



Summary Report for CANSA¹

Exploring the Experiences of Breast Cancer Survivors at Various Stages of Treatment: An Analysis of the Constructions of Breast Cancer and of Femininity

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Introduction: Purpose of Research

This research was conducted towards an Honours degree in Gender Studies at the University of Cape Town, as well as to contribute to the knowledge base of the Cancer Association of South Africa (CANSA). The focus of this research was to explore and document the experiences and needs of women with breast cancer, waiting for radiation treatment.

By applying a gendered framework through which to view these experiences, emphasis was also placed on breast cancer survivors' conceptualisations of feminine identity and how their breast cancer and treatment trajectory impacted on these.

Drawing on the narratives of women's lived experiences, it is my hope that information gained from this study will help CANSA to develop additional emotional support for women.

The Literature:

Previously, cancer has been referred to and conceptualized as an acute disease (Tritter & Calnan, 2002 as cited in McCann et al., 2010). However, medical improvements have made it

¹ This report is drawn from the Anja Mulder's 2012 UCT Honours dissertation of the same title. It was a collaborative study between CANSA and UCT, facilitated by the UCT Knowledge Co-op. The full thesis will be made available on <http://www.knowledgco-op.uct.ac.za/resources/>.

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This summary was submitted in March 2013. Content referring most directly to patients during the waiting period before treatment commences appears in blue font.

possible in recent years to be diagnosed with cancer and yet to be able to live longer with treatment. As a result, cancer is being reconceptualised as a chronic disease (Tritter & Calnan, 2002 as cited in McCann et al., 2010). According to McCann et al. (2010), having a chronic illness causes disorder to an individual's 'normal' daily routines and can cause 'biographical disruption' (Bury, 1982 as cited in McCann et al., 2010), affecting how patients perceive themselves and/or how they believe others to perceive them. Being diagnosed with cancer 'immerses the patient into a complex web of interrelated experiences' (McCann et al., 2010, p. 1974). Conceptualizing and dealing with cancer as a disruption to everyday life enables the exploration and understanding of cancer as situated in relation to the self. This disruption can lead to the perception of social isolation and/or of being different, compounding in a sense of feeling a failure to fit in (McCann et al., 2010). With regard to breast cancer patients, the removal of one or of both breasts may make women feel that they are no longer able to fulfil hegemonic ideals such as being heterosexually desirable 'objects' (Lorber, 1994). This shows that viewing cancer as a long-term illness, and understanding women breast cancer patients' experiences within a larger framework of patriarchal, hegemonic social structures, is vital to enable researchers' understanding of the necessity for adequate support structures for individuals battling with the disease (McCann et al., 2010).

Additionally, many studies have emphasized that the uncertainty during the wait for treatment and/or surgery is a monumental stressor (Fogarty & Cronin, 2008 as cited in Drageset et al., 2010). One of the factors underlying this sense of insecurity is a lack of information about breast cancer and the trajectory for treatment, as well as a limited understanding of available information (Gaudine et al., 2003; Saares & Suominen, 2005; Shaha et al., 2008 as cited in Drageset et al., 2010). Coming to terms with issues around mortality and acknowledging that breast cancer can potentially be fatal are other factors contributing towards heightened anxiety levels (Giske et al., 2009; Remmers et al., 2010 as cited in Drageset, 2010). Adjusting to, and accurately interpreting the situation, often requires psychosocial support structures and counselling (Mehnert & Koch, 2008; Mishel, 1988 as cited in Drageset et al., 2010). And it is important to note that accumulating unresolved distress frequently informs longer-term mental health problems. This, in turn can lead to difficulties in adjustment, to depression, and to trauma after the initial diagnosis has taken place (Lally, 2010).

According to various studies, the types of support needed by women affected by breast cancer vary considerably, depending on: culture, type of treatment and the amount of time

that has elapsed since diagnosis. These studies also note that women's needs frequently go unmet (Dickerson, Alqaissi, Underhill & Lally, 2011). [With the help of social support networks, individuals affected by cancer feel cared for, supported and understood.](#)

A cancer diagnosis is not limited to a person's physical experiences, but also impacts a person's soul and spirit. Minimizing these experiences to exclusively physical ones prevents women (and men) from being able to deal with existential and spiritual afflictions (Arman & Rehnsfeldt, 2003).

The literature reviewed examined key areas, including the social constructions of gender and femininities, gender and women's health from a medical perspective, and the silences that have prevailed around women's bodies. The review also investigated disparities in cancer care, breast cancer prevalence in South Africa, what it means to receive and cope with the diagnosis, and how disease is conceptualised and embodied.

- It would appear that there is a lack of qualitative research focusing on women's lived experiences, including women's illness anxieties, their uncertainties and their coping strategies throughout breast cancer treatment.
- Furthermore, it has been noted that breast cancer not only affects physical health, but also influences women's evaluations and perceptions of themselves and their femininity.
- Obtaining a diagnosis for breast cancer is a stressful, demanding and traumatic event (Cordova et al, 2007 as cited in Drageset et al., 2010) due to the fact that affected women are suddenly confronted with a change in health and are faced with a life-threatening disease. As such, the event can elicit many emotional and psychological responses (Helms et al., 2008).
- It is argued that women's lived experiences of breast cancer and the treatment process are important in informing and developing adequate health initiatives and providing health programmes to patients and survivors.
- The importance of psychosocial support structures and counselling is emphasized.

Research Method and Process:

A qualitative method was applied. Semi-structured, in-depth interviews were conducted with five black and coloured breast cancer patients residing at two of CANSA's care homes in Tygerberg and Athlone. Interviews were recorded and transcribed. Narratives were explored using a qualitative analytic method known as thematic analysis to identify, analyse and explore themes within the generated data.

Findings and Suggestions:

Themes emphasized various as well as common experiences, outlooks and coping mechanisms. Women's support needs varied depending on the stage and phase of the breast cancer trajectory. As such, it is vital to comprehend the ways in which women conceptualize support, in order to appropriately develop interventions (Dickerson, Alqaissi, Underhill & Lally, 2011).

Patients emphasized better education around the development and identification of breast cancer, specifically in rural and outlying areas; better accessibility to screening facilities; counselling for family members; somebody to help them understand and adjust to the diagnosis and maintain a positive outlook; Someone to talk to about self-image issues and patients' identities as women; a need for support networks and groups with other breast cancer survivors; and one specific person whom patients can consult about treatments and procedures.

- Interventions in terms of clinics and accessibility to screening facilities and support systems are needed. Current statistics, produced by quantitative research, may be skewed as a result of lower class individuals being less able to access such health facilities. This impacts on research and knowledge around breast cancer, as well as our understanding of how it affects women differently.
- Families are often dependent on the physical and emotional health of the woman, who represents the centre of the family. Thus, women were not only fighting death but also trying to maintain a stable family. In light of this, it should be important to consider how much counselling family members receive.

- Research participants with a deep faith in and a close relationship to God seemed to have greater/ deeper inner resources to rely on. These women were far more able to adjust to the breast cancer diagnosis and maintained a positive outlook on life.
- There is a need for a greater awareness and for education around breast cancer in rural and outlying areas. Women who have access to the internet and/ or health pamphlets, or who communicate well with their doctors, appear to show a higher degree of knowledge and feel more secure.
- In at least two cases concerns around the lack of information regarding their treatment, feeling out of control with regard to treatment decisions, and not feeling secure enough to voice their discomfort with being treated in certain hospitals, emphasized the paternalistic model in medicine. Namely that women's involvement in their own medical treatment processes of their bodies is often marginalized.
- Insecurities were heightened by doctors' unresponsiveness. Unsupportive interactions had negative impacts on patients' adjustments.
- Setting a date for treatment to begin is seen as a crucial aspect in giving patients a sense of control and a sense that the healthcare system will 'protect' patients (Drageset et al., 2010).
- There is a great need to have the same person(s), not only in the medical team, but during the psychosocial support efforts too, because a trusting relationship between patient and 'carer'/counsellor is absolutely key.

The study highlights that each patient's experience is unique and that addressing differences in experiences amongst breast cancer patients is essential.

Vital to understand is that a breast cancer patient's healing process needs to be addressed in a holistic manner, rather than solely focusing on the physical body. The stress that overwhelms breast cancer patients and their families needs to be reduced and managed. Furthermore, illness anxieties often inform adjustment. As such, counselling and pre-social support is felt to be very empowering to increase the fortitude in the monumental effort of leading a life of quality in the face of a life-threatening disease.

Psychosocial support needs of patients awaiting treatment:

- better education around the development and identification of breast cancer, specifically in rural and outlying areas;
- counselling for family members;
- somebody to help patients understand and adjust to the diagnosis and maintain a positive outlook;
- someone to talk to about self-image issues and patients' identities as women;
- support networks and groups in which to share one's experiences with other breast cancer survivors.

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