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Narrating Experiences of Breast Cancer: Reflections of Women Attending a Private Hospital in Bloemfontein, South Africa

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Abstract It is commonly thought that breast cancer, like many other cancers, is an illness equivalent to a death sentence. Though this may be true in some cases, the majority of women diagnosed with breast cancer do survive this illness. Breast cancer is a growing illness and is continuing to affect women worldwide, including developing countries like South Africa. Furthermore, this country's medical system operates in terms of a duality. Here, hospitals and healthcare are mainly situated in either state operated institutions or in privately run practices. This duality emphasizes the inequality within the socio-economic classes, treatment regimens, and ethic-of-care. This article deals with how women from the higher socio-economic stratum of the deeply polarized South Africa deal with breast cancer. The aim is to understand how each participant renegotiates and transforms her self-perception, her *identity*, and issues around femininity. In addition, the authors also seek to understand if this medical encounter influences the participants' sense of embodiment, as well as how the medical encounter impacts on their everyday lifeworld.

Keywords Breast Cancer; South Africa; Private Hospitals; Identity; Femininity

Cancer is a life-altering illness and does not discriminate in terms of demographics or socio-economic status. However, the manner in which people perceive, experience, and obtain diagnosis and treatment for cancer (and breast cancer in particular) varies greatly (Fregene and Newman 2005; Maree and Wright, 2010; Stilwell 2013). Due

to increased urbanization and exposure to pollutants, women from all walks of life are susceptible to breast cancer. Global public attention flared up when the celebrity, Angelina Jolie, announced her preventative double mastectomy in February 2013 (Payne 2013). This revelation by the actress sparked an increase not only in awareness, but also in

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testing services since Angelina Jolie went public" (Harp 2013:1). This phenomenon has been dubbed the "Angelina effect" and it underscores cancer's indiscriminate character. In the words of Annabel Crabb (2013:1), "one of the world's most genetically blessed women turns out also to be genetically cursed." Public awareness and concomitant health-seeking behavior in as far as breast cancer is concerned is prevalent throughout the Western world and even beyond.

Increased awareness has led to a change in attitude regarding breast cancer and increased media coverage undoubtedly leads to women having a renegotiated understanding of such a diagnosis. Previous notions of this illness have reflected stances of victimization and death, but due to celebrities' public openness about their personal battles with breast cancer and increased successful treatment outcomes, the common perceptions have been transformed to reflect hope, faith, courage, and strength. An organization such as CANSA (Cancer Association of South Africa) focuses a lot of attention on promoting awareness of breast cancer and uses many avenues to disseminate this knowledge: Internet sites, magazine articles, and awareness activities such as cancer month and the cancer *Shavathon*.¹

Although South Africa has undergone more than 20 years of democracy, the country still has a very unequal *dual* healthcare system whereby one either

health-seeking behavior, and an oncologist from London (in Harp 2013:1) noted that in England, "the amount of women having breast cancer screenings has doubled since Jolie's announcement." This increase in breast cancer awareness and health-seeking was confirmed by Dr. Jacobs, who found that "there has been an increase in referrals to genetic

¹ *Shavathon* is an annual event where people can either get their hair shaved, cut, or colored in solidarity with those who have lost their hair in the process of cancer treatment (CANSA 2013).

has the financial means to obtain private medical care (characterized by high-tech services and products) or one has to make use of the public healthcare system (characterized by generalized shortages of staff, medication, and diagnostic procedures) (Erasmus 2012; Van Rensburg 2012:77). Most of the middle-to-upper class population groups have the economic means that allows for private health and most of these groups have the additional safety net in the form of medical aid schemes. According to Health24, “17% of South Africans belong to medical schemes,” thus emphasizing that 83% of the South African population are medically uninsured (Erasmus 2012) and have to rely on public healthcare facilities.

Concerning breast cancer, anecdotal evidence collected during this research and limited documented research (Maree and Wright 2010) suggest that women from a higher socio-economic background view the diagnosis of breast cancer in a more positive light (i.e., as a curable illness). They tend to get diagnosed earlier given their access to private healthcare services which are often diagnostically oriented and thus preventative. As for women from lower socio-economic groups, they tend to perceive this illness as a death sentence given the late diagnosis thereof and a generalized lack of knowledge on issues related to cancer (Maree and Wright 2010). These differing perceptions can be attributed to the individual's socio-economic status, the concomitant exposure that a person has knowledge about breast cancer, and the fact that women with greater access to financial means can afford the best treatment and are therefore better supported medically to overcome this illness.

In this particular study, our research participants represent the privileged section of the South African population as each of these participants is able to afford and to access private medical healthcare. The focus of the study is on eight women diagnosed with and undergoing treatment for breast cancer in Bloemfontein, which is situated in the Free State Province in South Africa. This article investigates how these women diagnosed with breast cancer perceive and experience their diagnosis within the South African healthcare system. We are of the opinion that these women are influenced by a certain “healthcare ideology” which is socially and culturally constructed (Cheng 2010). Accessing care in a private medical institution within South Africa is worlds apart from using the services of the public healthcare system. Not only the care itself, but also factors influencing standardized behavior and the manner in which diagnosis and treatment are viewed form part of this broad “healthcare ideology.” The relevance of this study is not only related to the experiences of the privileged part of South African society. There is currently a growth in the diagnosis of breast cancer and increased awareness thereof in other developing countries. The main sociological driver behind this research is our curiosity about the experience of breast cancer given the dearth of social research on this medical condition. Little is recorded of the experiences of breast cancer survivors (Maree and Wright 2010), and this article sets out to contribute to this understanding.

What the Literature Tells Us

Knowledge surrounding breast cancer can, in most cases, be seen as a significant element leading to

improved coping. Knowledge is an important component of self-care and provides a good starting point in the event of diagnosis with any form of illness. How the individual implements knowledge of cancer can influence how she sees herself, her prognosis, and her overall medical encounter once diagnosed with this illness (Bury 1982). This, in turn, is strongly shaped by the particular “healthcare ideology” that the person is subject to. Within the middle-to-upper class segment of society, women mostly perceive a breast cancer diagnosis as a treatable illness due to their easier access to healthcare that normally guarantees a speedy, if not immediate, treatment trajectory (Klawiter 2008:4).

Breast cancer is likely to have a permanent physical and psychological impact on the individual's lifeworld, which results in a “biographical disruption” (Bury 1982). A biographical disruption is seen when an illness, such as breast cancer, causes significant disruption to an individual's everyday lifeworld and prompts her “to rethink her biography and self-concept” (Bury 1982:169). Currently, there is a high probability that treatment can cure an individual of breast cancer, but only after an extensive and expensive treatment regimen and in the case of early detection. Common treatments are surgery, chemotherapy, and radiation (sometimes pejoratively referred to as the “slash/burn/poison trilogy”) (Brockmeier and Carbaugh 2001:145). The treatment trajectory encompasses many side-effects: the loss of one or both breasts, hair loss, the burning of veins, blackening of nails, radiation burns on sections of the chest and neck, and a five-year-long suppression of the hormone estrogen.

Breast cancer is therefore not merely a temporary disruption, but an illness that will most likely mark an individual for the rest of her life. There are indications (Greenberg 2002; Brennan and Moynihan 2005:153; Sulik 2011:323) that women from the middle and upper socio-economic classes often view a breast cancer diagnosis as a periodic interruption that can result in a temporary to a permanent renegotiation of personal priorities and lifestyle choices. Thus, in the overall understanding of this illness, privileged women often view breast cancer as a *temporary* episode in their lives. However, due to the physical scarring and the overall experience of the treatment regimen, there is little doubt that certain aspects of the individual will be affected, be it her self-understanding, identity, or the manner in which she views her lifeworld.

Even amidst technologically well-equipped medical facilities and among well-qualified medical practitioners, some breast cancer patients can be subjected to and viewed as just being subjects in the institutionalized “regime of medicalization” (Klawiter 2008:75). In this regard, Terry Tien Cheng (2010:63) argues that during intense medical treatment an individual's self-identity is inevitably shaped by “socially and culturally constructed healthcare ideologies.” Therefore, although more affluent and socially well-adjusted women may regard breast cancer as an illness that can be overcome (a perception that is popularized in the mass media), there is little doubt that this illness will leave deep scars on the body and the identity of breast cancer survivors, and these occurrences are intimately linked to their experiences of the overall medical encounter.

Organizations such as CANSA are dedicated to promote public awareness of breast cancer, but the South African healthcare system is still very much divided between the well-resourced, private medical healthcare system of predominantly individually insured medicine, and the poorly administered public component provided by the state. Almost a decade ago, a well-known South African oncologist, Carl Albrecht (2006:4), who is the Head of Research at CANSA, emphasized that South Africa must anticipate a strong rise in breast cancer incident rates “due to migration to cities and [an] increased life expectancy.” Other factors, such as the later onset of pregnancy, fewer (if any) pregnancies, shorter periods of breastfeeding (or no breastfeeding whatsoever), and exposure to harmful environmental agents are all responsible for the increase in breast cancer. Accordingly, cancer (especially cervical, breast, and testicular cancer), on top of other burdens of morbidity and mortality in South Africa, is seemingly going to take on “staggering proportions” in the near future (Farmer et al. 2010).

The possibility of contracting breast cancer necessitates constant monitoring. It is often said that “early detection” is key to a better chance of healing and survival (Stilwell 2013). However, this appeal for *self-care* can at times be a double-edged sword, where women can be exposed to over-diagnosis and even be treated unnecessarily. Frequent mammography sessions might even increase the risk of developing breast cancer (Stilwell 2013). Although early detection is related to increased chances of survival, breast cancer survival brings with it other negative influences on women’s lifeworlds:

Women with breast cancer report difficulties with multiple areas of self-concept, including physical, personal, and social aspects...Body image was one of the most frequently mentioned themes by participants in all groups. Almost all patients reported that some aspect of their body image had been challenged by breast cancer, such as feeling unattractive, missing their breasts, feeling “lopsided,” and coping with weight change and hair loss. [Beatty et al. 2008:336]

Once diagnosed with breast cancer and accepting treatment, patients are faced with a host of medical and social interventions over a long period of time. Taken together these can be referred to as the “medical encounter.” Stewart and Kleihues (2003:271) state that most patients who have access to a well-functioning medical healthcare system will have a “uniquely structured treatment scheme” that caters specifically for her type and grade of breast cancer. In advanced medical care environments, medical practitioners are often encouraged to incorporate “behavioral medical care” into their outlook and interaction with patients. By incorporating “behavioral medical care” into daily practices, the medical practitioner “recognises the importance of a person’s subjective experience of illness and healing, including personal meaning and emotional responses, cultural and interpersonal context, and the individual’s decision-making and behavioural responses” (Schrodt and Sephton n.d. as cited in Donegan and Spratt 2002:959). “Attitudes and beliefs, social support systems, and health related behaviors are critical issues in all phases of breast cancer management, ranging from compliance with primary preven-

tative measures such as mammography to tertiary treatment decision-making and adherence to treatment” (Schrodt and Sephton n.d. as cited in Donegan and Spratt 2002:959).

When being treated for cancer, the oncologist is the face and voice of the entire surgical team and the oncologist’s sole purpose is to cure the patient of this illness that is damaging the health and functioning of the human body (Fawcett and McQueen 2011:109). In the research project on which this article is based, Dr. Aaron Jackson (pseudonym) was the leading oncological physician who acted as contact person with the research participants. The preliminary findings within the literature review reflect his acknowledgement of “behavioral medical care”:

Ninety nine percent of the patients you see are women in their fifties to seventies, and occasionally younger. So you deal with female patients...and emotional female patients with cancer. So sometimes you treat the emotions more than you treat the cancer.

Given the nature of a cancer diagnosis, the long journey of treatment, and uncertainty of the eventual outcome, paying attention to the emotional experience of the breast cancer patients is important as this will encourage a holistic approach when treating her. The oncologist’s primary focus is the breast cancer diagnosis, but how he/she sees and understands the patient will influence how the patient accepts her diagnosis and expresses or commits her willingness to undergo the recommended treatment trajectory. Breast cancer patients need to understand that the treatment regime will result

in varying side-effects: the loss of a breast or even both breasts, the loss of hair, nausea, discomfort, pain, the blackening of veins, are just some of the physiological changes. These changes will inevitably trigger emotional turmoil, making it essential to negotiate the patient’s willingness to undergo and fulfill her full treatment trajectory.

If you take away a breast or both, a woman will feel less feminine and, unfortunately, when you block a female’s estrogen, you take away her femininity. What gives you your secondary female characteristics? It is estrogen, and now we [oncologists] take it away for five years [as this is part of the hormonal treatment that follows the radiation]. You get hot flushes, dry hair, dry skin, you get painful joints, you get osteoporosis, you get vaginal dryness, you get bladder irritation and reduced bladder activity, and the list goes on. They [breast cancer patients] get fat and, yes, they are fat because they pick up ten percent of their body weight. So, yes, these things all have a very bad effect on a woman feeling feminine...they are one breast less and no hair. [Dr. Jackson, interview on 23/10/2012]

Breast cancer inevitably alters a woman’s self-image. How a woman views herself influences and affects her self-concept and ultimately how she perceives her femininity. According to Dr. Jackson:

Breast cancer is one of the easiest cancers to treat oncologically, but one of the most difficult cancers to treat emotionally. [interview on 23/10/2012]

It is accepted that women who are able to afford private medical care often reveal a higher level of

a positive “healthcare ideology.” A healthcare ideology influences to a large extent how patients will approach their healthcare in terms of health-seeking behavior, compliance, and adherence to treatment, understanding and knowledge of their affliction, and the perception of the prospects of healing and improvement. These, in turn, inevitably influence the manner in which healthcare workers will interact with patients and will impact on the ultimate experiences of the medical encounter. In this context, it is therefore important that healthcare providers encourage patients to be better informed, and that healthcare providers are “responsive to the patient-consumer empowerment” (Cheng 2010:63).

The Narrative as a Tool to Unwrap Meaning: The Methodological Account

Researching narratives implies a focus on the biographical descriptions that people give of their everyday lived experiences. The term biographical description overlaps with those such as autobiography, autoethnography, life history, life story, and documents of life (diaries or memoranda). To uncover meaning, we relied in this project on in-depth interviews which took the form of conversational, dialogical, semi-structured, open-ended, reflexive, collaborative, and guided encounters. The aim is that the participant collaborates during the in-depth interviews in producing accounts or versions of her past, present, or future actions, experiences, aspirations, thoughts, and feelings.

When interpreting and analysing narratives, the social reality underlying the narratives is seen as in-

trinsically dynamic and complex. The breast cancer patient is an active agent within the context of her lifeworld within which social action takes place and within which meaning is constructed. As narrative analysts, our understanding is an interpretation, and through the language we use, our interpretation becomes part of a process of meaning-making. This process entails, among others, that we draw on all available information concerning the structure within which the narratives are situated.

The narrative findings that we express below reflect the experiences of eight participants who had access to private medical care for their breast cancer. Their experiences therefore are not generally applicable to the overall South African population given the country’s pernicious and persistent inequalities, especially in the healthcare sector.

How one perceives events, actions, and experiences affects in how one recalls information and facts from one’s “stock of knowledge” (Audi 2003:1-2). Each individual research participant gathers her knowledge and experience from within her lifeworld and adapts to the demands of her life within the context of her experiencing breast cancer (Mouton 1996 as cited in Coetzee and Graaff 1996:16). Society and its norms, values, and beliefs play a role in how the individual understands and accepts a situation such as dealing with breast cancer. No one individual’s social existence is entirely freely created, nor is it strictly scripted. Each event allows the actor to write, produce, and act within her own social setting (Ritzer 2011:205). In this way, participants create their stories and the truth of these stories “is not only what *was* experienced, but equally

what *becomes* experience in the telling and reception” (Frank 1995:22).

The research focuses on eight women from Bloemfontein, South Africa, varying between the ages of 37 and 62 years. Their socio-economic background can be regarded as fairly similar and, as mentioned, they all had access to private medical healthcare. Seven of the eight participants obtained tertiary education qualifications. Each one of them had a sound bio-medical understanding of breast cancer. Each one was contacted with the assistance of the first *gatekeeper* who is their primary oncologist, Dr. Aaron Jackson. He informed his patients about the research and negotiated consent with willing patients. All eight participants declared their willingness to be involved in the study and remained willing to participate throughout the study.

The information was collected over two years (2012-2013). Each participant’s breast cancer diagnosis was her first diagnosis; and at the time of the research no participant suffered metastasis or a recurrent breast cancer diagnosis. Ethical clearance was obtained for this study from the Ethics Committee of The Faculty of Health Sciences at the University of the Free State in Bloemfontein, South Africa (ECUFS 150/2012). Given the sensitive nature of the research topic, each phase of the research was approached by obtaining a renewed assurance from participants that they were truly prepared to continue sharing their narratives.

Who Told Their Stories?

The narratives need to be situated within the broad context of the national health system of South Af-

rica, as well as the South African society. As mentioned before, the South African healthcare system is grossly unequal. The public sector healthcare as provided by the state is highly inequitable when compared to the free-market medical system where providers are mainly private entrepreneurs operating from privately owned facilities (Van Rensburg 2012).

The eight women who shared their narratives reveal the experiences of a small group of women belonging to the semi-professional upper-middle class. We read the stories of these women not only as stories of their struggle with breast cancer, but also as stories reflecting their lifeworlds. Three of the participants work in the field of education: two as teachers and one as an administrator in education. Another three work in the healthcare system: one as an emergency care practitioner and the other two as nurses. One woman owns and runs her own business, and the final woman is married to an entrepreneur and now runs her household.

Encountering the Medical World

One often hears that state-run institutions such as hospitals and clinics not only lack physical equipment, but also lack empathy and sufficient communication when treating patients (Oosthuizen 2012; Taylor 2012; Prince and Marsland 2014). One of the research participants, Anna, who was 37 at the time of meeting her, is a paramedic working for the state. She draws from her personal experience of working in the state hospital and compares it to her breast cancer treatment in the private healthcare set-up.

They are giving us soup and sandwiches and stuff, I did not expect this. They try and make it “home-ly” for you. You know, they are giving out blankets and we have these comfortable chairs. I thought [my treatment] would be like [that in the] state hospitals. Where you sit on a straight chair, get irritated the whole time, and the personnel is stiff [and unfriendly]. I did not expect this [private hospital experience]. You must understand that state hospitals and private hospitals [are] two different things. The experiences that I have [being] a worker [and employed] in the state hospital is completely different than in the private hospital [setting], especially with the personnel [because] in state hospitals they don’t care. They don’t even talk to you. They [just] put the drip up and that’s that. In [the local state hospital], where we take cancer patients to, there is no compassion, nothing. So I had this perception that this [private hospital would be] like [that].

Anna’s personal interaction and involvement as a paramedic with the public and private health-care sector might reflect a biased experience because she has always been on the supply side of public healthcare as an objective actor. Her personal experience with being diagnosed with breast cancer puts her in the shoes of the subjects having to deal with the medical gaze. Her personal involvement as a patient exposes her for the first time to a treatment trajectory. She is able to distinguish her treatment from those of the many patients she has encountered before.

When viewing the medical encounter from the research participants’ perspectives, it is clear that each participant felt like she was a priority to the

healthcare team within this private medical facility and the medical personnel in this private medical facility did not feel restricted by standard working hours. This sentiment was shared numerous times by Donna:

I have a cough on me and stuff like that because we are in the middle of winter and I am trying to go through chemo...and say, that night at nine o’clock or something like that; he [Dr. Jackson] will phone me and he is still in his office and is trying to help people...he is supposed to go home and not supposed to sit there.

Although Donna was probably the most negative participant among the eight women; represented in phrases such as, “I don’t know how to get up and go on with life again,” “I’ll rather shoot myself,” and “I don’t know if I am going to cope,” she expressed only positive remarks about the actual medical encounter. Not only was she satisfied with the medical personnel and her primary physician, but also appreciated the extra effort and care they displayed in the chemotherapy lounge.

They really do go out of their way. Like I said, the little sandwiches. And they put this little bug [heated bean bag], which they warm, and they put it on your hand before they put the wire with the needle in...they treat you so nicely.

By undergoing cancer treatment, participants express belief that they will overcome this illness despite the seriousness thereof. This belief is further strengthened by the quality of care in the medical

facilities that the private medical institute employs. Fiona reflects on her understanding of the treatment alternatives and their consequences.

[Breast cancer] is a serious disease, but the medical technology is so good that you don’t have to fear because there is treatment for it. So, I went for the treatment...[also] the medical view has also changed in the last few years. They tried to...they called it, um...breast reservation [or breast conservation therapy²]...Dr. [in the private hospital] explained it to me. They don’t want to do a mastectomy,³ if it is not necessary because they know a woman’s hair and breasts are sort of her main, um...features of femininity [and that is why] they would rather do breast reservation than doing a mastectomy.

A good relationship between medical personnel and patient influences how a diagnosis is perceived. Gina is, for example, positive about her breast cancer journey and the overall medical encounter.

There were these three beautiful people: the nurses working there, and Dr. Jackson himself is a very special oncologist. You know, he explains [everything] one hundred percent.

During the interviews with the research participants frequent mention is made of the role played by the three chemotherapy nurses who are an intricate part of all the participants’ medical encoun-

² Breast conservation therapy is seen when the surgical intervention is minimal in an “attempt to preserve the breast without compromising survival” (Rahman 2011:1).

³ Mastectomy “is the removal of the whole breast” (Breast cancer 101 2013:1).

ters. Each of the participants comments on the extraordinary service and compassion they receive from these women, as expressed by Hala:

The nurses remember me and they are friendly and chatty and they make you feel like family.

Anna, in turn, indicates that they treated her as a “human being, and not as a sickness.” While Gina has the following to say:

The three nurses are like these three angels working for God on earth. Such nice people, and I said to myself: “Thank goodness that it is these three that are there for us, they are kind and compassionate.”

Hala’s rendition of the medical encounter captures most of the sentiments expressed in the other research participants’ accounts:

Dr. Jackson was absolutely so sweet and the sisters at the chemotherapy, you know, you could not have asked for better. I couldn’t have asked for better medical personnel to treat me and to give me that chemo. They were so gorgeous, so friendly, and you felt so at home there. They went through so much trouble and they always wanted to find out if you were OK. And they brought us coffee or tea or whatever we wanted. The one day when I came there, there were the most delicious sandwiches, and they started with the chemotherapy. There is nothing that I could think of suggesting to them that they have to change. We had lovely Lazy Boys [a type of relaxing chair] to sit in so it was so comfortable and all the people were going through the same trauma. So everybody was so, so kind.

Medical Interaction between Patients and Practitioners

How the medical team views patients and interacts with them can influence how an illness is perceived and treated. Some of the research participants indicate that they wanted a more in-depth understanding of their illness after being diagnosed. Ella, who is self-employed and 49 years of age, is one of the participants who wanted to know more.

If I could change something for people that will be diagnosed in the future, is to give them more information the moment they tell you something is wrong. They have to tell you: "Listen... You know, after two weeks, I came to Dr. Jackson and he told me this is the type of cancer you had." When I went to hospital, they did the lumpectomy and the next thing they put me on the machine and they take a uhm, uhm a sonar of the skeleton. You don't...They don't tell you they will do that and why they will do that. I was...myself, I would like more information before I go through this. They must say: "Listen, we will take out the lump and then we will do this and this and this to see what is happening and then we will send you to the oncologist and these are the types of breast cancers you can have. We don't know yet, but this and this and this is the most uhm...most people... eighty percent has this one and twenty percent has this one." So you can just understand more before you go through everything. Uhm, it is just like...they diagnose you and then they send you to the surgeon and the surgeon doesn't tell you anything because he is just there to remove the lump. And then...you understand what I am saying? There must be some sort of support for people...And it is not the doctors'

fault. There must be somebody like a psychologist or somebody who tells the patient what is going to happen to you. More than one person said exactly the same when I talked to them. They would have liked to know before anything happens so you can take a...decide what to do and know what is going to happen. Because you just lie there in the hospital and, OK, now you are going for a...X-ray and now you go for a sonar, and you don't know why or nothing.

A patient's right to be informed about her diagnosis and the treatment trajectories are important aspects to fortify rapport in the doctor-patient relationship. This relationship must emphasize trust, "open dialogue," and advice on the advantages and disadvantage of treatment options (Wagener 2009:243). This is reflected in various personal testimonies which emphasize that the most common first response to a breast cancer diagnosis is shock and disbelief. This initial response is counteracted by collecting of information and becoming familiar with the diagnosis. In a study conducted by Barbara Delinsky (2001:4), findings revealed that her participants emphasized similar thoughts of their breast cancer diagnosis. One of her participant's states: "I wanted information immediately. I wanted to know which treatment plan was right for me...I sought the advice of trusted family, friends, doctors, and breast cancer survivors, so that I could be my own best advocate" (Delinsky 2001:4).

The research participants reveal that after the initial shock wore off, the majority of them sought information through books, the Internet, family, friends, and medical staff to broaden their knowledge and to regain some form of control over their lives.

Some of the participants are of the opinion that the diagnosing physician relayed the information and treatment trajectory in a manner that was comforting and informative. This also helps to build a trusting relationship where patients feel comfortable to ask questions and inquire about medical terminology. Hala states that she did not hesitate to further her understanding of her diagnosis.

I am not ashamed to ask [the doctors] if they are talking their [medical] language. [I would say]: "Please help me understand better and explain what that means."

Bella's experience reflects a holistic encounter in which her doctors explained and even elaborated by drawing pictures to fully depict what they would be doing and how they planned to do her surgery. This is how she relates the interim period between her diagnosis and undergoing a double mastectomy:

The doctor at X-ray explained [that] now the cancer is operable. "I will refer you to somebody who can operate on you and is very good." Then I met that doctor and she was a very funny lady and she explained [everything]. She even put up some pictures to explain and show me how she is going to work and what [she is going to do].

Carla also accounts an interactive and guided treatment experience with the medical personnel:

[The doctor] explained everything. What type of cancer. She even drew a sketch for me on what is happening and what she is going to do. So I understood [everything].

Fiona recalls the hospital personnel as portraying an optimistic view:

They were very friendly people [who exuded] high spirits. [They] never [make you] feel like [you are] a sick person when you entered the hospital.

None of the research participants felt side-lined or rejected by any member of the medical personnel. Each participant indicates that she experienced a rather open relationship with them, including face-to-face and telephonic interactions and participation in the negotiation of the treatment trajectory.

Experiencing Additional Interventions

Loue and Sajatovic (2004:9) indicate that "women have been expected to meet a certain body image, to conform to a contemporary standard of appearance and beauty." But, to meet these idealized norms of beauty while battling with a breast cancer diagnosis can be a challenging prospect. In addition to the medical intervention that often entails a mastectomy, breast cancer almost always coincides with hair loss. The research participants placed a strong emphasis on the trauma of losing their hair. Apart from the shock of the actual breast cancer diagnosis and surgery or chemotherapy, hair loss was expressed as being the most traumatic aspect of the illness experience. To combat this trauma the hospital made a concerted effort to help the patient to deal with this. Bella recalls one of her medical encounters:

The hospital brings in beauticians especially for breast cancer [patients]. They tell you even if you

don't attend [this] session you [must] come for another session. [They come and help] the people to clean their face[s] and have a cup of tea with us and talk.

She further praises the staff at the private hospital for not only accepting her, but also for making sure that everything was taken care of from the administrative side to the understanding of her surgery, as well as the different outreach programs. Participants spoke of experiences that are in line with an ethic-of-care approach. An ethic-of-care approach "stresses that the caring response is determined in a concrete way for each unique patient within that patient's particular network of relationships and given that patient's unique needs and desires" (Cates and Lauritzen 2001:58).

The staff accepted me and said I looked pretty. Even with my admission, they organized everything for me. [When] I was discharged, they organized that I go to [a local organization] with [these specialized] bra[ziers]. [They said that the lady with the bra(ziers)] will measure [me] and do all these things for the bra[ziers] so that [I] look the way [I] looked before [I was] operated on. [The hospital has] so many channels they can send you to after your operation. There were [even] some sessions where you were visited by these beauticians and they pamper[ed] you. There were about ten or twelve of us for the sessions that they [gave and it] is free of charge. They give you the cleansing material, the moisturizers, the lipsticks, and the blushes. They give [you] all [this] stuff that makes you look beautiful.

The treatment that participants received was to a large extent client-centered. Research participants

experienced being treated as important and not as just a body with an illness. They felt that their emotional well-being seemed to matter. It is clear that by focusing on the patient's well-being, the medical facility not only helps the individual to a better recovery, but also improves her outlook on her illness experience. Gina recalls her experience with the chemotherapy nurses:

I went for my first chemo[therapy and] they said to me: "Just cut your hair a bit shorter, so that the day you lose your hair, it is like shorter...shorter...gone."

Her curiosity about her illness led to the oncologist providing her with reading material:

I felt to myself that I am studying medical science now with [Dr. Jackson]. He even took my email address and he said to me: "I will send you articles on this." He said the HER2 positive [cancer] is a very aggressive cancer and [then] he sent me two articles that I read.

The Quest for Normalcy and Control

During the breast cancer journey each of the participants sought to balance her everyday roles (as mother and wife) with her treatment trajectory and its varying side-effects. Some of the participants indicate that they rely strongly on family support whereas others feel that the breast cancer battle is largely a solo journey. The decision to fight the cancer herself led Ella to ask family and friends to reduce contact with her:

I asked them not to contact me and phone me every day to ask me what is going on. I told them if I need them,

then I would phone them and ask them for help, otherwise they must just leave me. I will survive. I asked them to please phone my husband and ask him how I am feeling. Ask him and don't phone me, just leave me.

Other participants became accustomed to their new appearance and the side-effects of the treatment regimen. They are also comfortable with having their family and close friends see their altered appearance. According to Hala, she tried for a time to maintain her pre-diagnosis appearance and to continue her daily activities, but when she experienced the negative effect of the chemotherapy and radiation on her everyday lifeworld, she renegotiated her self-understanding.

At first I told myself I will never ever walk without this wig. I will not walk like that. That not even my children would see me without hair. But, because it was so hot during summer time, I just thought to myself: They must just see me the way I am because I am not going through this. They must just accept me the way I am. In the winter time, it is so cold without hair. So I used a beanie [a woolen hat] during the nights. But, it is OK. I realized that this is just a phase that I had to go through and, fortunately, nothing lasts forever and things will change and things have changed.

Carla notes that her breast cancer diagnosis is more traumatic to her family and friends.

I am coping and accepting, but the breast cancer diagnosis affects others.

Furthermore, she believes that once she comes to terms with her diagnosis, her life will carry on with a few adjustments such as her diet.

I am eating normal with lots of vegetables and fruits. I decided to change my lifestyle on my own...nothing is going to stop me from what I want. I am not sick.

Each of the participants finds her own ways to come to terms with her diagnosis. Having accepted her breast cancer diagnosis, each participant makes a concerted effort to find a renewed balance in her life. This includes beauty regimens, daily chores, and meal preparations in which partners and children are an integral aspect of maintaining normalcy. This way of balancing the illness with leading a normal life allows for a sharing of control, especially when a daily chore such as cooking is done by a family member or friend. Donna states:

The friend of mine helps when he cooks.

The effect can also be seen in Gina's family circle, which sees her grown daughter coming home to her parents to help them with their daily chores:

My one daughter phones me and says: "Ma, must I bring you food?," "I will come and make you food." Because I can't face food. This helps me and my family to continue with life as normal.

Weathering the Storms

Kathy Charmaz (1997) views a breast cancer diagnosis as a disruption to an individual's self-concept and immediate lifeworld. Cheng (2010:ii) adds that the diagnosis of breast cancer does not only disrupt a "woman's everyday life, but also, and more importantly, her self-identity: who she was before

the cancer diagnosis and who she becomes after the diagnosis." The shock of a breast cancer diagnosis can turn an individual's lifeworld up-side-down. The acceptance of this reality varies depending on the individual's self-understanding in combination with her immediate support structure. In each of the research participants' cases, the initial diagnosis came as a shock, but through their inner strength and support structures (family, friends, and religion), they were able to renegotiate their disrupted lifeworlds.

Shortly after her diagnosis, Carla struggled with various unanswered questions linked to this affliction. Despite this tragic diagnosis, she realizes that she has the power to renegotiate her circumstance by taking control in her treatment trajectory.

It was a shock...Sometimes when I am sitting alone, I get those questions which you don't have answers to...I am a person who fights and I don't just sit there and cry because no one is going to help you, if you don't help yourself.

Ella recalls that she felt very uneasy with her breast cancer diagnosis. She felt that not enough information was provided during her consultation with the diagnosing physician. This prompted her to seek guidance from a friend who had overcome her own breast cancer diagnosis.

I was so shocked, you don't know what to do. So I would have liked this to happen: the moment you are diagnosed, there must be somebody they send directly to you and who says: "Listen, this is what is going to happen to you." Because you don't

know...I was talking to one of my friends who also got breast cancer and she said: "The moment that you get diagnosed with breast cancer, you need somebody to tell you exactly what is going on." Because what they do is they say: "OK, it is cancer and it must be operated on, so which surgeon would you like?"

Bella is the only research participant who accepted her diagnosis immediately. However, she reveals that after her initial diagnosis, she was scared:

When I was diagnosed, I was a little bit scared, but I thought: Let me just accept this condition. Because if I don't accept it, it is going to be a little bit tough for me to go through everything concerning cancer. And I just prepared myself and accepted the condition as it is.

Bella explains that her strong and accepting self-understanding was influenced by an article that she received from her daughter in the period between her check-up and diagnosis.

My daughter came and said: "No, mama, it is not you alone"...She gave me an article with this person who has breast cancer as well. The story was written and the information was given...When I read this story, it was as if this story was mine. But, when I went down a bit, it was from somebody from the Eastern Cape. They were talking about the breast cancer...but that woman was afraid and couldn't accept herself.

Donna still juggles with her emotions when trying to come to terms with her diagnosis and the end of chemotherapy and radiation. She realizes that this

is not an illness that you can ignore because of the uncertainty of it returning one day. Initial acceptance is therefore not the issue any more; it is rather the prospect of the cancer recurring after the intense treatment. Her focus is now on coping with the looming possibility of metastasis.

I actually went into shock...all they could say is that it is third grade and very progressive and the lump must come out. And then in the operation itself they can say how far it is...Now, having finished chemotherapy, I feel I should see somebody about this experience. To get myself coping with the fact that the chemo is now finished. Because you get through this process of building yourself up and then it breaks you down again...I can't accept the fact that it is really over. OK, now I am going for the radiation and I must be careful with that so that my skin doesn't get broken. But, I feel now, what about if they test me now, and I have to go through all of this again? I don't think I am going to do that. I'll rather shoot myself. This is the stuff that goes through my brain. I don't think that you have to think positively. You are always fighting with yourself.

Support

In analyzing the treatment trajectory, it became evident that support from family members and close friends is vital in accepting a breast cancer diagnosis and finding strength in continuing the long treatment. Donna is the only participant who does not have immediate family and friends to aid her in her illness journey. She reveals that she has been divorced for many years and both her daughters live with her ex-husband and do not visit her often.

Due to her isolated everyday lifeworld, she finds comfort in Christian television and her church fellowship.

There wasn't any emotional support...I am still feeling very negative. I am reading a lot and watching TBN [Christian television] and I am looking to hold onto something in life...because you get into such a small world of just coping with the cancer. I am looking for something through TBN and through the Word of God.

Each of the other research participants reflects a positive outlook of her breast cancer experience, and this appears to be strongly linked to the support each of them received from family and friends. For some of the participants, a feeling of shame was accompanied to their physical appearance following their surgery (lumpectomy,⁴ partial mastectomy,⁵ or double mastectomy⁶). The husbands of these women also had to renegotiate their roles as partners and lovers. Those participants who are married reveal that it is difficult to accept their altered bodies and that their husbands' gaze is unsettling. According to Carla, it took her a while before she felt comfortable letting her husband see her naked after having a mastectomy of the left breast.

When you look at yourself, it is hard to accept yourself being like that, so I took time. I didn't even want

⁴ Lumpectomy—"where the tumor along with a rim of at least 1 cm of normal breast tissue is removed" (Roy 2011:443).

⁵ Partial mastectomy—"removes less than the whole breast, taking only the part of the breast in which the cancer occurs" (Rossi and Sokolowski 2011:154).

⁶ Double mastectomy—"the removal of both breasts" (Breast cancer 101 2013:1).

my husband to see because he is not used to seeing me like that...it took like two months before he can really actually look at me because I didn't want him to...Even when I was in the bath, he saw that I didn't want it. And he saw I didn't want him there and he accepted it.

Anna also voices her concern about how her husband will see her after her mastectomy and whether he will be able to accept her as she is now. She decided to discuss her insecurities and find out how her husband feels about the situation.

Is he going to accept me? You know, I think there it [femininity] may play a role. But, after we had a discussion and after the mastectomy we had intercourse again and after that everything went fine. It is like before. So it was just that anxiety and not knowing. Am I going to be accepted and am I going to accept myself...But, since then my husband and I had the talk and he assured me that nothing has changed.

Ella's breast cancer surgery consisted of a lumpectomy. She states that she was aware of her scar, but indicates that her hair loss was more traumatic. She takes care that her family does not see her without her wig. Ella's husband is accepting of her need to present herself as before her diagnosis and he even occasionally tries to lighten the mood.

I don't even show my family, not my children and not my husband. They must understand that this is personal for me and I don't want them to see me without my make-up and a wig on. They are very positive people and especially my husband is a very

positive person. But, for me, I don't want them to see me like that and I always put something on my head so they don't see me without hair.

Throughout the research the concept of hair and the loss thereof is a prominent theme. Some participants attempt to deal with their hair loss privately while others include supportive others in their experience of losing their hair. Gina is happily married and a mother of four, and her family shares her trauma when she shaved her hair. By removing her hair, she experiences that she is losing part of her identity and needs the support of her family to help her to come to terms with her new appearance. This traumatic event even encouraged her husband to propose that he, too, shaves his head in solidarity with his wife.

It is important. When my daughter was cutting my hair, my son was there and my husband was there supporting me. I was sitting there crying and if I look at my son, I could see his eyes as well [tears]. And I didn't look at my daughter, but she was like: "No, Ma, let me cut just a little bit off with the scissors and then I will take, you know, [the shaver]." My daughter is a qualified hairdresser. I also said to my husband that: "If I need a hand, yours must be there first." And shame, he said he would also shave his hair. And I said: "No, you are going to look like a bandit." Don't shave your head, I thank you very much, but don't"...[After I shaved my head] I was scared to lose my identity. Like if I take my wig off, then I think: who am I? It is still my eyes, but who is this woman looking at me? But, it's just temporary and I know that my hair will grow again.

Reflecting on the Future

Having a view on the future is an important dimension of how an individual perceives her diagnosis and the fight she puts on to overcome her illness. The biographical disruption accompanying the trauma can be seen to encompass almost the entirety of the research participants present and future lives. Most of the participants view their illness as a chapter in their lives and they display a determination to survive. This proactive mentality prompts a re-evaluation of family relations, daily living, and values attached to the concrete reality of everyday life. According to Carla, she is furthering her studies and uses the idea of losing out on seeing her granddaughter grow as inspiration to overcome her ordeal. Carla is also adamant that her life will carry on and that she will be able to reach old age:

I want to do my Master's thesis. And my little granddaughter, I will miss out on. I love her. She is so lovely and she is two years old now. I thought about many things: "Am I going to live?" "Am I going to die?" You ask yourself many questions, but at the end I said: "No, other people are still alive, so why not me." So I told myself I am going to fight and I am going to change my lifestyle...My goal is seeing myself passing this sickness and getting my certificate and continuing my life and my work.

Ella has re-evaluated her everyday lifeworld and has come to realize that material things hold little value to her and cannot replace the importance of her family. Her future is the one thing that is important to her now:

I have a different outlook on life and on the little things, you know. But, I am still me and I am just moving on. Not myself, but things in life is different for me. Things I see in the future and in everyday life is different. This is something I can tell you...I ordered myself a car...three months before I was diagnosed, alright...And it was very important for me to have that car. Now, I don't worry about the car because I wanted a BMW X3. I didn't want anything else because I wanted a BMW. But, now I don't worry if it's a Volkswagen or if it's whatever. It doesn't matter anymore. So that changed.

Donna believes that she will accomplish this self-renewal through what she calls The Word of God. Her strong need to find a balance between who she is and what she experienced through her illness may in part be ascribed to the fact that she initially experienced a lack in support structure. She relates that she needed to find the courage within herself to fight this battle on her own.

I am still feeling very negative. I am trying to find myself again. I am trying to restore myself to normal again. I know I must just find the love of God for me and I am struggling to get that because, you know, when you have no one, really [it is very difficult].

Fiona brings to light what she considers a very important feature in the breast cancer journey. She points out that one must take responsibility for oneself and states that she achieved this by implementing three principles to help her accept her diagnosis, undergo treatment, and see her future plans materialize.

I think about my life, it certainly has changed. The way I see my life and my future. But I still have

a purpose here. I think the one thing I learnt about this illness is that everybody has a responsibility towards oneself. You must have your regular check-ups every year. You must look after yourself, get exercise, eat healthy and keep your mind healthy, and think positively. A friend of mine said: "There are three things that you must do: live a healthy lifestyle, keep your mind healthy, and have faith." And I think those three things are the most important things that I try in my life. Now I really appreciate every day more than what I did in the past, really. Because the cancer can kill you and therefore I think I appreciate life more.

Throughout Gina's narrative it becomes clear that her family is the most important aspect to her life-world. Her family-orientated outlook is strongly reflected in her future aspirations. She hopes to retire with her husband in a home they specially bought for this and furthermore, she hopes to continue being part of the lives of her grandchildren.

I always say to myself: "You know, I have three grandsons, but I must still see one granddaughter somewhere." Because I always said to myself that I am always more of a girl mother than a boy mother. I love my son and to me he is something special, but I love my girls. My girls and I are very close and I am glad I got them. Now I have the three *boeties* [grandsons] and it is always: "Ouma touch, crouch, and engage" [a reference to the way rugby is played] and there is nothing Barbie. Always very physical. But, my children and grandsons...they make life worth living. Also, last year I bought a house in Smithfield and my husband is renovating it. But, it is six years before he retires. So we must hang on.

Each research participant makes a clear and conscious statement that once the treatment trajectory is completed and the cancer is in remission, she will continue her life and have future aspirations as planned before her diagnosis. There is a strong commitment to returning their lives to normal and to view this illness as an episode, not as a permanent and continuing condition. The illness experience did influence the individual's previous self-concept, but all eight research participants are unwavering in their resolution not to allow the illness to change who they are. They all aim to continue their futures in terms of their renegotiated selves and not only as breast cancer survivors. While this renegotiated self-perception might be influenced by certain aspects of the illness experience, research participants agree that they will not allow the illness experience to alter who they essentially are.

Conclusion

When trying to unwrap the meaning contained in the narratives of these eight women, we realize that it tells us only about a small part of the reality of women's experience of breast cancer in contemporary South Africa. The eight women who told us their stories do interpret and construct social reality, they experience the social lifeworld, and make sense of and constitute meaning. But, these constructions, experiences, and constitutions of meaning should also be situated polemically in relation to the broader social context and in relation to the possibility of alternative accounts, as Roy Bhaskar (2008:187) observes, "social structure and human agency are distinct, but at the same time highly inter-dependent entities."

It is the aim of this research to analyze the subjective views of each of the participants and to relate key aspects of their narratives. Perhaps due to the similarities between participants' socio-economic positions (background and educational levels) they share rather similar thoughts about their illness. Most of these women are interested in broadening their knowledge of their diagnosis and treatment trajectory. They all experience their ordeal as an important chapter in their lives. These commonalities inevitably influence their subjective experiences and understanding greatly.

From current understandings, it is clear that breast cancer is a multi-faceted illness affecting the individual psychologically, emotionally, and physically and also impacting on the immediate family members. From the narratives it appears that middle class women rely heavily on trusted relationships with medical personnel, the family, close friendship circles, and even religious networks to air their fears and to find strength. The narrative of one participant reveals that the medical healthcare system in South Africa exhibits a vast contrast between the state-run institutions and private medical care. Hospitals run by the state struggle on a daily basis with shortages in equipment, lack of medication, and understaffing (Cullinan 2006:21). Even though issues related to the public-run hospitals are of great concern, this article focuses predominantly on the privileged part of the South African population and thus on encounters with private healthcare providers. Therefore, the abovementioned narratives are not applicable to all South African women who are struggling with breast cancer. The narratives rather reflect the personal journeys that these eight participants experience.

Although the research participants view their illness as a chapter in their lives, most are adamant that breast cancer will not define *who they are* or *who they will be*, that is, merely a survivor. Not only have these women survived a breast cancer diagnosis, but they also see their illness as something that can be overcome. Once they have completed the treatment trajectory (surgery, chemotherapy, radiation, and five years of hormone therapy) and have obtained a clean bill of health, they want to continue with their lives as before their diagnosis (as a wife, a mother, a grandmother, an academic scholar, or whatever else). Donna is the only participant who mentioned the fear of a breast cancer recurrence. She finds this prospect threatening, but realizes that she must actively try to stay positive through her faith.

Based on the narratives, we can state that a breast cancer diagnosis does not appear to have permanently disrupted the participants' perception and concept of themselves, even though such an illness is lived as a profound existential experience. Each of the women still feels feminine although this sense of femininity often has to be re-enforced with the aid of a wig, make-up, or specifically designed clothing. Even though their physical body has been altered and this has resulted in scarring or the loss of breasts, none of the women feel that they need reconstructive surgery to be perceived and accepted as a woman. Rather, the illness is accepted as an experience and a memory that can even encourage her to pursue her future plans and prospects. In conclusion, this article does not overlook the seriousness of a breast cancer diagnosis. However, mostly due to the participants' financial ability to obtain excellent private medical care and to them having the extended support structure of family, friends, and religion, they understand and live their breast cancer ordeal as a chapter in their lives.

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