and seek early medical help for the symptoms of this illness. It will be interesting to observe how these data will be interpreted by public health specialists and by medical practitioners, and whether or not these data will shift the discursive framing of the breast cancer epidemic in South Africa.

In closing, this dissertation's deconstruction of the hegemonic social categories, which have been overused and oversimplified in existing breast cancer literature, is a significant intervention in a context where these categories are often viewed as absolute determinants of social and health phenomena. This ethnography has

therefore presented an uncommon attempt to interrupt the conceptual tyranny that racialises and genders illnesses experienced by women in Africa. In doing so, this dissertation points to the possibilities for more nuanced investigations of the complexities and commonalities in experiences of cancer, and illness more broadly, particularly in the context of post-apartheid South Africa.

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