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Kgatitswe, Lesego Bertha

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“We’re living in an era of facebook and blogs. It's a familiar and comfortable space”: Exploring the use of virtual support groups by women diagnosed with breast cancer.

LESEGO BERTHA KGATITSWE

Student number: 557788



Research Report Submitted to the Faculty of Humanities, University of the Witwatersrand,

Johannesburg, in Partial Fulfilment of the Requirements for the

Degree of Masters of Arts in Health Sociology

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DECLARATION

I, Lesego Bertha Kgatitswe declare that this research report is my unaided work. It is submitted as part of the requirements for the degree of Master of Arts (Health Sociology) by Coursework and Research Report at the University of the Witwatersrand, Johannesburg. It has not been submitted for any other degree or examination at any other university.

Signed: …….

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ABSTRACT

This research project explores the use of virtual support groups by women diagnosed with breast cancer in South Africa. Through a content analysis of the online forums and eight in-depth interviews with women of various backgrounds (age, race and socio-economic status) it becomes evident that women use these virtual spaces for information exchange, sense of belonging, search for meaning and most significantly support. Various factors within the *illness experience* of breast cancer influence the initial use, continuation, breaks and withdrawal from of these online forums. The analysis of online forums is framed around concepts of *lay consultation*, *gender*, *adaptation theory* and *social capital* to conceptualise and make sense of these virtual interactions. The virtual groups allow women to read and write on breast cancer according to their perceptions and experiences, thereby lessening the dominant medical power to create space for their personal voices. The interactions on the forums foster a sense of empowerment, social support and social engagement critical to their wellbeing and adaptation to the condition.

This study also brings attention to the lack of studies about virtual groups within the South African context which is increasingly becoming significant as more and more individuals use virtual groups as part of health lay interaction and consultation.

INTRODUCTION

Breast cancer is the most common type of cancer among women in South Africa and around the world, with one in 29 South African women diagnosed with breast cancer in her lifetime (National Cancer Registry 2011). A major concern regarding the disease is that the causes of breast cancer remain inconclusive. Moreover, despite ongoing research by various medical institutions breast cancer services in South Africa are fragmented and not comprehensive; as breast health and breast cancer are not regarded public health priorities both nationally and provincially (Breast Cancer Advocacy Coalition 2011). This is not surprising against the background of HIV/AIDS and TB as the biggest causes of the country's high mortality rate. However the growing incidence of breast cancer demonstrates that breast health can no longer remain in the backdrop of South Africa's health priorities. For this reason, this study aims to bring breast health discussions to the agenda by exploring an important aspect of the nature of and experience of virtual support groups for women with breast cancer.

Support networks are a substantial component of understanding the social context of health, illness and disease. Support networks, and more specifically support groups become important during the *illness experience* when the individual affected by a disease is in need of coping mechanisms. The internet is now a site where women with breast cancer both read and write about the illness, and in doing so negotiate identity and definitions of situation in disembodied space (Pitts, 2004). In this case online cancer support groups have become a viable alternative to 'traditional' support groups. Many agree that online networks offer social support, practical information, shared experience, helper therapy, empowerment, professional support, and advocacy efforts (Klemm *et al* 1999, Wright & Bell 2003). In this case concepts of *social capital*, *lay-referral systems*, *adaption theory* and *gender* are critical for analysing the interactions

observed on the virtual support groups as well as the health and *help-seeking behaviours* used by women in this group.

The study thus explores issues of virtual spaces as it relates to the transforming nature of support groups and social interactions; the gender-related factors pertaining to breast cancer and the illness experience influencing women to participate in virtual support groups. Overall this exploratory study is of an interesting and innovative nature as it focuses on the use of virtual spaces as a growing medium of social interaction and breast cancer as a gendered condition through these lenses.

AIMS, OBJECTIVES and RATIONALE

The framework of the research stems from the idea that illness is a social, cultural as well as a biological process. Illness does not only occur in the body; it has a wider social context within which we can understand how people make sense of illness and disease. It is this social context that helps us understand illness behaviour, health and help-seeking behaviour, and importantly, for this study, the nature of support networks and structures for those affected by the disease. This framework is also helpful in recognising how the illness experience of a chronic disease like breast cancer can be explained and understood within the psycho-social environmental approach. The use of support groups falls within the realm of illness experience; which is a much researched area that attempts to understand people's experiences and how they make sense of the various stages and occurrences during the process of the disease trajectory from prevention and diagnosis to treatment, care and recovery (Blaxter 2004).

As indicated, the main aim is to understand how breast cancer patients make use of virtual support groups by exploring the themes and topics discussed and examining the role of the support groups. In the same breath the research aims to explore the interactions and gender specific issues that arise out of these support groups.

Despite the fact that support groups play a significant role in this process, most studies are placed within the Western context, namely United States of America and Europe. Hence this study focused on a South African case study of virtual support groups on the internet, as there is no local research on this topic. The study draws from a number of previous studies on traditional and virtual groups (Wright & Bell 2003, Davison *et al* 2000, Klemm *et al* 1999, Pitts 2004) with an attempt of placing the explanations within a South African context.

The study further focuses on the sociological inquiry of the 'illness experience' of breast cancer and particularly of how the use of internet groups has changed social interactions and support

structures. This contributes to the body of knowledge in this area of heath sociology, breast cancer and support groups, specifically internet based structures. It also addresses the gender specific issues, which arise from breast cancer studies. In this regard the study fills in the gap identified in the literature. In addition the knowledge gained in this study has the potential to contribute to a more general understanding of the illness experience and use of internet support groups with similar conditions.

LITERATURE REVIEW

This chapter reviews the literature that informs and guides the study design. It is organized according to themes, all of which are relevant and important in exploring the role of online forums for women diagnosed with breast cancer. It begins with a discussion on breast cancer as a gendered condition, which is critical for understanding the *illness experience* and later the role of online forums which this study explores. Following this are themes of 'illness experience', 'medicalisation', 'social capital and health' and lastly 'self-help on the internet'. The literature chosen is multidisciplinary but mostly stems from sociology of health; this is useful in providing depth as well as a broader understanding in tackling the research question.

Breast cancer as a gendered condition

Simply being a woman is the main risk for breast cancer; while men also get the disease, it is about 100 times more common in women than in men (CANSA 2011). Biological risk factors such as menstrual periods, dense breast tissue, family history, genes and age seem to be just as important as lifestyle risk factors of alcohol use, tobacco use, not breast feeding, lack of exercise, high fat diets and being overweight or obese. Consequently, breast cancer awareness campaigns and messages are directly targeted at women, mostly covered in 'pink'; the traditional colour depicting femininity and girlhood, also typically associated with passivity, compliance and sacrifice (Sulik 2007). This development includes messaging and consumer products aimed at creating awareness and supporting women diagnosed with breast cancer such as the popular PinkDrive in South Africa

However, in response to the development above there are emerging critiques on the romanticized representation of breast cancer, one of these is the Scar Project; with the slogan "Breast Cancer is

not a Pink Ribbon". The Project's mission is to create public consciousness, raise funds and "help young survivors see their scars, faces, figures and experiences through a new, honest and ultimately empowering lens" (The Scar Project 2011). Through raw photographs of breast scars post surgery and treatment the project portrays breast cancer in a different light; different from the 'pretty' pink campaigns, such as the PinkDrive. As explained on the website:

"for these young women, having their portrait taken seems to represent their personal victory over this terrifying disease. It helps them reclaim their femininity, their sexuality, identity and power after having been robbed of such an important part of it. Through these simple pictures, they seem to gain some acceptance of what has happened to them and the strength to move forward with pride." (thescarproject.org).

The gendered nature of breast cancer can thus not be avoided especially since it has physical and social embodiments entangled within sexuality, disfigurement, femininity and motherhood (Coyne & Borbasi 2006). The disease trajectory affects women in specific and unique ways, particularly through stages of diagnosis, treatment and recovery. Of key significance to this study is how these stages of this gendered illness experience shape the use of support networks. For this reason, this study is guided and informed by the contested concept of social capital and feminist theories on coping and adaptation mechanisms takes this issue on-board.

Debates on the bio-politics of breast cancer emerged with breast cancer activists and feminists in the United States when they demanded more scientific research, medical progress and public awareness of the disease and argued that the federal government had neglected breast cancer because it is a 'women's disease' (Klawiter, 2008). Breast health has since come under the discourse of gender and body politics specifically on how breast cancer has been medically managed in individual bodies; through screening, diagnosis, treatment and rehabilitation. Sulik (2007) argues that women with breast cancer are required to break gender norms that stress compliance, nurturing, and putting the needs of others first to prioritize their own needs for care.

However as demonstrated in the study and care work literature it is often challenging for women to be on the receiving end of care. As such they "form ties with breast survivors, which enables them to again help others, recast themselves as nurturers, and reconstruct their gendered (although negotiated) identities with the support of their peers" (2007: 299). These ideas are explored through the support networks as well as the in-depth interviews to shed light on the gendered nature of the illness experience for women with breast cancer.

To further highlight the importance of gender within the illness experience of breast cancer Connell *et al* (2006) notes concerns about fertility, contraception, pregnancy, and breastfeeding expressed by women diagnosed with breast cancer. The gendered illness experience is also evident in a study conducted by Wilson (2007) on chronic illness and motherhood whereby respondents saw their illness as a threat to their identities as mothers. These women emphasized the need to 'fight the disease' for their children's sake. Wilson (2007) also noted that throughout the interviews, the respondent's rarely spoke of periods of illness in exclusively individual terms; respondents' often understood their diagnosis in collective rather than individual terms. The focus on the inter relationship between illness and identity is therefore useful as it problematises the *sick role* and the *biographical disruption* by providing a gendered context for a nuanced understanding. This useful perspective has been adopted in this study in order to broaden the scope of the analysis.

As advanced by the functionalist thinker Talcott Parsons (1952) the *sick role* "describes the patterns of behaviour which the sick person adopts in order to minimize the disruptive impact of illness" (Giddens 2006:267). Functionalists like Parsons view illness as a dysfunction which can disrupt the flow of normal state of being and understand the sick role as a social role with responsibilities and privileges. As such there are three pillars of the sick role; firstly the sick person is not personally responsible for being sick, secondly the sick person is entitled to certain rights and privileges including the withdrawal from normal responsibilities, and lastly the sick

person must work to regain health by consulting a medical expert and agreeing to become a 'patient' (Giddens 2006:268). Parson's sick role model received several critiques despite its usefulness in the analysis of how the ill person is an integral part of a larger social context (Giddens 2006). One of the critiques focuses on the fact that the model is unable to capture the experience of illness. The 'sick role' as developed by Parsons cannot be applied universally as it cannot be divorced from the social, cultural and economic influences which surround it, and more importantly the model does not account for chronic diseases whereby the sick person, despite their best efforts, does not heal or recover and continues with the roles held before the disruption. Its usefulness, therefore, accounts for acute diseases only (Giddens 2006) which is not the case here.

Highlighting the experience of illness is useful in explaining how women join online support groups when seeking information, meaning and sense of belonging, while struggling with the threat of the disease and the disruption it causes in their lives and those around them.

The gendered nature of breast cancer is also highlighted when it comes to issues surrounding lumpectomies and mastectomies. The breast as Klawiter (2008) explains signifies sexual pleasure and desire, as well as motherhood and nurturing, however a cancerous breast signifies danger and risk: risk of disease, risk of defeminisation, risk of deformity, risk of death. These meanings and representations of the breast affect the illness experience of women affected with breast cancer. This is perceptibly explained by Sontag (1978) in *Illness as Metaphor* when she says 'how we talk and write about a disease and the metaphors we employ will make a palpable impact on what it is like to experience the condition'. To some extent society has come to view breast cancer as a threat to femininity. Cancer has become a signifier for moral and social evils, representing anything chaotic, insidious, uncontrolled, corrupting, mysterious, and killing from within (Sontag, 1978).

The writings on breast cancer as argued by Broom (2001) are of battle, invasion, defence and the disordered femininity. Breast cancer is represented as something to be 'fought' and this as Sontag (1978) maintains becomes a strenuous exercise for those affected by the disease. This theme is further explored in this study by examining how women write and share their experience of breast cancer. This is mainly because of the importance of the language they use in the virtual group since it visibly depicts their illness experience and therefore is of great significance.

An additional concept coined in the context of breast cancer and related to the strenuous impacts discussed earlier, is that of *'conventions of concealment'* (Broom 2007). This concept relates to the efforts made to 'overcome' and 'cover' the physical effects of surgery seen mainly through breast reconstruction and prosthesis. According to Broom (2007) a prosthetic breast is an icon for the overall level of secrecy surrounding breast cancer (Broom 2001). However feminists argues that breast cancer is not (or rather should not be) a cosmetic problem as these are based on oppressing notions of beauty, appearance and femininity. Broom (2001) further maintains that false breasts are solely for appearance and the functions for breast reconstruction are for sexual incitement of others through concealing the material traces of cancer treatment. This is an additional dimension that facilitates a more complex interrogation of the illness experience by focusing on a central concept in this study that of the *medicalisation* of the female body and femininity as demonstrated in the next section.

Medicalisation

According to Conrad (2007) the term *medicalisation* refers to two interrelated processes. Firstly everyday/normal conditions and behaviours that are given medical meaning and defined in terms of health and illness. Secondly it refers to how medical practice becomes a vehicle for eliminating or controlling problematic experiences that are defined as deviant, for the purpose of securing adherence to social norms. Medicalisation can occur on various levels: conceptually,

when medical vocabulary is used to define a problem; institutionally, when physicians legitimate a programme or a problem; or on the level of doctor-patient interaction, when actual diagnosis and treatment of a problem occurs (Riessman 1992). All these levels are heavily critiqued, as many scholars argue that more and more of human life is coming under medical scrutiny (Illich, 1976 & Oakley 1981; Conrad 2007).

The process of medicalisation is manifest in the bio-medical model which views all illness and disease within the biological context. For example the bio-medical approach assumes that, the body can be repaired like a machine; "thus medicine adopts a mechanical metaphor, presuming that doctors can act like engineers to mend that which is dysfunctional" (Nettelton, 2008:2). The patient is seen as passive and powerless while the doctor is seen as having expert knowledge and power over the patient. This form of mechanical action towards the body and patient neglects the idea that the patient is a '*social actor*' and can also be an active participant in the process of medical treatment (Armstrong, 2000).

This is most apparent in Oakley's feminist critique towards medicalisation, in which she observes women who resist the extreme medicalisation of menopause by being active participants in decisions about the use of hormone replacement therapy (HRT). Her study found that women were not simply passive recipients of medical intervention, rather they were active in seeking and evaluating information about HRT, and also questioned the doctor's advice (Ballard and Elston, 2005). The social approach of health and illness, as adopted in this study, acknowledges that patients are social actors who can either facilitate or reject treatment of diseases. This dimension of the breast cancer illness experience is further examined here among women who make use of online forums, as this can be viewed as a form of empowerment and practice of agency. In the case of this study, it is within these virtual spaces, which exist outside the biomedical paradigm, that women communicate their shared experience of breast cancer and the illness experience.

While in the biomedical paradigm the patient is reduced to a body and a machine to be worked on, with the belief that medical knowledge and skills are sufficient to make the body better (Gilbert *et al* 2010). Barak *et al* (2008) thus argues that online support groups are designed to foster well-being, a sense of control, self-confidence, feelings of more independence and social interactions, which is denied within the confines of the biomedical paradigm. This is supported by Hardey (2002) in his study of personal accounts of illness on the internet, which demonstrates the transformation of people from consumers of health information and care to producers of information and care, which as he further argues, forms part of a broader reconfiguration of the relationship between lay and medical expertise.

These issues feature in the constant exchange of narratives on the online forums and provide insights into how breast cancer is understood by women outside the prevailing biomedical model.

Illness experience

Illness is a multi-phenomenal experience and a multi-layered object of analysis (Young, 2004) and this is because illness is a biological, cultural and social process. The term illness is used to conjure up the "innately human experience of symptoms and suffering"; illness therefore refers to how the sick person and the members of the family or wider social network perceive, live with and respond to symptoms and disability (Kleinman, 2004: 2). Disease on the other hand is an objective terms and refers to "abnormalities in the structure and/or function of organ systems; pathological states whether or not they are culturally recognized; the arena of the biomedical model" (Klemm 2000: 231). Because illness refers to subjective experience of disease, ailment or disability it is placed within the psycho-social environmental dimension advanced by sociologists. Sociologists argue that it is important to understand how different people interpret their experiences of health and illness, as these subjective interpretations influence their

responses to health and illness (Gilbert *et al* 2010: 10). Breast cancer should be understood within this social context as is the case in this study that focuses on the support structures used by women with breast cancer. Symbolic interactionists view illness as a lived experience; they are thus interested in the ways people interpret the social world and the meanings they ascribe to and in this case the interest lies in how people experience being ill or perceive the illness of others (Giddens 2006). Beliefs and perceptions about illness influence the *illness behaviour* and *health-seeking* or *illness-avoidance behaviour*.

Simply put *illness behaviour* is the way in which symptoms are "perceived, evaluated, and acted upon by a person who recognises some pain, discomfort or other signs of organic malfunction" (Young, 2004:2). This micro-sociological conceptualisation of illness behaviour has been modified and broadened over fifty years to include economic, cultural, psycho-social, structural, demographic, geographic and organisational factors that influence the reaction of the individual to illness, both chronic and acute (Young, 2004). The concept has grown to encompass both macrosocial and microsocial aspects of health-seeking (or illness avoidance) behaviour as well as illness experience. Use of online support groups in this regard may be seen as part of an illness behaviour, whereby women seek information and help on virtual spaces.

Literature on illness behaviour and illness experience shows how illness can disrupt an individual's life and this disruption requires various *coping or adaption mechanisms* (Nettleton, 2002 & Bury 2004). This is evident in the *illness narratives*, which in this study written on the online forums. Illness narratives refer to the story-telling and accounting practices that occur in the face of illness, and many argue that illness narratives help to deal with the altered situations and sometimes fundamental disruption which illness can create (Bury et al 2004).

Kleinman (1988) argues that illness narratives construct meaning at different levels by helping to address and fashion responses to the questions: 'Why me? Why now? and What can be done?-

the questions of order and control' which the medical model often finds difficult to answer (Bury *et al* 2004:83). In this case illness narratives are understood within the context and framework of the *adaption theory*.

The *adaption theory* explains how various adaptive or coping behaviours and perceptions shape the entire illness behaviour response set, including the choice of caregiver, the success of the interaction between patient and doctor, the patterns of healthcare practice, the degree of compliance with the prescribed regimen, and the degree of recovery and/or cure (Young, 2004). In their study of the social psychology of illness support groups Davison *et al* (2000) found that support seeking was highest for diseases viewed as stigmatised such as AIDS, breast and prostate cancer and alcoholism. Furthermore in the many different theoretical bases for discussion of illness such as structural/functional analysis, interactional theory, economic theory, geographic analysis, socio-psychological theory and socio-cultural theory, it is the *socio-demographic approach* and the *social network theory* that best explains why women with breast cancer would look to the various support groups to make sense of the illness.

The socio-demographic approach targets the macro-sociological effects of demographic variables on health facility and health systems utilisation (Young 2004). The typical variables used include age, sex, education, socio-economic status, race, ethnicity, religion and marital status.

This approach might help us understand the gender dynamic of why women are generally more proactive about their health than men, and thereby have higher health and help-seeking behaviour such as participating in support groups, specifically virtual support groups as is the focus of this study.

The socio-demographic approach also highlights class, education and race, which may be some of the factors that influence participation in support groups, specifically virtual support groups as is the focus of this study. Even so the demographic approach does not answer the questions of perception of illness and why people go or do not go into care with the same illness, thus the

problems with the demographic approach stem from the lack of explication of individual experiences, the complex interactions, the lack of proven causal behaviour pathways and the focus on utilisation of services rather than individual and local group experience (Young, 2004). In other words why would women with a similar socio-economic status and level of education have different illness behaviour and experience are some of the questions the theory falls short of explaining. To understand these complex interactions one would need to go beyond a socio-demographic approach and look to *social capital* as a guiding theory as is the case in this study.

Social Capital and Health

Beyond issues of illness behaviour and experience emerges the question of the role of support groups. This stems from the belief that there is a positive relationship between social support and health. Broadhead *et al* (1983) argue that *social support* has a positive effect on health status and serves as a buffer or modifier of the effects of psychosocial and physical stress on mental and physical health of the individual. Communication is commonly viewed as a key component of social support as it has been found to be important in helping individuals manage psychological stressors associated with a variety of illness and other health conditions (Wright and Bell 2003:165).

The concept of *social capital,* although contested, helps to explain the relationship between social support and health. Social capital is defined as a combination of social organization features such as networks, norms, and social trust that "facilitate co-ordination and co-operation for mutual benefit" (Ferlander, 2007:116) and social network is viewed as the core element of social capital.

Studies of *social capital and health* can be traced back to the work of Durkheim (1897), who showed that social integration was inversely related to suicide rate in societies; since then, social capital has been linked to mental as well as physical health (Ferlander, 2007). Durkheim's

theories related not only to the patterning of suicide but extended to other major outcomes ranging from violence and homicides to cardiovascular disease (Berkman *et al*, 2000). According to Ferlander (2007) the theoretical framework of social capital divides social support into emotional, instrumental and informational support and social companionship. This categorisation is most relevant to understanding the role of virtual support groups used by women with breast cancer. As mentioned earlier, studies on computer-based cancer support groups have found that the most important reasons that individuals participated in the group were for contact with others with similar experiences, information, encouragement, and emotional support (Klemm *et al*, 1999). Hence Wellman and Gulia (1997) argue that virtual communities are 'real' communities spanning long distances and can be just as empowering.

If the information exchange on the online groups has the potential of empowering women then a critical question that arises from this discussion is 'what is empowerment?' and more specifically what is empowerment within the context of virtual support groups. Empowerment as explained by Barak *et al* (2008) is multidimensional. It has various spiritual, social, organizational, economic, political, and psychological dimensions within a group status but within an individual framework empowerment entails "several personal factors that are experienced, including ability to make personal decisions, to exercise critical thinking, and to access relevant resources" (Boehm and Staples 2002) in Barak *et al* (2008).

Empowerment also entails both perceived capabilities in coping with various challenges and the perceived ability to overcome obstacles; emphasis is placed on the process of "self-perception, as well as on the anticipated outcomes" hence the term self-empowerment "describes an experiential mental state rather than an objective condition" (Barak *et al* 2008). Empowerment is likely to be understood and experienced in different ways through the on-line forum, as such it is not an objective condition.

Even so there are various factors that influence the relationship between social capital and health. Carpino (2006) for example argues that the amount of social capital that one possesses depends on the size of network connections that the individual can "effectively mobilise" and the amount and types of capital (e.g., economic, cultural or symbolic) possessed by each of those to whom he or she is related (2006:167).

In order to speak to the amount of social capital individuals possess through virtual interactions and support; it is important to question whether on-line relationships are narrowly specialized or broadly supportive. Wellman & Gulia (1997) argue that if the Net were solely a means of information exchange, then virtual communities played out over the Net would mostly contain narrow, specialized relationships; however, information is only one of many physical social resources exchanged on the Net. Instead many Net members get help in electronic support groups for social, physical and mental problems along with information about treatments, practitioners and other resources. Overall emotional support, companionship, information, making arrangements, and providing a sense of belonging are all non-material social resources that are often possible to provide from the comfort of one's computer (Wellman & Gulia, 1997). As such, participation in these virtual networks has the potential to create a 'real' supportive environment.

However, Wright and Bell (2003) define computer-mediated support groups as weak tie networks and provide a critical view to the relationship between social support and health outcomes by including intervening variables such as individual coping styles, adaptation to stressful situations, and perceptions of support providers and recipients in the context which support takes place. These variables apply to both traditional social support and virtual support through online forums. The extent of social support through virtual forums is challenging to examine as it is usually poised by traditional support and various intervening variables. Nevertheless, Adelman *et al* (1987) argue that weak tie networks, which are found on the virtual

support groups, may serve several functions including access to diverse information and facilitating disclosure of risky topics, or topics perceived to have a negative social stigma (Cited in Wright & Bell 2003). Since this dimension of social interactions has not been explored in the context of breast cancer within the South African context, it has thus been the focus of this study.

Self-help on the Internet

The internet is increasingly becoming a common space for seeking health information as well as communicating health concerns through virtual support groups. Wright and Bell note the unique communications characteristics found on health-related computer-mediated support groups, which include "the ablity of computer mediated communication to transcend geographical and temporal contraints", "the opportunity for people to disclose health information with less risk than in face to face contexts", "greater access to diverse sources of health information than are typically available in face to face contexts", "the facilitation of more heterogenous supportive relationships due to reduced social status cues in the computer-mediated environment", and finally "the therapeutic value for formulating health self-disclosures in written form" (2003:164). These features help explain why women with breast cancer (or other conditions) would join virtual support groups.

Much of the literature on disease-based support networks focuses on the socio-demographic factors that influence the use of support groups (Koukouli *et al* 2002), the effectiveness of support groups (Davison *et al* 2000 & Eysenbach *et al* 2004), and the transformative nature of social interactions due to virtual support groups (Wellman & Gulia 1997). There is however a need to focus on the interactions that occur in these support groups as the internet is a tool for collective action and activism.

The use of the internet for social networks has opened up a new and innovative area of research even in 'developing' countries such as South Africa. A growing concern is the potential

transformation of social networks and social interactions generally. However this study is interested primarily in its contribution to health and help-seeking behaviour as well as the illness experience through the establishment of virtual *social networks.*

Social networks as defined by Cockerham are "social relationships a person has during day to day interaction that serve as the normal avenue for the exchange of opinion, information, and affection" (2000:118), these networks include family, friends, and co-workers which is the local social world of the individual (Young, 2004). Several researchers have discussed the effects of social networks on illness behaviour (Sharf 1997, Klemm 1998, Davison *et al* 2000). Support groups are also part of social networks that influence illness behaviour.

The *self-help* concept stems from the assertion that people facing a similar challenge can help each other simply by coming together; the power of this approach lies in the belief that a collective wisdom is born through shared experience as the kinds of help requested and offered in this context are largely free of professional structures or assumptions (Davison *et al*, 2000). The authors go as far as comparing support groups to grass-roots networks because of the nature of shared experience and the emotional potency of common suffering. However there is a need for a more critical analysis of the content discussed in the support groups when examining the role of online forums groups for women with breast cancer as is done in this study.

In his study of internet support groups Klemm (1998) discusses the themes of information shared on the internet and identifies eight categories of responses. They are: information giving/seeking, personal opinions, encouragement/support, personal experience, thanks, prayer, humour and miscellaneous (issues that are unrelated to the support group). Some of these categories and themes have been examined when analysing the discussions on the on-line breast cancer support group in this study.

In addition Klemm (1998) identifies the advantages and disadvantages of *on-line support groups*. The main advantage of on-line support groups is that the site is available 24 hours a day and

there is accessibility to those that are homebound. The disadvantages are the cost of internet access and the lack of face to face interaction. These advantages and disadvantages can help one understand the possible reasons why women with breast cancer would use the support groups. Moreover Klemm (1998) sites three factors that have influenced the popularity of internet cancer support groups; first, one in three people will be diagnosed with cancer in their lifetime; second, the availability of internet access has increased dramatically; third internet cancer support groups may be resistant to some of the pitfalls of traditional groups, namely fluctuating attendance and inconvenient meeting times.

This brings into question the role of *internet support group* use in transforming traditional interactions and traditional notions of the meaning of community. This idea is discussed in various studies about virtual communities (Welllman & Gulie, 1997, Powell, 2004). The claim is that the ties people develop and maintain in cyberspace are much like most of their 'real life' community ties: intermittent, specialized and varying in strength. The only difference is that a virtual community is constituted by virtue of computer mediated communication, breaking through barriers of geographic distance and physical representation (Sharf, 1997).

One could also assume that women with breast cancer use virtual support groups to protect their confidentiality and anonymity, thus allowing them to discuss issues which they would otherwise not discuss in a face to face interaction. The use of virtual support groups also resolves the challenge of *health-related stigma*.

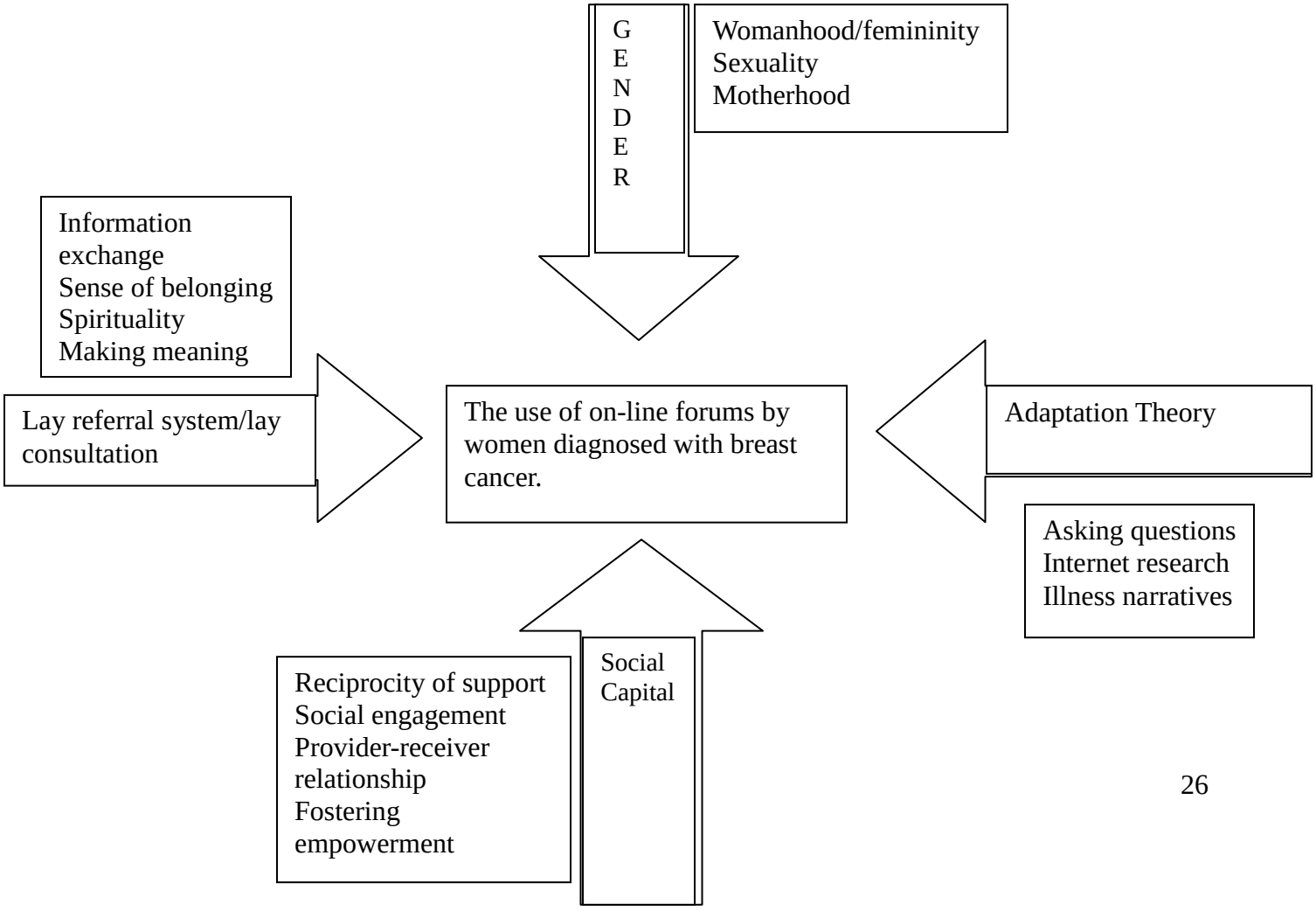
Stigma is typically defined as a "social process experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception reasonable anticipation of an adverse social judgment about a person or group" (Scambler, 2009:441).

Many of the studies on health-related stigma demonstrate how it threatens to spoil 'self-hood' through the notion of illness being a personal tragedy. This is important in the case of breast cancer as it is also a threat to femininity and motherhood. As such online support groups allows

for better and frequent interaction when it comes to 'intimate' issues which would otherwise not be discussed in traditional face to face groups. Issues of mastectomies, breast reconstruction and sexuality appear to be discussed openly on the virtual groups as anonymity and confidentiality are secured.

CONCEPTUAL-THEORETICAL FRAMEWORK

As discussed before this study explores the use of on-line support groups by women diagnosed with breast cancer. Through a selective identification and analysis of the themes emerging out of the virtual groups and the in-depth interviews, an illustrative conceptual framework was developed to make sense of the data. The critical theoretical concepts employed are *lay referral system*, *gender, adaptation theory* and *social capital,* discussed in the literature. The illustration below seeks to create a summarised and simplified picture of the discussions unpacked in the literature; thereby creating a structured understanding. The illustration is also useful in foregrounding how the literature is used in the study when exploring the use of virtual forums.



METHODOLOGY

The study is placed within the sub-discipline of the Sociology of Health and Illness; a fairly new field in South African Sociology which draws upon a range of sociological perspectives to amongst other things make sense of how health and illness is experienced and to critically examine society's response to health, illness and disease (Nettelton & Gustafosson, 2002). The shared premise of this field of study is that health, illness and disease are fundamentally social concepts, rather than purely biophysical ones (Nettleton & Gustafosson, 2002).

Qualitative research in the form of *content analysis* and *in-depth interviews* were used for this exploratory study.

As Strauss and Corbin (1997) point out qualitative research is about peoples' lives, stories, behaviour, but also about organizational functioning, social movements, or interactional relationships. Stories are a "way of knowing" thus making it a "meaning-making process" (Seidman 2006:7). Through these stories the study attempts to understand how women with breast cancer make sense of the disease as well as the factors that influence participation in virtual support groups. At the same time the research focuses on the nature of the support groups, as a space where social interaction takes form. Through qualitative research the study was able to gather in-depth narratives about the women's illness experience, help-seeking behaviour and their understandings of breast cancer as a gendered condition.

Qualitative methods were also used to uncover and understand what lies behind the phenomenon of support groups, and more specifically virtual support groups. The area of study and nature of the research problem; which has its focus on subjective interpretations called for qualitative method of research, since, in essence the study is concerned with subjective perceptions and experiences of breast cancer, lay beliefs and lay consultation occurring on the online groups, while trying to understand the social significance to such interactions.

As noted by Padgett (2004) qualitative research allows for an investigation of individual experiences as it is not limited to rigidly definable variables. Participants are able to provide data in their own words and more importantly qualitative research allows for exploratory studies such as this one.

Content analysis was employed to obtain data on the topics and themes discussed on the virtual forums concerning breast cancer. *Content analysis* is a technique used to extract desired information from a body of material by systematically and objectively identifying specified characteristics of the material (Smith, 1995). The process is seen as objective in a sense of yielding unbiased results that can be reproduced by other qualified investigators and subjective as the frameworks of focus and interpretation will differ. Smith (1995) also notes that by means of content analysis a large body of qualitative information may be reduced to smaller and more manageable form of representation. As such content analysis of the on-line forums informed the interview schedule for the in-depth interviews and more importantly it allowed for a detailed observation of the virtual interactions.

Through observation and analysis of the forums dominant themes became apparent which were later examined in the in-depth interviews with seven women diagnosed with breast cancer and one interview with a webmaster from one of the forums. As mentioned before content analysis may be used for exploratory research, theory development, hypothesis testing, or applied research (Smith, 1995) and in this case it is used as exploratory research to discover the themes or topics that emerge from virtual support groups. Content analysis is a research method that has come into wide use in health studies in recent years, as it is a flexible method for analyzing data (Heish & Shannon, 2005). It has also come into wide use as researchers in the field have come to recognize that how people talk and write about health and illness has implications on how they experience and understand diseases. An analysis of on-line forums pushes the boundaries by moving beyond a study of personal diary entries, journals, and personal blogs, to a study of

diverse voices and multiple interactions. Although there are visible regular posters or writers in all groups, the forums are fundamentally a space for interaction, as one participant describes “it is a give and take” process and form of support. These varied interactions add a level of complexity to the method of qualitative content analysis yet to be fully developed with the advances taking place in such research.

By definition qualitative content analysis is a research method for “subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Heish and Shannon 2005:1278). Arguably the goal of content analysis is to provide knowledge and understanding of the phenomenon under study; in this case the virtual forums. The definition exemplifies the process undertaken in this study. Upon joining the online forums I began by reading different posts as well as the replies and comments on the posts. I started noticing patterns and identifying themes that appear frequently. I then printed different conversations to allow me to code the themes manually. As the method used was qualitative content analysis and not a quantitative, the number and frequency of words and statements was not of significance, instead coding included identifying themes and the structuring of the forums. Following an analysis of the themes in the online forums they were classified into: information exchange, referrals, personal narratives, expressions of spirituality, words of support and gendered concerns. These themes provide a summary of dominant features of the online forums written and expressed in different ways.

For clarification, Heish and Shannon (2005) differentiate between three distinct approaches to content analysis; namely conventional, directed and summative and argue that all three are used to interpret text data from a predominantly naturalistic paradigm. Conventional content analysis is generally used with a study design whose aim is to describe a phenomenon, in this case the discussions on the virtual support groups. This type of design is usually appropriate when existing theory or research literature on a phenomenon is limited, and researchers avoid using

preconceived categories (Kondracki & Wellman, 2002), instead allowing the categories and names for categories to flow from the data. Hence researchers immerse themselves in the data to allow new insights to emerge. Many qualitative methods share this initial approach to study design and analysis (Heish & Shannon, 2005). The goal of a directed approach to content analysis on the other hand is to validate or extend conceptually a theoretical framework or theory, while summative content analysis allows for interpretation of the context associated with the use of words or phrase whereby researchers try to explore word usage or discover the range of meanings that a word can have in normal use. (Heish & Shannon, 2005). This study employed a conventional *content analysis approach* as it is explorative in nature.

As previously mentioned the *in-depth interviews* purposely followed the content analysis. This was useful in this regard as interviewing does not only inform us about the nature of social life; it also gives us access to the observations of others (Weiss, 1995:1). This method was valuable in understanding why women with breast cancer use virtual support groups as well as their perceptions of virtual forums. Eight women were interviewed; some active on virtual support groups, and others not or discontinued use. Seidman (2006: 10) sees interviewing as a basic mode of inquiry and argues that at the root of in-depth interviewing "is an interest in understanding the lived experience of other people and the meaning they make of that experience". The in-depth interviews allowed the women to reflect on their experiences while using their own words to construct and tell their stories; as done on the on-line forums. Although there was an interview guide, the women usually gave direction to the interview by emphasizing parts which were of importance to them. The content analysis and the in-depth interviews thus complemented each other as the same form of thematic analysis was used.

The interview guide was divided into three sections, namely biographical background, illness experience and use of virtual forums. Because every experience is different and unique there was no time allocation on the various sections. For example women who withdrew from the virtual

forums focused their narratives on the illness experience and other forms of support received during the illness trajectory. The rich data gained from the in-depth interviews demonstrates that "in the process of selecting constitutive details of experience, reflecting on them, giving them order, and thereby making sense of them, that makes telling stories a meaning making experience" (Seidman 2006:7). In-depth interviewing as a method is thus effective and valuable for a study of this nature; but it is worth noting that securing interviews was a lengthy and challenging process.

Various recruitment methods were used to get hold of women diagnosed with breast cancer. Firstly I left messages on two online forums, explaining the research and its purpose. I later invited participants who were interested to contact me. This was unsuccessful as I did not receive any messages or signs of interest. I then contacted the various group administrators to spread the message after which two women contacted me interested in being part of the study. I later emailed and send messages on facebook and more women responded. The rest of the interviews were gained through referrals, as such I later discovered that some of the women had not used virtual support groups. Some of the women who responded to research messages live in provinces outside Gauteng and could not be reached for interviews due to financial constraints.

At the end of some interviews I asked the participants why the response to interviews had been so low; one participant said most women do not want to talk about their illness experience as it might bring back the pain they went through, for some as she further explained want to remain anonymous and fear being known. These responses might explain why securing interviews was such a challenging process.

It is also possible that my limited knowledge and experience with breast cancer might have been a limitation in terms of recruitment. Upon embarking on the study I did not know anyone in my close circles diagnosed with breast cancer or any other cancer. I was never exposed to CANSA or any other organisations and institutions working in the field, lastly I was not aware of breast

clinics around Gauteng. Entry into the field was thus made easier by the internet. I coincidentally stumbled onto the CANSA website and began reading a section called 'Stories of hope' written by cancer survivors. I found a link on the website to the CANSA facebook group 'Champions of Hope', and later 'I am a Survivor' and "Pink but Neva Broken' through the interviews.

In selecting the participants two factors were considered; firstly the connection with the support groups and secondly how active they were in the virtual support groups. These factors are important as there could be participants who are not necessarily affected by breast cancer but participate to get more information or to help someone they know affected by breast cancer. Activeness on the forums is also important as there were participants who joined the support group a while back but never participated or discontinued use. Participants were therefore recruited and selected through purposive sampling which Shuman (2002) defines as deliberately selecting a group from a population for their distinctive social role or position. I also attempted to get women of different ages, race and socio-economic standing. This was successful as the ages ranged from 33 to 56, two non-white women, and two women who did not have medical aid. The women were also diverse in terms of marital status, number of children and family background. This kind of diversity became relevant in the various narratives of the 'illness experience'. This is further elaborated in the analysis of findings chapter which explains the factors that influence the use of virtual forums.

The online field study and the in-depth interviews were conducted in the period of four months; August to November 2011. In-depth interviews were an hour to three hours long and all were audio-taped and transcribed. I met with the women where it was most convenient for them, in all cases it was public spaces; restaurants and coffee shops.

One hour telephonic interview was conducted with the webmaster of '*Champions of Hope'*. The webmaster resides in Cape Town and could not be reached for a face to face interview. Extensive preparation was employed into the telephonic interview to ensure a quiet and conducive setting.

It shed light on group dynamics and the work that occurs behind the scenes for the groups to operate. The process was also useful in demonstrating the potential difference between organisation initiated forums and individual groups.

The constant communication through emails, short message services and telephone before the in-depth interviews was useful in that the participants got to know a little about me and vice versa. Before each interview a few minutes were set aside for personal introduction in order to develop rapport. This was essential in order to avoid what Oakley (1981) calls a "manipulative hierarchical relationship" whereby the interviewing situation is a one-way process in which the interviewer elicits and receives, but does not give information and interviewees are treated as objects of study or sources of data. Such reflections were of outmost importance as private and sensitive issues were expected. I saw it valuable that the participants get to know my background and my research interests. It helped develop a form of trust and comfort in sharing their journeys on breast cancer. This was also important as I got the opportunity to explain that I am not an expert on breast cancer or a medical practitioner. Most participants were interested in getting more information about Health Sociology as they never read studies on the social perspectives of cancer; this was not surprising as cancer is heavily framed within a medical paradigm.

I then gave them a chance to ask further questions about me and the research.

Ethics Consideration

This study was granted Ethics Clearance by the Wits University Ethics Committee and approved by the Faculty of Humanities. Participation in the study was voluntary. Consent forms and information sheet were given to the participants before the interview or emailed beforehand. Few minutes were set aside before the interview for questions and concerns on information sheet and consent forms. Participants were asked to select pseudonyms to be used in the study however most wanted their real names to be used as they saw no reason for concealing their identity. The

data from the interviews is not likely to cause any harm to the women, therefore first names are used as requested.

Other ethical considerations made were introducing myself as a researcher to the on-line support group and explaining the aims and objectives of the study. Breast cancer patients and survivors although not viewed that way by the participants are medically considered 'vulnerable subjects' hence a level of sensitivity was practiced without being patronizing.

On the subject of ethics and internet research Eysenbach & Till (2001) note that there are three different types of internet based research; namely passive analysis, active analysis and the type where researchers identify themselves as such and gather information in the form of online semi-structured interviews, online focus groups, or internet based surveys or use the internet to recruit participants for 'traditional' research. This third type is ethically appropriate as internet users and chat room participants know that they are being researched. Although publication on the internet may have parallels to publishing a letter in a newspaper or saying something in public meeting, there are important psychological differences, and people participating in an online discussion group cannot always be assumed to be 'seeking public visibility' hence on the internet the dichotomy of private and public sometimes may not be appropriate, and virtual communities may lie in between (Eysenbach & Till, 2001:1104). Even with the risk of 'disturbing' or changing the interactions on the virtual support groups, it was ethically important that group members know that I was using the online data for research.

Conducting internet research proved challenging as little has been written on the methodological intricacies and complexities, in order to prepare researchers for the virtual field. Further research is also needed to investigate the amalgamation of internet research and traditional methods such as in-depth interviews, as done in this study. Overall a qualitative study of this nature allows for nuances to be explored and sociologically understood, thereby contributing to the field of Health Sociology and internet research.

ANALYSIS OF FINDINGS

This chapter is divided into three main sections; firstly a description and analysis of the on-line forums, followed by an analytical discussion of themes that emerged from the forums. Lastly it looks at the gendered illness experience of breast cancer derived both from the online forums and the in-depth interviews. Theoretical concepts of *gender, social capital, lay-referral system* and *adaptation theory* were critical and useful for analysing the data presented. The following exploration thus intrinsically debunks the data to develop a sociological understanding of the use of virtual support groups by women diagnosed with breast cancer.

Virtual support groups/online forums visited as part of the study:

- *Champions of Hope* CANSA Facebook group (236 members)
- *Pink But Neva Broken* (110 members)
- *I am a Survivor* (13 members)

Champions of Hope: *CANSA Survivors* is a facebook group founded by the Cancer Association of South Africa to allow for on-line interaction among people affected by cancer. Upon visiting the group site, one is welcome with the following description:

"*The Cancer Association of South Africa (CANSA) is not only a volunteer-driven organisation, but more so, CANSA treasures our cancer survivors- as survivorship forms the essence of our organisation's existence. A survivor is anyone who has heard the words "you have cancer..."*

The group name and description emphasises 'survivorship', in so doing the organisation points to the idea that cancer is a manageable disease instead of a fatal condition that cannot be 'overcome'. The war language illustrated in the words 'survivor', 'champions' and 'fighting' represents the general tone used by group participants to describe and talk about cancer. This

form of language is also evident in the two other groups (*Pink But Neva Broken* and *I am a Survivor*) whereby cancer is seen as an 'enemy' to be fought and 'defeated'.

Upon joining the groups one gets a sense that they are becoming part of the fight against cancer. Joining the 'fight' against cancer in this case may begin in a virtual disembodied space, which holds elements of cause activism discussed later in the chapter.

The poem below, posted by one of the group members exemplifies how participants write and talk about cancer. The poem is followed by replies from several group members; appreciating the piece and strongly agreeing with the narrative and cancer description:

Never Back Down...
It seems impossible to stay tough.
It is just so hard to remain bold,
Once the cancer enters our lives,
Once the cancer starts to take hold.

We do our best to fight a good fight,
But the situation feels so unbearable.
Cancer has its way of inflicting pain,
Causing emotional distress that is terrible.

Yet here we are determined to stay strong,
Even as things around us begin to crumble.
We will not be taken down by cancer,
In our journey we will not stumble.

Fighting cancer involves finding a little faith,
And persevering in the roughest circumstances.
It is also about holding on to what is important,
And making the most out of all our chances.

Each day our energy and passion are restored,

And our hope is renewed and replenished.
We will keep battling and moving forward
To see this thing through until it is finished.

We will keep going until there is a cure.
Taking this fight to completion is the only answer,
Because someday we do want to live in a world,
Where nobody hears the words "you have cancer."

We will rise up and take our stand.
We will not fear. We will not frown.
In this battle we fight against cancer,
We will never back down.

Author Unknown

A: So true! It is a battle but also an amazing journey! xxx
B: Yes it is so true! We are like soldiers we will fight this battle until we win the war against this disease!!Luv Charlotte. (Champions of Hope)

The poem portrays cancer as an evil creature on a quest to inflict pain and destruction on its victims. 'Survivors' in this case are the ones that tirelessly fight and defeat the malicious creature by all means.

The analysis of how participants write and talk about cancer is significant as it underpins *lay-beliefs* and the *illness experience* of the condition. This is also maintained by Sontag (1978) in *Illness as Metaphor* who further argues that war language employed becomes a strenuous exercise for those affected by the disease. As will be discussed in the illness experience section, the strenous 'fighting' spirit is not always maintained as some participants make peace with the cancer through the 'living in the present' discourse. The *quest narrative* in the poem is only

representative of a few participants, and does not holistically capture what it is like to live with the condition. The emphasis on 'survivorship' in the *Champions of Hope* group description is not completely illustrative of how participants write and talk about cancer.

Reading further on the *Champions of Hope* forum one finds a brief description of CANSA's mission and purpose and a reason as to why people should join the group.

"CANSA's purpose is to lead the fight against cancer in South Africa by offering unique, integrated services to the public which involves holistic cancer care and support to all people affected by cancer. Its mission is to be the preferred non-profit leader that enables research, educates the public and provides support to all people affected by cancer."

"Your input and willingness to share your time, effort or needs with us will provide more aligned watchdog and support programmes to you and others diagnosed with or affected by cancer."

Compared with the other two groups *Champions of Hope* has the highest membership. This can be attributed to the fact that it is an organisation based group. More so *Champions of Hope* deals with all types of cancers although several posts are breast cancer related. As mentioned, the group has an employed webmaster whose portfolio includes observing group discussion, stimulating conversations, erasing spam and junk, revising the organisation's social media policy and writing a report on group progress (membership and participation). Her portfolio also includes making suggestions to keep the numbers up and maintaining the forum to remain relevant, productive and meaningful.

The time and resources put into this on-line forum by the organisation also explains the higher membership and participation. Because of these reasons the group may be considered reliable and trustworthy by those who join and participate in the forum. For example Yvonne expressed that after she was diagnosed with breast cancer she immediately called CANSA to seek help and information on treatment and oncologists. CANSA is possibly the first point of reference for

many as it is the largest and most popular cancer organisation in the country. The organisation has also positioned itself as 'leading the fight' against cancer.

This is an important element as many of the participants do not have anonymous profiles; in fact several participants have profiles with clear pictures of themselves. This is confirmed by the webmaster who said "*only a few use pseudonymous, most use their real names*".

To some extent this discounts the idea that individuals use virtual support groups to remain anonymous. Nevertheless the disembodied space of the virtual forums allows individuals to reconstruct and negotiate their identities in different ways. Not all members are active participants (writing and responding to posts); some merely read posts without commenting, while others rarely login to the forum. The disembodied space allows for group members to choose and change roles (poster or lurker) and in that way some form of anonymity may be maintained.

Considering that there are thousands of South Africans diagnosed with cancer a membership of 236 is considerably low. The women interviewed are computer and internet literate and have access to the internet either at home or at work. Participants also have internet on their mobile phones which they use to communicate and interact on the virtual forums. This trend means that computers are not a necessity for accessing the virtual forums, it also means that participants have an 'anytime' 'anywhere' access to the forums. As one participant expressed "*early hours of the morning are probably the loneliest and having that type of support is helpful*" (Jo). This is a common feature of all virtual forums studied.

The organisational set up of *Champions of Hope* allows for diverse interaction and membership (age, race, gender, geographical area) within the forum, furthermore the group is not only made of cancer patients and 'survivors' but also family and friends affected by cancer. The diverse membership contributes to the varied information and interaction on the forum as evident in the post below:

A: Hi all, hope everyone has a great New Year. Mine has started out on the bumpy side. I need your prayers for my brother. He was diagnosed last week with lung cancer, and it is unoperable. He has chosen to take chemo and radiation in hopes of putting it in remission. This is the the 6th close family member to have face the cancer beast in the last several years. All are gone except my brother, and we are praying he will be as lucky as I have been with mine.

B: Oh, Debbie, I am so sorry. My prayers are with him and you. Ironically, my sweet cousin, who is my soul mate, also just got diagnosed with Stage IV lung with mets to her liver. She is in such pain already and doing heavy-duty chemo.
(Champions of Hope)

The posts above are illustrative of the different voices found on the on-line forum. The narratives and posts are not just about the women themselves but also about other health concerns which affect the participants in various ways. This broadens the subject matter and themes that can be discussed and allows the individuals to find commonalities in other areas of their lives. This might be useful for sharing diverse information; it is also useful as different types of cancers have similar treatments and side effects. The setup of *Champions of Hope* thus allow for broad discussions and interactions. The wide discussions paint a broad picture of cancer but bring about a challenge when trying to surf for a specific narrative or post unique to a certain type of cancer. As one participant expressed "*I found it to be information overload*" (Debbie).

Pink But Neva Broken and *I am Survivor* are focused on breast cancer. Another difference is that the groups were developed by individuals (Connie and Yvonne) both diagnosed with breast cancer and became activists within the field. The two groups are dependent on the founders or group administrators for stimulating continuous discussion and participation and thus take the form of personal pages. Many of the members are family and friends of the group administrators, and many of the profiles lack anonymity. The group administrators utilize the forum for breast cancer awareness, information and sharing narratives of the illness experience. This is expressed in the following statements made by them:

"*it's more about my experience and sharing that, and hoping that it will help someone else*" (Connie)

"*It's based on the support I got and I saw what it did for me*" (Yvonne)

"*people are suffering in silence coz as far as our communities are concerned cancer does not exist*" (Connie)

Upon visiting the *Pink But Neva Broken* site one is greeted with the following description:

"I am a BLACK girl with Breast Cancer, that made me PINK but Neva broke any part of me... From my SMILE, my STRENGTH, my LOVE, my FAITH and all that is me is still intact and possibly grown to be even better! My journey is one big adventure…. Learning something new every day; about myself, about others and mostly about the PINK world! Welcome & lets Educate, Support and raise as much Breast Cancer awareness as possible!!!

Connie's social identity as a young black woman diagnosed with breast cancer plays a significant role in the forum. Her main motivation for starting the group was to create breast cancer awareness among black people, as she felt there were misconceptions about who it affects.

The emphasis on 'pink' alludes to the gendered nature of breast cancer and also complies with the popular colour coding of the condition. The 'pink world' mentioned represents a field of activism and support which the group commits to through sharing information and narratives.

There are several pictures on the forum tracing the illness trajectory and experience such as chemotherapy sessions, cutting off her dreadlocks and recently radiation therapy pictures. By sharing her cancer journey through narratives and pictures Connie demonstrates that being young and black does not make one immune to breast cancer, more so it portrays cancer as a manageable disease as done in *Champions of Hope*.

Yvonne developed *I am a Survivor* group after participating in several American virtual forums, which she found useful for information and support. Developing the on-line forum was also inspired by a lengthy participation in face to face breast cancer support groups, such as Reach for Recovery, whereby Yvonne was involved as the cause fundraiser.

She then invited her close friends to join the forum thus creating a space to stimulate discussions around breast cancer and other relevant issues affecting them. Like *Pink But Neva Broken*, *I am a Survivor* is also a close tie network. The close tie network is emphasized by the small number of group membership; the participants are mostly Yvonne's close friends, whom have also been diagnosed with breast cancer or some that want to follow her illness trajectory and experience. For Yvonne starting a virtual cancer group was part of sharing information, mutual support and encouragement. A critical feature of the online forum is the positive affirmations, which is to say "*cancer will only have the amount of power over me as I allow it to have*". As Yvonne further explains "*it's really about not letting the cancer define you*". This type of positive discourse is evident in the group label *I am a Survivor*. The emphasis on survivorship is used as a positive mental affirmation rather than a physical state of health. This is another way of adapting to the illness and fostering empowerment.

Through the online content analysis of the three forums, several themes were identified from the posts and responses written by the group participants. Only the dominant and significant themes were selected, these will be critically analysed so to explain how women make use of virtual forums. These are presented below:

Themes emerging from the online forums:

- Information exchange
- Expressions of spirituality, prayer and religion
- Words of support (empathy and encouragement)
- Gendered issues (motherhood, sexuality and appearance)

Support through Information Exchange

There is a consensus in the literature that the internet is a significant source of health information for lay people (Nettleton *et al* 2005). Individuals are increasingly using the internet to seek information on health and illness as the sites are relatively easy to access and there are multiple sources to choose from. Finding health information on the internet is also relatively quick, and takes seconds to scan through and read. Exemplifying this is the countless websites, blogs and chat rooms on health, illness and disease and more specifically for this study breast cancer sites. These sites provide a wealth of information on the biological, scientific and psycho-social aspects of the disease. As such the nature of the information on the online forums is placed within a mixed paradigm; biomedical and psycho-social. Even so, the rapid information exchange that occurs on the virtual support groups needs to be viewed critically as it can be both empowering and 'overwhelming' for the individuals using the sites.

Information exchange is a major component of the data available on the virtual forums, it includes giving and receiving of information from group members. Exchange of information is mostly sparked by a question from a group member after which people in the group reply in a thread. Information does not only refer to facts about diagnosis, treatment, healthcare and other health related questions and concerns, but it is also based on advice. This demonstrates the high reliance on 'lay knowledge' and the 'lay-referral system' instead of expert oncologists and researchers. Below is a common example of the interactions that occur on the online forum when it comes to information exchange.

> ***A:*** *"hello friends, please tell me, what is your take on breast reconstruction surgery following a mastectomy?"*
>
> 11 replied*: "....I did it…10hrs Op..Feeling Good..2 1/2years ago!"*
>
> ***B*****:** *"to be honest Colleen I was against it. I'm wearing a prosthesis and very happy with it. Don't want silicone in my body, too much of a risk!!"*
>
> ***C:*** *"I was also wearing prosthesis my doc is against it. But if you are still young why not it's your choice some are happy, and some said they sorry they had done reconstruction, it took more than one surgery to fix it and there is pain and swelling after,*

and not everyone is the same maybe you are one with no problems"

D: *"your oncology doc is the best one to ask if it will be the right choice!"*

E: *"Hi Colleen. Ek was 29 toe ek my mastektomie en rekonstruksie gehad het. Ook alles in 1 operasie gedoen vir 9 ure. Hulle het a flap gedoen van van lattismius dorsi spier + n protese. Ek moes die protese na n ruk laat verwyder want my liggaam het dit verwerp, Ek het baie problem met spier spasmas en ek raai jou af om diselfde te doen. Doen eers die masektomie, werk deur jou chemo en bestraling en dan besluit jy oor rekonstruksie*.

Translation: (I was 29 when I had my mastectomy & reconstruction. Everything was done in one operation for 9 hours. They have done a …. flap of lattismius dorsi muscle including a protese. I had to remove the protese after some time but my body rejected it. I have many problems with muscle spasms & I encourage you not to do the same. First do the mastectomy, work through your chemo and radiation & then you decide on reconstruction")

(Champions of Hope 2011)

The participant posing the question wants to know the other group members' 'take' on the matter. She is not seeking a professional opinion or scientific information regarding mastectomies and reconstruction but rather wants to know about the experiences of those who have been in a similar situation through a 'lay consultation' which provides 'lay knowledge', as well as a form of personal exchange and interaction, so necessary in times such as when one is confronted with such a feared condition.

As mentioned before lay knowledge refers to the "ideas and perspectives employed by social actors to interpret their experiences of health and illness in everyday life" (Bury *et al* 2004: 135). Through lay knowledge and lay information exchange women attempt to make sense of the breast cancer illness trajectory.

Bury *et al* also argue that the key characteristic of lay knowledge is that it is integrative and holistic: "drawing on multiple factors in a syncretic but not indiscriminate fashion; bringing together scientific or other professional sources of knowledge and reflecting the ideological

climate of the times, but also providing an incisive moral and political critique of them" (2004:137).

The holistic and integrative nature of lay knowledge can be seen in the replies from the group members to the question of breast reconstruction following a mastectomy. The diverse replies mention the risk factors, psychological dimension of being young and having no breasts, but also offers 'hope' that a breast reconstruction following a mastectomy can be successful. Through the online forums which have weak tie networks, participants get access to diverse information as the networks tend to be more heterogeneous than closer networks of family and friends, and "weak ties are usually better connected to other, more diverse circles, and hence are more apt to be sources of new information" (Wright & Bell 2003:166).

Although the women participating in the online forums are a heterogeneous group, it can be assumed that the South African women who use virtual support groups are mostly of a medium to higher socio-economic status as they are literate and have access to the internet. Moreover these support groups operate within a virtual space of social networks and can be exclusionary in nature; meaning only women with such resources can participate. Even so as demonstrated from the above example, the information exchange tends to be varied and diverse.

The information exchange on the online forums essentially forms part of a lay-referral system and lay-consultation, which can be understood within a framework of power shifts from the dominant bio-medical model to a more socially oriented one. Through lay consultation women's capacity for autonomy in dealing with their own health care is increased and provides a space where their 'knowledge' is legitimate. This is exemplified in the following: "*I spend most of my time on the computer, that's where I live… I felt so much more empowered*" (Connie).

Through virtual interaction Connie is able to gain more information on breast cancer on a regular basis; she can become more involved in her condition, and this is different from waiting for a monthly support group session to have her questions and concerns answered.

As alluded to before, lay interactions on the virtual space give "technology the potential for recalibrating power relations" between patients and health professionals and also highlights the "democratic imperative of the internet" by drawing attention to opportunities of empowerment and the fostering of patient and lay expertise (Nettleton *et al* 2005: 973). This is emphasized and demonstrated in the in-depth interviews whereby Yvonne mentioned that information on the virtual groups helped her to "*ask the right questions"* when consulting with the oncologist. By participating in the virtual groups Yvonne also familiarised herself with cancer terminology and language which helped her ask specific questions during consultations, and be able to communicate and understand medical jargon relating to breast cancer.

The use of virtual support groups for information exchange became central to her illness experience of breast cancer especially since she did not have medical aid and had to go a public hospital which was usually crowded and lacked extended one on one interaction with the oncologists and surgeons. In such settings the patients are generally powerless without any sense of autonomy, and they are left with several unanswered questions. They have minimum decision-making power towards treatment options as they usually do not have holistic information on the cancer itself. Without such informational power the illness experience becomes highly medicalised whereby the patient is treated as a 'machine' and their agency is denied. This is evident and echoed by Yvonne:

"*the doctor did not tell me what all my options were, I told her to explain to me, explain what the difference is between chemo, radiation and mastectomy and doing the one before the other...explain the guarantee I have if I just do a lumpectomy. I'm a very logical and factual person, I work on facts.....that's how they are, they do not expect somebody to take charge of their disease. Normally people do what the doctor tells them to do, and I wasn't gonna do that, I needed facts, but before then I had gone on the internet and checked sites"*

Considering that there other women going through a similar experience, Yvonne started an online group to facilitate conversations and information exchange on breast cancer. The on-line forum can thus be seen as one way in which women "take charge of their disease". The information exchange thus forms a major component of support within the online breast cancer groups.

There are however a number of challenges with virtual information exchange. For example one of the participants expressed how their oncologist discouraged the use of online forums saying "*too much information without context is dangerous....some people take the information and may decide to stop chemo for example and opt for eating green vegetables*"

One can understand the oncologist's statement and why he has made it; mainly since information that is digested without critical thinking can be harmful. Another participant found the internet to be an "*information overload*" (Debbie).

The oncologist's recommendation in this case seemed to hold much weight, however Jo mentioned that she uses *Moms and Babes;* an on-line forum used by mothers to exchange support and information on nurturing their children. She later stated that if she knew of any on-line breast cancer forums at the time of diagnosis she would have 'tried it out'; mainly because the online interaction is similar to the telephone system used by *Bosom Buddies* support group which she participated in at the time.

The oncologist's recommendation of avoiding internet information may also be seen as a way of maintaining medical knowledge and power during the doctor-patient interaction. For example a patient like Yvonne who enters a medical consultation with several questions, having done internet research on her condition may be seen to challenge the professional power of the oncologist.

One of the pillars in Parsons' *sick role* states that the sick person must work to regain health by consulting a medical expert and agreeing to become a 'patient' (Giddens 2006). The tension

arises in the idea of 'agreeing to become a patient' as the meaning to this is ambiguous. Under the 1952 medical dominance context in which Parsons wrote, the idea of 'agreeing to become a patient' essentially meant being passive and powerless while the doctor is seen as having expert knowledge and power over the patient. This form of biomedical approach towards the body and patient neglects the idea that the patient is a *social actor* (Armstrong 2000) and can also be an active participant in the process of medical treatment. For participants such as Yvonne 'agreeing to become a patient' means 'taking charge of the condition' which includes internet research so to become active participants in the process of medical treatment. Seeking information on the internet as well as consulting a medical expert form part of a *health-seeking behaviour* employed by forum participants.

Nevertheless it is still important to be critical of the health information on the internet as it is often unregulated and unrated. Health information provided by the group members on the online forum can either confuse the individual asking the question or assist and empower them in making an informed decision.

In this case there can be 'good' and 'bad' information; this is confirmed by the webmaster interviewed who expressed that she is responsible for cleaning out 'bad information' on the online forum. Part of her job portfolio as a content webmaster is to monitor and erase 'junk' and 'spam' such as marketing products and observe messages and information regarding treatment options and myths about cancer. She further describes her work as a 'watch dog'; responsible for protecting the public and online group members. While encouraging information exchange on the virtual group in the form of 'lay-consultation' she also monitors the nature of information exchanged. To some extent the content webmaster plays a double role, encouraging 'lay-consultation' and 'lay referral-system' but also discouraging information exchange that contradicts or conflicts with biomedicine. Virtual forums that are linked to an organisation are more likely to have an employed content webmaster than free-standing forums started by

individuals. The content webmaster is also responsible for writing a report indicating the growth or decline of membership, group participation or activeness and dominant themes emerging. This report is used within organisational planning and it demonstrates the growing inclusion of the online community for support, health and wellbeing.

As the webmaster points out, the organisation has seen the need for cancer patients and 'survivors' to interact with each other, in other words the lay-consultation is increasingly being promoted although within a context of surveillance.

Through lay-consultation on the online forums 'survivors' are able to offer information and support to newly diagnosed breast cancer patients by basing information on experience. In this way the women foster empowerment to each other.

Consequently Barak *et al* notes three critical elements and pathways of how information fosters empowerment; "improving understanding and knowledge", "enhancing decision-making skills" and "consequent behavioural actions" (2008: 1867). As was evident with Yvonne, participation on the virtual forums and internet research led to an improved knowledge and understanding of breast cancer, whereby she was able to "*ask the right questions*" when consulting with the medical expert. This consequently led to her deciding to have a mastectomy to avoid the daily six week radiotherapy sessions subsequent to a lumpectomy, which would have left her 'financially crippled' considering her status as a 'single self employed woman'. The consequent behavioural action from the information collected is essentially the treatment option that worked to her advantage and enabled greater coping mechanisms to her condition. Hence Barak *et al (*2008) also maintain that online support groups are designed to foster well-being, a sense of control, self-confidence, feelings of more independence and social interactions.

Gaining a sense of self control and self-confidence is critical in any illness encounter but more so for breast cancer as it is not only a threat to the physical body but also a threat to the social identity of womanhood, motherhood and women's sexuality. Sense of control and 'feelings of

more independence' is once again important to the specific women interviewed; considering their social status as working professional women, four of them owning their businesses, they are used to 'taking charge' of their lives. As Jo (chartered accountant) expressed "*I am used to being in control, having breast cancer terrified me,..... I went into complete denial. My mom was worse she wanted a second, third and fourth opinion*".

Through the use of virtual forums for information exchange participants such as Yvonne are able to gain a sense of self control by properly understanding what they are facing, self confidence in the medical encounter and feelings of more independence which ultimately translate into mental wellbeing.

This is strongly articulated by the post below:

One must not forget that recovery is brought about not by the physician, but by the sick man himself. He heals himself, by his own power, exactly as he walks by means of his own power, or eats, or thinks, breathes or sleeps.~Georg Groddeck, The Book of the It, 1923

(Pink and Black but Neva Broken)

Such posts are meant to encourage group members to 'take control' of their illness by seeking and sharing information on breast cancer. By taking control of their wellbeing the women are empowered and in turn they reduce the dominance of biomedicine within their illness experience. By sharing information on breast cancer they become active patients and 'survivors', not passive bodies to be mechanically worked on within the biomedical paradigm.

At the same time it is not only the access and exposure to information as such that empowers them but it is also their "very ability to share information with others", it is therefore not only the "receiver but also the provider of the information who is empowered, the latter by taking the role of guide, instructor and helper" (Barak et al, 2008: 1874). The provider-receiver relationship

displayed on the forums is a common feature of social capital, demonstrating reciprocity of social support.

As Connie conveyed: "*I am offering support while trying to get support too*". Through the provider-receiver relationship virtual support groups can foster a sense of empowerment as they are directly associated with three main attributes of personal empowerment modelled by Barak *et al* (2008); firstly reliance on self and peers rather than on authoritative professionals contributes to gaining a sense of personal competence, secondly voluntary participation and free choice that relate to decisions and planning contribute to feelings of self-determination, thirdly helping others and socially identifying with others contribute to perceptions of social engagement. All these elements are critical towards a form of social capital, which is underlined by the social support on the forums. Even more important is the positive implication and relationship between social support and health. The social support exchanged through information and social engagement assists in coping mechanisms which inversely improves physical and psychological wellbeing of those in need. This is exemplified here:

*"you need the information from the other girls, you want to hear advices like don't eat before chemo, it was more practical things, that's the support I needed"(*Liiza*)*

Much of the information exchange on the online forums is based on experience with breast cancer. At the same time it is difficult to confirm whether all the informants participating in the online groups have personally experienced breast cancer as in the 'face to face' support groups. Some of the posts do not require experience with breast cancer, for example a question such as "*Anyone know where I can buy a wig (100% human hair) in Durban" (Champions of Hope 2011)* can be answered by anybody with such information. As such, these networks draw on information from bigger networks and not just the women diagnosed with breast cancer, which means the forum offers access to greater resources.

Overall the information exchange on the virtual support groups takes different shapes and forms. It includes information relating to symptoms, diagnosis, treatment, to information on side effects and dealing with changes occurring in the body. Information exchange may also be as simple as asking where to go for wigs, breast prosthesis, and underwear, to questions requiring experience with breast cancer such as breast reconstruction following a mastectomy. It can be argued that the information exchange on these sites foster a sense of empowerment in different and unique ways as demonstrated here.

Spirituality, Meaning and Support

A number of posts on the online forums contain expressions of spirituality and prayer, and these form part of the support system exchanged on the groups. Spirituality can be understood as "that which allows a person to experience transcendent meaning in life" (Vachon 2008: 219). In this case spirituality allows for meaning in illness (breast cancer) which is a critical element of exploration, as spirituality was reported to me more than just a coping mechanism, but "an active, dynamic response and a positive psychological outcome" (Vachon 2008:220).

Responding to a post of distress, fear and confusion participants often reply in prayer and quotes of spirituality. Such expressions can be understood within the psycho-social framework of medical pluralism in which women believe there is a higher power beyond biomedical knowledge that may heal the illness and help them find meaning in the experience. Women explain their diagnosis of breast cancer in different ways; often transcending the simple explanation of the 'malfunction of the body'. Initial reaction to diagnosis leads to questions of "Why me, why now?" which biomedicine cannot answer; meaning is thus constructed through these lenses. Posts below signify how 'prayer' forms part of support on the virtual forums:

A: *"Please **pray** for a very dear friend of mine her name is Morne. Just been diagnosed with breast cancer. She has 2 very young kids under the age of 15"*
B*: "So sorry! She and her family are in my **prayers**! Luvxxxx"*

C:"Dear Cancer Survivors. I had cancer in the year 2005. I am still going strong and would like to encourage everyone living with cancer to always have hope, enjoy every day to the fullest and above all TRUST IN GOD. Life is awesome and I love reading all the wonderful stories. Have a great day!!!"
*D: Thank you for sharing! You are our hero…..is wonderful news when someone tells you they survive this disease for so many years!! I met someone new who was diagnosed with stage3 bc last month it is really heartbreaking! My hope and **prayers** is in cure for this disease!! Sending your way **Gods Blessings**! and many more years to come!"*
*E: Thank you for your kind words. May **God bless** you greatly!*
*(*Champions of Hope)

A: "*She is one of our soldiers, she is holding on….Can we rally behind her and **pray** for strength for her and her family. Jeanett Moloi-you are in my **prayers**" (*Pink & Black but Neva Broken)

The posts consist of prayer requests (please pray for me/us), prayer offerings (I will pray for you) and a testimony (affirming trust in God). From the above it becomes evident that many of the women share a similar belief system of spirituality, in other words trusting in a higher power (God) during the illness experience. An expression of spirituality and prayer is another form of reciprocating support in coping with the distress, grief and fear of cancer. Some of the spiritual expressions such as "*My hope and prayers is in cure for this disease",* are detailed and specific prayer support, such posts demonstrate another way in which women become active participants in their condition. The power and responsibility over treatment and cure is not just left to medical knowledge but it is also entrusted within spirituality or 'higher power'.

Despite the specifics of prayer support, perhaps the more pressing question is what does it mean to offer and request prayer? The reciprocation of prayer demonstrates the sense of empathy and

support practiced within these virtual groups. It is similar to the provider-receiver relationship demonstrated in information exchange, thus displaying critical elements of *social capital* such as social engagement.

It is about taking the time to read the grievances and fears of others and responding with empathy and prayer support to offer hope in the situation. In this case the group goes beyond the realm of the physical breast cancer and into a spiritual realm of interaction and engagement.

On a more critical note the posts of prayer support may also be the 'appropriate' thing to say, especially when the outcome of diagnosis and treatment is unknown. Posts of prayer support and spirituality may also help reduce anxieties and fears felt over breast cancer, and help them deal with their condition, for example the posts below address fears over mortality and uncertainty about the future:

"For as long as I can remember, I've never been afraid of ***death****! But the older I get, that notion seems to change... I guess because I see people around, people I've known for years suddenly* ***pass on****. Whether from accidents or even illness... Nothing can ever prepare us for* ***death*** *other than our* ***faith in God****. Tonight, I'm sending my love to those who have ever had to deal with the reality of* ***loosing a loved one****. Let* ***God*** *grant us the strength to move on, peace in our hearts & the* ***faith that all is in his hands****... Keep still & let him heal & fill the vacuum we feel in our souls. I love you all". (I am a Survivor)*

"Do not be afraid of tomorrow; for God is already there" (Champions of Hope).

The impact of prayer and spirituality was also expressed by some of the women in the in-depth interviews. One of the participants mentions how her faith in God carried her through the fears and anxieties over the illness:

"*there were days I would cry myself to sleep and pray God and say please its just the two of us. I don't want to leave her, abandon her. I don't want her to be with some random people. I don't want to give my sister a burden of a child. And that helps, you wake up in the morning and you feel good. You need an outlet. I can't go to my friends and cry about that, then I'm putting the*

burden on them. So to have faith in something that really helped. I know I can pray about it and I think He listened" (Connie)

Vachon's (2008) typology of the six themes of psycho-spiritual wellbeing is useful in articulating the relationship between spirituality, support and wellbeing explored here. These are self-awareness, coping and adjustments, relationships and connectedness with others, sense of faith, sense of empowerment and confidence, living with meaning and hope. The most evident theme is 'relationships and connectedness with others' demonstrated on the virtual forums through interaction with one another and engagement in the posts written.

Beyond coping with the illness through spiritual means is the idea of finding meaning in the illness. As mentioned before questions such 'Why me, Why now' cannot be answered by biomedicine. The prayer support and engagement also contribute to making sense of the illness.

Lipowski's (1970) model of 'meaning of illness' is useful and relevant in this analysis for explaining how women come to understand their illness through spiritual lenses and how spirituality informs meaning. The model depicts 'meaning of illness' in the following words: illness as challenge, illness as enemy, illness as punishment, illness as warning illness as loss, illness as strategy, illness as relief, illness as weakness and illness as value. For many of women interviewed and in the posts apparent on the virtual forums, illness is given meaning as ''value'. This is most evident in the expressions below:

''That's how focused and driven I was…..but when I looked at what needed to change, those were the things. I make radical statements saying I would never have managed to live the rest of my life without getting cancer……I either would have died of a heart attack or stroke, but something would have had to happen, so I could have died. In a way my life was not balanced…. I had all these achievements but no maturity to deal with it….I was arrogant, I was egotistical, and you know what I had a mentor that loved that. In my mind this had to happen"(Yavi)

"*I believe in my heart that it was stress related, I had hectic 7days a week job in the television industry and always on the go... I just think it was just too much, I was always on the go and my*

body had to say something..... it was a life changing decision that we made to move to the farm… uhhhm and if it works it works and if it doesn't we'll move somewhere else but I will not move back to joburg, not to a city" (Liiza)

The narratives demonstrate how the women constructed a meaning of 'value' in the illness encounter and experience. In the first instance the participant believes that the '*cancer had to happen'* in order for her to change her values and outlook on life. To some extent she believes the cancer awakened a realization about her character and in the second instance the cancer awakened a realization about a lifestyle that needed to change. In both instances 'illness as value' is constructed, which is to say that the illness goes beyond a biographical disruption (threat to the self-hood) but rather contributes to enhanced perceptions about the self and life trajectory.

Posts of spirituality and prayer form part of a support system exchanged on the virtual forums. They also underpin meaning making in the illness encounter and experience. Support on the forums is thus constructed in different ways; this includes prayer support, information exchange as discussed and a fostering of belonging discussed below.

Belonging, meaning and support

The on-line forums and the in-depth interviews conducted were pivotal in explaining the factors that influence women to join virtual support groups. Many of the women expressed that one of the reasons for joining an online cancer support group was to be with people who understand their experiences, women who have travelled the same road of breast cancer, and women who know what it feels like to hear the words "the lump is cancerous". They yearn for a space where they feel a sense of belonging, a space of interacting with a community of women who have been diagnosed with breast cancer. This is specially the case for women who do not have a history of cancer in the family, who, as expressed in the interviews come from a background of 'healthy'

families. They find themselves in a changing reality, an illness reality filled with uncertainty, questions and loneliness.

Sense of belonging in this case is closely linked to the idea of a collective identity and collective experiences. Sense of belonging can be defined as the "experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment" (Hargety *et al* 1992: 173). Sense of belonging can also be drawn from a broader concept of human relatedness; Maslow for example identified belonging as a basic human need, ranking it third in his hierarchy (Hagerty *et al* 1992).

There is a positive relationship between sense of belonging and health as alluded to by Durkheim (1897), who showed that social integration was inversely related to suicide rate in societies. Senses of belonging and social integration are sometimes used interchangeably in social capital literature to demonstrate the relationship with health. Being part of a support group whether it is face to face or virtual may diminish and possibly get rid of feelings of isolation, loneliness and uncertainty. However conceptualizing and measuring 'belonging' is a complex project as it is somewhat an abstract construct. Sense of belonging may go further than just getting acquainted with other women diagnosed with breast cancer; as expressed by one participant it is also about "*being understood*" *(Cheryl).* This is articulated further in the expressions below:

"*you need to get in contact with another female whose going through cancer or has gone through it, whose on the same level as you…and that's where I think the internet is amazing"(Liiza)*

"*my husband went through hell and back, and my parents too, what can they do, they can give you a hug and say toemaar (sorry) but what more can they do, but on-line I can just say today is not a good day and any chemo person will know exactly what I mean*"*(Liiza)*

A critical feature of belonging is to feel less alone, to feel like a part of a whole, to feel understood. This is not to say that the online support groups can provide a complete sense of

belonging as the illness experience differs, but by participating in the virtual forums women receive some form of social integration in the collective illness identity.

Hagerty *et al* (1992) concept of 'two dimensions of sense of belonging' is thus useful as they argue that belonging is about valued involvement; which is the experience of feeling valued, needed and accepted. Secondly it is about fit; the person's perception that his or her characteristics articulated with or complement the system or environment. Once an individual acquires an illness identity they are likely to feel different from everyone else around them, and this is evident during cancer treatment side effects such as hair loss. Jo echoed this here:

"*you are more worried about looking sick, you just want to look normal that's all.....other cancer patient's don't look at you like you are sick"*

The participant did not want people (specifically at work) to know that she has breast cancer as she was afraid they would treat her differently; "*I did not want them to pity me*". Her sense of belonging was restored in the cancer support group sessions through the experience of feeling 'valued, needed and accepted', as articulated "*other cancer patient's don't look at you like you are sick*".

Participating in the virtual forums means reading and writing about breast cancer on a number of occasions. This constant exchange of information, advice and referrals normalizes an illness which might otherwise be viewed by society in stigmatizing ways. Thus McKenna and Bargh (1998) maintain that individuals have the need to feel connected to others, to have a sense of group belonging, and to feel like a special, valued member of a group (Brewer 1991 in McKenna & Bargh 1998). This is exemplified here:

A: Can anyone help me please - I had a single (left) mastectomy last year and chemo and radio - the radio burns were really bad and i've been left with ugly scarring and very sensitive skin tissue from radiation. My oncologist has said I cannot have reconstruction. My problem is I want to wear clothing and swimwear that is not frumpy and old fashioned! I need to find a place that

can supply or manufacture sexy underwear, swimwear and tops/dresses which I can wear my prosthesis with - in the KZN area. ***I am sure I can't possibly be the only one experiencing this****.*

B: I got my prosthesis from LES Femmes at parklane in PMB. They do sell costumes. I'm gonna get mine from them. The no is 0333941123. Good luck
A: Thanks carla - I knew someone on this site would be able to help me! Long drive from umhlanga but hopefully worth it
C: Hi Sue,I bought a swimming costume at Edgars. It has pockets with padding at the breast which i just removed, made the opening bigger and put my prosthesis in there. Good luck!! (Champions of Hope 2011)

The participant's knowledge that she "*can't possibly be the only one experiencing this*" is affirmed by the group members who reply to her question. Through the replies she knows that she is not alone, she knows that other women experience similar situations and that idea may provide a sense of social integration or sense of belonging. Within the contextualised view of virtual support groups a sense of belonging also fosters empowerment to the women. Being part of a system such a virtual group creates further opportunities for lay consultation, lay referral and most importantly support.

The Gendered Illness Experience

Much of the data on the virtual forums and interviews relates to narratives on the illness experience of breast cancer. The online forums provide a space whereby women read and write narratives of what it means to have breast cancer. The narratives confirm that the breast cancer illness experience is unique in each case, with common features and characteristics emerging at different intersections. I draw on these common characteristics in developing an analysis of the illness experience and further exploring the use virtual support groups. For a clear and systematic discussion the illness experience is divided into four dominant stages; discovering the lump,

diagnosis, treatment and remission/survivorship. These simplified stages are useful in understanding the use of online forums at different points of the illness trajectory.

The first stage identified in the illness experience of breast cancer is 'discovering the lump'. This is when the women first detect an abnormality in their breasts by noticing a lump which they have not felt or seen before. Discovering a lump in the breast was often by accident, meaning the women were not doing a self breast examination at the time but felt it by chance. The lump was not recognised or interpreted the same way by all the women; some immediately recognised it as a symptom for breast cancer, while others were uncertain of the meaning:

"it was the first of July 2004, I have pretty dry skin so I have to like put on lotion everyday and all of a sudden I felt it in my cleavage. The moment I felt it I knew, I'm not a negative person but the moment I touched it I knew" (Yvonne).

"Whether you call it fate or what but at that moment when I was showering and found the lump, the doctor said I would have died if it didn't position itself that morning, and if I would have never taken a shower and lifted my arms, I would have never found it. I never saw the lump again until the day they removed it" (Yavi)

"I never had a mammogram, I thought I was too young, I was always busy, so I was coming down an escalator, and I scratched the side of my breast and I felt this lump, something in me knew that this was bad…" (Debbie).

Of the seven women interviewed only one had gone for a mammogram prior to discovering a lump in the breast. This is explained through the health beliefs held about themselves and the perceptions of risk to breast cancer.

Discovering the lump did not only create fear and anxiety but it also threatened the health beliefs the women held about themselves:

"I was just so healthy, the only problem I had was allergic sinusitis but I've never been sick in my life" (Yvonne)

"I'm a healthy person. There's no cancer in our family whatsoever" (Liiza)

*"we have no cancer in the family, I'm the first, in fact we are a very healthy family"(*Debbie)

Health is a relative, multifaceted, and much contested concept. This is articulated in the literature on lay health beliefs whereby people define and understand health in multiple ways. Drawing on that literature it becomes evident that the respondents understood 'healthy' as being free of pain, having fit bodies and able to function without any restrictions. Discovering a lump in their breasts threatened that health belief even before diagnosis. As some expressed:

"*I knew something was wrong*" or "*I got that ice cold feeling….and something in me knew this was bad*" and "*I am not a negative person, but the moment I touched it I knew*" (Connie, Debbie and Yvonne).

This demonstrates that the experience of health and illness even before medical and professional intervention is an important point of focus. Following discovering the lump some of the respondents consulted with internet sites to find out what the lump meant while others spoke to friends and families. Below Yvonne discusses the different channels of consultation which eventually led to a medical interaction.

"in fact the first thing I did was call CANSA and I said I needed to know the shortest way and most inexpensive way of getting from point A to B in terms of what is necessary and the only thing they did was send me to Reach for Recovery and Reach for Recovery send me to the Gen, but no one could give me a simple answer… so I eventually booked an appointment"

The duration between discovering the lump and seeking medical help becomes critical as it is in this period where lay consultation can be most evident within the illness experience. At the same time there are individual determining factors to this, such as age, health beliefs as well as

personal and family medical history. The lay consultation taking place, which include virtual support groups may later affect the illness behaviour. This shows the importance of social networks in the illness experience and illness behaviour, as individual's perception of symptoms often depends on the perception of others (Blaxter 2004). This is exemplified here:

"I spoke to a friend of mine who has breast cancer and she said no its probably nothing. I went to the doctor immediately the next day and he said its probably nothing but go ahead and get a mammogram anyway , uhhhm he knew immediately but he did not want to freak me out coz I had to drive, and I went to a doctor, had the mammogram, sonar and within half an hour I knew I had breast cancer"(Debbie)

Gifford's (2002) notion of the ambiguities of risk in comprehending the meaning of lumps is critical and useful. She categorizes the ambiguities of risk into epistemological risk, lived/experienced risk and lastly clinical risk. She explains this by saying that the concept of measured and unmeasured risk can be applied to understanding the different dimensions of epidemiologic, clinical and lay knowledge of benign conditions and breast cancer. While epidemiologists create scientific risk, lay people create and experience lived risk, and clinicians mediate between and bridge these dimensions of risk. In assessing breast cancer risk, many of the women draw from experienced risk of discovering a lump and epidemiological risk of their age, family background and race. For example a young woman like Connie the risk of having breast cancer may be estimated to be low; hence she describes her cancer as "*bringing something new and foreign to the family*". The same ambiguity of epidemiological risk is expressed by forty five year old Debbie:

"I never had a mammogram; I thought I was too young. I was always too busy".

This was also the case with other young women below age fifty; however some considered the stressful occupations and lifestyle as a risk factor to clarify the ambiguities of risk: "*I believe in*

my heart that it was stress related, I had hectic 7days a week job in the television industry and always on the go" *(Liiza)*

Such comprehensions combine the objective epidemiological factors with subjective lived experiences, and this demonstrates the intersection of lay and medical knowledge. The intersection of the two is carried through in the virtual support groups when women seek information, meaning and belonging after discovering a lump.

Even after discovering the lump by themselves and having their health beliefs threatened, being diagnosed with breast cancer still came as a 'shock' to many of the women. "*I went through extreme denial" (Jo)*

Diagnosis by the medical practitioner confirms the symptoms, changes the health beliefs, and further threatens the self-hood (social roles and activities) of those diagnosed. It further threatens their sexualities and identities as women and mothers:

"being told that I couldn't have children that was the hardest part for me, so I definitely went through denial, anger, I did not tell anyone" (Jo)
" it freaked me out coz I felt its directly threatening my femininity, if I was 60 and done with kids and everything then maybe it would have been ok"(Connie)

"the breast make you who you are, whether we claim how beautiful we are inside. You don't wanna have one breast or none, I think psychologically it would have changed everything for me. I think that's why people don't wanna talk about it, it's difficult. If I lose a breast how do I face the world, how do I say yes I've got breast cancer. I thought about it; I would not have coped. I'm not a girly girly type. I don't wear super tight clothes and stuff, but they mean that much to me. If I have to wake up in the morning and stuff my breasts that would have been traumatic for me as a woman. I think it takes so much away from you as a woman" (Connie)

On the other hand fifty six year old Yvonne expressed that: "*I'm still the same person, one boob or two boobs*". This follows a question on the perceptions and feelings over breast cancer as a threat to femininity. For thirty three year old Connie a lumpectomy was less of a threat to her

femininity than a mastectomy. It becomes evident that age difference plays a critical role in how women perceive and experience breast cancer.

In the last two stages of the illness experience (treatment, remission/survivorship) what becomes most evident is what Burles (2001) calls the 'living in the present' discourse. This is a common characteristic in all the illness experience narratives analysed in the study.

As Burles (2001) explains, cancer experiences often prompt significant shifts in the way that individuals view life and the future; these shifts include feeling a greater urgency to enjoy life and make the most of their life. This is evident here:

"*we treasure health so much more.....we appreciate and treasure family time"* (Jo)

"*I'm not that same egotistical, materialist person, in fact I don't even know who that person is*" (Yavi).

This is similar to the idea of 'illness as value' discussed earlier and can also be noted in the idea of the *biographical disruption;* the idea that identification of a disease can force one to reflect and reassess one's life (Bury 2004).

Through these narratives women further negotiate and reconstruct their identities on the virtual forums.

General Discussion and Conclusion

The study set out to explore the use of virtual support groups by women diagnosed with breast cancer. What emerged is the idea that virtual forums can be understood in the context *of lay-referral systems* and *consultation,* thus providing opportunities for social support, social engagement and the fostering of empowerment. Conceptually the use of virtual support groups reduces the dominance of medical power in the illness encounter and experience, while increasing lay interactions and networks of support.

A unique feature about online support groups is in the notion of crossing geographical boundaries. A woman residing in Cape Town can interact with a woman in Polokwane with the possibility of forming relations and mutual support. It is within these disembodied spaces that women search for information, meaning, support and sense of belonging. The exchange of narratives based on perceptions and experience frame these online forums within *lay consultation*. At the same time there are posts framed around medicine and science but are considerably less to the psycho-social posts. The virtual support groups thus operate within varied paradigms yet significantly foster a power shift differing from the professional control in the clinical interaction. It is within this social paradigm that we can highlight support networks in the illness experience.

Compared to many European and North American countries, the use of virtual support groups in South Africa is notably low. This can be attributed to the differing socio-economic levels, illiteracy, and limited access to the internet. As Facebook is increasingly becoming widespread, specifically on mobile phones, more individuals are using the forums to interact, exchange information and create new illness support groups.

Overall this study has brought attention to the lack of South African internet research, including methodological implications of conducting research on a virtual space. Such studies are increasingly becoming important as people are notably using the internet for health and illness information as well as to exchange illness narratives. More so organisations such as CANSA are incorporating online groups as part of the holistic support offered to cancer patients and ‘survivors’. This also brings attention to the dynamic and multifaceted nature of ‘support’ as a concept.

APPENDIX

Getting to know the women

The table below attempts to give a brief snapshot of the women interviewed.

Connie Age: 33 yrs old Race: Black	Biographical Information Worked in credit management for most of her life Not married- has a boyfriend of one year- "was very supportive" Mother died 2006, has a father, sister and brother (close family) 16 yr old daughter 12 June 2011- felt the lump while showering- (under her breast) Kept the lump a secret for months. Illness History Never did self-examination or mammogram Felt the lump while showering Diagnosed October 2010 with stage 3 breast cancer- was scared- "cannot die and leave my daughter without a mother" No history of cancer in the family "it was one of those foreign things". Myths from community and friends that cancer is a "white thing" Had a Lumpectomy Lady from work was diagnosed a few months back- helped her get an oncologist, got her the CANSA survival kit, approached by Reach for Recovery, went to a few sessions, felt that she could not relate as she is

	black and young. Worried about black women in the township with no breast clinics and private oncologists. Wanted to find out more about breast cancer- joined the virtual space- started her own online group "Pink and Black but never broken" whereby she writes about her experiences with breast cancer Currently going through radiation therapy.
Debbie Age: 45 yrs old Race: White	<u>Biographical Information</u> Not married- has a boyfriend (his father died of cancer)- no children- father passed away- two brothers, a sister and two nieces Educator- (trains teachers and children with learning needs)- Self-employed Connects the cancer to education "if you catch cancer early you can fix it" "if you find out about a child's learning need early you can fix it" <u>Illness History</u> No history of cancer- "healthy family". Walking in a shopping centre-scratched her breast and felt a lump. Got "an ice cold feeling", knew something was wrong. Diagnosed- 2008- Bilateral mastectomy Had family and friends and Reach for Recovery for support- "you find out who your true friends are" Volunteered with Reach for Recovery and CANSA for counseling newly

	diagnosed breast cancer patients. Wrote an MA thesis during her treatment. 4 months of chemo and seven weeks of radiation- "transition from one person to another", "less neurotic, less anxious, able to say no, less of a controller" Did not have medical-aid, went to Joburg Gen- treated by one of the best oncologists "I was very lucky". After diagnosis went on to the internet "got too much information", myths about cancer "if you eat cherry tomatoes you won't get cancer" "the journeys are different"- comparing of oncologist – got confused and decided to go offline. Spoke to her oncologist to get information and facts about the illness.
Yvonne Age: 56 yrs old Race: White	<u>Biographical Information</u> Single, No children Both parents passed away, has half brothers and sisters Afrikaans background, English upbringing, Family spread around the world maternal grandmother might have died of breast cancer (from memory) and half-sister diagnosed with lung cancer "she was a smoker all her life" Qualified nurse, started own business in web design, did not have medical

	aid, never went for mammograms. Illness History Felt the lump, knew something was not right, because of financial problems “my crisis was not having cancer but having to deal with it” “it stressed me out tremendously” called CANSA: was referred to ‘Reach for Recovery’, was not satisfied with the information received. Started surfing the net to understand breast cancer and the treatment options Attended treatment at Joburg Gen; got an appointment six weeks later Finance influenced treatment option, decided to do a mastectomy. Did not have to go through radiation Started an online group “I am a survivor” Feels it is a good space whereby women can interact with each other
Yavi Age: 36 yrs old Race; Indian	Biographical History Married 15yrs Has a 4year old daughter comes from a close net family Worked in the banking sector for most of her life and recently started her own business as part of a lifestyle change “less stressful” Illness History Felt the lump while showering

	Diagnosed with breast cancer Source of support "family, friends and colleagues" After diagnosis biggest concern was not being able to have children Gave birth two years after remission Participated in the Moments in Time Campaign, was spokesperson of Estee Lauder Breast Cancer Campaign, was very involved within breast cancer initiatives. Went for counseling Feels the cancer changed her to be a better person "I was arrogant, materialistic and driven by my career". Never went online at the time of diagnosis as she did not know about virtual support. Says she wishes she knew about it- feels it might have helped her to cope better by interacting with other women.
Jo Age: 35 Race: White	<u>Biographical History</u> Married 8yrs 7month old daughter, two adopted sons 11 years and currently pregnant with twins Has a mother, father and brother- 'supportive' Chartered Accountant, moved from big banking to small banking. Currently working on her research proposal for MBA <u>Illness History</u> Did self-checks, discovered the lump at home.

	No cancer in the family (grandmother had breast cancer which was hormone induced through oestrogen testing for menopause- not genetic) Diagnosed: 2005 biggest concern after diagnosis was not being able to have children Says she "likes to be in control" and the cancer made her feel out of control Had chemotherapy and lumpectomy surgery after that. later gave birth to a baby girl after two year remission Attended Bosom Buddies support group Never went online- oncologist told her that the internet is "full of information out of context" She however participates in "Moms and Babes" online forum to interact with other mothers, whereby they advice each other about babies.
Cheryl Age: 55 years old Race: White	<u>Biographical History</u> Married ten years owns a financial consultancy company one son, one step-son- Both parents died last year. <u>Illness History</u> mother, sister and sister-in law had breast cancer (went to the same oncologist and clinic that her mother went to) Never did self-examinations or mammograms. Found the lump after the dog bit her on her nipple while playing Diagnosed August 2011 with stage 2 cancer and went to go see a surgeon

	Bilateral mastectomy and reconstruction after that "I'm hospital phobic, needle phobic, operation phobic and illness phobic"- which influenced the treatment choice Advised by the doctor to avoid the internet Has 3 friends who have been diagnosed, one of them invited her to the group 'I am a survivor' (13members- myself included) She logs in once or twice a week but hardly participates- "I have enough support from friends, family and colleagues" Posts her breast cancer journey on her facebook page-, she posts positive things about cancer. Currently on chemotherapy (3 of 6) Currently writing a book (comic strip) to give cancer a humorous perspective.
Liiza Age: 45 years old Race: White	<u>Biographical History</u> married, no children Both parents still alive and married, has two brothers Worked in the television industry, long and intense working hours Relocated to Limpopo 4yrs ago to the Family Farm at 39 where she discovered the lump. <u>Illness History</u> Discovered the lump in the shower Believes that the cancer was stress-related, "always on the go"

	No cancer in the family- “I was actually a healthy person” went to regular mammograms annually family was supportive encouraged by a friend to join a virtual support group point of diagnosis “shocked” Contacted by ‘Reach for Recovery’ directly after her mastectomy, did not relate to the lady who approached her. Because of geographical area, she could not reach the support group meetings met a lot of people online, was able to get more support there, as she felt she did not want to worry her family all the time as the husband and parents had a difficult time dealing with the cancer wrote about 10 messages in the period of five years. Participated regularly after diagnosis wanted practical information regarding the ‘does and don’ts’ during treatment Does not log in often anymore

Information Sheet and Consent Form

Hi

I am Lesego Kgatitswe. I am studying towards a Masters of Arts degree in Health Sociology at the University of the Witwatersrand. I am interested in understanding the use of virtual support groups by women with breast cancer.

I am carrying out this research to understand the role of virtual support groups in the illness trajectory of breast cancer. I would also like to examine the themes and topics discussed on the virtual groups as part of understanding breast cancer as a gendered condition.

I would like to invite you to take part as I think it will be an interesting and helpful exercise to all concerned but you will not be forced in any way to take part. Your participation in this study is completely voluntary. If you choose not to take part you will not be affected in any way whatsoever. If you agree to take part, you can stop at any time if you do not want to carry on being involved. If you refuse to take part or stop at any point during the study, you will not be affected in any way and you will not be discriminated against.

All the information you choose to give me will be kept confidential. Only I will have access to the linked information.

The in-depth interview will take around 1-2 hours to complete during which I will be asking you a few questions. I ask that you are as open and honest in your answers. If you feel a question is inappropriate or too sensitive, you are free not to answer it.

If you have any questions about this study, you can contact me on 0786245018, or by email at lesegokgatitswe@yahoo.com

Many thanks,

Lesego Kgatitswe

My Supervisors are:

Dr. Terry-Ann Selikow (terry-ann.selikow@wits.ac.za) and Prof. Leah Gilbert (leah.gilbert@wits.ac.za)

Consent Form

I _____ hereby agree to participate in Lesego Kgatitswe's study on virtual support groups. I understand that I am participating freely and without being forced to do so. I understand that I can stop the interview at any point if I do not want to continue and that this decision will not affect me negatively in any way.

The purpose of the study has been explained to me and I understand what I am expected to do as a participant. I acknowledge that I will not benefit personally (financially or in any other way) from the study.

I have been informed that, if required, feedback on the findings of the study will be given to me once the research has been completed.

Signature of participant _____

Date: _____

Signature of Researcher _____

Date: _____

Additional consent to audio recording

In addition to the above, I hereby agree to the audio recording of this interview for the purposes of data capture. I have been informed that information taken from the audio recording will remain confidential. I understand that the recordings will be kept in a locked cupboard for a minimum of seven years.

Signature of participant _____

Date: _____

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