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Just a “Click” away from evidence-based online breast cancer information, advice and support provided by a specialist nurse: An ethnonetnographic study

Cynthia Ann Witney
Edith Cowan University

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**Just a “Click” away from evidence-based online breast
cancer information, advice and support provided by a
specialist nurse: An
ethnonetnographic study**

This thesis is presented for the degree of

Doctor of Philosophy

Cynthia Ann Witney

Edith Cowan University

Faculty of Engineering; Health and Science

School of Nursing and Midwifery

2015

Abstract

Breast cancer has had, and will continue to have, a devastating impact on the lives of many Australian women, their families, friends and the wider community. The concomitant treatment of this disease places a considerable burden on the health care system and the supporters of the person diagnosed with this disease. While there are many government and non-government organisations that provide treatment and support services for the person with breast cancer, these services are usually provided in person either in the home or at the organisation's offices. This study extended the information advice and support aspects of these services to the online or Internet based realm via the design and development of a breast cancer focused online support community www.breastcancerclick.com.au and explored the role of the expert nurse through the employment of a specialist breast care nurse as a member, moderator and health professional within this online community.

This study used an ethnonetnographic approach, including online (on the Internet) and offline (face-to-face) methods, to explore the role of the specialist breast care nurse within the online, breast cancer support, community. The study was comprised of three phases, Phase One, the offline and online identification of the information, advice and support needs of Western Australian women with breast cancer and their Internet use; development of a website designed to meet those needs and to foster the development of an online support community; Phase Two, the employment and introduction of a specialist breast care nurse as a member and provider of evidence-based information, advice and support for online community members; Phase Three, the online and offline collection of data relevant to the role of the specialist breast care nurse within the online support community.

The identification of the expert nurse as a linchpin in the patient's care and communication has implications for future nursing practice and curricula as well as consumers of health care. Recommendations arose from the findings in relation to further research, nursing practice, education these recommendations indicate an innovative extension to expert nursing practice and together the elementary guidelines for health professional when developing an illness specific online support community foreshadow a future direction for nursing, in line with the digital age.

The declaration page
is not included in this version of the thesis

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I sincerely thank the following people for their assistance in the completion of this thesis. My doctoral supervisors, particularly Drs Joyce Hendricks and Dr Vicki Cope of the School of Nursing and Midwifery, Edith Cowan University, Western Australia, two very knowledgeable and skilful people who provided endless support and encouragement, and whose suggestions and criticisms were vital to my research journey.

My infinite thanks to the Clickers, my friends on the Click, online, breast cancer support community, without their selfless input, this study would not have been achievable

Finally, my special thanks to my family; my children Monique, Jarrod and Chris and my grandchildren Ryleigh, Oliver, Maya, Solomon, Lucy and Beau who have been patient with me on this seemingly never ending quest. To my wonderful mother Kate, sisters Jeanette and Jayne who have always been there for me.

In memory of my beloved husband Jeffrey 'the wind beneath my wings'.

This thesis is a gift to you all.

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Declaration

To Whom It May Concern

I, Cynthia Ann Witney contributed a minimum of 50% to the following papers:

Witney, C., Green, L., Costello, L., & Bradshaw, V. (2012), Building an online community in the context of an existing social network site. Paper presented at and published in the *Proceedings of the Eighth international conference on Cultural Attitudes towards Technology and Communication 2012 (CATaC)* 18-20 June, Aarhus, Denmark.

Bradshaw, V., Witney, C., Green, L., & Costello, L. (2012). Embodying knowledge of breast cancer in a disembodied community? *M/C Journal*, 15(4)

Costello, L., Witney, C., Green, L., & Bradshaw, V. (2012). Self-revelation in an online health community: Exploring issues around co-presence for vulnerable members. In C. Anyanwu & K. Green (Eds.), *Proceeding of the 2012 Australian and New Zealand Communication Association Conference*. Adelaide: Australia.

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Witney, C., Hendricks, J., and Cope, V. (In Press) The specialist breast care nurse within a netnographic online support community: adding the 16th moment of cancer care *International Journal of Human Caring*.

Witney, C., Hendricks, J., Cope, V. (In Press) Munchausen by Internet and nursing practice: An ethnonetnographic case study. *International Journal of Nursing and Clinical Practices*.

Witney, C., Hendricks, J., Cope, V., (2015). The specialist breast care nurse's role in the identification and minimisation of member distress in an online breast cancer support community. Submitted to the *International Journal of Nursing and Clinical Practices*

Witney, C., Hendricks, J., Cope, V. (2015) Ethnonetnography: A variation of Kozinets framework and its application to nursing research. Submitted to *Nurse Researcher*.

22/05/2015

I, as supervisor of the candidate endorse that this level of contribution by the candidate indicated above is appropriate.

22/05/2015

Chapter One

Introduction

Breast cancer has had, and will continue to have, a devastating impact on the lives of many Australian women, their families, friends and the wider community. One in eight women will develop breast cancer and one in 37 will die as a result of the effects of it before they reach the age of 85 years (Australian Institute Health Welfare Cancer, 2012, p. 1).

In 2009-10 breast cancer was responsible for 27% of all cancer-related deaths and 3% of all hospitalisations among females in Australia. In this period, there were just over 113,000 female hospitalisations due to breast cancer, which was 72% higher than those in 2000–01. Given the ageing population, the number of females diagnosed with invasive breast cancer is expected to continue increasing. Projections suggest that in 2020, the number of new breast cancer cases will be approximately 17, 210. This would equate to 47 females being diagnosed with breast cancer every day in 2020 (Australian Institute Health Welfare Cancer, 2012, p. xi).

Statistics are important because they show the prevalence of breast cancer among women but it is only through a description of the potential impact the illness can have on a person's quality of life that a clear picture can be seen. The following is such a description:

Following diagnosis of breast cancer an individual's quality of life can be challenged physically, psychologically and functionally. Depression and anxiety may result from the distress of diagnosis, fear of a life-threatening disease and tumour recurrence. Breast surgery may also impact psychologically on a woman's body image and sexuality. Side effects such as: nausea and vomiting; hair loss and fatigue; secondary lymphedema; and symptoms associated with therapy-induced menopause, such as hot flushes and emotional liability are just some of the physical consequences of breast cancer treatments. Therefore, to the individual patient, breast cancer is not only a medical problem, but also one having a serious psychological, emotional and social impact. Effective management requires a professional and holistic approach. (Cruickshank, Kennedy, Lockhart, Dosser, & Dallas, 2008, p. 2).

Breast cancer is considered to be a chronic condition requiring a complex response over an extended period of time that involves coordinated input from a wide range of health professionals (Mazaleski & Schiano, 2014). Chronic conditions place a great strain on already overstretched health care systems that are largely constructed around acute episodes of care (Barnett, Mercer, Norbury, Watt, Wyke, & Guthrie, 2012; Stuckler & Siegel, 2011; World Health Organisation, 2011). Better coordination of services across the continuum of care would be the logical way to approach the delivery of health care services for those with a chronic condition (Fortin, Chouinard, Bouhali, Dubois, Gagnon, & Bélanger, 2013). Health care systems differ from country to country so it is unlikely one delivery system will be appropriate in all instances; therefore it remains the task of each country or, as in Australia, each state, to find and implement a system best suiting particular resource and patient requirements.

In Australia, nurses are the largest occupational group involved in the provision of care for patients (Health Workforce Australia, 2014). This care occurs in a variety of settings such as hospitals and other institutional environments, residential care facilities, community operations including private practice, community health services and non-health settings, such as schools and workplaces. Nurses, due to the ubiquitous nature of their work, are present at many points along the patient's continuum of care, especially the communication aspects of care that involves liaison and case consultation with other members of the health care team; thus they are in an ideal position to provide advice and support for the patient.

A breast care clinic encapsulates the continuum of care for individuals with breast cancer, with face-to-face care provided by a team of oncologists, surgeons, nurses and therapists, before during and after a diagnosis of breast cancer. This 'hands on' patient care, together with advice and support, is usually provided during regular working hours. However, individuals with breast cancer and their families and friends, (referred to as supporters in this research study), do not necessarily have access to advice and support after hours.

Breast Cancer Care of Western Australia (BCCWA) is a charitable organisation that aims to provide personalised emotional, practical and financial support for people and their supporters affected by breast cancer (Breast Cancer Care WA, 2007). This organisation complements the services of hospital-based breast care clinics by providing in and out of hospital nursing care, advice and support using a team of specialist breast care nurses, social workers and counsellors.

BCCWA's services, centred on face-to-face or telephone communication and two, breast cancer focused websites, were launched to increase patient access to health information, support and advice. Its website was the main or 'mother' site designed to promote the organisation's breast cancer support services, provide information about breast cancer and promote fund raising activities (Breast Cancer Care WA, 2007). In contrast the Purple Boot Brigade website is a social network site, aimed at education and early detection of breast cancer plus the marketing of "purple work boots" to raise funds to support the BCCWA services (Purple Boot Brigade, 2008).

The majority of Australians have access to the Internet and go online at home or in transit, using three or more different devices to connect to the Internet (Australian Communications and Media Authority, 2013-2014). With increased and virtually constant access available to most people in Australia, the Internet can be likened to a 'secret weapon' for people who have complicated or chronic health issues or who want more information about their ailment. People with these conditions often 'surf the net' to find information about their illness and/or to diagnose it (Fox & Purcell, 2010, p. 3). These authors contend some join online illness-specific support groups to ascertain this information or to share their knowledge with someone who is in the same situation. In doing so, they may find the strength to persist with their condition. "They unearth nuggets of information. They blog. They participate in online discussions. And they just keep going." (p. 4)

A report by McDaid and Park (2010) showed that at least six in ten Australians make some use of the Internet to search for advice on health, medicines or medical conditions; while one in three of American adults have gone online to "... figure out a medical condition" (Fox & Duggan, 2013, p. 2). Of these, it is the family and friends,

caring for those with illnesses, who are most likely to go online to gather information about medical problems, treatments and drugs (Fox, Duggan, & Purcell, 2013, p. 2).

This situation may occur because the person with the illness is too unwell to use the computer, or is not aware of the availability of online information about their illness. They may also be in denial of their condition. Nevertheless, whoever searches for online reports they are doing so to gain a better understanding of the illness, its treatment, what the patient is going through, and what lies ahead (Fox, 2011; Hu, Bell, Kravitz & Orrange, 2012).

Background

Health Information

Health information is sought online but its quality can vary; therefore it is difficult for users to ascertain whether the information can be trusted (Corritore, Wiedenbeck, Kracher & Marble, 2012; Hardiker & Grant, 2011). One study by Tustin (2010) found dissatisfaction with the information provided in person at the time of their diagnosis and proposed treatment, thereby prompting them to seek further information online. This finding is supported and amplified by the following comment:

[The] doctor just called on the phone and said I had it and did I have any questions. I was in too much shock at that moment and was crying and emotional so I couldn't think of anything to ask. Later, I got on the Internet (sic) and went to many sites that gave me very good and helpful information. My fears were calmed somewhat ... (Fox & Purcell, 2010, p. 18)

The above comment also highlights the need for the health care provider, such as a nurse, to be aware of the emotional effects such information can have on the patient, and the importance of providing them with, or guiding them towards, evidence-based information sources (Cutilli, 2010).

Information available on the Internet may be either read-only medical advice whereby no interaction occurs between site users (for example, www.Medscape.com), or interactive wherein users can read as well as post information, photographs and videos and communicate with other users of similar interest. Many of these interactive

sites are illness-focused, online support communities, such as, www.patientslikeme.com/, which have both information dissemination and various interactive technological capabilities. Examples of this mode of communication include: live chat, instant chat, blogs, home page or wall posts, forum posts, photo and video uploads and private messaging. Whether or not an individual employs these sources of information it is a personal choice, but Fox and Purcell (2010) note that individuals with chronic illnesses are likely to write a blog and/or contribute to online health discussions.

Interactive websites are sometimes referred to as ‘social network sites’, a ‘social networking site’ or ‘online communities’. A well-known social network site is www.facebook.com. boyd and Ellison (2008) differentiated between social network sites and social networking websites by describing the former as a web-based service that allows:

“... individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system” (p. 210).

The term networking makes important the act of relationship initiation, often with strangers, whereas the user of a social network site such as Facebook, is primarily connecting and making visible only their personal friends and connections; and is not seeking to connect with strangers (boyd & Ellison, 2008). Such differentiation of networking terms may prove to be redundant in the near future as researchers have begun to use them interchangeably, thus reinforcing the notion of little difference between the organising features of these sites (Cha, 2010; Chou, Hunt, Beckjord, Moser, & Hesse, 2009; Mew & Money, 2010). Mew and Money regard the description of the website to be dependent upon how the individual uses the site and may not be pre-determined.

The sociality of a website is also dependent on its social affordances; that is, the technological capabilities of the website, which have evolved and changed over time, from email only to instant messaging, chat rooms and forums, all of which enhance the user’s local and global connectivity. However, it is also important for the user to be

confident and capable of using the technology and that it be appropriate to their needs and the social context in which the communication occurs (Hsieh, 2012).

Online Community

Community is a word meaning different things to different people, dependent upon where they live and how they interact with others. Prior to the advent of telecommunication technology and modern transportation systems, the word community was generally agreed to mean a close-knit group in a single location with any interaction between the group members occurring primarily face-to-face (Watson, 2013). This definition of community has become less useful now that people can communicate globally and facelessly via the Internet. Researchers like Haythornthwaite and Kendall (2010) who consider the strength and nature of relationships between people to be a more useful way of defining the concept rather than physical proximity.

The global connections forged between people via the Internet have seen the emergence of 'online communities' or 'virtual communities'. These are networks of communication facilitated through the use of a computer and an Internet connection; they reflect the evolution of the term 'community'. The seminal work of Anderson (1983) proposed a view of community as an imagined community, "... because the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion" (p. 6).

This 'imagined' view can also be applied to members of an online community designed to support those with breast cancer, because the members may only have the experience of breast cancer in common, this experience providing the bridge and context to enable the 'imagining' of the manner in which others, with the same condition on the other end of the Internet connection, are feeling (Bonniface, Green & Swanson, 2006). Kozinets (2010) is of the view that online communities "... are real communities populated with real people ..." (p. 16); therefore in his view it is a reasonable conclusion that online relationships between real people can develop as they learn more about each other, through online textual interaction and photographs or videos, thereby obviating reliance on their imagination.

Rheingold (2000) who is considered to be a founding father of online communities, succinctly described them as “social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace” (p. xx). Online communion between real people can herald the beginnings of a new online community (Watson, 2013, p. 275); however the formation of an online community in this study could be problematic if insufficient numbers joined the site, or if many joined with minimal textual interaction ensuing, these interactions lacking ‘human feeling’ according to Rheingold (2000) Porter (2004) proposed a more pragmatic definition of an online community, describing it as:

“... an aggregation of individuals or business partners who interact around a shared interest, where the interaction is at least partially supported and/or mediated by technology and guided by some protocols or norms”(Defining virtual communities, para. 2).

Both Porter’s definition and Kozinets’ statement are congruent with the online community exemplified in this research study, because the community has links with other websites BCCWA and PBB having the same focus, breast cancer. This research is designed for individuals to come together to share their illness experiences in a supportive environment. From the previous discussion, and Rheingold’s (2000) description of an online community, it is also logical to conclude the possibility of online communities forming within social networks and social networking websites.

The choice of joining an online community is a very personal one and the type of community joined usually reflects the person’s intense interest or concern (Rheingold, 2000). The researcher in this study was cognisant of this matter; therefore the website was advertised as being for members only, who were individuals with breast cancer, and their supporters.

It is acknowledged that there are numerous online breast cancer support communities, the online interaction of the members having been the focus of a number of research studies (Batenburg & Das, 2014; Blank, Schmidt, Vangness, Monteiro, & Santagata, 2010; Han, Kim, Yoon, Shim, McTavish, & Gustafson, 2012; Hersh, 2011; Kim, Han, Shaw, McTavish, & Gustafson, 2010; Sillence, 2013). Often the information and advice shared is based on the individual’s experiences with their

diagnosis and treatment for breast cancer, and tending to be ‘see, write and share’, rather than garnering information based on evidence or research findings. Klemm et al. (2003) in a review of the literature noted that “... the quality of on-line information available can be unreliable ... (p. 140), and that “the vast majority of online cancer support groups do not have a professional facilitator” (p.139).

Online breast cancer support groups have evolved, often being integral to the websites of government or non-government fund raising organisations, such as, Breast Cancer Care UK (Breast Cancer Care UK, n.d), Aussie Breast Cancer Forum (Aussie Breast Cancer Forum, 2005) and Breast Cancer Network Australia (Breast Cancer Network Australia, n.d.). Although these sites may provide members with access to health care professionals, such as a specialist breast care nurse, through scheduled online chats or personal telephone calls, nurses did not appear on these sites as ‘regular’ members of the online support community.

Specialist Breast Care Nurses

Specialist breast care nurses, also known as breast care nurses or specialist breast nurses have for many years played an important informational, emotional and practical support role for patients at key points along their breast cancer care continuum. The Specialist Breast Care Nurse (SBCN), in Australia, is a registered nurse who is educated, preferably to a graduate diploma level, and employs this advanced knowledge of the health needs, preferences and circumstances of women with breast cancer, to optimise the individual’s health and wellbeing at various phases across the continuum of care, including diagnosis, treatment, rehabilitation, follow-up and palliative care (Yates, Evans, Moore, Heartfield, Gibson, & Luxford, 2007).

The scope of nursing practice and the related competencies of the SBCN include five core domains: supportive care; collaborative care; coordinated care; information provision and education; and clinical leadership (Yates et al., 2007). The settings in which these nurses practise are various and can include a hospital, an outpatient clinic, the patient’s home and charitable organisations, such as BCCWA.

The SBCN can be with the patient in person or offline to answer questions and allay fears both pre- and post-operatively for breast surgery, inclusive of chemotherapy and/or radiation treatment. The nurse can maintain telephone contact and/or visit the patient at home, and/or support the patient when they return to the breast care clinic for review of their condition (Beaver, Williamson & Chalmers, 2010; Benedet, 2011).

The provision of detailed information across the continuum of care reduces distress by enhancing the person's sense of control; this enhanced sense of control relieves anxiety and assists cancer patients to manage their illness (Benedet, 2011) It can be employed as a strategy to enhance the patient's health outcomes (Garcia, 2014; Hong, Pena-Purcell & Ory, 2012; Prouse, 2010).

Specialist breast care nurses do not recommend treatment but provide information and support to enable the individual to make informed decisions about their treatment (Benedet, 2011; Hong, Pena-Purcell & Ory, 2012). In effect, Benedet agrees the SBCN is often viewed as the linchpin of communication between the patient and treating doctor.

In one research study conducted by Salzmann-Erikson and Eriksson (2011) the authors describe the interaction between peers in an online community as 'nursing each other', a form of cyber-nursing of self; they cautioned against registered nurses becoming involved in the education of these communities, unless they demonstrate the ability and necessity to provide evidence-based care and self-care information. The education and competencies, previously mentioned, outline the requirements of registered nurses before they become a specialist breast care nurse, thereby minimising the concern which might be raised in relation to this research study.

The research literature concerning the role of an SBCN in an online breast cancer support community is seemingly non-existent; therefore this research study aims to fill this knowledge gap by exploring the role of the SBCN in that online realm.

Purpose of the Research

The purpose of this study is to develop a breast cancer specific, online support community to provide evidence-based information, advice and support to members and supporters, and to explore the role of a Specialist Breast Care Nurse (SBCN) as a member/moderator and facilitator of this community.

Significance of the Research

This study is significant because it has necessitated construction of an online community from the outset, for the purposes of research, which, according to the literature, has only been completed on one other occasion (Costello, 2009). In this instance, a specialist breast care nurse was employed and introduced to the online community to determine the implications of this employment for the information, advice and support needs of the community members. No literature was found that specifically referred to the employment of a nurse in an online community; therefore the insights emerging from this study will enhance and extend future nursing practice.

Aims of the Research

1. To explore the role of the Specialist Breast Care Nurse (SBCN) as a member and provider of information, support and advice in a purpose-built online breast cancer support community.
2. To expand the knowledge related to cancer nursing practice.
3. To offer an alternative method of gleaning and understanding health information related to the breast cancer care continuum for those with breast cancer and their supporters.
4. To develop elementary guidelines for nurses who wish to implement an online illness specific support community.

Research Topic

To explore the role of a Specialist Breast Care Nurse (SBCN) in a breast cancer specific, online support community both as a member and an expert nurse employed to provide evidence-based information, advice and support for members and their supporters.

Subsidiary Questions

- Do individuals with breast cancer self-report the use of blog writing and structured written emotional expression methods (SWEE) as assisting personal coping, and what is the role of the SBCN in this situation?
- What embodied knowledge about breast cancer can be shared in the disembodied realm of an online support community?
- Can members of an online social network be used to ‘seed’ an online community?

Methodology and Theoretical Perspective

The chosen approach for this study was blended ethnography/netnography, hereafter referred to as ethnonetnography, a qualitative, participant-observational research methodology based in online fieldwork. Kozinets (2010), who first coined the term netnography, has since designed a model that shows a finely balanced continuum with pure ethnography at one extreme, and described as research consisting of entirely face-to-face cultural interaction and data collection, to pure netnography, described as research whereby the cultural interaction and data collection is entirely online at the other. The balance of these two approaches at the centre of the continuum is ethnonetnography. This is a blend of offline and online cultural interaction and data collection enabling the use of a combination of online and offline research techniques (see *Figure. 1*)

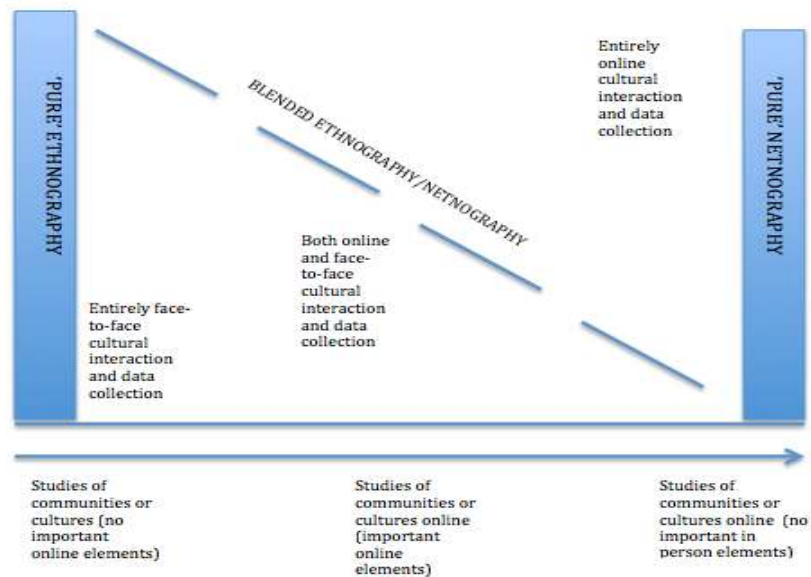


Figure 1. Coordinating online and face-to-face interaction and data collection (Kozinets, 2010, p. 67)

This approach provides a holistic view of online community members, both individually and as a group, in keeping with the perspective proffered by pre-eminent breast cancer researcher Orgad (2009). She contends:

offline and online data to be vital to the understanding and meaning of this communication, because the patient’s online participation is deeply embedded in their everyday experience of chronic illness, and if we are to understand the patients’ online contexts, we clearly have to acknowledge their offline contexts; that is the everyday life aspects of coping with breast cancer (pp. 38-39).

The employment of ethnonetnography was appropriate to this study, which explored the introduction of a specialist breast care nurse (SBCN) to a purpose-built online support community for individuals with breast cancer and their supporters. This research methodology allowed the exploration of the role of the SBCN, to develop freely, being well supported by an ‘interpretive and naturalistic perspective’ (Crotty, 1998, p. 5). This allowed the researcher to gain insights into the ‘social realities’ of the

online community members and apply a constructionist view of epistemology, which according to Crotty recognises that research participants construct their own meanings (p. 5).

Importantly, the immersion of the researcher in the online community differed from traditional ethnographic immersion in two ways. First, entry to the community and consequent interactions occurred mainly online; and second, the website was purpose-built as part of the study, having the aim of fostering a member-to-member online support community, which hitherto had not been established prior to the researcher's investigation. The researcher was 'immersed' in the community from the launch of the website, thus removing the need for a request to join the community and conduct the research. This is an *entrée* requirement of researchers when they seek entry into an already established online community Kozinets (2010).

Immersion for the researcher began with input into the design, development and launch of the website, with the mandate of building an online community through text-based communication. This was followed by online participation in the website as moderator and researcher, this being integral to the community processes and interactions when conducting this study. Immersion in the online culture revealed insights into the emotional elements of the study. Members of the online community with a breast cancer diagnosis and their supporters experienced emotions that challenged their perception of 'self' as wives and mothers, husbands and friends, all facing the potential loss of a key member of the family, life partners or friends.

A variety of methods was used to collect the data necessary for a comprehensive view and analysis of the phenomenon in this study. These included online surveys, participant-observation integral to the netnographic process, a focus group and in-depth interviews. Additionally analysis of the member posts to all areas of the purpose built online support community occurred. Participant-observation ensures the researcher is actively involved as a peer member of the online community and observes, records, analyses and interprets all relevant occurrences in the computer-mediated, online community. The focus group deployed was a semi-structured, researcher-to-group interview, semi-structured because, although the researcher has a list of topics or open-ended questions planned, the ensuing discussion did not preclude new topics or issues

raised. The aim of a focus group is for the researcher to gain insights into the manner in which the stakeholders view the issue or setting, while the participants are given the opportunity to discuss the issue from their own perspective while being alerted to the feelings of others (Ivey, 2011).

In this study, a focus group was conducted to elicit information specific to the design, utility and informational content of the website. The social processes of the website facilitated live chat, instant chat, blogs, home page or wall posts, forum posts, photo and video uploads and private messaging thereby providing online community members with numerous means for interacting with other members online. The ethnonetnographic methodology encompassed the collection of both online and offline data collection and the methods activated to collect necessary data. The triangulation of data were facilitated, enhancing the validity of the findings.

In order for ethnonetnographic methods to explore the role of the SBCN as a key component in filling the communication gap in the breast cancer continuum of care for the individual with breast cancer, the study was divided into three phases using a variation of Kozinets' (2010) netnographic research model comprising five steps,. The three phases incorporated in this study were: (1) research planning and website development incorporating ethical considerations and procedures; (2) community participation and observation including the introduction of the SBCN to the community; and (3) data collection interpretation and documentation of research outcomes. The researcher was also cognisant of ways to combine ethnography with netnography and was knowledgeable about the online social environment being a source for revealing the cultural context of diagnosing breast cancer.

Research Phases

Three six-monthly research phases were planned for the study. These phases were (1) planning and development of the website prototype; (2) community participation, observation and data collection; and (3) data collection and analysis. An overview of these phases of this research study compared with Kozinets' five netnography research steps is provided in Table. 1 of Chapter Two. It shows that the five steps of Kozinets (2010, p. 61) netnography method are incorporated into three

phases to enable a better comparison with the research phases of the current study. These netnographic and ethnonetnographic research phases will be fully discussed in the next chapter.

Researcher's Position

The researcher's entree and immersion into the community as an ethnonetnographer was partly influenced by a background in nursing, as some knowledge of the effects of breast cancer on individuals and families developed through experiencing the deaths from secondary breast cancer, her grandmother and aunt approximately six years prior to the commencement of this research study. The researcher was not an 'expert' nurse concerning the online community, as this was the role of an SBCN employed specifically for that purpose. The researcher's knowledge of breast cancer and its treatment increased exponentially through reading the posts, and chatting on and offline with the SBCN:

The researcher had experience of the Internet through the social networks Facebook and Instagram and had completed numerous online searches for health information, with a focus on finding research trials that were seeking participants who had pancreatic cancer and someone with the same diagnosis as her late husband to chat with online. The largest provider of information on pancreatic cancer at that time (2008) was www.pancan.org but its online interactive facilities were limited. The information on this site was clearly evidence-based and very useful, but unfortunately a 'feeling' of being welcomed and supported was not felt because the researcher could not interact online with others on this site (Pancreatic Cancer Action Network, n.d.)

The above feelings attracted the researcher to this study that concerned people with breast cancer, the main research question reflected the needs of a nurse, to be a useful interlocutor, through an Internet connection, for those who needed information, advice and support about their life-threatening illness. This research would provide a template for the development of a similar online community designed for those with pancreatic cancer. This intense interest, 'a passionate concern' is a reflexive research process described as 'reflexivity as introspection' by Finlay (2003, p. 6). The researcher had discovered this research study at a time when a personal and professional

commencement of new challenge was being sought. In essence this research study was the starting point for becoming a person deeming to become a serious researcher, both as a nurse and a newly widowed woman, with all the accompanying stressors both personally and professionally those circumstances generate. Some critics might say that this was not an appropriate time to commence this research but each of these facets contributed to a life online and offline, and the positive development as a researcher and a person because of being able to understand and share, partially, at least at some level, the Clickers breast cancer stories Parker (2003, p. 6).

From the experience of being a supporter of a person with cancer the researcher had the self-belief of empathising with the supporters, who were engaged similarly for their loved ones with breast cancer. However, she had no experience as a participant in an online community dedicated to the advice and support of people with an illness. This was a whole new experience and would be for many members of the proposed online community.

The role as researcher/ ethnonetnographer, member, participant-observer, analyst and reporter was created before the online community was born, and personalised later during and after the employment of the SBCN. The researcher's challenges from the outset of this investigation were to understand and interpret online and offline data in order to answer the research questions posed and formulate guidelines that would assist another person to develop an illness-specific, online support community. Thus the need was to be reflexive as a researcher by continually analysing the research processes implemented and the ongoing conclusions made, as well as shining a critical light on the researcher's conduct of the various analyses (Markham & Baym, 2009, p. 143).

Ethnonetnographic methodology was chosen for this research study; however, other methodologies focusing on how the researcher is situated and acts within an online research context were also applicable. Three of these methodologies: passive analysis, active analysis and self-identified active analysis articulated by Markham and Baym (2009) were examined in relation to this study and the researcher's position

Passive analysis involves understanding how information and textual interactions are exchanged in the online community without researcher participation. Active analysis occurs when the researcher is an active participant in the exchange of online dialogue. Self-identified active analysis, is achieved when the researcher identifies themselves and their research interests, before entering the website (Markham & Baym, 2009). These analytic methodologies are usually applied to netnographic research conducted in an already established online community, whereas this research involves a website purpose-built from the outset. Nevertheless, these research methodologies - have relevance to this research study as explicated below.

The members' only website was designed to appeal to individuals with breast cancer and their supporters, with the hope they sufficiently identified to join and to interact with other members regularly, and interacted often enough, long enough, and with enough human feeling to be accepted as a member of the online support community. Thus the passive analysis involved joining similar breast cancer focused online communities as a supporter; and to gain an understanding of how information and textual interactions were exchanged in those communities. In particular what provisions were available and utilised, and if or how the community was moderated? Was there a health professional clearly designated and available for online interaction? Data gained from this passive analysis were complemented by data from face-to-face interviews, focus group interactions, and an online survey launched from the PBB social network. The offline research methods and the online survey were aimed at understanding the relevance certain topics of conversation to the members; days and times preferred for use online; and the type of health professional preferred in the capacity of 'information giver, advice giver and support provider' roles in the online community. Passive analysis also occurred through the research and development of the research proposal, which included question identification. Self-identified active analysis commenced immediately the website was launched through the clear identification by the researcher of the research information embedded in the membership process and the videotape on the home page. Active analysis occurred through regular online interaction with the Click members and the concurrent collection and analysis of data. The researcher became immersed, as were the new members, in an online life, a life that

for one member resulted in a significant change in their offline life. The latter is further explicated in Chapter Four of this thesis.

The online life of the researcher as a very active participant and moderator, took place in the early stages of the development and formation of the online community; this became more observer and less active participant, when the SBCN became the central figure and provider of evidence-based information and advice. The balance of the researcher's role shifted naturally from equal parts participation and observation to a greater emphasis on observation once the SBCN was familiar with online activities. This was a necessary manoeuvre to enable the 'screen' to be a 'clean slate' upon which member/SBCN interactions could be written, observed and analysed without the role of the researcher becoming involved too obviously. The researcher's personal messages of encouragement and infrequent attendance at chat sessions maintained the peer support role on the Click.

The researcher/ moderator position ensured access to all member data and saved the transcripts of the transitory digital trails left by Click Chat sessions, selected popup chat sessions, and personal messages for application in the study. Markham, an early netnographic researcher of online communities, refers to her lived experience as a member and researcher in an online community in Kozinets (2010) as being, "simultaneously a tool, a place and a way of being" (p. 30). This is a realistic and apposite way to describe the researcher's life both online and off during this study.

Offline interaction with members who chose to participate in a focus group or interview, conducted in the member's home, and field notes gave further anecdotal insight into the member's everyday life; but this background information has not been used as data in this study.

Ethical Considerations

The ethical focus of ethnonetnography, initially introduced in the marketing environment, is on the prevention of any ill effects to online consumers of goods and services in already established online communities (Kozinets, 2010). The use of

ethnonetnography in this study however, focuses on the physical and virtual construction of an online support community of and for individuals with a specific illness who, although seen as consumers of health information, advice and support, are not consumers of products. Therefore, the ethical considerations differ in some respects from that applied to a traditional netnographic study (Bowler, 2010).

In keeping with Kozinets (2010) stance on ethics, the researcher disclosed fully any presence, affiliations, and intentions to the potential online community members through information provided prior to them joining the community and again during the membership process (Appendix A and B). Links to information about the research study were also embedded in the website (Appendix C).

The researcher took steps to ensure the privacy and anonymity of informants. To report on the outcomes of this study, cloaking was used to protect the privacy and anonymity of the research participants. Cloaking is the term used metaphorically by Kozinets (2010) to describe the covering of the identity of online participants' to ensure that they are not recognisable. He refers to four levels or types of cloaking: uncloaked, minimum cloaking, medium cloaking and maximum cloak (Saddatdoost, Sim, Mittal, Jafarkarimi, & Hee, 2014). Uncloaked means the pseudonym or real name of the research participant is included in the research report. Minimum cloaking infers the name of the online community is given but usernames and real names, if used, are changed and verbatim quotes are utilised in the research report. Medium cloaking in the online community portends no naming and no usernames or real names are used. Maximum cloaking ensures the online community is not named, all participant names are altered and no verbatim quotes are used (Kozinets, 2010, p. 154).

In this investigation, minimum cloaking was chosen whereby the name of the community was known but no real names or usernames were used. It was chosen because the online community was clearly designated as a research community for those with breast cancer and their supporters, and the research participants voluntarily chose to become members of the community. Verbatim quotes were used in order to demonstrate the theoretical concepts that arose from this study. The researcher also 'member checked' with the SBCN regarding the accuracy of the conclusions drawn

from the data, specifically, the conclusions made about the deceptive behaviour of one online community member. This behaviour is discussed in detail in Chapter Four of this study.

Minimum cloaking of the participant's identity was applied in two different ways. Firstly, participants were referred to by their membership status, that is, as person with breast cancer is designated BC, or a supporter is designated BC (S). Secondly, Clicker BC and Clicker S were used alternatively or their username was changed. These cloaking methods were aimed at minimising the possibility of harm through identification occurring to the online community participants.

Kozinets (2010) also suggests the researcher should take a cautious position on the issue of whether the online environment is a private or public medium. It is commonly understood by Internet researchers that webpages are free to access without a password should be considered as public (Salzmann-Erikson & Eriksson, 2012). The online community in this study was designed for members only and password protected; therefore it was considered as a private medium. However, it was acknowledged by the research that some individuals, untruthful about their membership particulars, could join the community and access other members' textual data, all except members' private blog posts. Blogs are deemed private by the member's selection of 'just me' in the privacy and comment privacy drop-down boxes on their blog page. This prevents the website search engine from showing the blog in the blog list and/or other members reading or commenting on the blog.

The private, members only, status of the research website and the synchronous interaction occurring through instant chat and chat room sessions, meant that all participants were required to complete informed consent forms (Appendix C, D), thereby indicating acceptance and understanding of the research study requirements. Informed consent was sought of participants online during the membership process and in hard copy before participation in offline, face-to-face interviews or focus groups (Appendix A). Consent was also incorporated into the online surveys embedded in the PBB website and in the new website. The researcher was overtly and clearly situated in the online field from the launch of the new website.

The proposal for this research study was submitted to and approved by Edith Cowan University Human Research Ethics Committee. Having secured ethics approval, the interview and focus group participants, who had been identified through the BCCWA and PBB staff, were contacted and mutually agreed arrangements for completion of these activities made. The participants were advised of their right to reconsider their involvement in the study at any time. Each interviewee and focus group participant was advised of the aims of the research study and the part they could play. Adopting the following strategies safeguarded the human rights of all participants in this study.

It was clearly indicated to the research participants that they:

- Had the right to withdraw their consent for involvement in the research and they could voice concerns, or make comments at any time during their participation.
- Had the right to withdraw from the interview or focus group and/or request the researcher to turn off the digital recorder.

Adopting the following measures protected the privacy and confidentiality of each participant:

- Interviews were held in the interviewee's home or a place, mutually agreed to by the researcher and interviewee.
- The focus group was held in a university venue
- The use of pseudonyms or generic names such as BC or BC (S) in the study.
- Digital recordings and transcriptions of data were kept on a password protected computer, and hard copy de-identified information pertinent to the study was kept in a locked filing cabinet and will be destroyed by incineration five years from the time of examination of the thesis, as per the University's Research Record Keeping policy.
- Online data, screen grabs and chat transcripts were stored on a password-protected computer, which can only be accessed by the researcher.

- No information about the participants will be revealed to people unless written authorisation is gained from the participant. The information was obtained solely for the purpose of this study.

The participants have the right not to be harmed in any way during the course of the study. The focus groups and interviews may cause the participant some distress over what may be revealed of their experiences with breast cancer. The researcher was prepared for individual emotional responses to the study experience; therefore they were advised of access to BCCWA counsellors, the breast cancer support line or Lifeline if required.

Participant Selection

The numbers of participants in offline interviews and focus groups could be predetermined to some extent, but the number of online participants could not because there was no way of knowing how many would join the website or the volume and type of interaction that would fulfil the description of an online community. The researcher explained the purpose of the study to interested groups and individuals who had breast cancer, or supported others who had breast cancer, before inviting them to participate in an interview/conversation, designed to elicit data to address the study questions and to join the website when it was launched. This was in line with (Sandelowski, 2000) belief it is imperative to a qualitative approach that it focus in depth on participants who demonstrate the criteria required to answer the study questions.

To gain the theoretical saturation required to enhance rigour in interpretive research, it is important that participant inclusion continues until the researcher is reasonably satisfied that all possible issues and/or aspects for analysis have been revealed. In relation to a research study conducted in an online community, theoretical saturation is dependent on the number of members that constitute the online community; the number and content of the posts; and the regularity of these online textual interactions (Salzmann-Erikson & Eriksson, 2012). The authors further asserted that "... even if a minority of posters contributes to a majority of the posts with a low frequency of postings, the data might be useful" (p. 258). These researchers were referring to a research study conducted purely online or pure netnography as described

by Kozinets (2010). Whereas this study incorporates face-to-face interviews, focus groups, surveys and online textual data. In short, the study used a combination of research methods better described as an ethnonetnographic methodology, which is centrally situated in Kozinets' netnographic continuum. This research methodology was employed to obtain a holistic view of the online support community culture and to explore the role of the SBCN in that community.

Participants

The research participants were individuals with breast cancer and those that supported someone with breast cancer. These individuals participated and contributed information offline during the planning and website development research phase and data analysis phases, and online during the community participation and observation data analyses phases. At the conclusion, the study had 420 members; however only a small core group of 25 members had interacted regularly online with sufficient warmth as described by Rheingold (2000), for the Click to be considered an online support community.

SUMMARY OF CHAPTER ONE

This chapter has introduced the concepts and literature pertinent to this research study, including a discussion around the meaning of the term 'online community' and how online communities can benefit individuals with breast cancer and their supporters. The need for a breast cancer online support community in Western Australia can be interpolated from statistics showing one in eight Western Australian women will be diagnosed with breast cancer, and that current information, advice and support is primarily face-to-face and telephone occurring within usual working hours. The BCCWA breast cancer charity and PBB social networking sites are introduced as the 'parent' websites that enabled the formation of the new online community.

The work of a SBCN in the offline health care setting is outlined, together with the importance of accurate health information and how this can contribute to the care continuum of individuals with breast cancer and their supporters. This research study charts the purposeful design and build of the website, followed by the development of

an online support community. The main research question derived explores the role of an SBCN in this breast cancer focused online support community.

The researcher's background as a registered nurse and previous supporter of a relative with breast cancer has been noted and underpins the role as a researcher who is cognisant of the necessity to incorporate reflexivity into the research processes. The ethical perspectives relative to online research and the procedures to protect the research participants, including the cloaking of the participant's online identity to protect their anonymity, are discussed.

The ethnonetnographic research methodology that resides at the centre of (Kozinets, 2010) continuum of netnographic research methodology, and the research phases of this research study are then contrasted and compared to those delineated by Kozinets. This thesis continues in Chapter Two with further illumination of the methodology used in this investigation.

Chapters to Follow

This thesis is presented to meet the requirements of a thesis with publication. The eight papers in this thesis include four that have been published, two in press and two submitted for publication. The papers are listed below in the order that they appear in the thesis:

Witney, C., Hendricks, J., Cope, V. (2015) Ethnonetnography: A variation of Kozinets framework and its application to nursing research. Submitted to *Nurse Researcher*

Witney, C., Green, L., Costello, L., & Bradshaw, V. (2012), Building an online community in the context of an existing social network site. Paper presented at and published in the *Proceedings of the Eighth international conference on Cultural Attitudes towards Technology and Communication 2012 (CATaC)* 18-20 June, Aarhus, Denmark.

Bradshaw, V., Witney, C., Green, L., & Costello, L. (2012). Embodying knowledge of breast cancer in a disembodied community? *M/C Journal*, 15(4)

Costello, L., Witney, C., Green, L., & Bradshaw, V. (2012). Self-revelation in an online health community: Exploring issues around co-presence for vulnerable members. In C. Anyanwu & K. Green (Eds.), *Proceeding of the 2012 Australian and New Zealand Communication Association Conference*. Adelaide: Australia.

Witney, Cynthia, Lelia Green, Leesa Costello, and Vanessa Bradshaw. Creativity in an Online Community as a Response to the Chaos of a Breast Cancer Diagnosis, *M/C Journal*, 16(1) (Mar. 2013).

Witney, C., Hendricks, J., Cope, V. (In Press) Munchausen by Internet in an online, breast cancer support, community: An ethnonetnographic case study. *International Journal for Nursing Care and Practice*

Witney, C., Hendricks, J., and Cope, V. (In Press) The specialist breast care nurse within a netnographic online support community: adding the 16th moment of cancer care *International Journal of Human Caring*.

Witney, C., Hendricks, J., Cope, V., (2015) The specialist breast care nurse's role in the identification and minimisation of distress in a members' only, breast cancer focused online support community. Submitted to the *International Journal of Nursing and Clinical Practices*.

The first paper in Chapter Two concentrates on ethnonetnography, the methodology used in this study and its appropriateness to nursing research together with a description and comparison of this study's research phases with those of netnography as described by Kozinets (2010). Chapters Three and Four feature papers that arose from the building of the Click website and participation in and observation of, the textual behaviour of the Click members (Clickers). Chapter Five provides the conclusion to the thesis and consists of a summary of each phase of the research and the conclusions drawn in reference to the research questions. This is followed by the limitations of the research, implications for current and future nursing practice and recommendations for further research.

Chapter Two

Introduction

Chapter Two provides an in depth explanation of the methodology employed in the three research phases of this study, a summary of the data obtained and a researcher commentary relevant to each of the phases. The phases were planning and development of the website prototype and community development; community participation /observation, and data collection and data analysis. These phases are contrasted with the five netnographic research steps proposed by Kozinets (2010), an overview of the variations from Kozinets' is provided in Table 1.

This is followed by a paper demonstrating the efficacy of ethnonetnography as a research methodology suitable for deployment in nursing research.

The key variations between the Kozinets' (2010) steps and this research study were: firstly, this study commenced prior to the website being built then entailing the development of an online community, whereas Kozinets' research process involves the identification and selection of an already established online community to study. Secondly, entrée and immersion in the community were not a primary consideration in this study because the researcher was already a member of the online community unlike Kozinets' process, which required deliberation as to entrance to an established and a selected online community. This difference was significant due to the time spent in the setting up of the purpose built website. Her steps at the outset refer to the identification of a suitable online community to study, together with an appropriate method of entry to the community. Thus, building a purpose online community, whilst challenging, was less time-consuming and ensured participants met the inclusion criteria, the researcher being acknowledged as an integral member of the community, thereby ensuring immersion in the community was achieved.

Table 1

Summarises the three phases in this study compared with Kozinets' five netnography research steps

	Research Model - Netnography Steps Kozinets (2010)	Research Model - Ethnonetnography Phases (Variation of Kozinets (2010) steps)
Phase I	Planning and Entrée (Steps 1,2) Planning of research study including development of questions and identification of online community and how the researcher should enter it.	Planning and development of the online community based on both online and offline data collection and analysis. The researcher is a founding member of the purpose built research website, therefore entrée is not required but online communication and participation with the members is essential for the formation of an online community. Ethical considerations and approval by ethics committee.
Phase 2	Data Collection (Steps 3,4) Communication with members and participation in the community. Decisions made about data collection and storage based on the size and type of data available. Data collection and data analysis are intertwined. Ethical procedures	Community Participation/ Observation and Data Collection. Continued online communication and participation in the community. Introduction of Specialist Breast Care Nurse to the online community; concurrent data collection and analysis.
Phase 3	Data Analysis (Step 5) Two types of analytical processes, analytic coding-based and hermeneutic interpretation. Iterative interpretation of findings. Research findings written and reported and/or theoretical and/or policy implications	Data Collection and Analysis Collection of more offline data, synthesis with online data, content analysis of the data, theme identification, inductive analysis and hermeneutic interpretation of the research questions. Findings and/or theoretical and/or policy implications documented

The following discussion of the research phases in this study will further demonstrate the variations to Kozinets (2010) netnographic steps.

Phase 1: Planning and development of the website prototype

The first phase of this research study entailed the planning and development of the online community. Planning began with the development of a research proposal, including a literature review, background to the research, aims of the research and the research questions. This is similar to step one, Kozinets (2010) planning and entrée) in her netnographic research process, the research questions having been decided in this phase. However, rather than identifying an online community to research and then gaining entry or entrée to the community, the construction of a website and development of the online community was encompassed in phase one. Ethical considerations and the University Human Research Ethics Committee's approval, pivotal to the research proceeding, was sought and received in phase one. Kozinets manages ethical considerations in step four prior to data collection, because the identification of an online community does not impact ethically, on the online community members in his research study. It is only when netnographic entrée to the community, data collection and documentation methods are considered that Kozinets' addresses ethical issues relevant to the researcher's identity, the research topic and the members' privacy.

Once ethics approval was received phase one of this research commenced. This involved the gathering of background information from potential members of the proposed website, that is, individuals with breast cancer and their supporters, regarding their information-seeking behaviour, their information, advice and support needs; and their Internet usage. This was completed by face-to-face interviews, a focus group and an online survey. The interview and focus group question protocols and online survey questions were prepared, submitted to and approved by the University Human Ethics Committee before the research activities commenced.

Interviews

The interviews were conducted prior to the final formulation of the survey, so that the face and content validity of the survey questions could be established prior to the survey protocol being posted online. In essence, the survey was piloted before an online link was forwarded to the PBB members requesting their participation in the research and to complete the survey. The email included an overview of the research

and the online survey itself incorporated an informed consent section, which each participant must agree to before continuing with the survey (see Appendix A, B). Clicking on the submit tab at the end of the survey was also considered to be implied consent.

Invitations to participate in an interview or focus group were emailed to the potential research participants who had been identified by BCCWA and PBB staff members. The email included the following attachments: a personalised invitation to attend a focus group or interview; a relevant activity information sheet; an overview of the research study; and an informed consent document (see Appendices A, B, C, D). If a response was not received in a timely manner, follow-up email/telephone calls was made to re-issue the invitation. The informed consent document could be signed and emailed back to the researcher or completed before the interview/focus group commenced, a hard copy being returned to the researcher.

Interviews were scheduled according to the interviewees' timeframes and in a convenient location. Of the eight interviews conducted, five were face-to-face in the participant's home; one was held at BCCWA and one at the university. The eighth interview was conducted by telephone. The length of the interviews varied from one to two hours, depending on the issues concerning breast cancer they wished to discuss. The interviews were digitally recorded and transcribed by the researcher, then stored on a password-protected computer.

The research cohort consisted of six females aged 38 to 61 years and one male (age in the late 30s), all of whom had been diagnosed and treated for breast cancer, plus a male supporter (age in mid 30s) of a woman undergoing active treatment for breast cancer. The interview questions commenced with an explanation of the research and its processes including informed consent and the researcher's role. If the interviewee had not emailed back a completed consent form, a hard copy was given to them and signed before the interview began.

One researcher noted that some interviewees with breast cancer, found interviews to be therapeutic because of the discussion had, about their illness with a previously unknown person who has no preconceived ideas about their condition

Cannon (1989, p. 65). Therefore, before the questions specific to the research aims were asked, a general or icebreaker question about their breast cancer experience, or that of their family member, was posed. This question served two purposes providing the interviewee with an opportunity to discuss their situation and ease into the interview situation providing the researcher with a clearer understanding of the interviewee's situation, thus setting the scene for the questions and follow up of comments or issues not identified in the formal question process. The interviewees' responses to the protocol questions go to the heart of the website design, including the information, support and advice aspects (see Table 2)

Table 2 *Interview Themes*

Aspect of the Website	Issue
Website Design and Content	It must be easy to read and understand Timely response to questions Contain a forum Show peoples stories Show where to find help e.g. financial Your rights as a patient Treatment and side-effects from diagnosis onwards Contact information for services Glossary of terms How to get started on the website
Information and Support	Support specific to carers Where to go for bras, reconstruction Provides a sounding board Peer support/validation of feelings Information is there and available when needed Someone who has been through it and knows what it is like
Health Professional	Brilliant idea especially because the service may not be available offline Provides access to correct information when it is needed Knows what is normal/abnormal Survival rate. Alternative treatment paths and consequences

Focus Group

A focus group of five participants was implemented to examine and perhaps gain a different perspective of the information, advice and support needs, and design aspects of the proposed online community website through group interaction. This study cohort comprised of; two females aged 42 and 46 years, who had undergone surgery and chemotherapy following a breast cancer diagnosis; and two females aged 36 and 61 years, and one male aged 45 years, all of whom were supporters of a patient with breast cancer. And two of whom were also employed as a SBCN and a social worker/counsellor respectively and were able to provide both a professional and personal perspective in their responses to the questions. The male focus group member supported his mother who had recently undergone treatment for breast cancer.

Each of the focus group participants provided a signed consent form or completed one before the focus group commenced. They introduced themselves, providing the group with their breast cancer or breast cancer support story. The group discussed pertinent research issues arising from these stories. This introductory phase was followed by questions similar to the interviews; the significant themes arising from the responses to those questions being tabulated in summary (see Table 3).

Table 3

Focus Group Themes

Aspect of the Website	Issue
Website Design and Content	Would like to talk online with others because doctors don't have the time Can share your breast cancer experience Lifestyle changes Where to find help example, child care Treatment and side-effects Current Information is essential
Information and Support	What to expect from treatment, like pain Alleviate loneliness when 'stuck in bed' at home alone - it's nice to be able to access someone online
Health Professional	Great to see a breast care nurse but would also like to see an oncologist, dietitian, psychologist A health professional would provide the correct information delivered respectfully

Online Survey

This survey was based on the Toronto Information Needs Questionnaire – Breast Cancer (TINQ-BC) developed by a team of researchers (Galloway, Graydon, Harrison, Evans-Boyden, Palmer-Wickham, Burlein-Hall, Ruch-van der Bij, West, & Balir, 1997). Permission to use the survey tool was sought from and given by the authors. The survey questions were amended so as to reference whether the respondent was an individual with breast cancer or a supporter. A number of questions relevant to Internet use and the types of health professionals in the online community likely to be contacted were added.

The survey items were divided into three sections: demographic details, site design and information, and advice and support needs. The content was reviewed and approved by the BCCWA specialist breast care nurses and counsellors before being piloted by patient and supporter groups; their personnel were interviewed or attended a focus group earlier in the study. The piloting of the survey provided face and content validity for the survey items and the utility of the survey process, thus ensuring any relevant amendments were made before the survey was published online. PBB members were invited by personal email to complete the survey online using the link provided or through a link on the PBB site. Information about the study was posted on PBB, and the survey button placed on the menu bar. Respondents were required to read the conditions and agree that they understood the requirements of the research project, before ticking a box in the survey to indicating consent to participate. The following summarises the survey results.

Summary of Survey Results

Demographic data.

The online survey was conducted via a link to the PBB website. Potential survey participants were identified through the PBB database and email invitations regarding completion of the survey sent to 320 people. 194 responses were received, a response rate of 60.5%, 118 respondents consenting to be part of the research study. Of those that completed the survey, 77 were individuals with breast cancer and 41 were supporters of someone with breast cancer. N = 118 in all graphs to follow.

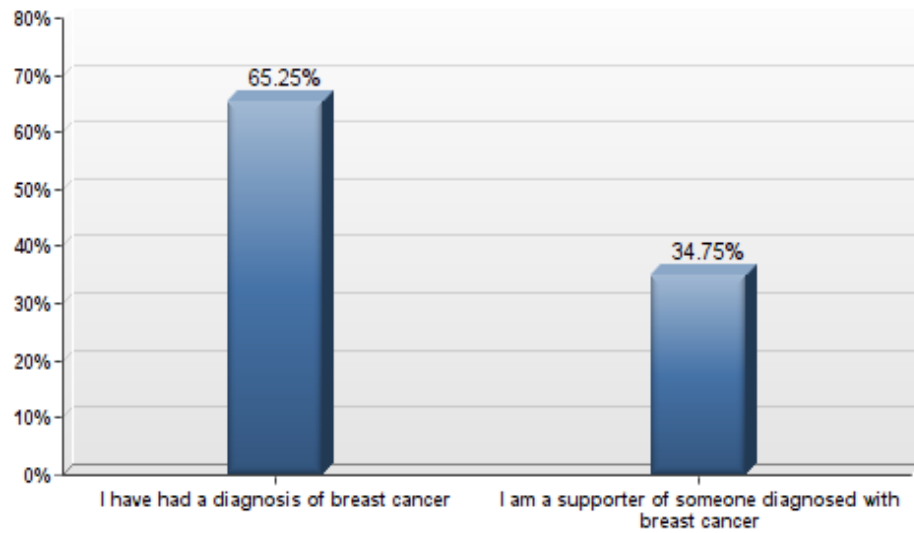


Figure 2 Types of respondents.

Ninety nine per cent of respondents were Australian, with one person from the United Kingdom and another from the United States of America. According to the postcode data, 70% were Western Australian s and 25% Eastern Australian postcodes. Five males and 113 females responded (see *Figure 3*).

Eighty five per cent of the respondents were aged between 35 and 64 years, (see *Figure 4*).

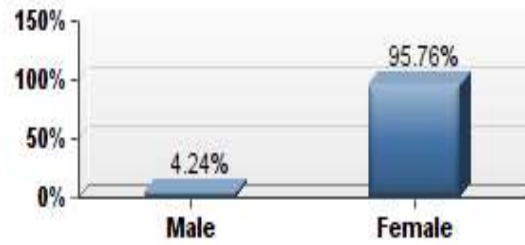


Figure 3 Gender of survey respondents

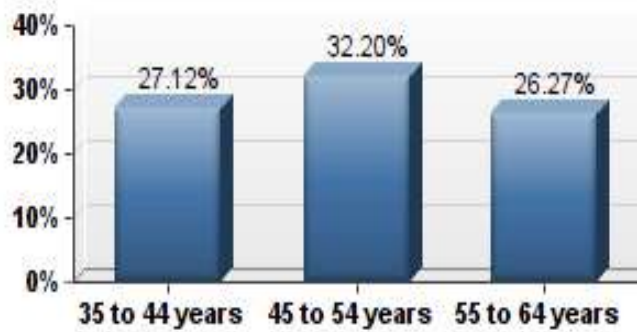


Figure 4 Respondents predominant age groupings

Responses regarding Internet use and breast cancer information and support needs (see *Figure 5*) indicates that most respondents chose the Internet as the usual source of information about breast cancer, followed by pamphlets and books.

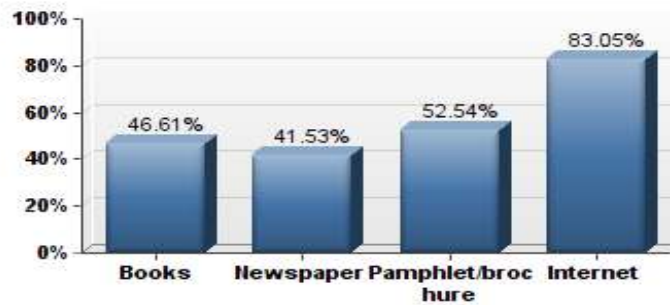


Figure 5 Usual source of information about breast cancer

The majority of respondents indicated they used the Internet daily or more than 3 times per day (see *Figure 6*)

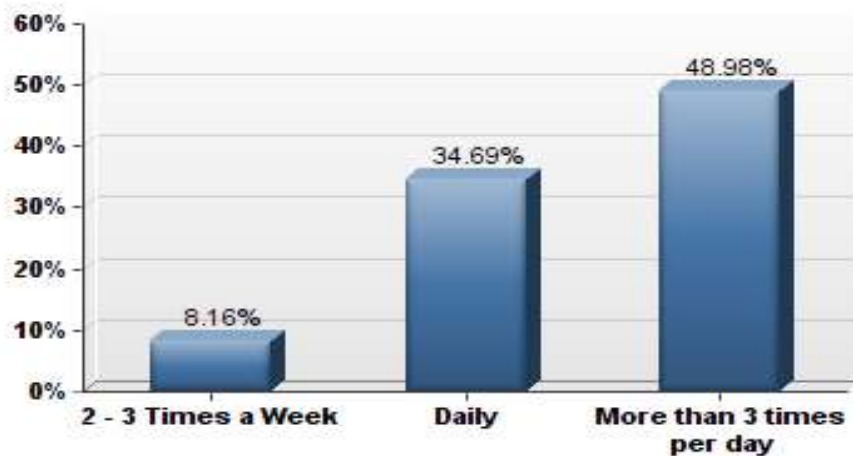


Figure 6 Frequency of Internet use

Respondents were slightly less likely to access the Internet at weekends compared to weekdays.

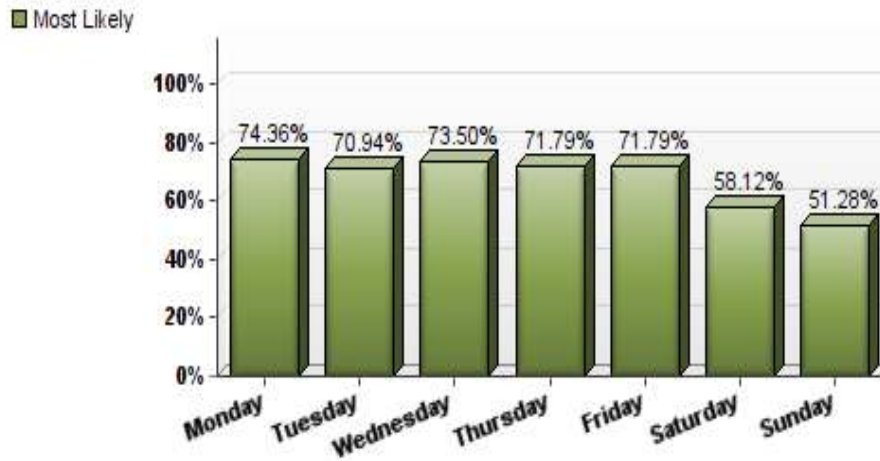


Figure 7 Days of the week most likely to access the Internet

Evenings were chosen as the part of the day respondents was most likely to access the Internet for online support.



Figure 8 Part of the day you would be most likely to access the Internet

The features respondents preferred to see on the proposed website were online advice and support, breast cancer information, and event information. .

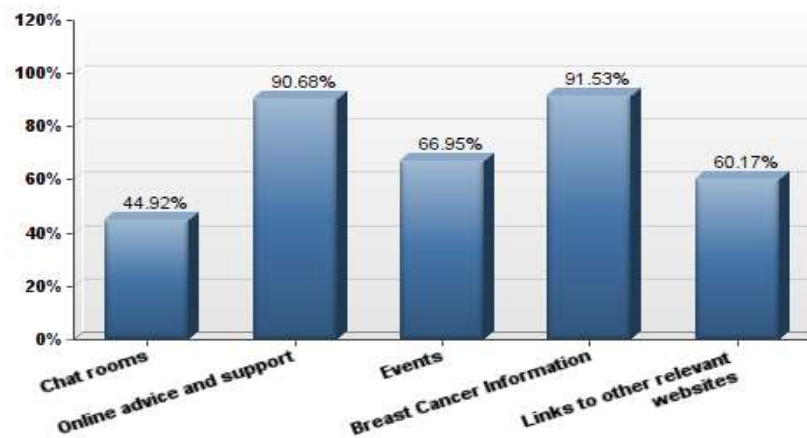


Figure 9 Preferred website features

A doctor, particularly an oncologist, was chosen as the preferred provider of breast cancer information online, followed by a nurse and a counsellor. A person/survivor of breast cancer was listed the fourth most important person from whom to obtain online breast cancer information.

■ 1

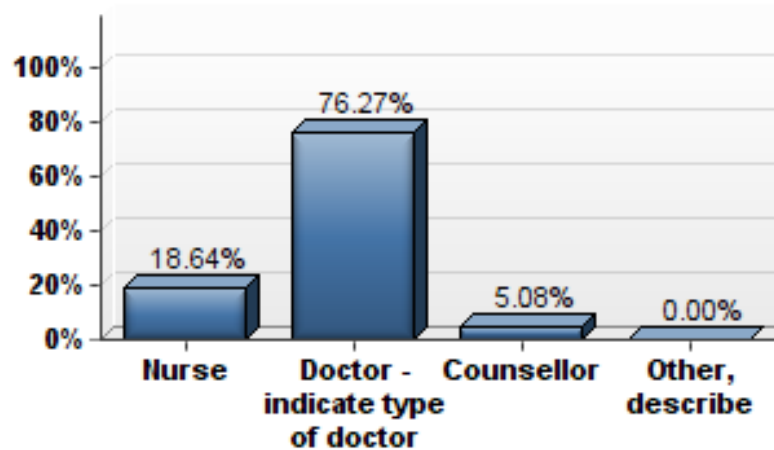


Figure 10 Preferred provider of online information

The respondents chose a nurse as the person they would most prefer to provide online support followed by a counsellor, thence a person/survivor of breast cancer.

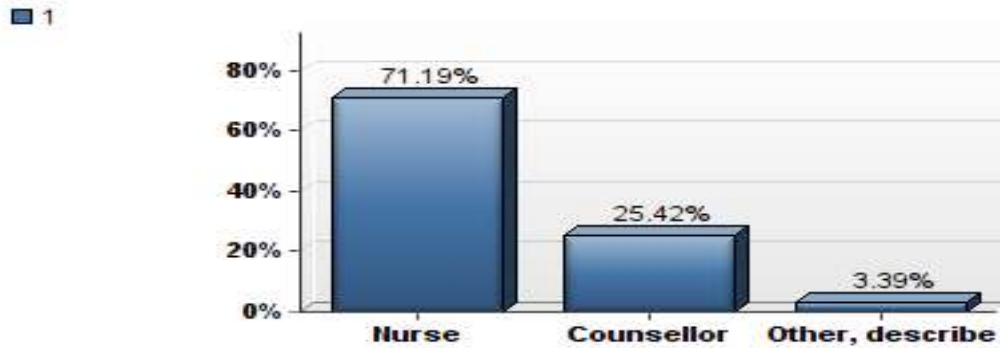


Figure 11 Preferred provider of online support

The information and support needs of those individuals with breast cancer and their supporters are noted in the following paragraphs.

Individuals with breast cancer

The four extremely important topics chosen for online information were seeking information about the types of treatment available so that the respondents could make an informed choice, information about what a treatment would be like, coping with the anxiety associated with treatment, particularly surgery, and the necessity for long term treatment such as Tamoxifen.

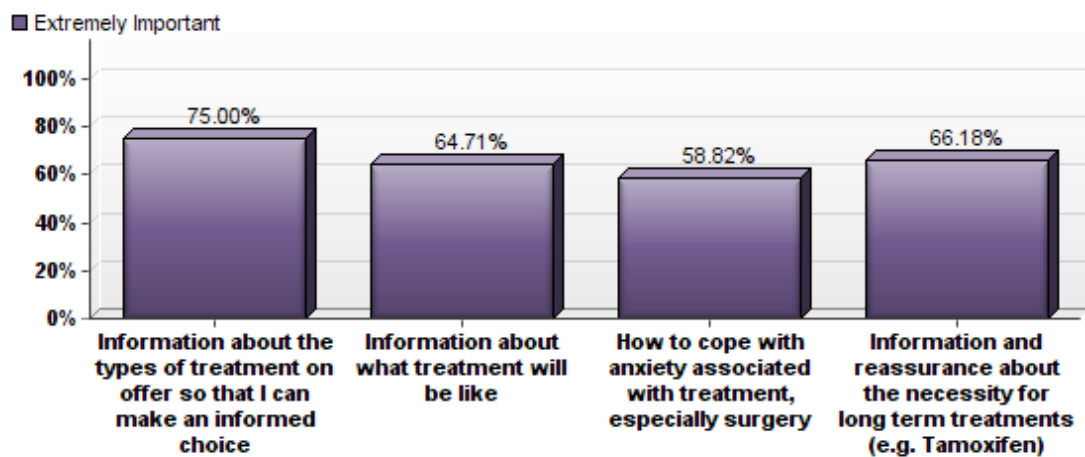


Figure 12 Extremely important information needs of individuals with breast cancer

With regard to their support needs the survey respondents chose the following items as their extremely important support needs: being treated as an individual and having the attention of a specialist breast care nurse; being reassured that kind of symptom which manifests itself is not necessarily cancer; and getting on with life again (see *Figure 13*).

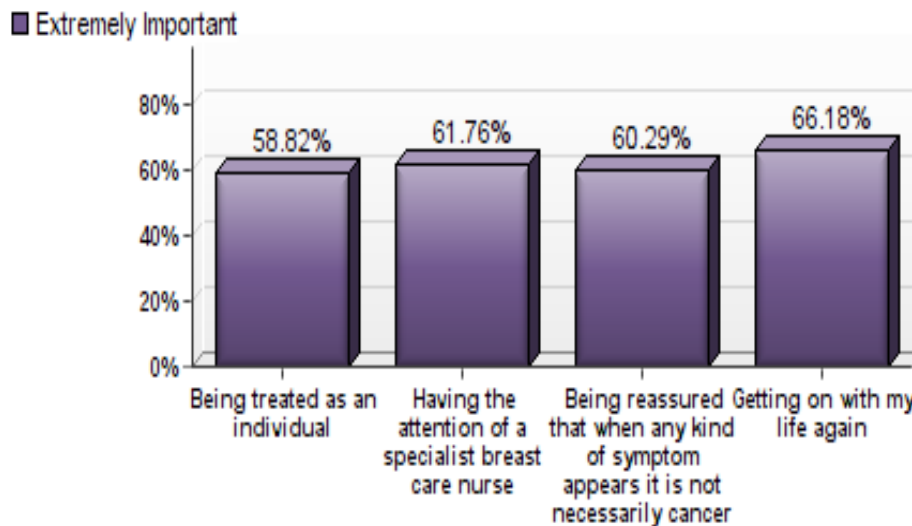


Figure 13 Extremely important support needs of individuals with breast cancer

Supporters

The information and support needs of the family and friends (supporters) were similar to those identified by the individuals with breast cancer with one important difference, the supporters' feelings of loneliness and isolation as a result of their partner/friends breast cancer diagnosis and treatment. Research has shown supporters of individuals with breast cancer to suffer as much stress as the patient (Bigatti, Brown, Steiner & Miller, 2011; Bevans & Sternberg, 2012; Proot, Abu-Saad, Crebolder, Goldsteen, & Luker, 2003).

The survey results together with interview, focus group and the later user group discussions comprised data used to identify the following: breast cancer resource material to include on the website; the scheduling of live chat sessions; and the development of the health professional's duty statement. A specialist breast care nurse was to be sought to work in the online community, as the research budget could not

stretch to the employment of a doctor, although guest appearances online were possible. The collection and analysis of data from individuals in their offline or face-to-face world revealed the beginning of what, in this research study, would become the intertwining of the offline and online social worlds as described by Kozinets (2010, p. 163). The next section of this planning phase was the development and launching of the website leading to the formation of a small, yet vibrant, online support community.

Website Design and Development

Phase one of the study reflects Kozinets (2010) netnography Step 2 - Community identification and selection, with two major differences. Firstly, the type of online community had already been identified, and secondly, the website comprising the foundation stones of the community interaction would be built from scratch. It was to be a breast cancer focused online support community with data obtained from offline interviews, focus group and an online survey of potential community members employed to inform the design process. Invitations to members of an online social network, PBB, and BCCWA clients to join the website would follow, and it was envisioned these members would form the basis of the online community. This idea did not ignore the possibility of others joining the community after identifying the support community through an Internet search. All members would be welcomed providing they indicated in the membership process that they either had breast cancer or were a supporter of someone with breast cancer. The website was to be clearly designated as a research site and members were required to read the research study information and agree to participate before they were admitted as members.

The researcher and the website designer met frequently over the following six months to discuss and consolidate a website design brief. The design process was not without its challenges. The researcher was a novice who had some ideas about what would be appropriate to have on the site based on the use of similar sites and existing academic knowledge. In contrast, the website designer and the research supervisor were experts in the community web design field, knowing what could actually be achieved from technological and budgetary perspectives even though they were not familiar with the relevant literature. To reach a consensus on the website features, the experts had to share their design knowledge with the researcher who to learn the basics

of online community interaction using the features incorporated into the website quickly.

The domain name or user related link (URL) of the website had the potential to be a major issue there being numerous breast cancer support websites with a variety of names incorporating breast cancer or a euphemism for breasts in their URL. One more URL could simply get lost in space. The question was how could this site stand out from the others and attract people to join? The team suggested clever names such as 'Bosom Buddies' and 'Breast Friends', together with more mundane titles such as 'Breast Cancer Care' or 'Breast Net', but all were found to be in use already. Finally, an academic co-supervisor suggested the name Breast Cancer Clique. The URL of which signified to Internet searchers that this website concerned breast cancer suggesting some exclusivity through the use of the word 'clique'. The website had been designed exclusively to meet the support needs of people with breast cancer and their friends or family, so this name appeared appropriate. The website design team discussed the name and agreed it to be an apt depiction of the website's mission, but considered the term 'clique' was not in common use should be changed to 'click'. This minor change did not affect the connotation of exclusivity and 'to click' was appropriate to its usage.

The information technologist conducted a search of all Internet domain names reporting no Breast Cancer Click was to be found. Both Breast Cancer Click.com.au and Breast Cancer Click.com became the registered domain names of the new website. The registration of two domain names ensured that, if the services provided were well received, and the BCCWA budget allowed, the worldwide domain name BreastCancerClick.com could be used in the future. The website name was quickly shortened to 'the Click' by all team members and relevant functions of the site were named accordingly, such as the 'Click Chat' for live chat and Clickers for members.

Once the domain name was established the researcher prepared and uploaded the documents necessary for the smooth operation of the site. These included terms and conditions of use, privacy, code of conduct, research information and a certificate of consent, linked to the membership process and embedded in each webpage (see Appendices A, B, C, E, F) The membership process also required the applicant to

indicate their distress thermometer score (see Appendix G) A glossary of breast cancer terms and acronyms, and a list of ‘smileys’ or emoticons was added to the forum topics on the website (see Appendix H) It was then time to test the website functions, this being done in the first instance by the design team. Subsequently a plan was implemented to test the website with potential members of the Click.

Testing the Click prototype

After reaching the point where the design team was satisfied with the design and purpose of the prototype website it was decided to test its technological facilities and potential user-friendliness on real people. The evaluation was conducted in real-time and a real-life setting away from ‘work’ constraints. The researcher and the BCCWA supervisor travelled to Marcus Island in South Western Australia, home of the web designer, a four-hour journey from the metropolis. During this road trip, a greater understanding of each other’s perspectives on life, family and the research process occurred. However there remained some confusion about the primary function of the Click.

The designer and supervisor were of the opinion that one-to-one counselling was a primary function of the site; whereas the researcher understood the site was designed to facilitate members in the provision of support for each other through peer-to-peer interaction. While the health professional could provide necessary professional support, their role would be for the purposes of information and education. Once these many views were considered, a greater understanding and acknowledgement by all was apparent; the current resource base and the part-time nature of the health professional’s role meant that the Click could not provide one-to-one counselling for members. Instead, it would aim to provide members with referrals to the appropriate human or material resources needed with the web-based health professional providing more in-depth, one-on-one counselling through the Click’s messaging facility, and possibly through the chat functions.

The major focus of this meeting of minds was to test the nascent Click website with three women, who had undergone breast cancer treatment; they agreed to trial the Click functionality in order to understand the processes and better ascertain its ease of use. The web designer had identified these women and the researcher had completed the necessary arrangements for this informal meeting, including completion of consent

forms, on the nominated day. Each of the women was a self-confessed computer novice and infrequent Internet users; but they were interested in the idea and purpose of the Click. Of these potential Click members, one was aged in her mid-30s with two in their early 60s. Unfortunately at the last minute, the younger woman was unable to attend due to family commitments, leaving the two older women to test the site, Joanne and Leonie.

Each woman took it in turns to sit at the laptop computer with the home page in front of her and asked to proceed through the process of becoming a member while advising the research team of any problems/difficulties experienced during this process. The research team noted the difficulties raised by the users and, where possible, the web designer immediately addressed the problem. Problems with the technology that could not be addressed immediately were documented and addressed by the web designer at a later date. The issues raised by the two women were subsequently addressed by the web designer or researcher (see Table 4)

Joanne and Leonie indicated they would "... probably use only a few features [of the Click] at first and try the other things as I get to know the site". As a result of this initial user feedback, and the data obtained through the interviews, focus group and survey, the site was both refined and expanded. The Click website now includes a videotape, embedded in the Click home page, which introduces the researcher and BCCWA project coordinator who explained the research rationale and welcomed the members to the Click.

Table 4

Click testing

User issue	Click Moderator Response
There was no information about membership on the home page until they were signed in	A video introducing the researcher and the research process was added to the home page. This was changed at a later date to include the introduction of the SBCN
There was confusion over the words such as should 'sign up' be 'sign in' or 'click here to join' rather than 'sign up'?	The sign in words remained and it was indicated that it was a free website
There was no appropriate time zone option for Western Australia.	The time zone was deleted and replaced with a list of countries
What is meant by the term 'user name'?	While a member can use their own name, they might wish to remain anonymous by using a 'nickname' or pseudonym unrelated to their real name.
Show the characters on the passwords to make it easier to get it correct, rather than having the typing come up as asterisks.	The login password process remained the same but it was pointed out that the letter remains for a second after it is typed. Keeping the password in a convenient place could also assist the process.
Delete the word 'journey' in all areas of the site as the notion of a 'breast cancer journey' is not currently favoured by those with breast cancer.	This was done before the website went live
They could not see where to ask questions about the site.	The women were coached in how to run the mouse over the menu item, and how to post a question to the forum and reply to one.
It wasn't obvious how to use the chat room	A 'type here then click enter' message was added under the chat room box where text was typed.
There was confusion regarding the 'friends' section.	It was explained that other members can be invited friends and they can agree, or ignore the request. Once persons are friends they can instant message or email the friend to arrange a time to be online and have a 'live' chat. Instant messaging could provide an immediate response, providing the friend is logged into the Click at the same time. How to friend would also be added to the get started topic in the forum was explained.
The volunteer testers expressed privacy concerns about joining the website.	They were advised that adherence to the Click privacy and confidentiality policy was part of the membership agreement and only people breast cancer, their supporters and staff and breast care nurses could join

A 'Getting Started' item explaining how to use each of the Click features was added to the forum (see Appendix I). It was also decided that feedback on the ease of use of the site and suggestions for improvement would be routinely sought from the online community members during Click Chat sessions. This did not preclude members posting their difficulties to their wall or personally messaging one of the moderators.

Creating the Click Membership

Once the website was ready to launch, the Click research team participated in an entry to the university's "Google Ad Words" competition to determine the best words to use in advertisements on the Google web search engine in order to attract members to the Click. An example of the words used in this four week Google Ad Words campaign occurred under the heading, Breast Cancer Discussion – Reliable, straightforward information – Share your story! The Click website address followed. Although the effects of the campaign were difficult to quantify with respect to whom or how many people joined the Click as a result, it did impact on the site's presence in web searches. There were 2,200 clicks on the Ad Words campaign and 146 people reported 'internet search' as their form of locating Click when they signed up for membership during that period of time. From then it was envisaged that a support community would quickly build, with the foundation members being sourced from the PBB membership base; however this proved to be an incorrect assumption. The first paper in Chapter Three titled *Building an Online Community in the Context of an Existing Social Network Site* discusses this outcome in detail.

Launch of the Click

The website, the research study and website were launched by a Click founding member, Tanya, during a BCCWA 'Purple Bra' day fundraising function held at the University and attended by approximately 30 people including faculty members, individuals with breast cancer and their supporters.

BCCWA clientele and PBB members were advised of the Click launch by letter from the BCCWA CEO, and a notice on the PBB and BCCWA websites. The Click was further promoted through business cards and a stall at a health expo held on Edith Cowan University's Bunbury campus and through a radio interview on the local radio

station. A video introducing the Click team and the research study was uploaded to the home page of the Click.

The website was moderated by the researcher and the BCCWA representative, both of who were members of the potential online support community and who participated fully in the community interaction. The moderators welcomed each new member who had successfully completed the membership process, encouraging them to complete a structured written emotional expression exercise (SWEE) in their blog page as a way of dealing with any distress they may be experiencing as a result of their breast cancer diagnosis and treatment or, if a supporter, the distress they experienced as a result of their friend or family member's breast cancer.

The planning and research phase of the website development section exemplifies the intertwining of the offline and online worlds of the participants and the researcher's presence in both realities, necessary in an ethnonetnography.

Phase 2: Community Participation and Observation

An influx of members to the Click occurred during the first few weeks after its launch, but the majority of online interaction happened between the researcher and individual members, rather than between members. The researcher participated in all facets of the website, welcoming new members and encouraging them to complete a SWEE on their blog page, providing information and support for the members or referring them to the BCCWA SBCNs, when the question asked was too difficult; or referring them to their doctor if their distress score, obtained through a Distress Thermometer, completed during the membership process, was high. Blogs were written and other Clickers blogs commented on, quotes of the month were sought and posted, videos and photos uploaded and many Click Chat sessions joined.

The following are some examples of the researcher's Click posts both as the researcher and as Clicker. The Click researcher was identified as such, clarifying for members the researcher's name and role within the community:

Information Post

If any of you are looking to change your diet and nutrition to help you fight your battle against breast cancer, you might like to read the Cancer Council nutrition information on the Click and/or red (sic) more by authors such as Jane Plant “Your Life in Your Hands” see link in the forum or the “Healing Power of Food” by Aussie Cheryl R see link below

The Healing Power of Food – Health and Wellbeing – Ark House Press

Quote of the Month

We learn something from everyone who passes through our lives. Some lessons are painful, some are painless, but all are priceless. Anonymous

Welcome Post

Hi Karen, Welcome to the Click. I see you have a high distress score so would suggest that you contact your local breast cancer support service or ring BCCWA on 0893243703 and ask if they know of a support group for supporters in your state. They will also be able to give you some advice about any immediate concerns you have which are contributing to your distress. You might like to write a blog or SWEE (which stands for structured written emotional expression) where you write how you are feeling about your partner/family members/friend's breast cancer. According to research - doing this for 10-15 minutes for 3 days in a row may result in you feeling less distressed. I do hope you find someone to talk to soon and please join a Click Chat for more support. Cyn x

Comment on Annie's blog entry

Golly Annie you are having a rough trot. Regarding the flu as you are doing everyone washing their hands after handling food, dishes etc. and covering their mouths when they cough helps prevent the spread of the bugs. You might like to try drinking lots of water and maybe take some mega doses of Vitamin c to help prevent you getting it. If you are getting a sore throat Betadine gargle is great. Short of shifting house Good hygiene is the key particularly if you are going to Bali. Make sure you get a good rest, eat healthily, lots of massages and iced cocktails should do the trick. Distant but heart felt hugs from Cynxx

Cynthia

The Click Researcher 

It took approximately three months, after instituting Click Chat sessions, for the online support community was fully operative with a sufficient number of members interacting regularly and with enough warmth to fulfil Rheingold's (2000) and Kozinets (2010) description of an online community.

Employment of Health Professional

During this time the online role of a SBCN was developed. Recruitment of an SBCN had commenced in Phase One of the study but was complicated by the lack of applicants for the position. More time was allocated for the SBCN recruitment, and this extra time allowed for consolidation of the online community. The difficulty in recruitment may be attributed, in part, to the role being a relatively new role and an innovative extension to their offline nursing practice. Finally an SBCN applied for the position, and at her request was offered and accepted a one-month trial of the position. At the end of that time she found she could not fit it in with her offline workload and her family life, particularly because chat sessions were held in the evening and were a regular feature of the Click. The position was re-advertised online and through the SBCN professional networks several suitable candidates identified. After interviews were held, a SBCN was appointed who, serendipitously, also worked part-time in a city-based breast clinic. This is further discussed in the next phase of the study.

The successful applicant commenced work as a member, moderator and specialist nurse when the Click online community had become established through the Click Chat sessions and these had become a favoured method of communication on the Click. The SBCN became a co-moderator and then the primary moderator of the regular Click Chat sessions, with the researcher gradually taking on the role of observer and recorder of the online interaction with intermittent participation.

Data Collection

Collection of textual data had been occurring from the launch of the Click and the commencement of Phase Two. Although it should be noted that while the forum and blog data remains on the website, in perpetuity, the Click Chat session data were only available to the researcher. The instant chat session data were ephemeral in that it could not be saved and read by the researcher unless permission was gain from individual

members to do so. This occurred when the SBCN saved the transcripts of her chats with Diana, the central protagonist in one of the papers in this study.

Kozinets (2010) refers to data collection and data analysis as being intertwined and this was particularly relevant to the online textual data in this study. From the very beginning and throughout this study data were analysed and items or themes identified used to formulate papers for publication and to support the conclusions made.

Data were collected in the following way. Each of the weekly Click Chat sessions was examined for pertinent points raised by members with these highlighted, in a different colour for each of the Clickers. The chat text was invisible to other Clickers. It was agreed between the researcher and the SBCN that the SBCN would save for review any personal chats and instant chats she had with Clickers. The transcripts of chat sessions were then copied and pasted to a monthly Click Chat file. The data were stored on a password-protected computer, which could only be accessed by the researcher. Notably the data from the forum or wall posts was limited, perhaps because the majority of the online interaction took place in the Click Chat sessions and on the blog pages.

Phase 3: Data Collection, Analysis and Interpretation

After nine months of the SBCN's professional involvement in the community, 15 interviews were held, 12 face-to face offline and three via telephone, to determine what effect the employment of the SBCN had on members' knowledge of breast cancer and its treatment, their distress levels and the general value of having a breast cancer professional as a member of the Click. Three interviews were held with the SBCN to explore her perceptions of the role and its benefits/downsides for the Clickers' management of their breast cancer diagnosis and treatment.

The Click online support community was a relatively small online community but the content and number of textual interactions in the 12 month period relevant to the development of the Click community was considerable (see Table. 5).

Table 5

Type and Number of Online Textual Interactions -12 month period

Type of Online Interaction	Total Number
Chat Sessions	154 - averaging 2 hours each
Instant message sessions	36 - averaging $\frac{3}{4}$ hour each
Blog Posts	140
Forum Posts	31
Wall posts	1664

This textual data were collected and analysed to determine any themes and/or compiled under the name of the Clickers who comprised the core of the small online community. This data were then used to answer the research questions and write the papers for publication. It should also be noted that the SBCN interacted with Clickers per the personal messaging system (not visible to other Clickers), although any particular problem or issue she considered important for other Clickers to know about was posted to the forum, with the permission of the Clicker concerned. The textual themes discerned from the blog, chat and forum posts are shown in Table 6.

Table 6

Themes and Clickers (N=24) involved

Themes in Text	Clickers Involved
Effects of breast cancer treatment on their bodies and how to avoid or deal with the complications/side-effects	All
Response to their diagnosis by family and friends - positive and negative	10
Pros and cons of Tamoxifen therapy	8
Personalities and abilities of their surgeons and oncologists	8
Practical advice for those about to undergo treatment	All
Emotional support for those about to undergo treatment or attend a follow up visit with their doctor	All
Expression of emotions about what was happening and the loss of their previous life	10
Dealing with the chronic nature of breast cancer i.e. not knowing if and when they will be cured	7
Exercise and nutrition	12
Reconstruction pros and cons – prosthetics and other equipment	9
Recipes, television shows and lots of good humoured banter (particularly on the chats)	15
Eulogies for family members who have died as a result of breast cancer	4
Work Issues	7

An online survey was formulated to determine how the Click website was and could be used and what assistance the members required to facilitate their online interaction. The survey also required each respondent to document their current distress level, whether or not they had completed a SWEE, and to comment on aspects of their online relationship with the SBCN. This online survey was embedded in the Click website and members were invited to complete it. The response to the survey was poor, considering there were 375 Click members at the time and only 36 members completed the survey, however those that did complete the survey, included members that formed the Click community by interacting on a regular basis in the Click Chat room, forum or blogs. The outcomes of this survey relevant to the SBCN, distress and the SWEE are reported on in Chapter Four of this study.

In the third phase of the study more offline data were sought. This differed from Kozinets' (2010) netnography steps four and five, wherein analysis of data, interpretation and reporting of findings occurs. It was only after this offline data were obtained and synthesised with the online data, that analysis and interpretation took place, followed by the reporting of the major research findings of this study. The iterative interpretation of findings noted by Kozinets (2010) in step four is exemplified in paper two, chapter four of this study.

It must be noted that data were analysed and interpreted, throughout all phases of this research study's and these interpretations formed the basis of the papers, and the conclusions reached, in this study. Unlike Kozinets' (2010) step five, that lists reporting of the research findings and their implications, this study reported on the findings, in a contemporaneous way, per the topics of the papers that were written and published throughout all phases of the research process. As a result of this analysis, a new model of nursing care across the breast cancer care continuum was formulated together with several guidelines for nurses who wish to practice in an online support community or establish a disease or health-focused online support community.

A paper focused on the usefulness of ethnonetnography as a research methodology for nursing research concludes this chapter.

Witney, C., Hendricks, J., Cope, V. (2015) Ethnonetnography: A variation of Kozinets framework and its application to nursing research. Submitted to *Nurse Researcher*

Introduction

Online communities are one of the contemporary means to provide advice to women suffering from breast cancer and their supporters. It is well recognised that family caregivers and social support has important benefits to those suffering chronic illness (Keim-Malpass, Steeves & Kennedy, 2014; Stolee, Steeves, Glenny and Filsinger 2010), who noted that poor health information sharing and limited staff time for healthcare communication in traditional hospital care settings impacted on patient satisfaction, with online communities becoming a contemporary scaffold to source information and more effective evidence-based healthcare communication to complement traditional care.

There is a plethora of healthcare websites and online ‘chat communities’ to assist people in seeking healthcare information relating to their personal experience. Online support communities for those with breast cancer have been researched widely by researchers such as Han et al (2012); Lieberman and Goldstein (2006); Orgad (2005); Rodgers and Chen (2005); Shaw, Han, Hawkins, McTavish, and Gustafson (2008); Winzelberg, Classen, Alpers, Roberts, Koopman, Adams, Ernst, Dev, and Barr Taylor (2003). There is compelling evidence on the effects of social support within online communities (Burke, Kraut and Marlow, 2011); however, there is a paucity of evidence related to the introduction and addition of an expert as a separate support phenomenon and the communities becoming a site for undertaking research on those virtual communities.

An emergent research method netnography, developed by Kozinets (1998) and extended into the Kozinets' research model (2010) and the LiLEDDA forum-based netnographic research method for nursing science (Salzmann & Eriksson, 2013) offer ways of conducting research of online communities; the latter in relation to nursing.

This paper will discuss ethnonetnography, a hybrid between pure ethnography and netnography, and its application to nursing research using the Specialist Breast Care Nurse (SBCN) as the expert support phenomenon and the purpose-built online community support website: www.breastcancerclick.com.au for individuals with breast cancer and their supporters as the online community to elucidate the relevance and value of this method for nursing research.

The ‘Click’ online community

The ‘Click’ www.breastcancerclick.com.au was purpose-built to be a research website. The aim of the site was to build an open-entry, non-hierarchical community around the experience of breast cancer, then explore the employment of a SBCN this person would integrate professional information given within a contextual, and illness focused, on-line community.

Membership of the Click community required the individual to have a diagnosis of breast cancer or be a family member or friend of someone with breast cancer. This limitation on membership guarded the context of members for research purposes, and provided members with the security of being part of an online community with others sharing the same experience. This meant members were able to interact with immediacy, perhaps becoming online friends with others in this communicative ‘online’ space. The potential for immediate connection with another, living the same experience, through mobile technology and user interface, such as mobile phones, tablets and laptop computers has been purported to enhance support whilst a person is undergoing a critical life event and transcend the limitations of a time-based world which enabled communication with others when required (Piacenti, Rivas & Garret, 2014). Members were always able to remain connected to another member or the SBCN. Chayko (2008) noted that these connections facilitated an “easy and portable sense of community” (p. 4) sanctioning “... real and consequential social bonds with people ... never seen face-to-face” (p. 3).

Origins of Ethnonetnography

Netnography is a qualitative research methodology whereby ethnography is adapted in order to study *online* cultures and communities (Kozinets, 2002) with the aim of describing the customs, symbols, beliefs and practices of individual peoples and

cultures. A virtual or online community is by the definition of Ridings, Gefen and Arinze (2002), “groups of people with common interests and practices that communicate regularly and for some duration in an organised way over the Internet through a common location or mechanism (p. 273). In this instance, the individuals concerned had breast cancer or were their supporters, and the SBCN within the purpose-built Click website community.

Netnography is related to ethnography often being termed Internet ethnography. When Crotty’s (1998) ‘scaffolding’ or ‘framework for research’ is applied to netnography, the methodology may be positioned in one of two ways. It either falls as a variation of ethnography (p. 5) or, because of the way the study is pursued online through observation and interaction between researcher and research participants, it may be conceived of as a new type of methodology. Kozinets (2010) contended that netnography does not require a particular theory be applied to the study of online communities. Instead, Crotty avows netnography to allow the online community to develop freely and is well supported by an ‘interpretive theoretical perspective’ (p. 5). Crotty’s interpretation and Keim-Malpass, Steeves and Kennedy (2014a) maintain virtual technologies are flexible. The data generated in, and by these environments, privilege the voice and experiences of the individual with the illness and capture the corollaries of these experiences in ‘real’ time, without the need for recall as is the case with in-depth interviewing. This approach allows the researcher to gain insight into the ‘social realities’ of the online community members. Hine (2008) states that, even though there is no physical boundary defining place, ethnographers undertaking research online must still immerse themselves in the social situation being studied, to learn the socially relevant things happening there (p. 262).

Ethnonetnography

Kozinets (2010) model reflects a finely balanced continuum of researcher interaction. At one end of the continuum is pure ethnography, which is a methodology for studying communities or cultures without important online elements. It consists entirely of face-to-face cultural interaction and data collection. At the other extremity of the continuum pure netnography rests; it is also employed for the study of communities and cultures, but conversely has no important in-person elements, cultural interactions and data collection being entirely online.

Blended ethnography/netnography or ethnonetnography is at the centre. Ethnonetnography then becomes a research methodology for studying communities or cultures online and includes the use of important online elements; it also incorporates both face-to-face and online cultural interaction and data collection. This is the approach of choice for this study (see *Figure 1*)

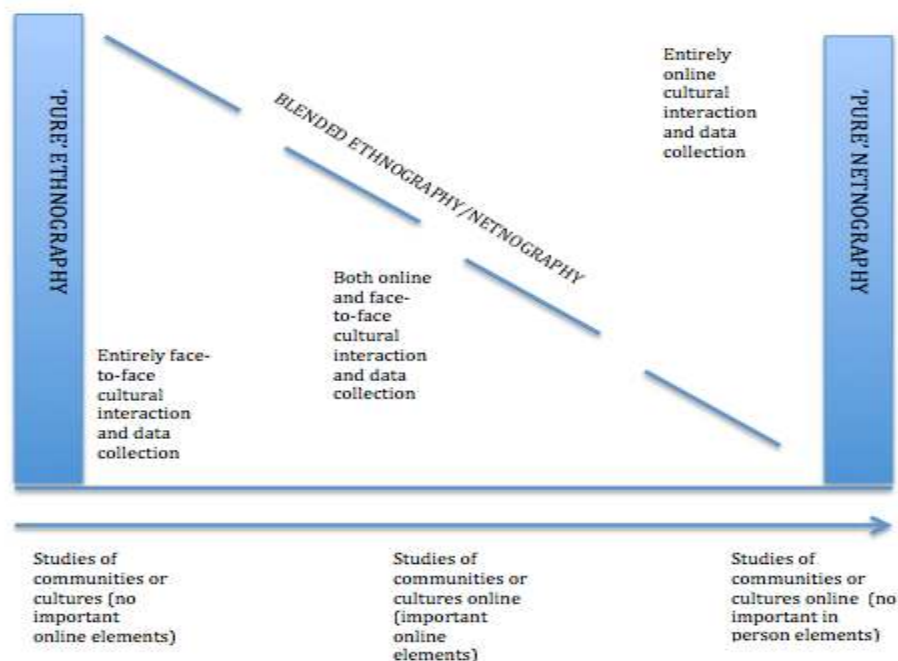


Figure 1 Coordinating online and face-to-face interaction and data collection (Kozinets, 2010, p. 67).

The ethnonetnographic method differs from most methodological research methods because the communication of the lived experience of the participants is, in the main, mediated by technology. Thus the majority of the interactions between researchers and the researched are textual in nature, taking place through computer technologies. This research method is well suited to the study of online communities, in this instance an online support community for those people with breast cancer and their family and friends, because it is 'faster, simpler and less expensive than traditional ethnography and more naturalistic and unobtrusive than focus groups and interviews (Kozinets, 2002, p. 61). Further, he (p. 5) asserts that, "... online social experiences are significantly different from face-to-face social experiences, and the experiences of ethnographically studying them are meaningfully different".

Kozinets' (2010) guidelines follows five steps: research planning, *entrée*, data collection, interpretation, ensuring ethical standards, and research representation, further describes two important areas prior to undertaking the five steps. First, the researcher needs to understand when and how to combine ethnography, which uses data gathered through in-person or face-to face cultural interactions, with netnography, using data gathered through online interactions. Second, the researcher needs to understand the differences of the online social environment, in order to guide appropriately and consistently the adaptation of ethnographic techniques. Kozinets recommends the following methodological stages and procedures for netnographic studies.

Research Planning: Prior to this study commencing, Ethics approval was obtained from the University Ethics Committee. No contact with potential research participants was made until approval was given. Kozinets (2010) advocates the conduct of netnography in accordance with research ethics. The researcher fully disclosed her presence, affiliations, and intentions to online community members during the research, and ensured confidentiality and anonymity of members.

Kozinets (2010) purports that the researcher must first seek *Entrée* which requires the formulation of research questions and the identification of an appropriate online community for a study. Unlike Kozinets step and Keim-Malpass's (2014a) application of netnography, this study varied this approach somewhat by building its own online community for research. In this way, the population of interest was readily

accessible through this purpose-built online community with the members of this community interacting with one another after becoming a member. Kozinets' (1998) requirement that the online communities be relevant, active with recent and regular communications, interactive with a flow of communications between a critical mass of participants displaying an 'energetic feel' and with a number of different participants offering detailed descriptive rich data were met within the Click (p. 89). Welbourne et al., (2013) noted the current possibility for online group members to feel a sense of community or togetherness, or a 'sense of virtual community'; these feelings are what distinguish an online community from an online group (p. 129). Kozinets further suggests that more than 20 persons equates to the formation of an online community.

Kozinets (2010) demonstrates how to construct and focus research questions appropriate for netnography, offering guidelines for writing broad research questions to guide qualitative inquiries (p. 81). He suggests that researchers ask one or two central questions followed by no more than seven related sub-questions. The central question should relate to the specific qualitative strategy of inquiry using words such as: "what" or "how" to convey an open-ended and emergent research design. The research should focus on a single phenomenon or concept making use of exploratory verbs such as "discover", "understand", "explore", "describe", or "report".

The broad purpose of this research was to develop a breast cancer specific, online support community to provide evidence-based information, advice and support to members and supporters, and second, to explore the support role of a SBCN could support online community members. The subsidiary research questions concerned: Do individuals with breast cancer self-report that blog writing and SWEE assist personal coping and, what is the role of the SBCN in this situation?

Data Collection: Three types of data were collected during this study: the direct copies from the computer-mediated communications of online community members; the observations of the community, its members, their interactions and meanings; the researcher's participation within the site; and finally, surveys, interviews and focus group interactions. These data elements were important and represented the 'digital stories' of those with breast cancer and their supporters. The skilful ethnonetnographer

must develop relationships with others online and enjoy immersion within the culture under scrutiny, and be able to tell and retell the member's stories and situations (Schensul & Le Compte, 2013).

In traditional ethnography the researcher must be 'immersed' in the study of the culture under examination. As an extension of the concept of immersion, culture is viewed as membership in the online community as the researcher was in this instance. Immersion within the online community is achieved through the design of and activity on the website. The online community is built and strengthened through text-based communication. The researcher participated on the website as a founding member and was integral to the community processes and interactions. Primarily, discussion focused around members' information, advice and support needs related to their diagnosis of breast cancer

Copious textual data were collected; however, the textual data related to the interactions members had with the SCBN were the focus of the study. Narrative text included actual blog entries, which tended to be 'see, write and share' SWEEs (Chung & Kim, 2007), as well as comments posted in the forum, instant and scheduled chat sessions. This is in keeping with Kozinets (2010, p. 133) who states, "I would fully expect (ethno) netnographers to deploy any of a number of techniques as they approach the rich lived worlds of cultural experience that people share and experience online".

The research focused on the online interaction between peers, being either people with breast cancer or their supporters. The researcher moved back and forth between the remit of the emic with the experientially close observation of online communities and cultures, and the etic of experientially distant and theoretically focused representation of them (Kozinets, 2002; 2010). Central to the period of data collection and analysis was the process of acknowledging personal preconceived ideas and judgments about the research phenomenon by the use of memos on a daily basis by the researcher. This reflexivity allowed the researcher to reflect on the interests of the research participant ensuring their often-silent voice is to the fore. Continuous reflection was essential to online ethnonetnographic research design, and adherence to these principles achieved an ethically grounded and reflexive body of work (Lincoln & Guba, 1985). The privileged researcher position must be consciously acknowledged. The

readers of this ethnonetnographic study will have the sense of having made contact with members of a breast cancer focused, online support community, thus gaining an understanding of them and the issues they faced and overcame, through their interactions with fellow members including, the researcher and the SBCN (Kozinets, 2010).

Analysis and interpretation: The interactions and textual data of the members, known as Clickers, was classified, analysed and contextualised, all communicative acts being examined. The researcher's role, as in the traditional ethnographic sense, is one of description and analysis of the lives, the 'online' lives and experiences of the online support community members in relation to breast cancer and its treatment. To fulfil this role the researcher must be accurate, sensitive and reflexive towards the members within the confines of the website in which the action occurs (Ziebland & Wyke, 2012). As in Kozinets (2010) netnography, ethnonetnography is an approach aimed at collective analysis at the small group or meso level not at the individual micro level or the entire community macro level. Analysis of data on the Click was conducted at a micro individual level through the examination of textual posts and discussion between individuals; it was then used as data in case studies and to answer the research questions. The ability to provide total numbers of textual posts, blogs, and uploading of videos and photographs (n=1891) together with 154 chat session transcripts and 36 instant chat transcripts occurred. Unlike Kozinets' requirement for 'Public Discussion', the Click online community is a closed community, being a member's only site; therefore analysis of public interactions was not conducted.

Similarly Kozinets (2010, p.9) avers interactions need to be '*long enough*' for relationships and/or authentic contact to develop. Honesty, reciprocal support, trust, expressions of affiliation, and expressions of intent to be social with one another must be evident within the research. With regard to the Click Chat sessions, many members had ongoing relationships with each other, whilst others may have joined one chat and not returned. Many people who identified as members were transient in their online activity. However, a group of members regularly interacted with enough human warmth to meet the description of an 'online community'.

The final feature required by Kozinets (2010) requires the online community under scrutiny '*form webs of personal relationships*' suggesting a social entanglement exists between individual members of the group as well as between the groups as a whole. Individual members who first met on the Click arranged to meet offline, either through Click Chat or personal messaging. The whole group of Clickers, who had been regulars on Click Chat sessions, within a close geographical distance also arranged and met for lunch. The five steps of Kozinets' (2010, p. 61) netnography method are incorporated into three phases to enable better comparison with the research phases of this study (see Table 1).

Discussion

The purposive intent of this study was to design a disease-focused, online community, which catered to the requirements of individuals with breast cancer and their supporters to ensure their voices were heard. This intent deviated from Kozinets (2010) approach as the website was purpose-built to undertake this naturalistic and unobtrusive research. The researcher's focus on the phenomenon is not dependent upon researcher presence in the field as dialogue is digitally stored and can be accessed at any time. Unlike face-to-face interviews, the researcher does not rely on the participants' recall because the digital data can be stored, accessed and analysed at any time (Seale et al., 2010).

The online communicative space, which does not have a physical boundary defining geographical place and time, allows ethnonetnographers conducting research online, to immerse themselves in the social situation and cultural interactions within the space. The advantage of this method is that it allows researchers to connect with people instantaneously or with immediacy. Restricted membership provided members with the opportunity to divulge their private selves in a forum with others of the same ilk. This same online communicative space allowed for a rich tapestry of data inclusive of text, blogs, and SWEE's providing digitally the hermeneutics of patients' lived experiences and illness narratives (Keim-Malpassee, Steeves & Kennedy, 2014b, p. 1686). This inquiry was critical in understanding the experience of breast cancer from the perspective of the building of the purpose-built website specific for encouraging interaction of the members and exploring the role of the expert clinical nurse (SBCN).

Table 1

Summarises the three phases in this study compared with Kozinets' five netnography research steps

	Research Model -Netnography Steps Kozinets'(2010)	Research Model – Ethnonetnography Phases (Variation of Kozinets (2010) steps)
Phase I	Planning and Entrée (Steps 1,2) Planning of research study including development of questions and identification of online community and how the researcher should enter it.	Planning and development of the online community based on both online and offline data collection and analysis. The researcher is a founding member of the purpose built research website, therefore entrée is not required but online communication and participation with the members is essential for the formation of an online community. Ethical considerations and approval by ethics committee.
Phase 2	Data Collection (Steps 3,4) Communication with members and participation in the community. Decisions made about data collection and storage based on the size and type of data available. Data collection and data analysis are intertwined. Ethical procedures	Community Participation/ Observation and Data Collection. Continued online communication and participation in the community. Introduction of Specialist Breast Care Nurse to the online community; concurrent data collection and analysis.
Phase 3	Data Analysis (Step 5) Two types of analytical processes, analytic coding-based and hermeneutic interpretation. Iterative interpretation of findings. Research findings written and reported and/or theoretical and/or policy implications	Data Collection and Analysis Collection of more offline data, synthesis with online data, content analysis of the data, theme identification, inductive analysis and hermeneutic interpretation of the research questions. Findings and/or theoretical and/or policy implications documented

Conclusion

Online support communities for people with a serious illness are not new but the inclusion of a specialist nurse as both a member and an employee of the site sponsor to provide the community with information advice and support is an innovative idea; it was the cornerstone for the development of breast cancer online support community known as the Click. The application of Kozinets' (2010) framework for nursing research meant that his five steps were varied to three phases of research for this study thereby demonstrating that the role of a health expert, in this case an SBCN in an online ethnonetnographic community has significant power to engage patients and effect adaptive behaviour change regarding diagnosis, care and treatment through advice and support. This study also demonstrates an extension of the continuum of care beyond clinic hours.

Ethnonetnography as a standalone research technique will depend on its continued deployment by researchers. Expert nurses who care for their patients in an online and offline capacity are in the enviable position of being able to add another dimension to holistic patient care by either addressing care concerns and issues online and/or incorporating the issues together with the planned actions, into their daily nursing care plan. Conducting research online to determine whether the patient has a knowledge deficit and/or has concerns about their disease is accomplished. The treatment and its effect on themselves and their family and friends can be addressed online and where possible offline, resulting in better patient care and greater satisfaction.

Summary of Chapter Two

Chapter two has provided an in-depth explanation of the methodology and methods used to complete the three research phases in this research study. These phases were planning and development of the online community; community participation/observation; and data collection and data analysis. These research phases were contrasted with the five netnographic research steps suggested by Kozinets (2010); Most of the research steps were found to be similar, the major difference being that the website in this research study was clearly identified as a research focused website,

designed to become an online support community, and the researcher being placed within the website from the outset, whereas Kozinets refers to the researcher identifying an already established website before requesting entrée from the site moderators to conduct the research. An important similarity between the two sets of research phases is the intertwining of data collection and data analysis throughout the research process.

This discussion of the research methodology was followed by a paper, prepared for publication, which discussed the use of netnographic methodology and its application to nursing research.

Overview of Chapter Three

The chapter to follow is comprised of four published papers. The first paper provides insight to the difficulties faced when a website is created with the intent of populating the online community using members of a social network site and the problems encountered with this process. The second paper demonstrates how participants, known as Clickers, used the online community called the Click as safe, disembodied space, which enabled members the share experiences of physical changes to their bodies with others. The third paper discusses the use of blogs and poems as a creative outlet for managing the devastation that breast cancer presents to the lives of individuals and their families. The final paper outlines the offline behaviour of one member, which illuminated the disparity between personal revelations shared online with the actuality of the life lived offline.

CHAPTER THREE

Introduction

This chapter begins with a published paper that documents the development of the online support community known as The Click with particular emphasis on the planned use of PBB members to seed the community. It was found that the members of this social network didn't join the purpose built online community for individuals with breast cancer and their families. This was an unexpected revelation as it was anticipated that those seeking information about cancer on the PBB would also become members of an online community which provided information, evidence-based advice and support from a professional online. The restrictions to membership and the ensured safety of members was felt to be an attractive feature which would encourage membership but this may have been challenging to those who were dealing with a cancer diagnosis and treatment.

The next paper provides an overview of the Click Chat sessions. The chat sessions proved to be the most important facet for community building. Riding, Gefen and Arinze's (2002, p.273) described an online community as people with common interests and practices that communicate regularly over a period of time in an organised way over the Internet. In this instance, the individuals concerned were individuals with breast cancer, their supporters and the specialist breast care nurse (SBCN). The topics

discussed and the content of these chats formed the basis of the next two published papers. The Click membership process precedes the second of these papers to demonstrate the difficulties encompassed in ensuring members are who they say they are. The final paper of this chapter shows how creativity in the form of blog writing can help individuals with breast cancer deal with the catastrophe that this diagnosis presents to them.

This first paper, to follow, answers the research question “Can an online support community be built using the members of an already established social network site to seed the community?” It was concluded that attempting to seed a purpose-built, online community website with social network members, will not result in the ‘flowering’ of an online support community, primarily because both sites have breast cancer as their focal point.

With respect to the development of the Click community without the envisaged seeding by PBB social network members, the following three points should be noted. First, of the 242 Click members who joined in the six months between the launch and declaration of online support community status, only four were members of the PBB online social network. Subsequently, only one of the four PBB members posted to the Click forum or participated in the Click Chat sessions and was present online when a sense of community became evident. Second, the majority of Click members indicated on their membership application that they had learned of the Click’s existence through an Internet search. Thirdly, the Click online support community formed as a result of the Click members’ interaction and participation in the regular Click Chat sessions, rather than posts to the forum or the members’ own page.

Witney, C., Green, L., Costello, L., & Bradshaw, V. (2012), Building an online community in the context of an existing social network site. Paper presented at and published in the *Proceedings of the Eighth international conference on Cultural Attitudes towards Technology and Communication 2012 (CATaC)18-20 June, Aarhus, Denmark.*

Abstract

This paper compares the characteristics of the Purple Boot Brigade, a social network for supporters of Breast Cancer Care WA, with the characteristics of Breast Cancer Click, an online community. Whereas online communities might be

conceptualised as relatively flat structures, in which membership is developed as a result of time spent online and in communication with fellow members, a social network can be seen as hierarchical, where members invite their face-to-face colleagues and friends to join with them in online activities.

In the case of this research it was hoped that the two environments would offer different benefits and exhibit complementary and mutually supportive characteristics. The Purple Boot Brigade is a well-established social network site, which espouses consciousness-raising, education and sponsorship to develop knowledge and awareness of breast cancer in its many forms. However, this social network had a number of drawbacks when it came to supporting people with breast cancer. Hence it was decided to establish Breast Cancer Click as an online community where people with breast cancer could seek support. This paper interrogates the contemporary challenges of building an online community, even with the benefit of a pre-existing social network site.

Introduction

Although online communities have a significant history, the context in which they are built and used is continuously changing. This paper examines the challenges faced in 2011 while creating an online community for people affected by breast cancer, even though there was a starting point for community recruitment in the shape of an existing breast cancer-related social network site, the Purple Boot Brigade (PBB).

The heart of the actual research project, which will only be touched upon here, centres upon the role of the professional advice-giver in an egalitarian, flat-structured, online community. The project has two stages: firstly Breast Cancer Care WA, a charitable organisation, sought to establish an online community to support people affected by breast cancer. This has been done, and the development of an online community with a strong research component, Breast Cancer Click ('the Click'), is the subject of this paper. Subsequently, and this is the stage of the current research, Breast Cancer Care WA seeks to create opportunities within the operation of Click to provide health-related professional advice to community members on request. While investigating and recording the provision of such advice, the research project will analyse the change of dynamics in community interactions (if any), and subsequently

develop a set of guidelines to help other organisations and professionals in equivalent circumstances to introduce the services of advice-givers with minimal disruption to the effective functioning of an online community.

Breast Cancer Care WA has already had award-winning success (AMI 2008) in setting up a social network site, the Purple Boot Brigade, to support “national awareness and education” about breast cancer (PBB 2012). The PBB project, created by safety boots manufacturer Steel Blue, manufactured a product line of purple safety boots as a talking point to raise the subject of breast cancer between wearers and those with whom they interact. People joining the PBB network can test their knowledge of breast cancer in terms of signs, symptoms and risks as part of their engagement with the site. This equips PBB members to talk about the illness when asked questions as a result of their wearing purple safety boots. The site is not set up to provide support to people with breast cancer or those who care about them. Whereas Breast Cancer Care WA does offer such support, these services had previously been provided in person or via the phone. Aware that some people were attempting to use PBB to access support for their breast cancer journey, Breast Cancer Care WA decided to set up an online community to meet the needs of people affected by breast cancer who chose to access services online. As part of their service provision, they were keen to offer professional advice from a breast care nurse experienced in counselling people with breast cancer and their families. When looking for guidelines as to how best to introduce and integrate such advice giving, it became clear that such guidelines were yet to be written. This is a future priority of the research discussed here.

Research Methodology

The methodology adopted in this research combines perspectives from media and communications studies, online ethnography (‘netnography’, Kozinets 2010) and cultural studies. The media and communications studies work is mainly drawn from audience studies, including debates around the domestication of technology and technology uses, and the integration of technology into everyday domestic life (Silverstone & Hirsch 1992). It also engages with the concept of “the user as an agent in the field of technological development” (Bakardjieva 2005, p.7). One example of how this methodology was used was when a number of people affected by breast cancer

were interviewed in order to determine the kinds of features they would like included in the site to be built. This phase of the research involved identifying target users and working with them as they navigated prototypes of the Click site, interviewing the potential users about their current online behaviours, and investigating the features they would like to have as part of the Click service. The research has also used surveys as a means of determining, for example, good time-slots for line chat sessions.

Online ethnography, or netnography, is the term used for the application of ethnographic principles to web-based online community research. It aims to achieve the scientific description of the customs, symbols, beliefs and practices of individual peoples and cultures. In this instance, the individuals concerned are breast cancer patients and their supporters, i.e. family, friends and carers, and the culture to be investigated is that which is developed by, and expresses, the Breast Cancer Care WA online community, Click. According to Kozinets (2010, p. 1), netnography is “a specialized form of ethnography adapted to the unique computer-mediated contingencies of today’s social worlds”. One example of the use of netnography to research an earlier online support community is HeartNET, a community for heart patients and their supporters, developed and researched by Costello (previously Bonniface), Green and others (e.g. Bonniface et al. 2005; Bonniface et al. 2006; Green & Costello 2009).

One aspect of conducting ethnographic research online is that the process of community construction leaves digital trails that are themselves accessible to analysis. As Kozinets notes, “the term persistent world has been coined to refer to the persistence of virtual worlds online, and changes made to them by users.” (2010, p. 72).

Where due ethics processes have been undertaken, and a site is clearly labelled as being for research, the development of an online community can be investigated from inception to autonomic operation. Thus, as well as using netnography to examine the details of community development, it is possible to examine the texts through which the community develops. In this way the netnographic element of the methodology shares practices with textual analysis from media and communications studies. Additionally, as indicated previously, the project also includes face-to-face interviews and small-number focus groups in the form of prospective user-gatherings.

Like cultural anthropology, netnography emphasises full participation of key researchers in the community under investigation. This element of participant observation is a cornerstone of much cultural studies research (Gray, 2003, pp. 79-106). It is through interacting with the community that the netnographer becomes a community member. Membership allows community members to feel confident that the researcher truly understands their circumstances and can accurately interpret what they say. This knowledge builds trust, and that in turn allows people to share personal and, in some cases private, feelings. The netnographer in this project, Witney, combines being a community member and a moderator. It is because of this dimension of participant observation in a community, and the trust engendered, that Click is clearly signposted as a research community. All community members are guaranteed that any identifying details about them will be obscured in materials cited from the site and through the use of pseudonyms when their posts are directly quoted.

Literature Review and Definitions

Social Network Sites

boyd and Ellison (2007, p. 210) describe social network sites as being “web-based services that allow individuals to: (a) construct a public or semi-public profile within a set system, (b) show a list of other users with whom they share a connection, and (c) see and move through their list of connections and those made with others within the site”. This complements Lin and Lu’s (2011, p. 1152) rather more prosaic description of the ‘social networking site’ as offering “an important social platform for computer-mediated communication [...] employing computers as a collaborative tool to accelerate group formation and escalate group scope and influence”.

The terms social networking site and social network site are often used interchangeably, or without discrimination. Whereas boyd and Ellison (2007, p. 210) give Facebook as an example of a social network site and Lin and Lu (2011, p. 1152) use it as an example of a social networking site. Ahmad says: “social network sites are also called ‘social networking sites’ to emphasize relationship initiation, often among strangers” (Ahmad 2011, p. 522). Chen argues that, in addition to using online communication to maintain existing offline networks, “An equally important function of social network sites is networking, i.e. expanding one’s online social network beyond

existing offline relationships” (Chen 2011, p. 14, original emphasis). However, Boyd and Ellison argue that there is a valuable distinction to be made between social network sites and social networking sites. They say that:

What makes social network sites unique is not that they allow individuals to meet strangers, but rather that they enable users to articulate and make visible their social networks. This can result in connections between individuals that would not otherwise be made, but that is often not the goal [...] On many of the large SNSs, participants are not necessarily ‘networking’ or looking to meet new people; instead, they are primarily communicating with people who are already a part of their extended social network. (boyd & Ellison 2007, n.p.)

Naturally, what might be designed as a social network site, in which people who are already bound by strong ties offline also connect with each other online, can also be used for the purposes of networking (Harrison & Thomas 2009, p. 120), and weak ties can be transformed into strong ties through extended communication and emotional investment (Granovetter, 1977; Verbrugge, 1977).

Under boyd and Ellison’s definition, PBB is a social network site. As one of its originators commented, when asked about its inception and history, its initial purpose “was to encourage people to support PBB and invite their existing social networks to view educational content, purchase boots and sign up as members.” The idea had been that members would post stories about their fundraising, and about how useful it had been to have the additional knowledge and information about breast cancer. However, that was not quite how it worked out: “Being a PBB member was like a ‘badge’ to show support for people touched by breast cancer and to be an active member [in] sharing breast cancer education and information within [a person’s] own social circles” (Personal communication, email, 23/04/12). One aim of the research was to use PBB as a way of seeding Click, so that the online community could start life with a critical mass of members.

There is reason to believe that a social network recommendation can be an effective spur to action. Pintado (2009, pp. 123-4) conducted a test whereby he sent personal invitations to his 200 Facebook friends, inviting them to become fans of a

particular website, to see if over a seven-day period he could increase the number of fans on this site. The number of fans increased from 34 to 116 during this time, showing that there is considerable power in an individual's personal recommendation and there is also the ability for a group to be formed quickly and efficiently through a social network site suggestion. However, a recommendation is not sufficient to guarantee engagement, and Pintado's experiment was not designed to develop a community on the site he recommended.

Online Communities

While a community used to be thought of as a group of people who live in a specific geographical location, and have similar local concerns, this is no longer the case. Instead, the definition now more commonly applies to shared social exchange where "people come together to get and give information or support, to learn, or to find company" (Preece 2001, p. 347). Online communities formed soon after the inception of the internet and burgeoned with the development of the World Wide Web. Whereas the first social network site is judged by boyd and Ellison (2007) to have started in 1997, with the launch of SixDegrees.com, the formally recognisable online community was already well into its second decade at that point.

Rheingold's book about *The Virtual Community*, first published in 1993, contains his definition of how a digital environment is transformed into an online community, where people feel they belong. He said online communities are "social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyber space" (Rheingold 2000, p. xx). This definition makes it clear that it is time, intensity and commitment that underpin the transformation of a group of interacting people into an online community.

As social network sites and communities mature, however, so the differences between them seem less significant. Further, Rheingold's definition of community operates independently of any overarching digital environment: a community can form anywhere that 'personal relationships' are built. Pintado's view (2009, p.116) is that social networks offer "a platform for building online communities of people who share interests and activities and who may also want to explore other's interests and

activities”. Sethi (2010) combines the terms to talk about how “Online social communities have made it easier for us to connect to, and stay in touch with people who are either important to us or share similar experiences to ours, or both”.

The two terms, ‘social network site’ and ‘online community’, are not interchangeable however, and this implies a continuing differentiation. One perceived difference is with the separate structures of these online environments. Social network sites assume the primary role of importing existing relationships into the online environment, whereas online communities assume the building of new relationships online. Such relationships would usually form around a shared community of interest, which might be geographical, demographical, or topical (Hagel & Armstrong 1997). In the case of Click, the shared interest is in the topic of breast cancer, although there is also a demographical dimension since most people diagnosed with breast cancer (although not all) are women, and most of the women engaging with Click are also in their middle years.

Essentially, the purposely-built online community begins as a flat social structure that seeks to attract members and encourage them to interact. Status online reflects a community member’s engagement with the community, rather than a person’s status offline. It is not dependent upon who invites whom to join, or related to the people with whom someone interacts, but is instead driven by time and investment in community membership (Lampel & Bhalla, 2007). Apart from moderators, the online community starts off with all members joining as newbies and collaboratively developing a shared sense of belonging. Community lies in communication and in company: in the construction of shared social capital.

Social Capital

There has been intensive interest in what makes a network or community thrive (Howard, 2010). Arguello et al (2006) contend that the survival of an online community depends on whether or not it provides the benefits and experiences that members seek. Posts and emails are still the main means through which members communicate online, although the use of voice over internet protocol networks is growing. Either way, to gain any benefit from this medium, the member must attract others to respond to, and share, a conversation. Members’ responsiveness to posts and blogs is an essential

element of any successful online community. This assumes a critical mass of engaged members, which can prove a challenge in the early stages of building a community: people will only interact if there are others to engage with, and others only engage when they see people interacting.

According to Putnam (2000), the core idea of social capital theory is that social aggregates have value; that social capital is the connection among individuals, along with the norms of reciprocity and trustworthiness that arise from them. This is sometimes called civic virtue or a 'public good' (Pruijt 2002, p. 109), but it is only powerful when embedded in a network of reciprocal relations (Putnam 2000, p. 19; Wellman et al 2001; Best & Kruger 2006). While online community members create social capital through their interactions, the more frequent the interactions, the more likely it is that a norm of generalised reciprocity and trust will be produced. Putnam describes this as "I'll do this for you without expecting anything specific back from you, in the confident expectation that someone else will do something for me down the road", and argues that this trust in others "lubricates social life" (2000, p. 21).

There are two different dimensions to social capital, notes Putnam (2000, p. 23): bridging or inclusive and bonding or exclusive. Within communities and networks alike, the social dynamics are such that some people are invited into a conversation through a bridge that links them with others who are well-established members, while other people are excluded by the close bonds that already connect those who are involved, and the cost of acquiring sufficient social capital to gain entry to the communicating circle. Networks can help in these circumstances since being linked with someone who already has membership in a social setting can serve as an introduction, and allow the sharing of established bona fides on the part of the newcomer.

The Internet is increasingly a site for the building and use of social capital, through networks and communities. This became particularly evident in the week of March 13, 2010, when Facebook overtook Google as the most visited website on the Internet (Dougherty, 2010). At this point, arguably, the desire of people to use the Internet for social and networking purposes overtook the desire of people to use the Internet as a place to search for information or do business.

Case Study: Using a Social Network Site to Seed an Online Community

The Purple Boot Brigade (PBB) was set up in 2007 as a social network site by Breast Cancer Care WA (previously Breast Cancer Foundation of Western Australia) in conjunction with Steel Blue, a leading safety footwear manufacturer also based in Western Australia. As part of their sponsorship of the site, Steel Blue began making purple boots for workers who were willing to pay a few extra dollars to support people with breast cancer. Community take-up was so enthusiastic that an initial ambition to raise \$30,000 (AMI 2008) was dwarfed by the eventual income generated for Breast Cancer Care WA, currently around \$500,000 (Personal communication, email 30/04/12), leading Steel Blue to introduce men's and women's boots in an everyday boot style as well as the originally-planned men's and women's safety boots. With the slogan "these boots were made for talking", purchasers were encouraged to use the PBB website to educate themselves and others about the facts of breast cancer, and to work with people in their networks to overcome ignorance and misinformation. The exceptional outcomes of this association between Breast Cancer Care WA and Steel Blue resulted in the two organisations receiving a 2008 Australian Marketing Institute Award for Excellence in the sponsorship category (AMI 2008).

As is the case with most social network sites, PBB recruits new members through the active engagement and recommendation of existing members. It also benefits from the support of Steel Blue, and hotlinks are provided from Steel Blue's website and from the Breast Cancer Care WA website. People who wish to become members of PBB apply via completion of an online form and providing a personal profile. Administrative sign-off is required before a person is accepted as a member. Membership of the site is available to everyone apart from people who might wish to promote or sell merchandise or services on the site. Once membership is established there are facilities to email other members and to post a message on the individual's 'my page'. Members can post videos and photos, and some start blogs on the site. They can also 'friend' other PBB members. The site is regularly monitored by an administrator in order to avoid offensive content or language, sales advertisements, copyright infringements and to determine if the content posted is relevant to the PBB's general theme:

The objective of the Purple Boot Brigade is to support education and awareness programs across the nation, with our first project supporting the great work of Breast Cancer Care WA (formerly the Breast Cancer Foundation of WA) as they target youth to make the younger generation breast aware. With the number of women being diagnosed with breast cancer increasing from one-in-eleven to one-in nine over recent years, the need for breast awareness education from a young age is vital. (PBB 2012, 'Our story')

The PBB site is very much focused on awareness-raising to support the work of Breast Cancer Care WA and the majority of blog posts, or 'boot stories' as they are known, refer to the members' reasons for purchasing their purple boots, or their experiences at fund-raising events. The following from the 'Our Story' section of the site is one example.

My mum recently passed away following tragic accident. The first thing that springs to all our minds when thinking of our mum's particularly wonderful style is her Purple Boots - which she'd only had for a few short months - but already the whole town knew about them. Now I have found where she got them I will recruit all my friends and family to the Purple Boot Brigade! What a fabulous way to support a fabulous cause (PBB post, 2009).

The PBB site has a Breast IQ section featuring a breast awareness quiz that asks questions about breast cancer signs and symptoms. The score achieved by a member is an indication of whether or not they know as much as they think they do about breast cancer. The site also advertises fundraising events with a purple theme, which raise money for Breast Cancer Care WA. Purple Bra Day is the major community-based fundraiser for the organisation with men as well as women joining in the fun (Perth Now 2010). While Breast Cancer Care WA provides a range of counselling and other support service for people with breast cancer, PBB was not designed to reach out to patients and their friends and family in that way. Even so, there were occasions when people experiencing breast cancer would post to the PBB site and be supported through referral to the phone and in-person services provided by Breast Cancer Care WA.

Ultimately, it became a Breast Cancer Care WA priority to build a community in which people affected by breast cancer could support each other, leading to the

blueprint for The Click. The hope was that the existing network on the PBB site would seed the online community, kick-starting the kind of engagement and exchange required to fulfil Rheingold's recipe for a community: enough people carrying on public discussions long enough, and with sufficient human feeling, to form webs of personal relationships (2000, p. xx, paraphrase).

The Click was developed in 2011 to be "A new Australian support site for those with breast cancer and their supporters, friends, family and carers. This is a place for you to connect with others, share your experiences in a safe environment and know you are not alone" (Click 2011). The same IT professional who had designed PBB, engineered the site from the ground up to be compatible with the existing social network. People who knew their way around the PBB site would also feel at home on Click.

Since Click was established to provide a support site for people who have been touched by breast cancer, to help them gain advice and share support with others in the same situation, the site is a closed or 'members only' website, and provides resources and information about breast health. Membership is restricted to people who have had a diagnosis of breast cancer and their supporters or health professionals. As well as creating a community to offer online support, Click was set up to be a research website, funded through an Australian Research Council Linkage partnership between Breast Cancer Care WA, supported by sponsors Steel Blue, and Edith Cowan University. One aim of the research was to build an open-entry, non-hierarchical community around the experience of breast cancer and then establish guidelines for integrating professional advice and information from a health specialist such as a breast care nurse or counsellor. This meant that the researchers hoped to build a vibrant and viable community prior to introducing the services of an online health professional. In this way the research could establish whether the communications dynamics had been altered as a result of introducing an expert into a flat-structured online community.

To become a Click member, an applicant must provide key demographic details i.e. name, postcode, birth date, and select the type of membership category they belong to: a person with breast cancer, or a supporter; and indicate where they heard about Click. The prospective member must also read and agree to the terms and conditions of

the site and the code of conduct; read the research project details; and consent to participate in the research project. People are also asked to provide a current indication of their distress level, where 0 equals nil distress and 10 equals extreme distress. This latter indicator gathers data, which will eventually help assess whether communicating in an online community helps members deal with some of the fear and uncertainty associated with experiencing breast cancer. In the early stages of the community, every membership application was independently checked prior to the member being accepted, but this procedure meant that there was a gap between application and enrolment and a number of would-be members never returned to the site. Eventually it was decided that people needed to be able to access the site at the point of need and desire, and anyone completing the online requirements was accepted immediately, the view being that 'undesirables' could be handled after the event. A 'captcha' system for authenticating human engagement with the website was deferred pending more funding.

The Click website was launched as a trial in April 2011 to ensure all the features worked correctly and to allow the Click team, which consisted of the netnographer, research supervisors and the web designer, to become familiar with the site and their respective roles. PBB members were emailed an invitation to join Click at the beginning of May 2011. The indications of activity (below) demonstrate that people joining the site was necessary, but not sufficient, to ensure the development of community. The jump in membership in May was associated with a flurry of posts, page views, comments and blog entries, but these then tailed off to a low point in September until the introduction of live chat sessions in October 2011.

Table 1. Month by Month Click membership activity.

	Apr 11	May 11	Jun 11	Jul 11	Aug 11	Sep 11	Oct 11	Nov 11	Dec 11	Jan 12	Feb 12	Mar 12
New members	11	80	22	17	9	10	15	17	9	4	12	21
Sign-ins		913	216	103	177	90	158	337	266	255	315	313
Page views	3715	9788	5088	2571	3931	3119	5448	6265	6698	6748	13139	10799
Posts		464	127	59	119	66	104	159	92	75	148	170
Comments		78	36	24	22	20	66	128	82	86	73	101
Blog entries		176	3	4	2	1	3	2	4	3	3	11
Forum posts		34	10	2	6	2	12	6	1	4	15	9

Click membership started with an influx of members over the first month, as a result of the publicity on the PBB network, but the majority of members did not post anything on the site. Those that did post were generally responded to by the Click team members, rather than by community members who had personal knowledge of the concerns and problems faced by people with breast cancer and their families. This situation continued for the first four months of operation, and whilst new members joined the site they were not active posters.

In October, the research team decided to instigate live chat sessions or ‘Click Chat’ on a fortnightly basis, at a specific, advertised time, to be hosted by members of the Click research team. While the numbers of members joining the Click Chat sessions increased from two members (plus the Click team) at the first Click Chat to anywhere between six and ten members (plus the Click team) at more recent Click Chat sessions, the effect of bringing members together in a specific time and place was galvanising.

The live chats were originally scheduled to run for a three-hour period, but they occasionally over-ran, and during that time members were able to engage in Rheingold's (2000, p. xx) "public discussions long enough, with sufficient human feeling" to create personal relationships with each other and with the Click team. As a result of these live chats, members who have joined in the sessions have carried over their chat engagement to post on the forums, and to message those they met during chat.

The Click Chat session is now weekly, in response to member requests, and there are burgeoning signs of community growth.

Table 2. PBB and Click membership at the end of the first 11 months of each website's operation

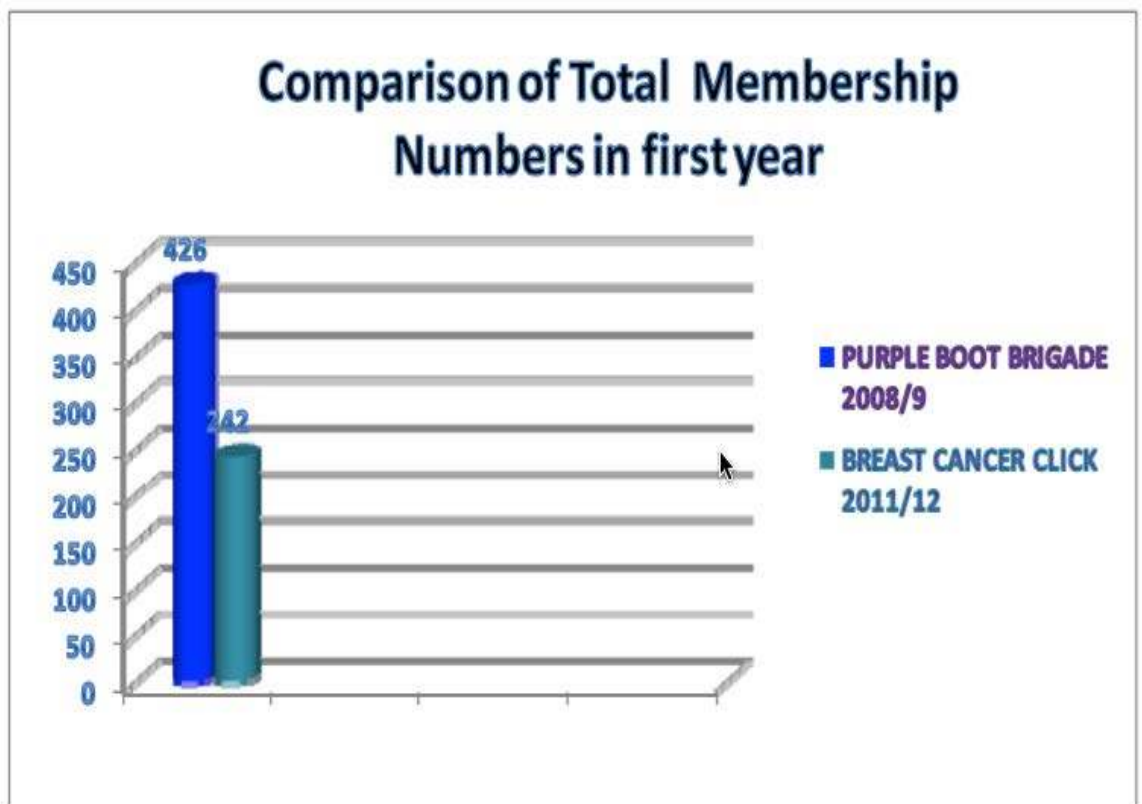
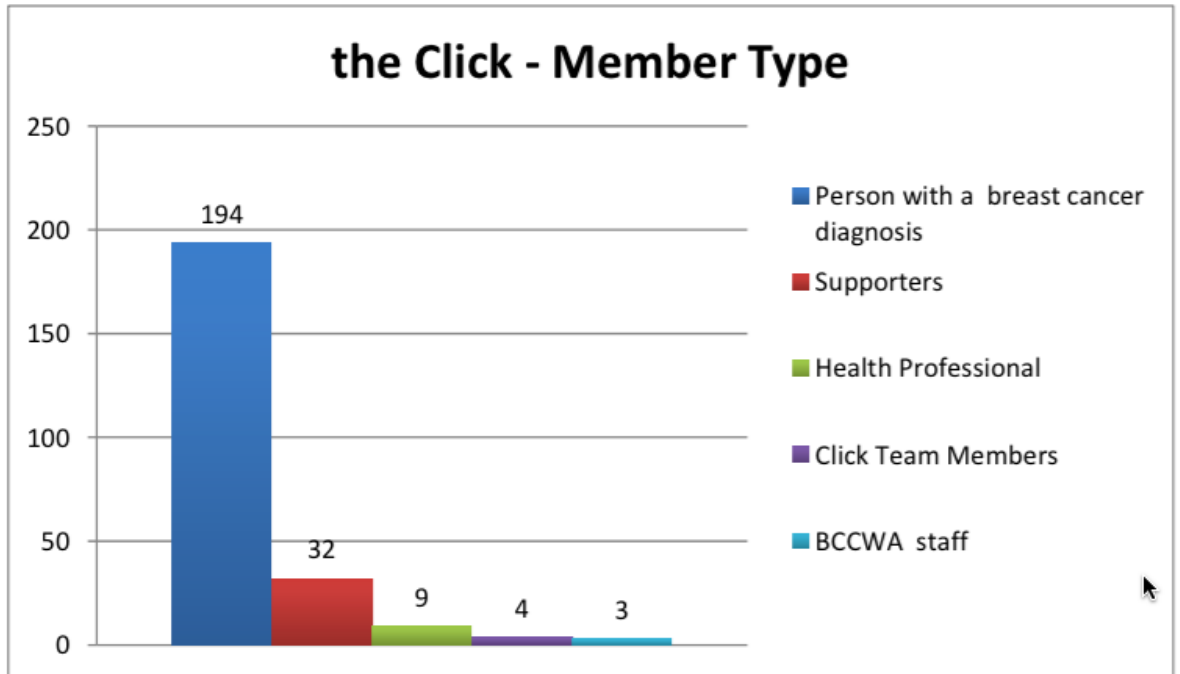


Table 3. Click membership categories



Discussions and Conclusions

While the authors had some success around the construction and operation of online communities in the mid-2000s (e.g. Boniface et al. 2005, Green 2010, pp. 152-8), the take-up of Click proved problematic, even though it started with the benefit of a thriving social network as a lead-in source through which to recruit Click members. An online community needs to offer more than the potential of 'community' to thrive. It needs to offer a real opportunity for connection, and to demonstrate the potential benefits of community membership. Notwithstanding the influx of members as a result of PBB-based recruitment, it was difficult for the site to present a vibrant and viable community to first-time users without there being regular online activity. In the absence of a critical mass of online engagement, what community there was withered away.

The circuit breaker in this dynamic was the introduction of Click Chat. These live chat sessions might seem to be undermining the benefits of a self-sustaining online community in that they are staged 'events' unlike those that might seem ordinarily associated with the everyday operation of a digital community. In particular, they tie up personnel resources in terms of team members, who make themselves available for Click Chat, which occurs outside normal working hours. Such events do, however,

have precedents in terms of everyday communication. They operate as a get-together or a coffee with friends. Such events are very much a part of everyday communities and are a major means through which people meet new acquaintances and possibly develop new friendships.

For those involved, and as the data indicate, there is no question that Click is now a success. As envisioned, membership combines access to both a supportive network of people with experience of breast cancer and also to caring moderators and healthcare professionals. Click needed more than awareness and an unmet need to get started. It needed to prove itself to potential members before people would trust it enough to share their thoughts and feelings in a way that builds community.

Click Chat Topics and Processes

The topics Clicker discussed in the Click Chat sessions were many and varied but in the main focused on breast cancer treatment, the changes this made to their bodies and how this affected their families and their work. Their Click membership number identified the Clickers in the chat sessions which maintained their anonymity, but most of regular Click Chat participants then introduced themselves with their real names. The textual flow of the chats, appeared disjointed because it was whoever has the faster typing fingers, gets their comment on the page first; therefore the chat could be difficult to follow, particularly if you joined half way through a chat session. The chats themselves were always interspersed with laughter and were sometimes conducted with one eye on an off-screen item such as a television, as this transcript from an early 2012 Click Chat session between Clicker with breast cancer, shows:

282: Did you have chemo M...?

104: I did B...

104: and Radiation

104: Surgery April, 2011, Chemo then 7 weeks radiation finished in November 2011

282: I'm 2/3 way through chemo, have radiation next then Tamoxifen

282: Are you feeling okay now?

314: B... I am same but ¾ way thru chemo

282: Is that possible???

104: Well, I'm not sure of your particular circumstances B but I actually thought radiation was a breeze, but then again people have told me I am a little nuts

351: RPA starts in a few minutes, good show, can't watch ops though.

282: Oh excellent N - getting there!!

282: Oh I think nuts helps!!! Hahaha

314: won't miss chemo, thats for sure

104: I am feeling good. Still get tired. But yes, being nutters helps!

The next paper focuses on the content of Click Chat sessions. Without focusing on any particular Click member, it evidences the importance of sharing experiences of changed bodies with other members', in similar situations, in a friendly and sometimes humorous manner that affirms the experience of having cancer and allows the re-contextualisation of these changed bodies, lived in an albeit, disembodied, space.

The question as to the role of embodied knowledge about breast cancer which could be shared in the disembodied realm of an online support community was considered. It was apparent that most of the discussion topics or items pertinent to the online embodiment of breast cancer that were discussed in this paper, have remained constants in Click Chat conversations since the formation of the Click community. Only the people who initiated the conversations have changed, as newly diagnosed members and their families now occupy this space.

This paper was written early in the establishment of the regular Click Chat sessions and it should be noted that the term breast care nurse (BCN) used in this paper was changed to specialist breast care nurse (SBCN) in the papers included in chapter four, in recognition of the specialist nature of this nursing practice.

Bradshaw, V., Witney, C., Green, L., & Costello, L. (2012). Embodying knowledge of breast cancer in a disembodied community? *M/C Journal*, 15(4)

Introduction

Few life experiences have a greater impact upon one's sense of self than the diagnosis of a life-challenging illness. Breast cancer is such an illness, and the sudden transition from 'well' to 'ill' is unsettling for a person's sense of knowing who they are in their own body. What you know about your body, what others know about your body and what your biology knows about your body becomes suddenly problematic. This paper addresses what people know about their bodies before and after experiencing a breast cancer diagnosis by examining relevant theory and empirical data drawn from an online community for people with breast cancer, their families and supporters.

In the Breast Cancer Click (BCC) online community, members are encouraged to blog their breast cancer journey, engage in discussion forums, use a private messaging function to talk in real-time with each other and a breast care nurse, and to participate in live group chat. The records of all these activities have been used in a netnographic study, which aims to examine the efficacy of this mutual support community. In this paper we present some of the material generated by and within the online community to consider the embodied experience of breast cancer. Evidence from online community members is addressed to consider what a western cultural experience of breast cancer, as captured by a disembodied online community, can tell us about embodiment and embodied knowledge.

How Do We Know?

In 'Knowing and Being', Polanyi argues that knowing is related to two separate methods of investigation that nonetheless need to be integrated. On the one hand is the detailed knowledge of the particulars, and on the other the grasping of the big-picture conceptualisation of the whole. "A medical student," he writes, "deepens his knowledge of a disease by learning a list of its symptoms with all their variations, but only clinical practice can teach him to integrate the clues observed on an individual patient to form a correct diagnosis of his illness, rather than an erroneous diagnosis which is often more plausible" (460). The implication here is that there is more at stake than a formulaic

listing of symptoms. The 'knowing' relates to knowledge around the disease of breast cancer; the 'being' relates to the experience of being a breast cancer patient.

The necessary theory underpinning the identification of disease, the progress of symptoms and the side-effects of treatment fail to capture the experience of the breast cancer patient, which is mutually recognisable among other patients even where superficial aspects of the disease manifestation diagnosis and progress may differ. Lekkie Hopkins writes of her immediate and bodily experience of hearing the diagnosis of her breast cancer:

Thwack! 'The good news is that you won't die of this. The bad news is that you will have to lose a breast'. Whoosh earthwards. Floor opens to swallow my life force. Body a shell. Head empty, uncomprehending. Within seconds, whoosh again, upwards this time. Blood rushes to head; face blooms red, eyes zoom onto the tiny points of calcification on the x-ray image, ears boom. Lose a breast, lose a breast, lose a breast ricochets off the walls. Kind eyes, gentle hands, steady voice: 'Can I call someone? Your partner?' Kind eyes, gentle hands, steady voice. Lose a breast, Lose a breast, Lose a breast (132).

Such embodied knowledge may not be recognisable within a medical/scientific context. Conflict can arise between a woman's embodied knowledge of her breast cancer and the medical/scientific understanding involved in her treatment (Thomas-McLean, *Memories of Treatment*). Perhaps surprisingly, the body can appear absent in medical discourse and alternative approaches are needed to provide an embodied perspective. Considering poet and feminist scholar Adrienne Rich's invitation to women to learn to think through the body, Lekkie Hopkins wondered "what it must mean to lose part of that body" (134). Thomas-McLean has noted that frameworks of health and illness can fail to capture the "complexities associated with living with an altered body" (*Beyond Dichotomies* 202). She promotes the idea that "women speaking for themselves, about their own experiences" is an important part of the repository of knowledge and understanding about breast cancer (*Memories of Treatment* 629). Our knowledge comes from our physical nature, our embodiment within our world and the meanings attached to the body within our social context.

An online community constructed using community networking technologies may seem an unlikely place for reclaiming the knowledge of the body. However, deep connection between members has been observed in online communities studied in detail (Bonniface et al.). The qualitative richness of complex experiences, missing from the medical discourse, can be found in such communities and constitute an alternative source of data to traditional interview methods. As mentioned, it is not an aim of this paper to address the efficacy of the Breast Cancer Click community, but to use some of the material which has been created in the community's activities to consider the embodied experience of breast cancer. In speaking for themselves in the Breast Cancer Click community, women reveal both their knowing and being as breast cancer survivors.

Online Support in a (Dis) embodied Community

The research question addressed in this paper is “What embodied knowledge about breast cancer can be shared in the disembodied realm of an online support community?” Women experiencing the betrayal of their bodies seek the authenticating experience of sharing their stories with others whose lives have embodied analogous experiences. Breast Cancer Click (BCC) was set up to provide a connection between breast cancer patients and their supporters with others who are currently undergoing treatment and those that have completed their treatments wishing to support others. This peer-to-peer support is expanded through interaction with an online Breast Care, providing education and information and unravelling the medical terminology and diagnosis for each specific patient where requested.

Through personal messages, forum threads and group online chats, regular contact is maintained with newly diagnosed members, those currently involved with treatment, and those considering reconstruction and other post-surgical options. It is through these active members' dialogue that we can appreciate the value provided by this disembodied communicative space. Using the principles of netnography (Kozinets), which applies ethnographic techniques to online communities and environments, the posts, chat, forum contributions and private messages (all de-identified) were archived to provide the raw data for this study. Transcripts were analysed to identify themes arising (Strauss & Corbin) and to select content that illustrates these themes and illuminates the experience of participants and the value or otherwise of the online

community. Necessarily, with hundreds of thousands of words posted as part of the ongoing research project, only selected material is presented here.

Three major areas of discussion are presented for this paper: development of a new normal, breast image and holistic health. We have not ‘personalised’ the contributions of Breast Cancer Click members, but have indicated verbatim quotes via the attribution to (BCC).

The ‘New Normal’

“I have silicone implants and swimming now feels VERY weird.”(BCC)

This statement is indicative of a range of language comparing the pre-diagnosis, or pre-cancer, body with the changed circumstances that embody the results of the cancer even while the medical model excises it. Insights and comments on the bodily experience arise in a range of circumstances including the experience of hair loss following chemotherapy and questions about authenticity and reconstruction following surgery.

I’m expecting to shave my head as soon as I see hair loss.

I have already had my hair cut shorter to help my kids adjust etc.

I cut my hair short too before chemo so I get used to the idea haven’t shaved it yet though. (All BCC)

These comments indicate the intuitive use of simulation strategies as a means of adjusting to the anticipated response of the body to the experience of chemotherapy. This simulation strategy reintroduces a sense of agency for the BCC member, allowing them to feel as though they have chosen to change their appearance.

Sometimes the edge of the new normal can be softened by the experience of social and emotional solidarity conveyed through others embodying their support for the person with a breast cancer diagnosis:

Oh when I lost my hair, my boss (at the time) was so lovely, and he shaved his head, and we had our pics taken together). Mine

too- the school did greatest shave just as I lost my hair. Raised \$900 (Both BCC).

Although the experience of losing hair through chemotherapy is very different from that of being shaved, the embodiment of 'different' can serve to offer consolation and companionship for those who are embarking on a breast cancer journey. A return to the 'old normal' can be a cause for celebration, along with a recognition that the body continues to function as it had pre-cancer: "I remember the feeling when my hair was long enuf to dye back to blonde :) was fabulous when it got long enuf for a bit of a style instead of just fluff!" (BCC)

Breast Image, Mastectomy and Reconstruction

Within the breast cancer community, the issue of reconstruction following mastectomy becomes a very personal one, while also sometimes encompassing wider gender politics. Although it might seem this is an elaboration of the discussion around challenges to the concept of the 'pre-cancer self' and the new normal, women's breasts have such a range of associations in Western culture that it is difficult to be objective about the new embodiment of the post-cancer self.

I had a lumpectomy but its obvious size wise and I lost my nipple completely ... but I won't reconstruct or wear padding.

We all look great (scars are not so lovely) but with swimwear or a bra on we are all OK. I went from a small a cup to a c cup as the plastic surgeon suggested we 'may as well kick a goal as a point'. (Both BCC)

Sometimes the experience of the disease is such that the 'new normal' places the body into an anomalous category. There is an embodiment of strangeness, which overrides the conscious understanding about biology and function. The rational, knowledgeable, self can sometimes be seen to be in conflict with the experiential being of the post-treatment breast cancer patient. This was the case with a 29-year-old BCC member who successfully fell pregnant after her diagnosis. This exchange was via live chat between the breast care nurse (BCN) and the BCC member, so it sometimes reads in a disjointed way as the message's respond to each other's posts in a semi-synchronous way.

Do you think you will breast-feed? (BCC Breast Care Nurse)

probably not. (BCC)

I feel weird about my boobs now. (BCC)

How do you mean? (BCC Breast Care Nurse)

Like I'd make sure baby got first milk etc, and then bottle feed. (BCC)

Oh umm it's hard to describe, they don't feel like they are for that purpose anymore. (BCC)

I don't like the left one being touched much. (BCC)

Good plan - good for baby to have some breast milk. (BCC Breast Care Nurse)

No - I guess it feels odd - not normal? (BCC Breast Care Nurse)

As in this exchange, the online community operates to validate the experiences of its members, to offer support and understanding. The politics around breast feeding, as with those around a woman's physical appearance, mean that people with a diagnosis of breast cancer often perceive they are subject to a range of social 'shoulds' at a time when they are trying to re-learn (or to learn) an authentic sense of being in communication with, and being in communion with, their body.

Holistic Health

We went for a brisk walk around west-end with heart rate monitors on to check our pulse rates. It was great to do the exercise in a group situation. I am looking forward to getting in touch with my pre-diagnosis body again. I gently stretched my 'bad' arm which was OK.

I am very happy to say that my energy levels have already improved and have just been for a walk. My unused muscles are waking up and I feel excited now

I realise it is possible for me to return to my pre-diagnosis fitness levels and activities. (Both BCC)

The physicality of the experience of cancer and its treatment can act as a spur to people who wish to reassert control over their bodies and bring their body back into a positive relationship with health and fitness. Sometimes this impetus can provoke an almost super-human response on the part of the person with breast cancer:

I had been attending Body Pump 2 or 3 times a week for 10 years prior to my diagnosis and made casual acquaintances with other regular attendees. [...] I returned to the classes myself while still on chemo, I was having a weekly light dose for 3 months so felt OK. While my energy levels were a bit low I managed to do about 75% of the class with light weights and just stopped when I became tired. The instructor and other class members were so supportive. It helped me to feel like I was getting back to normal just being able to participate in the classes. (BCC)

On occasions, BCC members will post in a way that invites support from those who have developed successful strategies or responses to similar challenges. Here the mind is sometimes seen as determining the response of the body:

[I'm] finding it hard to get motivated enough to go out. This is made worse because I have put on lots of weight and am so unfit compared to my pre-cancer body. So doing exercise just isn't as much fun anymore. Hopefully it will get better. (BCC)

When a person with a breast cancer diagnosis seeks strategies to move beyond a place in which they feel stuck, it is often through harnessing a sensory image. The means of moving through a challenge, or towards an acceptable new normal, might be via the use of senses, simulation and experiential movement:

I feel like I'd like to have someone gently hold my hand and lead me to do all the cardio, exercises and stretching. Having been through so much I feel like being nurtured but instead I have to be strict and a bit tough to take steps to go forward. [...] Often I pop outside and if the sky is clear and it's not too cold I walk around the block. (BCC)

Communication and the Body

What is clear from these communications between members is that an experience of breast cancer can trigger particular responses associated with physical embodiment. Even as the person with a new diagnosis of breast cancer tries to rationalise the diagnosis, the treatment and the prognosis, so they are assaulted by a range of highly physical sensations, from feeling sick, to feeling crushed, to feeling as if even the certainties of gravity have been challenged by this embodiment of change (Walker, Plant, Hopkins).

For those working through their response, initial analysis of the data from the disembodied BCC community indicates that accommodating the post-cancer self often takes a physical form, an acceptance of the revised self and its engagement in sensory and simulated ways with the wider world. For example, it is often aspects of the post-surgery body that BCC members use to highlight the possibility of a lighter, more humorous, response to the challenges of their experience:

haha XX [friend who has had a breast cancer diagnosis] and [I] still go to lift the boob when washing in the shower haha.

a friend of mine had [a] double reconstruction a few years back and needed 'replacement nipples' that were imported from the US - we all laughed when she announced they have arrived in the post for her! (Both BCC)

In terms of the research question, "What embodied knowledge about breast cancer can be shared in the disembodied realm of an online support community?", the data presented indicates that experience of the life-changing disease of breast cancer can trigger a new appreciation of the physicality of the human condition. This can be shared with others in a similar situation, seeking confirmation of shared experience.

The disembodied community allows the member-self to move from the cognitive realm into an experiential one. It foregrounds the strangeness of the revised body through temporary but highly visible indicators, such as the loss of hair following chemotherapy, and permanent but less visible changes, such as the removal of a breast.

It allows these changes to be reconceptualised as the new normal, and provides a safe space in which to explore and imagine further responses to these embodied challenges such as whether to use a prosthesis, or to embark upon a reconstruction. The physically disembodied community of the BCC may constitute a lived space where the daily experience of breast cancer is addressed; “simultaneously part of bodily forms and their social constructions” (Moss and Dyck 49).

This initial analysis of BCC community posts indicates that one way through the maelstrom of diagnosis, treatment and living with an altered body is a renewed focus upon experiential data and the sensory life. Simulation is often used and described as a means of coming to terms with the new normal. Theoretical discussions around embodied knowledge may yet prove to have practical outcomes by contributing to a composite and shared understanding of the disease and in supporting people whose lives have triggered a radical re-appraisal of what it is to be an embodied being.

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The third paper, from this study, resulted from the identification of one member who used different names, one on her home page and another in the Click Chat sessions. The two names caused confusion in the newly established online Click community. Angel, the member using two names, inadvertently misled the Click community but this was later clarified in a chat session that followed.

In this chat session the initial conversation had focused on Angel’s diagnosis and that she wasn’t having any treatment apart from having had a mastectomy 12 months earlier. Her verbatim transcription is included here to set the context: Angel (BC) explains “I will not compromise the quality of life I have now, at 60 years of age...for something that may not do me any good and they reckon I haven't got cancer anymore anyway....” The Click team empathised with Angel’s decision. However, the story told by Angel was the same as another Click member, named Mary and when the researcher spoke to Angel of this similarity. Angel said:

Angel: “OK [...], thanks. Maybe it’s me....what’s her name?”

Researcher: “Angel check out Mary under general Click Chat in the forum”.

Angel: “Ummmm, LOL Mary is... ME....LOL. I use Mary as a name, because that was my mum’s name. LOL”.

With the benefit of hindsight, Angel’s reference to her breast cancer treatment paralleling her mother’s and her cheery chat may have hidden a deeper turmoil not easily detected by others. During the above chat session, Angel invited other members in the chat session to meet for lunch offline. This meeting took place three weeks later and the incident that occurred forms the basis of the following paper.

The third and penultimate paper in this chapter has also been published. The paper used a case study, to highlight a situation where the online and offline worlds of members intersect and the repercussions of this meeting, to ensure the health and safety of all concerned.

Costello, L., Witney, C., Green, L., & Bradshaw, V. (2012). Self-revelation in an online health community: Exploring issues around co-presence for vulnerable members. In C. Anyanwu & K. Green (Eds.), *Proceedings of the 2012 Australian and New Zealand Communication Association Conference*. Adelaide: Australia.

Abstract

Problem: This paper addresses the implications of working with vulnerable groups in the context of an online health community when members move from co-presence online to co-presence offline.

Theoretical Approach: The case study presented in this paper challenges the expectation that self-revelations are usually more common in online environments because of the anonymity and comfort experienced there.

Methodology: Taking as its example the events in a research project designed to investigate the relative features of online communities and social network sites by using a ‘netnographic’ approach, this paper examines the introduction of live chat sessions with a view to building social and emotional involvement in community members who

had been, to that point, somewhat disengaged.

Findings: On the fourth live chat, held shortly before Christmas, one community member suggested that they meet for a meal, effectively moving the co-presence from the online community into the offline world. This duly occurred the following week, but the situation did not develop as the research team members had envisioned and instead they found themselves dealing with a member who, in person, was revealed to be feeling suicidal.

Conclusion: Addressing the case study in terms of the implications of co-presence and self-revelation in research settings, this paper goes on to describe the changes in policy and process instigated by the support organization to prepare for other possible events of this nature.

Introduction

This paper discusses the challenges faced by the Breast Cancer Click site in the first year of its launch. It argues that the formation of an online health community, where members can seek and acquire support while co-present online, may also lead to members desiring a co-presence offline in order to reveal new information about themselves that had not been disclosed in the online setting. This is the inverse of what might be expected. It is usually the online setting itself that encourages more open disclosures. A number of studies indicate that co-presence online enables revelations about one's self that may be too difficult to reveal face-to-face (e.g. Joinson, 2001; Rheingold, 1993; Reid, 1991), at least in the first instance and usually early in the relationship. This paper explores the opposite scenario, where an unexpected and disturbing revelation was shared when members of an emerging online community were physically co-present. Prior to this, the interactions, which had taken place online, gave no indication of what was to be revealed offline. This paper provides an example for other researchers, whose projects might involve co-presence (online or offline), and raises awareness of contingencies that might arise and how to cope with them. It addresses the use of the strategy of having scheduled online sessions to encourage members to participate and to create social capital, and then describes the chaotic outcome of one online meeting, during which participants decided to meet offline.

Research methodology

The authors are members of a research team which includes a project coordinator representing the industry partner, two senior academics and a PhD candidate who is the recipient of an APAI award, the second author of this paper, and who is referred to in this paper as the 'netnographer' (see below). The second author is also charged with conducting the broader research project as part of an Australian Research Council (ARC) grant. The two senior academics are experienced in the creation and operation of online communities, but are also aware that this is a fast-evolving space in which to work and that the notion and practice of online community and online engagement is constantly changing (McQueen and Green, 2010).

Although the broader research project applies a netnographic methodology which uses a combination of postings collected online (chat room dialogue, discussion threads, messaging, and other interactive tools), along with interview, focus group and survey data, this paper relies upon one specific data point, namely excerpts from chat dialogue, and a case study of an event that followed one particular chat session. These two sources of evidence are interrogated to support the assertions made. According to Robert Kozinets, who first introduced the technique in 1998, netnography is 'a specialized form of ethnography adapted to the unique computer-mediated contingencies of today's social worlds' (2010: p. 1). In a similar vein to ethnography, it aims to achieve a scientific description and deep understanding of phenomena but with less emphasis on the application of theory or preconceived frameworks to aid understanding (Ward, 1999). Instead, netnography recognises that the members who are invested in their development construct the cultures of online communities; hence their description and any construction of theory should be derived from the community members in question. In order to protect the rigour of this approach, a range of cultural studies theories provide the undertone for the broader research and are kept in reserve for checking against the final interpretation.

In this instance, the culture being investigated is that which has been developed by, and expresses, the Breast Cancer Care WA online community, the Click site, and the individuals growing the fledgling community are breast cancer patients and their supporters, i.e. family, friends and carers.

The aim of the broader research is to investigate the impact upon a flat-hierarchy community of the introduction of specialist counselling and advice. The supposition is that this inclusion of an 'expert' changes an otherwise egalitarian dynamic and that guidelines are needed to assist communities such as this one to handle that additional element (Lampel and Bhalla 2007). Such guidelines do not currently exist but will be prepared as one of the outcomes of this research.

The project also offers the opportunity to examine the differences between the operations of an existing social network site (SNS) (boyd and Ellison 2007) created by the charity partner Purple Boot Brigade (PBB, 2012), and the operations of the online community set up as part of this research.

The project involved researching what constitutes contemporary best practice in online community construction, within budget, and constructing a community to embody this perspective. There was even the hope that the online community might harness something of the 'viral growth' of social networks (Gross and Acquisti 2005, p. 1; Boyd, 2007). The partner organization already had an award-winning not-for-profit SNS (AMI, 2008) and sought to make the online community and the SNS interoperable, even though the target memberships were very different. Indeed, one of the spurs for the establishment of the online community had been the harnessing of the SNS by members affected by breast cancer who were seeking personal and emotional support. It was clear that there was an unmet need for such services and the online community was set up, in part, to address that need. Even so, notwithstanding existing support-seeking behaviours on the SNS, the online community faltered. After some months of trying to establish an authentic, mutually supportive community, none was clearly evident and the research was falling behind schedule.

The aim had been to establish a vibrant community and then add an expert, advice-giving role. It was decided instead to create live discussion forums as part of the preparation for introducing the role of the professional advice-giver. The membership would be circulated to inform them that the netnographer and project coordinator would be present for 'live chat' one or two evenings per month (the evening varying between Tues, Wed and Thurs; early evening in W A, late evening on the Australian Eastern coast) and members would be invited to take part. Although only a few members signed in for the first Click site chat, those that did were engaged and contributing, and the chat

ran for several hours – longer than had been anticipated. This raised issues about the importance of co-presence for developing a sense of connectedness and belonging, and about the predictability of a human presence at the point of engaging in online communication.

Indeed, the idea of netnographic enquiry implies a need for human presence in communication in that it extends the notion of an ethnographer doing research in order to gain a ‘deep involvement in the subject’s worlds of experience’ (Denzin, 1997: 35) to one which involves the netnographer in the role of being part of the research (Ward, 1999). Given online communication means that a mutual text is created, the netnographer shares the research role with participants as they require and acquire information. Both parties contribute to an ongoing dialogue in the online space. The implications of the ‘next step’, however, which involved some of the founding members of the Click site and the netnographer and project leader moving from the online space (their virtual co-presence) to a physical co-presence, is the focus of this paper.

Literature review

Online community

Insofar as online communities form around self-disclosure and ‘human feeling’ sufficient to form ‘webs of personal relationships in cyberspace’ (Rheingold 1993, p. 5), professional online advice has the potential to introduce hierarchical relationships (Foucault, 1980) that change communication dynamics. This may be because the ‘altruistic’ driver of contribution to an online community is associated with status-seeking behaviour (Lampel and Bhalla, 2007) and it is harder for an amateur to contribute at a level significant enough to win much status where a community also includes expert participation.

Whether or not the introduction of an ‘expert’ will affect the community dynamic or sense of support created through peer interest and response (Lieberman and Goldstein, 2005) is the subject of the broader research not reported in this paper. Nonetheless, establishing a basic sense of what constitutes online community provides the contextual foreground when excerpts from the Click site’s chat room, and the events that followed, are later discussed.

Although Rheingold's definition of community and research – involving well people – is among the most comprehensive and widely cited, Elizabeth Reid's honours thesis is particularly relevant to tracing the origins of online community. Her subsequent works have been included alongside Rheingold's in leading computer-mediated communication (CMC) texts, edited by some of the most influential scholars in the field: Steven Jones (1994), Peter Ludlow (1996), and Marc Smith and Peter Kollock (1999). It was her seminal work (1991), however, on the dynamics of chat specifically, which is most relevant here. She noted that the 'threads holding IRC [Internet Relay Chat] together as a community are made up of shared modes of understanding, and the concepts shared range from the light-hearted and fanciful to the personal and anguished. The success of this is dependent upon the degree to which users can trust that the issues that they communicate will be well received – they depend on the integrity of users' (Ch. 7, online).

Therapeutic outcomes of online community

The therapeutic and health outcomes of online community have been varied, perhaps because the benefits have been difficult to attribute to the community component given the lack of controlled settings (Eysenbach et al., 2004). In 2005, however, Rogers and Chen conducted an in-depth and longitudinal study of an internet community group for breast cancer patients and found that there was a positive correlation between the degree of participation and psychosocial well-being. In other studies, online community has demonstrated benefits in diverse settings, including: reducing sense of isolation for those who experience infertility (Malik and Coulson, 2008); increasing emotional support in suicide prevention (Barak, 2007); and supporting a sense of normalcy and a sense of self for transplant patients (Bers et al., 2010). Blogging, which is often used in online communities, has also been shown to increase social integration and satisfaction with friendship interactions that are important to a sense of wellbeing generally (Baker and Moore, 2008). In terms of behaviour change, Wise, Yun and Shaw found (2000) found that online communication, compared with two other interventions – information and interactive planning – delivered via the CHES website, correlated positively with diet change and smoking cessation. Although they did not determine if patients established the kind of personal relationships that define online communities, this work does identify that online

communication, which is a precursor to online community, delivers measurable benefits.

The take-home message from online community research is that engaging with such communities does tend to improve perceptions of life quality (e.g. Idriss, 2009) for various groups who are in need. Still, online communities should not be viewed in utopian terms; negative outcomes have also been attributed to them. For example, children engaging with others in an online community are at risk from sexual predators and underage solicitation (Ybarra and Mitchell, 2008), cyber-bullying (Dooley, Pyzalski and Cross, 2009) and eating disorders (Lynch, 2010). Our previous, health-related research has also demonstrated the negative dynamics of online community when a dispute between a few members raised issues around privacy; hacking and personal harm (Green and Costello, 2007).

In most cases, however, research has pointed to the positive, health-promoting outcomes of online community engagement for people living with a life threatening condition, and studies have documented that the social and emotional links generated online between strangers can transfer into practical support in the offline environment (Bonniface, Omari, and Swanson, 2006). It has also established the existence of a philanthropic response by some (health) patients engaged in the online community that sees them keen to reciprocate by offering support to the community through communication and advice (Bonniface and Green, 2007). However, the kinds of strategies that had worked to establish online communities before SNS were not working on the Click website and other strategies had to be developed and trialed.

Co-presence: Live chat and offline meetings

In relation to online chat, Reid (1991) implicates co-presence by asserting that there is no way to interact with IRC (Internet Relay Chat) without being a part of it – it is interaction that creates the virtual reality of channels and spaces for communication. Immersed in this specific, though not ‘local’ in any geographic sense, context, players of the IRC game are involved in turning upside down the accepted norms of the external culture (Chapter 6, online).

What is considered to be normal externally (offline) is negotiated in a new way to form a new kind of shared culture when members come together online. A concept

underpinning this co-present engagement has been referred to as ‘consciousness of kind’ (Gusfield, 1975). It communicates something that is inherently believed or known by members about the online environment and does not suggest that members must have physically met each other in order to acquire it and be part of it. Essentially, when members can ‘imagine’ their own communities (Anderson, 1991) online, they can behave in ways that become more acceptable or accessible than those which might necessarily be afforded in an offline setting.

Turkle (2005) has equated this to a form of compromise offered online, between the ‘intimacy’ of face-to-face communication and the undemanding nature, but constant availability, of computer-mediated communication:

Terrified of being alone, yet afraid of intimacy, we experience widespread feelings of emptiness, of disconnection, of the unreality of self. And, here the computer, a companion without emotional demands offers a compromise. You can be a loner, but never alone. You can interact, but never feel vulnerable to another person (p. 279).

This is not to say that each environment does not support the other. Indeed, having a ‘telepresence’, along with a ‘physical presence’, can be mutually supportive for human relationships (Naughton, 2001). In any respect, Larsen et al., (2006) argue that face-to-face (co-present) meetings are “central to [people’s] social lives and to the building and maintenance of their social capital, and of social capital more widely” (Larsen, et. al, 2006, p. 125). Arguably, the centrality of co-presence is also true online where the meeting takes place in a shared temporal space, rather than a shared physical space. That is, co-presence is important online whether it provides a ‘compromise’ for face-to-face interactions, strengthens face-to-face interactions, or provides the impetus to seek out face-to-face interactions. Certainly, this capacity for strengthening emotional engagement was the impetus for establishing the Click site chat service in the fledgling online community.

The strategy of live chat certainly had an impact on the type of personal communication exhibited on the site and created a core of communicating members who then seemed more willing to invest in online interaction and asynchronous postings. Where a more authentic style of interaction is identified it typically has the

result of prompting more communication. On Click Chat this authenticity was experienced when members revealed something of their personal stories, struggles, achievements and a personal appreciation for the site's launch. This sense of communication prompting a desire for co-presence has been discussed by Graham (2001, pp. 165– 6: original emphasis):

... it has long been recognised that, as well as substituting for travel, telecommunications can actually generate or *induce* many new demands for physical movement ... a demand for physical co-presence leading to new forms of physical travel that might not have taken place without the telecommunications linkage.

In the case of the online community in question, the chat session led to suggestions that, since many members were in the same Australian state, people should meet and be physically co-present. Since the research team (Bonniface et al., 2006) had had positive results in equivalent circumstances, along with other CMC scholars whose work informed our strategies (Wilbur, 1997; Xie, 2008; Wellman, 2001), the proposal that people should meet face-to-face was welcomed.

The paper now addresses the transition from community membership to online co-presence, and from co-presence online to co-presence offline, and discusses some of the issues arising from what happened in this research context. This is presented as a case study, which is story-like in nature (Yin, 2009), leaving the more structured netnographic analysis for subsequent papers when all of the data sources have become available.

Case Study

There had been four live chats before it was first suggested that participants should meet face to face. The first had been scheduled for a Thursday (7.00pm) and ran for three and a half hours. The members in this first session concentrated solely on the issues surrounding a diagnosis of breast cancer. The major topic was 'how friends and family had coped (or not coped) with the diagnosis and treatment' of the cancer. There were two members making a major contribution to the first live chat session, Donna and Karina (all names have been changed to protect confidentiality).

The second Click Chat was held three weeks after the first, on a Wednesday, and attracted four members, three members with a breast cancer diagnosis and one who was supporting a family member with a diagnosis. Karina was one of the members participating again, which indicated that she had found the first session useful. The research team was pleased that the scheduled discussion had successfully attracted additional participants.

The third live chat was on a Tuesday evening, to experiment with different days. It included a specialist practitioner as a guest participant. This health professional was considering taking on the role of breast care nurse for the online community in a contracted capacity as part of the research project. While the chat was going on it could be seen that several people had logged in, but seemed to be having difficulties in connecting. Eventually one of these, Angel, joined the chat room just as the discussion was concluding at 10.45pm, so she was encouraged to join the fourth live chat and the team resolved to address the access and communication issues that had arisen.

The success of the live chat had been growing steadily over the three sessions. This success was measured not so much by the number of members online, but by the depth and tone of the conversation, the positive feedback, and the length of time the members spent in discussion. Even though the Click Chat had been advertised as a three-hour session, it had run on occasion for five and a half hours. Its success could also be gauged by participants offering information, advice and support to one another. Five community members attended the fourth session, four with breast cancer plus a support person. The research and support team, including the acting professional advice-giver, were also online. Overall, even in view of its length, this was a lighthearted discussion with a focus on pets and hobbies together with one or two more serious subjects.

Angel was one of the first to join the fourth Click Chat: ‘Glad I’ve actually made it here - last time chat was on, I tried for 2 hrs and couldn’t get in....grrrrrrrrrrr’ (Angel). She was the only member in the chat room for more than an hour when Sarah joined, followed at intervals by Lindy, Gaye and Beryl. Possibly because she was first online, the initial chat had focused around Angel’s diagnosis and the fact that she wasn’t having any treatment for her cancer apart from an operation that had been carried out 12 months previously. ‘I will not compromise the quality of life I have now at 60 yrs of

age' said Angel 'for something that may not do me any good and they reckon I haven't got cancer anymore anyway.' The Click team empathised with Angel's decision not to have additional treatments such as chemotherapy and radiotherapy.

After a conversation on other topics, however, some members asked Angel what had influenced her decision not to have additional treatment for her breast cancer. She replied: 'after seeing what my mother went through with chemo I always knew that if ever I had BC I wouldn't want chemo. Mind you, never in my wildest dreams did I think I'd get BC. There was a lot of pressure from the 3 oncologists, the surgeon and my GP to have the chemo. To me it simply didn't make sense to have it.' (Angel). Lindy responded very positively: 'Chemo isn't for everyone. But I've coped really well with it; it does really depend on the individual' (Lindy).

At the conclusion of the evening's chat, Angel suggested that maybe people would like to get together for lunch the following week. This was agreed and two people plus the project coordinator were seated at the lunch table when the netnographer arrived at the scheduled time. As everyone introduced themselves the researcher realised that neither of the diners were members of the Click research community. Angel, the organizer of the lunch and Beryl, the other member who had expressed an interest in coming, were nowhere to be seen. Angel arrived just as one of the potential members was leaving, and appeared happy and upbeat, apologizing for not being there sooner. At the end of dessert, as people were deciding whether to have coffee or not, Angel took a folded piece of paper from her bag and announced: 'you know I've written a suicide note'.

The lunch companions were extremely shocked. No-one had had any inkling that this was what Angel had been thinking about. The project coordinator persuaded Angel to go with her to see a counselor associated with the charity. The netnographer volunteered to drive the remaining potential member home since she had been very unsettled by the turn of events. The project coordinator, who does not have a professional health background, found herself tied into an extremely unsettling counselling session for the rest of the afternoon. Angel was later to write (post edited to remove identifying features):

[Project coordinator] put me in her fabulous Mazda sports, we had the top back, we put on our Christmas crowns and drove to West Perth... had a... deep [and] meaningful... with a lovely lass there, [the project coordinator] stayed with me the whole time. My son came and got me. Got assessed at the local hospital, they said I could come home... getting back into therapy asap... seeing my GP tomorrow. I will never be able to say this enough times... but... THANK YOU, THANK YOU, THANK YOU... for today, in my deepest despair you supported me... I am beyond words. (Angel)

Angel re-joined the site for a short time after this incident but approximately two weeks later sent a personal message to the netnographer saying that she had just been discharged from a psychiatric ward where she had been admitted the previous week:

I still have a lot of intense therapy ahead of me, which will be arranged next week. I've decided to pull back from on line BC support as I think it is depressing me, although it's lovely to have the encouragement of the other ladies with BC, I think I have to move my focus to other less stressful things in order to help me recover from my depression.....on day [sic] I hope to come back to...BC Click....but for the moment I think I need to step back. I hope you will understand. (Angel)

Discussion and Conclusion

In most cases the anonymity of online interaction means that members can disclose their intimate thoughts and feelings in ways that they may never do in face-to-face 'real world' settings (e.g. Joinson, 2001). Alternatively, people may self-disclose only after making an initial, minor disclosure to establish whether the online space is comfortable. The opposite situation is observed in the case presented above. Here, the co-presence shared through the online Click Chat did not provide the reassurance to disclose a vulnerability that was being experienced by one of the members. Instead, the revelation was made offline, only after the members who had previously become acquainted online were all able to meet together face-to-face. This seems to challenge the norms associated with the types of revelations one might expect people to make (or not to make) when members who are relatively unknown to each other meet or are physically co-present; however it does align with recent research that contests the view

that online environments are more ripe for personal disclosure than offline contexts (Ngyuen, Bin, and Campbell, 2012). It is possible; however, that the co-presence shared online generated enough trust to instigate a face-to-face revelation, which might otherwise not have been offered. It is also possible that Angel engineered the co-present meeting in order to stage a 'cry for help' in a manner that would ensure that she received people's personal attention.

As a result of this incident, BCCWA developed additional guidelines for handling this type of occurrence. Having been a successful support charity in a complex field, the organization already had a range of relevant protocols in place, as well as an onsite counselor, breast care nurse and Indigenous liaison worker, not all of who were full time. It was acknowledged that similar situations are a possibility, and have happened in the past. The team discussed what had happened and decided to include a statement on Click's home page to notify members that the site is not designed for one-on-one counselling, and to say that members in an emergency should contact their treating medical practitioner or Lifeline in their state.

The situation as it developed highlighted the need for research team members to be prepared for all contingencies and to be constantly aware that community members encompass a range of life experiences and health issues, including both physical and mental. Given that two team members were present as the sequence of events developed, duty of care could be provided to those who were affected. It is now a formal policy, that at least two team members attend offline meet-ups to support each other should something unexpected occur, and to calm the other group members if one member of their community should unexpectedly have an emotional episode or need medical assistance.

The case study indicates that co-presence is an important element of building trust in a community and in supporting self-revelation. The live-chat sessions seemed to serve as a catalyst in encouraging a fuller and deeper engagement with the online community. It is interesting that it was Angel, the person who might be considered to be in acute need, who suggested moving the online co-presence to an offline co-presence. Arguably, her experience of the online-moderated live discussion helped her to feel that the researchers on the site were trustworthy and could be relied upon. This engagement then deepened with her personal experience of the support team in physical co-presence

when Angel arrived (late) at the lunch she had set up. It may be that Angel arrived late because she felt unable to handle social niceties without immediately moving to the crux of her agenda: her desire to seek immediate support in dealing with suicidal feelings.

The netnographic approach employed in this study requires that the researchers implant themselves in the online environment, freeing themselves from pre-conceived ways of knowing. However, it is the cultural studies frameworks that provide the conceptual foundations for investigating online community. The signs of online community are evident here in their early form: that is, the sense of safety and trust in the Click community that underpinned Angel's desire to express her self-concept and her locus of control, juxtaposed with that of her mother. This was hinted at online, but only fully revealed in the offline meeting. We have yet to approach Angel to see if she is willing to take part in the in-depth interview phase of the netnography.

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The final paper in this chapter commences below:

Witney, C., Green, L., Costello, L & Bradshaw, V. Creativity in an online community as a response to the chaos of a breast cancer diagnosis, M/C Journal 16(1).

Introduction

A catastrophe is often considered to be a final decisive event, resulting in a disastrous end. Two recent examples of catastrophes satisfying this definition were the 2012 super storm Sandy in the United States of America and the 2011 floods in Brisbane, Australia. The progress of these disasters was reported worldwide, yet coverage soon disappeared from the headlines, leaving people to deal with the aftermath of rebuilding homes, businesses and lives without public attention and support. The diagnosis of breast cancer is an individual's personal catastrophic event. While not on the community-wide scale of the disasters mentioned previously, it can

have disastrous effects on not only the affected person but also their close family and friends. At the moment one in eight women can expect to have a breast cancer diagnosis in their lifetime. In Australia alone this means that approximately 1,375,000 people are likely to be affected. This paper addresses how breast cancer can and does prompt women and their supportive friends, families and partners to become more creative as a result of their breast cancer diagnosis. In these cases creativity, defined as doing something a little differently or thinking outside the square, can offer some remedy for catastrophe. Becoming totally involved in the creative moment so as to lose all track of time and forget the trials and worries of BC is referred to as experiencing flow (Nesbit). Flow is one fruit of the creative process.

This paper refers to women, as having breast cancer because the majority of people diagnosed with breast cancer are women. However men do constitute 0.8% of the total number of people diagnosed with breast cancer (Breast Cancer in Australia). Responding to public concern, a range of charities has been formed to support people with breast cancer. One such charity is Breast Cancer Care WA (BCCWA). Together with the Australian Research Council (ARC) and Edith Cowan University (ECU), BCCWA supports an online community for people with breast cancer called Breast Cancer Click (Click). The membership of Click includes several male Clickers who are partners and supporters of Click members with breast cancer. Many of the verbatim quotes used in this paper are taken from the www.breastcancerclick.com (Click) website. Instead of identifying a speaker with a personal attribution; the term 'Clicker' is used, and then qualified as either a Clicker with breast cancer (BC) or a Clicker who supports someone with breast cancer (Supporter). The Click website provides members with an opportunity to express themselves and they often respond creatively.

The chaos and catastrophe of a Breast Cancer Diagnosis

When a woman is first diagnosed with breast cancer, it is often as a result of her bi-annual mammogram. She expects a routine visit but is advised instead that she requires further investigation because abnormalities have been detected. This is not what she expected. Probably all previous mammograms have been normal. The personal catastrophe occurs when the woman receives a definitive diagnosis of breast cancer. Chaos is added to catastrophe as the patient and her family struggle to grasp

the meaning of the diagnosis and the multiplicity of treatment options. For some, the diagnosis is quickly followed by another catastrophic event, the removal of one or both breasts. For others the catastrophe occurs by increments. This is evident in a member's blog on the Click website,

Here we go again been awake since 2.30am ... Lordy Lordy I thought I was over this!!! I guess I'm not really okay with the need for more surgery. My head gets it, but my heart is heavy. At least I know what to expect right? Does that make it easier to digest? Hell no! So many fears running around my ever active mind. How will I cope with this one ... well that's easy - the same way I always do. Just get on with it Mary! How will my lovely man cope with this one. Not so easy to answer. I worry. I feel responsible for the amount of pressure he is under. The way he looks so sad when he looks at me. I feel like I've let him down. He's a good man with a heart bigger than any other person I know. But my heart is heavy. No-one can convince me this isn't my fault. If I didn't have this ... well the picture is there - no need for words. How much longer can my work/employers be so accommodating? I try to give as much as I can - lately that hasn't been very much at all. I know I'm entitled to put myself first. I get that .. but my heart is heavy. More surgery ... dammit !!!!!!!!!!! I just want this over NOW. The whole lot. I want my hair back, I want my working life back, I want the smile back on my man's face. I want ME back. I want to dance again. I want to have a conversation with friends that doesn't include my diagnosis or prognosis ... short term, long term ... any bloody term !!!! I want to feel useful again. I want to be a valued member of a team again. I want to be able to hold my beautiful grandson close. I want my man to hold me without fear of hurting me. I want to ZUMBA again !!! I DON'T WANT THIS ANYMORE!!!!!!!!!! But I need more surgery. I need to have more taken from the affected area ... just in one little spot as there was only 1mm clear margin & that's not good enough. I need to have a full axillary clearance as 2 of 4 sentinel nodes taken for biopsy revealed cancer cells present. I need to have more time off work, more time to rest & recover. More time to wait for the next round of chemo to begin & in turn more time to wait for rads to start & this whole damn process to be finished. My head gets it But my heart is heavy. (BC)

People with a breast cancer diagnosis do not always have an endpoint in sight, or an acceptable endpoint at all, and the chaos of treatment and recovery is focused on coping with the present and the next treatment on the horizon. Given the chaos and catastrophe inherent in a breast cancer diagnosis, what can individuals do to make a positive difference?

Creativity arising from Chaos

When people receive a life-threatening diagnosis such as breast cancer, they sometimes choose to think outside the square, to do things a little differently, to change the way they relate to others, to learn a new art or craft or to take up a musical instrument. Being creative seems to provide distraction from the treatment and maybe something to look forward to when the treatment is over. Some choose to participate in a formal creative therapy program, while others seek out a creative pursuit that they can do at home. For some women with a breast cancer diagnosis, joining the Click website is itself a creative act. Contributing to the online community provides them with new skills and allows other people to benefit from their advice and experience:

“Hi everyone. I know we all have different ways of dealing with our cancer. Mine has been to be more mindful of the wonders around me and savor every possible moment of joy. I have decided to start my own Blog to give myself a creative outlet and share my experiences (Clicker, BC).”

There may be a number of reasons for participating in an online community of people with breast cancer and their supporters. Whatever the motivation, it requires a person to think laterally and learn new skills in how to navigate and post to a website. A rookie member enters a relationship with people she hasn't met or seen face to face. She can choose to create for herself a new persona using an avatar, or simply devise a username that represents her online.

Creative Therapy and Breast Cancer

Some women may choose to participate in formal creative therapy programs to help them deal with the treatment of their cancer. According to Geue et al (168) in a recent review of research papers on art therapy and cancer patients, the creative response is used by more female than male cancer patients. This intervention used with breast cancer patients has been shown to enhance psychological well-being by

decreasing negative emotional states and enhancing positive ones (Puig et al 224). Music therapy with a group of breast cancer patients waiting for a chemotherapy cycle appeared to directly reduce patients' anxiety and physiological arousal, and enhance their sense of well-being and control (Bulfone et al 241).

Blogging and Breast Cancer

The creative pursuit may already be part of woman's 'normal' or pre-diagnosis life, or may be identified and pursued as a result of the diagnosis and used as informal therapy to keep the chaos at bay; for example, through joining a support website and blogging. Still other women find new ideas and direction for their creativity as a result of their breast cancer diagnosis or extend their writing skills from blog to memoir or book. The memoir or book may be used to vent their feelings and to gain perspective on their breast cancer journey or it may be written to help others facing a similar journey.

It seems that a number of women find that blogs offer a creative response to their breast cancer journeys, as evidenced by the collection of blogs on www.breastcancerblogs.org. The breast cancer blogosphere is a vibrant record of resistance to the disease. Click members are encouraged to blog, and are given space on the site to do so, with full privacy if they choose. A study conducted by Chung and Kim (2007) showed that cancer patients and their companions found blogging activity to be helpful in emotion management and for information sharing.

The Clickers are also encouraged to complete a SWEE in their blog. SWEE stands for 'structured written emotional expression', in which a person writes about their breast cancer journey for 10-15 minutes each day for three to five days in a row. The Clicker has the opportunity to creatively express their positive and negative feelings about their breast cancer diagnosis. Research shows that writing a SWEE can be good for both your physical and emotional health. (Pennebaker 540), (Lieberman and Goldstein 859), (Butcher & Buckwalter 114), (Stanton et al 4165), (Low & Stanton 87).

One Click member, the author of the Paw Paw Salad blog, received a top blog award from the breastcancerblogs website. She not only writes about her life and

family but also writes verse focused on her breast cancer journey. This is a snippet of a poem related to the headscarves she wore when having chemotherapy, and was triggered by a request for her to pass them on to another woman newly diagnosed with breast cancer.

Nine Squares

Discovered, bought and sent to me
By mother, cousin, friend
They have been lying in my drawer
My treatment at an end.

Another woman needs them now
Though she has not met me
A friend of hers is friend of mine
And asked if they were free.

So sorry she has need for them
I'm glad to make the gift
I hope that in tough times ahead
They give her heart a lift.

Mammoirs

Some bloggers (non-Click members) have gone on to write what is affectionately called a 'mammoir' or a book that recounts their breast cancer journey or provides advice and information for those newly diagnosed with breast cancer. This is the term applied by Clickers even to established works of literature in the genre, such as Professor Brenda Walker's award-winning 'mammoir', 'Reading by Moonlight: How Books Saved a Life'. The book describes how Walker took refuge from the chaos of her breast cancer diagnosis in the books she'd always loved. Her experience of chaos prompted her to turn towards the creativity of others, which in turn triggered renewed creativity in the form of her memoir.

Creativity, Click and Flow

Susan Nesbit was diagnosed with BC in 2000 and she used everyday creativity and self-actualising creativity to tackle the challenges of BC and to experience flow (61). Flach and Richards in Nesbit (2006) describe creativity as having two conditions: one is originality and the other is meaningfulness. They argue that people behave creatively when they have the knowledge and skills related to the activity they are pursuing. Nesbit used “everyday creativity to maintain a good attitude and positive spirits” and refers to the ‘flow’ that occurs when participation in an activity becomes so gratifying ...

“that I am doing it for its own sake, and when I become so involved ... that I become spontaneous and almost automatic, I am experiencing flow. My energy flows smoothly, I feel relaxed, comfortable, energetic and totally absorbed, losing track of time (Nesbit).”

One Clicker (BC), who produces handmade cards at home, was inspired to hold a Skype card-making education session for rural and remote people (with and without BC):

Today is a day of craft for me. I held my first remote workshop (a class via Skype) and it was a huge success. Just made a couple of Father's Day cards for a customer and decided to share some of my work with you all. I'd love you to take a peek at my album "what I do" ... doing what I love to do was and is my therapy to get me through each new crisis xxx (Clicker BC).

It seems that this Clicker may have achieved flow through the act of making the cards for her own pleasure and then met most of the conditions for maintaining that flow through the planning and execution of the online card-making class, which was a success. The results of this session might inspire this Clicker to conduct more sessions for others, helping them also to achieve flow. Ripples in an online creative space reach out towards a widening pool of card-makers, assisting them to cope with chaotic occurrences.

Conclusion

A diagnosis of breast cancer is, for most women, an imminent catastrophe. The newly diagnosed person is aware that this diagnosis may well be followed quite quickly by a mastectomy. This catastrophe, together with adjunct treatments such as chemotherapy and/or radiotherapy, causes chaos within the woman's family and friend networks. Each woman and her supporters deal with the catastrophe and ensuing chaos in their own individually creative way.

Creative expressions include personal blogs, poetry, such as haikus and free verse; and simple venting of feelings about diagnosis and treatment. The SWEE technique seems to indicate that this written engagement helps people cope with their diagnosis and illness. Attendance at art or music therapy sessions has been proven to be therapeutic and 'mammoirs' have been written to help others to avoid the pitfalls of the health system or to deal with treatment and its side effects.

Both informal and formal or organised creative therapy appears to have positive psychological effects on the woman with breast cancer. Whether each individual with BC achieved flow, as described by Nesbit, is not known, but it appears from the Click community that many do use every day creative acts to help them deal with the ongoing chaos of their diagnosis and treatment.

The Click was created to provide a blank canvas for those with breast cancer and their supporters to reach out to others in similar situations. This reaching out often also involves 'reaching in' to harness creativity. Websites such as Click make a difference in a range of ways to those that build community using the communication tools provided, but one of the ways they make a difference is through allowing people to respond creatively and to have those creative responses validated.

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Summary of Chapter Three

Chapter three presented the issues, which transpired during the evolution of the Click online support community. The papers provided insights into online community development and member interactions: First, it was not possible to ‘seed’ an online support community with members of a social network, even though breast cancer was the focus of both sites. Second, the physically disembodied space, that is the Click, provided a safe space for Clickers to explore, discuss and imagine their future responses to the changes in their bodies, as a result of breast cancer. Third, how some online community members embraced creative pursuits, such as blogging and card making, as a way of dealing with the sometimes-catastrophic effects of breast cancer in their lives. The final insight related to members not necessarily sharing their innermost thoughts in online conversations; therefore raising the issue of online community moderators having guidelines in place to manage concerns should they arise and prepare for offline meetings accordingly.

Overview of Chapter Four

The next chapter is comprised of three papers that highlight and affirm the value of the SBCN's role in an online support community.

Chapter Four

Introduction

This chapter consists of three papers. The first paper focuses on the importance of the SBCN's role in terms of the continuum of care for breast cancer patients, in particular the '16th moment' of cancer care, which is a significant finding of this study. The second paper examines factitious illness behaviour on the Internet (Munchausen by Internet) and how this illness may be detected, by a SBCN in an online support community. The final paper demonstrates how the role of the SBCN may be used to manage member distress through the identification of problems and issues from posts, personal messages and blogs, particularly if written in the manner of a structured written emotional expression exercise or SWEE.

There is an abundant amount of research literature that demonstrates how nurses practice their profession within the hospital and community setting (Cruickshank, Kennedy, Lockhart, Dosser, & Dallas, 2008; Lev, Daley, Conner, Reith, Fernandez, & Owen, 2001) and the effect(s) of this practice relationship on patients, including recent research conducted by (Benedet, 2011; Hemsley, Balandin & Worrall, 2012); and, the role of the nurse in maintaining this relationship (Beaver, Williamson & Chalmers, 2010). However, there is a dearth of research literature, which explores how nurses may practice their profession online through the provision of information, advice and support for members of an online support community, and, the effect(s) of their practice on an online community member's management of their breast cancer treatment.

The paper to follow has been accepted for publication in 2015. This paper demonstrates how an SBCN became the link between the breast cancer treatment team members and the patients (Clickers) and through a combination of on and offline nursing practice and the implications for those with cancer, and as an innovative nursing care model for future nursing practice.

Witney, C., Hendricks, J., and Cope, V. (In Press) The specialist breast care nurse within a netnographic online support community: adding the 16th moment of cancer care *International Journal of Human Caring*.

Abstract

The presence and active participation of a SBCN as both a member and employed health professional in an online support community can have positive effects on the knowledge, understanding and supportive care of those online community members who have been diagnosed with breast cancer and their supporters. The nurse in this instance is a SBCN; however other specialist nurses could undertake a similar role within other disease-specific support websites.

Keywords: Caring, netnography, breast cancer, specialist breast care nurse, online support community

Introduction

This paper describes the value of a specialist breast care nurse (SBCN) within a purpose-built online community called 'the Click'. The diagnosis of breast cancer for most women may be an imminent catastrophe and patients experiencing this diagnosis need various forms of support to enable them to cope with their changing life circumstances. A breast cancer diagnosis can quickly escalate to surgery inclusive of mastectomy, adjunct treatments such as chemotherapy and/or radiotherapy, and other forms of medical intervention that impact on the woman and her family and friends.

Breast cancer is a priority issue for the Australian health system because of the many people it affects either directly through a diagnosis of breast cancer or indirectly through the effects on family, community members and carers. On average, one in eight Australian females will develop breast cancer and one in 37 females will die from it before the age of 85 years (Australian Institute Health Welfare Cancer, 2012, p. 1).

Research has shown that patients in their first year post surgery for breast cancer are just as satisfied with nurse-led follow up, through regular telephone contact together and subsequent mammograms, as they are with traditional hospital-based follow up visits. Hospital follow up visits, which in most cases last about 10 minutes, usually

occur at three, six, nine and twelve months post-surgery, and are conducted alternately by the surgeon, breast care nurse, medical oncologist and radiation oncologist (Kimman, Bloebaum, Dirksen, Houben, Lambin, & Boersma, 2010, p. 2). Breast care nurses also usually provide a telephone follow up. The telephone call was often 15-20 minutes long and often included a semi-structured interview that encouraged the patient to discuss “physical ... and psychological symptoms, treatment side effects and hormone therapy...”, which allowed the BCN time to obtain information about the patient’s general wellbeing, family life, relationships and work integration where relevant (Kimman et al., 2010, p. 3).

Online communities are one of the contemporary means to provide support to such patients and their family and friends. It is well recognised that family caregivers and social support has important benefits to patients. Poor health information sharing and limited staff time for healthcare communication in traditional hospital care settings impacts on patient satisfaction, therefore online communities are becoming a contemporary scaffold to source information to complement traditional care (Tustin, 2010).

Kozinets (2010) first coined the neologism ‘netnography’ to describe research conducted in online communities. There is a plethora of healthcare websites and online ‘chat communities’ to assist people in seeking healthcare information relating to their personal experience, with compelling evidence on the effects of social support, however there have been significant changes within these communities with the introduction and addition of an expert nurse as a separate support phenomenon. Indeed, it is this feature that makes this study significant. The research evidence is strong in showing that nurse support has long-term consequences on health, education and psychosocial outcomes and makes a positive impact on patient care (Kirk & Marshallsay, 2013). Breast care nurses have significant power to engage patients and effect adaptive behaviour change with regards to diagnosis and treatment (Anderson, Porter-Steele, Yates, McCarthy, Whiteside, Young, Hargraves, White, Byrne, & McCarthy, 2012) and online access to support aids in understanding of treatments and recovery (Mo & Coulson, 2008).

This study uses the reflections, texts and stories of the SBCN and the Click users to inform understanding of the role and value offered by the SBCN to care through

online presence at the 16th moment of cancer care, critical to the enhancement of breast cancer nursing care, and thus gives a more informed understanding of online nurse-led care communities.

Online Communities

While a community used to be thought of as a group of people who live in a specific geographical location and have similar local concerns, this is no longer the case. Instead, the definition more commonly used focuses upon shared social exchange where people come together to receive and give information or support, to learn, and to find company (Hendricks, Cope & Harris, 2010). Online communities formed soon after the inception of the Internet and burgeoned with the development of the World Wide Web. Whereas the first social network site is judged by (boyd & Ellison, 2008) to have started in 1997 with the launch of SixDegrees.com, the formally recognisable online community was already well into its second decade at that point. Rheingold's book *The Virtual Community*, published in 1993, includes his definition of how a digital environment is transformed into an online community in which people feel they belong. He said online communities are "social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyber space" (Rheingold, 2000, p. 5). This definition makes it clear that it time, intensity and commitment underpin the transformation of a group of interacting people into an online community.

The Internet has been also been described as a social medium wherein individuals seek to improve their psychological wellbeing by interacting with and seeking support from others online (LaRose & Eastin, 2004). People living with a chronic disease such as cancer, and who have access to the Internet have been described as having a "trump card" because online they have each other for support (Fox & Purcell, 2010, p. 4).

The SBCN - 16th Moment of Cancer Care

The advent of an online SBCN is a technological extension of what has been occurring via telephone and clinic follow up of breast cancer patients for almost 20 years (Gotay & Bottomley, 1998). Telephone counselling of patients with cancer has been found to promote more favourable and optimistic coping strategies that have resulted in patients feeling they can manage their cancer, which in turn enhances their emotional wellbeing and that of those around them (Downe-Wamboldt, Butler, Melanson, Coulter, Singleton, Keefe, & Bell, 2007). The new imperative is to seek information and support for oneself as a healthcare consumer, aiming to become the 'expert' of one's own disease. Concerned health professionals recognised the need for the creation of new positions for health experts within these cyberspaces, thus creating the new 'cyber-nursing' role (Eriksson & Salzman-Erikson, 2013).

The '15 moments' of breast cancer care as described van Wersch and team in 1997 remain the gold standard protocol of breast cancer care. However, they are reflective of the fact that in 1994 the surgeon and surgery usually played the most significant (and frequently the only) role in the care of breast cancer patients. Now there is a system in which a multidisciplinary approach allows others to have a significant role in care, although the surgeon remains pivotal. The increasing use of neoadjuvant treatments (chemotherapy, hormone therapy) alter the order of 'moments' and can involve very complex treatments provided by different disciplines, with hospital stay being significantly less. Results are usually given at the post-discharge clinic appointment.

What is now added is an extra moment - the 16th moment - that is, online SBCN care. This study has shown that the SBCN plays a pivotal role in supportive care to users of the Click. The study demonstrates why a SBCN, who incorporates both online and offline support into her role, provides a vital communicative and support link in the continuum of communication that impacts on patient care, effectively a 'secret weapon' with the capacity to be the 16th moment of breast cancer care. The SBCN, if employed in a multidisciplinary breast clinic and in an online support community of people with breast cancer, can become the 'linchpin' or information clarifier in the continuum of communication for both the patient and the treating doctor, as well as a supportive adviser of the patient before and after diagnosis (Beaver & Luker, 2005).

This role of linchpin is supported by a recent study in 2013 by Ruland, Andersen, Jeneson, Moore, Grimsbø, Børøsund, and Ellison (2013) that described patients' use of a multi-component eHealth application named WebChoice, designed to support cancer patients in illness management. Through WebChoice, cancer patients could make use of individually tailored evidence-based self-management support through questions to a clinical nurse specialist and were able to communicate with other patients in a forum and use a diary. The major finding of this study was that the e-mail communication with nurses was valued highest. The provision of online advice and support, together with evidence-based information and education and the opportunity to discuss sensitive issues, gives breast cancer patients and their supporters the ability to incorporate the 16th moment of care and make use of that 'secret weapon', the SBCN online.

The Click

In this study, a purpose-built online community was developed inclusive of a specialist breast care nurse (SBCN) as a member and was called 'the Click'. In the case of the Click, the shared interest is in the topic of breast cancer. The Click was established to provide a support site for people who have been touched by breast cancer, to help them gain advice and share support with others in the same situation. Within the context of Western Australia, geographically the largest state of Australia with the majority of its population clustered around the coastal fringes of the state, it was acknowledged that people who live in the remote inland areas of the state are less likely access to breast cancer support and education than people in towns and cities. In either setting, however, only people who have access to a computer and an Internet connection, together with sufficient computer skills, were likely to become Click members and participate on the site. It is also known that many Internet technologies are used as much for local contact as they are for distant communication (Hampton, Sessions, Her & Rainie, 2009) so even those living in the midst of many, but lacking support and advice, can make contact with others with the same disease that live in their immediate neighbourhood or who live in different countries.

The Internet is the technology that facilitates this contemporaneous interaction of people with a diagnosis breast cancer through their membership of the Click online support community. Fox and Purcell (2010) in their Pew Internet and American Life

Project (PIALP) described the Internet as being like a ‘secret weapon’ for people who have complicated health issues not easily solved by the addition of the best, most reliable medical advice. Those online have each other and, according to the report, having a chronic disease increases the probability that they will share what they know and learn from their peers. “They unearth nuggets of information. They blog. They participate in online discussions. And they just keep going” (Fox & Purcell, 2010, p. 4). The Click is not the only online support website for those with breast cancer. Susan.Komen.org and BreastCancerCare.org.uk and Australian Breast Cancer Network.org.au also offer forums for those who seek advice and support from peers with occasional online chat sessions with health professionals. In 2003, the Australian National Breast Cancer Centre’s Specialist Breast Care Nurse Project Team conducted a multi-centre study of an evidence-based Specialist Breast Care Nurse (SBCN) role in practice. It showed that from the perspective of other health professionals, the SBCN “...improved continuity of care, information and support for the women, and resulted in more appropriate referrals and use of the time of other members of the team” (Liebert, Parle, Roberts, Redman, Carrick, Gallagher, Simpson, Ng, Khan, & White, 2003, p. 91).

The Click, however, is the only online support community that employs a health professional, in this instance a SBCN, who is also an online community member and a moderator, to field members’ queries and to provide evidence-based online education, advice and support. For a person to join the Click they must have had a diagnosis of breast cancer or be a family member or friend of someone with breast cancer, thus Clickers can feel assured they will find someone in the same situation who they can interact with immediately and perhaps become friends with online. Via mobile technology and user interface on mobile phones, tablets and laptop computers, a Clicker can always remain connected to another Clicker whether it is another member or the SBCN. They are only a click on their phone or tablet away from getting advice and support from a person they know online or as (Chayko, 2008) noted, these technologies “...facilitate an easy and portable sense of community ...” (p. 4) and form “...real and consequential social bonds with people we have never seen face-to-face ... we can do it nearly all the time, everywhere we go” (p. 3).

Research Aim

The research aims concerned exploring the role of the SBCN in terms of support and care via the online community ‘the Click’ to the patient both pre and post a visit to their treating physician and what influence this support has on the patient’s journey.

Method

The SBCN was asked to write a reflection of her role after six months in employment as online support health professional. A textural analysis of Clickers’ comments was undertaken over the same period in relation to the support provided by the SBCN.

Results

Three key areas of the SBCN’s role online were identified. They were information giving and clarifying, continuity of care, and support. All are captured in the reflection below.

She says:

The benefit for patients who meet me ‘online’ soon after diagnosis is that I’m usually able to assist them at this very stressful time with any queries about information they’ve been given but may not have understood – frequently a major concern for newly diagnosed patients as they are often shell-shocked at the time. I can also usually explain further regarding possible treatments or options. Importantly I always try to discuss and assess their main concerns, look for ways to address these, and inform them of relevant resources or local services that may assist.

When they join Click is that it’s a continuation of the relationship that began in the clinic of providing information and support etc., however in a different setting, hence providing them the fantastic opportunity of gaining benefit from other members, reading information, . Also they can send messages or blog at any time (evening, weekend, etc. They already feel comfortable, as they ‘know’ me from clinic, therefore a ‘trust’ relationship has already been established (critical aspect in confiding their fears and trusting the information I provide - and therefore the site by association).

Likewise when I meet people in clinic after first interacting on the Click, this allows a similar form of continuation of care, and is fantastic for us both to extend the relationship beyond one that relies purely on ‘written words’,

allowing a warmer and more trusting bond to form. This is also hugely beneficial to both as I have a far greater understanding of the person's ideas and concerns, and they have had the opportunity to explore this prior to attending clinic, hence a more productive interaction and outcome at appointment. And of course we get to have a 'hug'!

Further:

I think it is a fantastically ideal situation to have someone who – particularly if you can have an individual that you can know is there as your own personal nurse or person. I think it is very difficult to have that as a reality because no one is available 24 hours a day. The greatest advantages of the Click site are it is not big. It doesn't have a large number of members that would become overwhelming, and you perhaps would have to have more than one nurse if it grew to that extent. That's when you lose the personal touch.... Years and years ago when I was the only nurse at the facility, so therefore every patient I was it, so in some sense it was that scenario. If the women came in I was the only nurse, they would know that I was the one to contact and I would see them each visit, so there is that continuum of care but we can't do that. It doesn't work practically now, the way the clinic runs. So you don't get a particular nurse each visit, you get whoever is available. It loses a lot of the personal touch. Sometimes you don't know the patient who is coming in and it may be their second or third visit... The advantage with the Click at the moment is that it is small enough that I am able to keep a personal relationship with each person and that is so different when somebody comes on and they feel like they know you. Even if they have never met me, because on the Click a lot of them have never met me, but they have an interaction with you, therefore they kind of... it breaks the ice, they feel like they know you and they feel a lot more comfortable to ask questions. That's where we're at now. To be able to achieve that in any other setting I don't think is achievable to have that level of a personal touch; with one nurse you can have a continuum of care.

It is really when you build that trust that people will come on and say – I've just got a question, is that ok? They know you enough to do that.

The continuity of care in support, communication and education is enhanced when the SBCN has a presence online. A relationship of trust, immediacy of response to questions and support needs, coupled with a community of others who are sharing a similar experience, is clearly evident from the reflection.

The specialist breast care nurse brought 20 years' experience as a specialist breast care nurse to the online community and was also actively employed in her offline SBCN role. The dual facets of the SBCN's role resulted in two important benefits for the entire Click community: one, the provision of current, evidence-based health care information for Clickers when research has shown that when information is shared in online support groups, the information is usually from the group member's personal experience and is unlikely to be factual medical information. This is what occurred during the early days of the Click site when the Click team members and other Clickers were the initial respondents to new members' queries. However, Clicker questions about a specific medical issue were responded to by suggesting they speak with their specialist doctor, general practitioner or one of the specialist breast care nurses employed by BCCWA.

Two, the SBCN often received and responded to queries per the personal messaging or instant chat system. When she recognised queries that were different to those already posted on the forum she prepared a detailed response that, with the consent of the Clicker involved, was also posted, with no Clicker name attached, to the forum, for the information and education of all Clickers.

One downside of the personal and instant messaging system is that no other persons see these messages, so the Click may not be seen to be a very active community. Some Clickers also send private messages to the SBCN and other Clickers when they join, but do not post anything to the rest of the site, so this activity is also not visible. These systems do however allow for Clicker privacy, which is very important to those who wish to discuss issues of a highly personal nature with the SBCN or other Clickers. The SBCN, after the initially welcoming the Clicker may also private message them, particularly if their initial post provides evidence of distress.

The following is a Clicker's private message and the SBCN's response, which highlights the knowledge and experience of the SBCN and the fact that some members may not feel confident enough to post anything to the site for others to see. The SBCN also posted the issue discussed in this exchange to the forum, after the Clicker concerned gave permission.

Z wrote: sorry for not writing too much on the click am not very good at it. Do have a question; had lumpectomy on the 31 May, now I need to go back and have axillary clearance because there was one with cancer. Q: Does this mean that cancer is spread everywhere in the body? Do appreciate your help and support. Thank you Z

Hi Z No - the cancer is very unlikely to have spread anywhere else in your body. The spot of cancer found in the sentinel lymph node indicates that a few cancer cells had managed to travel from the breast to the lymph node under your arm - and the axillary clearance operation is to remove more lymph nodes just to check that no more have cancer cells in. Fortunately the lymph nodes work as filter stations and trap any cells in the lymph fluid (including old cells, bacteria and cancer cells). The nodes then attempt to break down and destroy these cells. Over time the cancer cells are able to overcome this and grow in the lymph node, and possibly spread to the other lymph nodes in the same area. If this occurs, then the chance of cancer cells getting further around the body becomes higher (the more lymph nodes that have cancer cells in the higher the chance), though this is still not definite. The aim of the axillary clearance is to check the rest of the lymph nodes and remove any cancer that may be there. Once this is known (after surgery when the full pathology report is available), then the team can assess if there is a risk the cancer cells may have gone further. Scans may then be arranged to assess the rest of the body, and other treatments may be recommended to deal with this. Hope that helps to answer your query Z. Please ask anything you like . I'd love to help if I possibly can. I'd also like to post this query in the FORUM section... because I'm sure many women have similar concerns. Is that okay with you? (I would post your query and then my response). Please let me know. Thanks. Love SBCN xx

The SBCN's interactions with Diana included copious information support and advice during the member's time on the Click. She provided Diana with woman-to-woman advice and support about her health, family and marital issues from an expert health professional's knowledge and perspective. They considered themselves to be sisters and friends. This interchange demonstrates all of the above facets of their relationship:

Diana: real sick tummy again

SBCN: Yes ... are you taking any tablets to help the sickness?

Diana: yes mum tell Diana time to go to bed

Diana: hey big headache

SBCN: okay. Go to bed Diana!

SBCN: I need to go hang out the washing. Hope you have a good rest...

Diana: ok well will talk in chat tonight then

SBCN: That will be wonderful. See you then XX

Diana: is it sunny there we r raining

Diana: see u sister and friend

SBCN: No, sunny and hot. 38

SBCN: see you too Diana sister friend xx

The SBCN was the person who was there for Diana when she needed her. Unfortunately Diana's constant need for interaction and support seriously impinged on the time the breast care nurse had for the other online duties required within her job description, the most important of these being her time to provide advice and support for the other Click members. The intellectual disability that Diana referred to in her chat may also have contributed to her high-need requirements.

It would seem that Diana chose to join the Click because it was an online support site for people with breast cancer and if she believed she had breast cancer then she would expect to be interacting with like-minded individuals who would provide her with support and in turn this interaction would have a positive effect on her psychological state. Diana may have felt she was being her 'real' self when online in the chat sessions and, in particular, the one-on-one chats with the SBCN, whereas offline she may not have felt as free. The concept of 'real me' proposed in Orchard and Fullwood (2010, p. 158) suggests that when people feel comfortable in a social

situation, they are more likely to communicate effectively. Because the SBCN was new to the site and available, Diana may have thought she was likely to respond to her requests for a chat, therefore she requested a chat on a frequent basis.

The SBCN communicated with different ‘tones’ when communicating with Click members dependent upon the questions or interactions within the messages. There are communications that range from a more formal, perfunctory tone when providing referral to a more ‘caring and sharing’ tone, particularly when responding to newbies who were obviously distressed and needing urgent advice and support.

The ensuing quotes show examples of the tone of messages posted both before and after the SBCN joined the Click. The tone of the message in the Click context refers to how the members of the Click, either a team member or Clicker, responded to a post. When the Click first launched, the posts were quite formal and usually posted without a sign-off or any concluding remarks. When she became a Clicker, the SBCN usually ended her posts with endearments such as “warm hugs or love “or her name and the kiss symbol. Other Clickers, particularly the Click team, began to do the same.

Although Click team responses to Clicker questions were informative, they were not always so ‘caring and sharing’ as this quote shows:

Beryl, have you checked out the resources - Cancer Council WA, Cancer Australia they have good info. Contact BCCWA and make an appointment to discuss anything you are not sure about. She also does home and hospital visits if you want some information and advice pre and post your mastectomy.

In contrast, this post from the SBCN in response to a complicated query from a Clicker clearly demonstrates a warm persona.

Goodness - what a lot of information! I hope some of this is useful for you Lee. Also if anyone has any other comments to add for Lee or anyone else, please feel free.

Love SBCN xxx

Then the Clicker's response:

Wow SBCN, you've been working very hard on this one!

Thank you for the response, I may need to re-read this again to take it all in. I didn't realise I asked quite so many questions, no wonder my head was spinning :)

I will certainly be reading those articles, thank you I appreciate your effort and information xoxo

Love Lee

Clickers have confirmed the importance of having the SBCN as a member of the online community, in particular with regard to providing information, advice and quick responses to their concerns. It is also evident that the SBCN has forged a close, caring relationship with the Clickers and that this care is reciprocal. A good nurse-patient relationship has mutual benefits.

Discussion

Knowledge is the cornerstone of care; professional knowledge as well as the perceived and actual knowledge of the issues surrounding the patients' condition and family circumstances. Relationships between nurses and their patients at the bedside are not always ideal, often fraught with tension and restricted by time. Literature abounds that the best care is received when it is provided by the appropriate health care professional in a holistic manner, with trust, time and teamwork in evidence (Kuijpers, Groe, Aaronson & van Harten, 2013).

Effective communication comprised of information based on valid research is an essential component of health care. In reference to a cancer diagnosis, the main factors that contribute to helpful communication are “...perceived provider sensitivity and sufficient information provided about diagnosis or treatment” (Robinson, Roblin, Alexander, Greene, Firmeno, & Mazor, 2012, p. 150). Many papers have been written about the interpersonal communication between health professionals and patients and the quality of this communicative exchange, in particular the doctors’ communication, has been the subject of copious research and discussion about the broader systems of communication within health care institutions (de Haes & Bensing, 2009; Ong, de Haes, Hoos & Lammes, 1995; Ong, Visser, Lammes & de Haes, 2000; Ruiz-Moral, Pérez Rodríguez, Pérula de Torres & de la Torre, 2006).

Nurses are in a unique position within the health care system because a nurse is present over a 24-hour period and can provide the patient with information or explain the treatment, at the time the patient needs to know. Communication can have an influence on a patient’s behaviour and well-being. Improvement in the quality and flow of communication can be attributed to the patient’s better understanding of their disease and treatment process. This better understanding occurs through the active and reactive communicative intervention of the SBCN, both online and offline, who provides clarification of medical terms, explanation of treatment options and emotional support and advice. Once the patient has a good grasp of what is encompassed in their treatment, they are more likely to feel confident about asking the physician questions when untoward symptoms of the disease or side-effects to treatment occur.

The nurse is an integral part of the multidisciplinary breast cancer care team and has knowledge and understanding of the tests related to breast cancer diagnosis and the processes involved in the treatment of breast cancer. They are able to answer any questions the patient may have felt too stressed to ask at the time of diagnosis. The fact that the SBCN is usually a woman may also encourage the patient to ask questions she may feel disinclined to ask a male doctor or feel unable to question a person she considers to be in a powerful position because of their professional qualifications and experience. In essence, the SBCN is the linchpin in a three-way conversation between patient, physician and other healthcare professionals.

Factors Enhancing the Role - Consumer Expectations

Consumers have become more knowledgeable about seeking medical information through the Internet as they assume greater responsibility for seeking out information and support. They now actively engage in the planning and provision of their own care (Jackson, Daly & Nay, 2009), while still holding nurses in high esteem. Indeed, nurses consistently top surveys on the trustworthiness of professionals and their capacity to provide positive interventions in care (Jones, Hendricks & Cope, 2012).

The Click allowed women and supporters to tell their stories. What began as a site for the simple venting of feelings about diagnosis and treatment unfolded into an online community full of evidence-based education and personal storytelling. The presence of the SBCN on the Click community site helped people cope with their diagnosis and illness and encouraged Clickers to connect. This has been proven to be physically and emotionally therapeutic, with texts written to help both one and others avoid the pitfalls of the health system or to deal with treatment and its side-effects (Witney, Green, Costello & Bradshaw, 2013).

Barriers to the Role

Recent studies concerning the use and uptake of technology note that whilst patients appreciate the availability and the possibility of using web-based support and information, they often do not choose to use it. The lack of uptake was usually related to having access to sufficient information elsewhere, preferring other types of healthcare communication such as telephone or face-to-face contact, or being hesitant about getting onto 'public' sites due to privacy and anonymity concerns (Antheunis, Tates & Nieboer, 2013, McKee, 2013). Difficulties in accessing and using websites can also be responsible for a lack of uptake, and so technological support is essential, especially if online support is the ultimate aim of the user and research of that support is also a quest (Børøsdund, Cvancarova, Ekstedt, Moore, & Ruland, 2013). When some Clickers expressed difficulties in accessing the website, particularly when using a tablet computer or mobile phone, the SBCN provided support for these technological problems, within her knowledge and skills base, and the Click web developer dealt with any problems related to the website itself.

Participants in this study felt worried that everybody could read their personal questions and these fears were allayed through the use of usernames or ‘nickname’ or online pseudonyms. Both the patients and nurse not only needed to be computer savvy but also needed to recognise that interactions online are not the same as traditional approaches to care. In the absence of physical interaction, members have to be able to use words that convey requisite warmth and knowledge and, in the case of patients, a genuine need for specific information and support.

The language used by the professional can also be a barrier to uptake. In this study the SBCN concentrated on providing evidence-based information that was not only up to date and correct but also, as much as possible, pitched at the patients’ individual level of understanding. Whilst access to the Click was fabulous for the Clickers, it was detrimental to the SBCN, who found it difficult to detach from the role whilst at home.

Future Directions for the Expert Nurse within Online Environments

As the number of online communities of support for people with chronic conditions continues to grow, it will be imperative for more nurses to be educated in the technology that enables them to take on the role of online expert nurse and/or community moderator. Web-based interventions are increasingly used in various chronic disease settings to enhance patient empowerment, and the influence of nursing interventions on quality of life, hospital readmission rates and management of chronic conditions is evident in the literature (van Uden-Kraan, Drossaert, Taal, Seydel, & Van De Laar, 2009; Welbourne, Blanchard & Wadsworth, 2013).

What is not evident is the role of the online expert nurse, the person uniquely positioned to support evidence-based patient-centered care within an online context. This role is an extension of the telephone triage nurse or Telehealth nurses who work from scripted protocols, whereas the SBCN in this study uses expert knowledge and many years of nursing experience to provide spontaneous responses while also having the time to research and consider the evidence underpinning topics of interest to the members.

Implications for Research

Diagnosis of illness correlates to patients experiencing numerous physical and psychosocial problems for which they will seek and need support from healthcare professionals. Internet-based, interactive healthcare communication offers patients the opportunity to seek information, interact with others and engage in e-communication with expert healthcare professionals (Ruland et al., 2013). Collaboration between health professionals and patients is essential for positive clinical outcomes (Aiken, Sermmeus, Koen Van den Heede, Sloane, Busse, McKee, Brunyneel, Rafferty, & Griffiths, 2012) and the collaboration in this study is inherent between the SBCN expert and the breast care patients and their supporters within the Click.

The expert nurse role in online communities in contemporary healthcare is under-utilised and largely under-described. This study has identified a design scaffold for future expert nursing roles in the Australian health care system and indeed for the world. This study acknowledges the contributions that the expert nurse makes to health care, propelling nursing forward, influencing patient care outcomes and generally providing better support for patients.

Further research is required by regulatory bodies to provide an overview of the concepts of the 'scope of practice' and competency standards for online nurses and their role. Research is also required about future technological training provided to nurses as the uptake of online consultation continues to increase.

Summary

In summary:

1. The SBCN, who in this instance was also employed in a hospital based breast clinic, can provide online and offline informational and emotional support for the patient pre, during and after their appointments with their treating doctor, thereby filling potential gaps in communication.
2. The SBCN via online community membership can give timely provision of diagnosis and treatment information relevant to the needs of the individual member.

3. The SBCN can lead weekly chat sessions on topics generated by the questions commonly asked of the SBCN online and/or offline, as well as questions identified by the SBCN about new or controversial treatments.
4. The SBCN can introduce chat members to each other so that these members can connect on and offline for support, advice and social activities.
5. The SBCN instigated a private question and answer function through the Click's private messaging (email) facility for those members who did not want their very personal issues (e.g. sexual intimacy post mastectomy) to be viewed online. The topic and the SBCN's response were then de-identified and with the member's consent, then posted in the forum for others to read and comment on.
6. The SBCN in association with the Click site generated evidence-based information on breast cancer and its treatments in the form of education packages. These education packages were timely and relevant to the online community; relevant because they were generated in response to questions asked by members and timely because they were relevant to the identified needs of the individual and the support community. This information remains on the site, so old and new members can access it at any time of night or day.
7. The SBCN gave referral to appropriate agencies (in the member's geographical area whenever possible) when the members question or concern was outside her scope of practice and expertise.

Conclusion

Newly diagnosed women with breast cancer experience high stress and anxiety that impairs critical thinking, decision-making and assimilation of new information and it is those women that the Click SBCN has been able to help the most. Hospital-based bedside education and support may be considered a thing of the past. The process and facilitation of this ongoing care may be shifting to a new frontier - the online expert nurse. The Internet is now an integral part of everyday life, with most people in the world able to access a computer for information. Nowadays when a disease burden is encountered, many people will seek information and support in cyberspace. Blogging and chatting may soon become the main source of patient information and education. However, an online community needs to offer more than the potential of 'community' to thrive. It needs to offer a real opportunity for connection, and to demonstrate the potential benefits of community membership. There is no question that Click succeeds

in this way as demonstrated by the influence of the expert nurse within this context. Support for this new online nursing role should be forthcoming as these nurses demonstrate their effectiveness on patient outcomes and quality of care, carving a new niche role in nursing and within the wider health workforce. Our nurse says:

My online role has been probably one of the most informative things that I've done recently in my career. It has opened up the whole world of what happens from the patient perspective. You can be a health professional – for about 16 or 17 years I'd been doing the role before I joined the Click – and although I'd had some family members who had gone through breast cancer so I'd seen a bit of the other side of the fence, it still only gives you one or two different perspectives. Coming on the Click and seeing what people post and then seeing it from their perspective when they blog, and really seeing what they go through, and seeing it on a continued basis – a lot of what I do is in the early diagnostic and surgery phase of treatment – so seeing what happens further down the track and seeing how many of the questions that they have, things that I would not have thought would worry them. Tamoxifen is a far bigger issue than I ever thought it was. It's huge on the Click and that's opened my eyes to our glibly saying – now that you have finished all your treatments we are going to put you on Tamoxifen, it's just a tablet you take and it might cause some hot flushes but generally it's fine, most women tolerate it really well, and off you go – five years of treatment. That's changed my concept of Tamoxifen as a treatment. It's changed my concept of what happens once the big treatment is finished because you realise that women can't and often don't go out the door and re-establish their life. To them it is something that carries on all the implications of the diagnosis and their treatment carries on and on. Forever for a lot of them. It's certainly hard to get back to a completely pre-diagnosis state in their lives. Even to a point where they are feeling comfortable about things. We have people five years down the track who come on and say that they're struggling and don't even know why they're struggling. It's given me such a broad sense of what really goes on for people, and not just from a health professional's perspective of what you think is going on and what you think are priorities for people. It's opened my eyes up endlessly which has a huge impact on my

offsite role in the clinic. I have a far better perspective of what people are facing and what is likely to matter to them as they go through their treatments and in the longer term. It's incredible.

Acknowledgement

This paper reports on one aspect of a larger study that was supported through funding by the Australian Research Council and involved collaboration between Breast Cancer Care WA, Steel Blue and Edith Cowan University. Special thanks go to the members of the Click www.breastcancerclick.com.au for their participation in this research at an extremely distressing time of their lives. The paper to follow examines the identification of factitious illness behaviour, only made possible by the role and presence of the SBCN owing to specialist skills in cancer nursing. An expert in cancer nursing on-line in a support community made it possible to detect behaviours and cancer stories that were not viable, given the context and information provided. Given that the Internet is now an integral part of everyday life the disease burden of authentic members does not need exacerbation by those who are not self-aware and providing erroneous information and details of their breast cancer experiences.

There is no question that the Click succeeded in demonstrating the influence of the expert nurse within this context, but it also illuminated how Feldman's clues to factitious illness behaviour on the Internet (Feldman, 2000), were used to determine whether or not one of the Clickers was suffering from Munchausen by Internet. The role that the SBCN played and the implications for online nursing practice in illness-focused support communities are also discussed.

Witney, C., Hendricks, J., Cope, V. (2015) Munchausen by Internet in an online, breast cancer support, community: An ethnonetnographic case study
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Abstract

This paper used Feldman's clues to factitious illness behavior on the Internet (FIBI) to determine whether the online behaviour of one member of an online breast cancer support community www.breastcancerclick.com (the Click), moderated by a specialist breast cancer nurse (SBCN), could represent a case of Munchausen by Internet (MBI) and why identification of this behaviour is important for online nursing

practice. This was a focused ethnonetnographic and qualitative research study in which the online behaviour of one member was observed and compared with Feldman's (2000) clues. The online data showed that nine out of 10 of Feldman's clues were applicable to the member's behaviour in the Click online community. The relevance of these findings are discussed in relation to the effects this behaviour can have on other community members, the attendant legal ramifications and the necessity for online nurses and other health professionals to be aware of and recognise the behaviour.

Key Words: Munchausen, Internet, factitious illness, Feldman's clues, behaviour, nursing

Introduction

In 2014, three billion people will access the Internet (Worldometer, 2014). Many of them will search for information to maintain their health, diagnose an illness, identify treatment options or gain socio-emotional support (Fox & Duggan, 2013). Others will search for the same information but with a different motive: to obtain information that enables them to pretend to have an illness and assume the 'sick role' (Pulman & Taylor, 2012). Offline, this behaviour is known as a Factitious Disorder (FD) and in its extreme form it is referred to as Munchausen Syndrome (MS) (FeldmanBibby & Crites, 1998). Online, affected individuals pretend to have the illness that is the particular focus of an online illness support community, such as the breast cancer online support community www.breastcancerclick.com.au (the Click), which is the online community that lies at the heart of this paper.

People join online disease support communities to access information and socio-emotional support as they battle with the symptoms and treatment of their disease and it is not unreasonable for them to expect that the other members of the support community are truly in a similar situation to them (Welbourne, Blanchard & Wadsworth, 2013). Online support community members must take on trust the validity of the information they receive and the authenticity of the person they interact with. Not all members are who they say they are, nor do they provide information that is truthful, and member authenticity can be difficult to determine and manage (Uridge, Rodan & Green, 2012). More generally, the illness- or disease-specific information that individuals find on the Internet may not be reliable or accurate and may cause individuals unnecessary stress (Williamson, 2005). This medical information may also be a source of knowledge, albeit unreliable at times, for those seeking to formulate a deceptive online persona

based on a particular illness (Swains, 2009). The employment of a health professional, in an online support community, may go some way towards ensuring the provision of accurate evidence-based health information and the correction of member misinformation (Witney, Hendricks & Cope, In Press).

This paper provides an insightful look into a potentially increasing and difficult-to-detect condition suffered by some members of online communities. If nurses are employed to provide expert information, advice and support for online community members, as was the specialist breast care nurse (SBCN) employed by the Click, then it is important for them to be aware of MBI so that detected individuals are referred to appropriate help resources and that the online community is not adversely affected.

Background and Literature Review

Factitious Disorder and Factitious Illness Behavior on the Internet

Factitious illness behaviour on the Internet, was first reported on by Feldman in 1998, and named Munchausen by Internet (MBI) by him in 2000. Feldman developed a set of clues for the detection of FIBI (Feldman, Bibby & Crites, 1998) from the details of more than 20 cases that were reported to him via his website <http://www.munchausen.com> (Feldman, 2000). Factitious Disorder (FD), more commonly known as Munchausen Syndrome (MS), is recognised as a mental disorder by the American Psychiatric Association (APA) and a person with this disorder "...feigns, exaggerates, aggravates, or self-induces physical and or psychological illness or injury with the goal of assuming the 'sick' or patient role" (Cunningham & Feldman, 2011, p. 185). The person has the goal of assuming the 'sick' or 'patient' role in order to receive intrinsic rewards such as attention, nurturance and sympathy from others; to control others; to express rage; or to display medical knowledge that enhances their self-esteem (Cunningham & Feldman, 2011). There is debate about the appropriateness of the use of FD and MS interchangeably (Feldman, 2004) because some consider MS to be the more extreme and most dangerous form of FD, accounting for only approximately 10% of reported cases of FD (Feldman, 2000a; Turner and Reid, 2002; Dyer and Feldman, 2007).

The more elaborate and dramatic tales of illness and recovery or tragedy, are known as *pseudologia fantastica*, together with peregrination, where the individual moves about seeking different doctors and hospitals, are particular features of MS (Turner & Reid, 2002; Feldman, Bibby & Crites, 1998). It would therefore be appropriate to refer to individuals, who do not include such tales or visits to numerous doctors in their deception as suffering from a FD but not necessarily MS.

While there is a significant amount of literature relevant to Munchausen Syndrome in the offline situation, there is a dearth of literature on Munchausen Syndrome by Internet. Exceptional is the work of Dr. Marc Feldman, who is the primary author/co-author of articles and books, such as 'Playing Sick' (2004) that focus on Munchausen Syndrome and Munchausen by Internet. This literature has been the fundamental source of information underpinning this research study.

In order to assume an 'online sick role', the individual writes text and posts false illness and personal history details and factitious illness behaviour on the Internet (FIBI), particularly to illness support websites that have forums, chat rooms, instant chat and personal messaging, such as the Click, Cunningham & Feldman, (2011). The most recently reported cases of MBI have revealed a new way in which individuals with MBI can avoid suspicion and discovery; that is, by using other identities or personas, known as "sock puppets" Cunningham and Feldman, (2011). The individual can join many illness support communities, using the same or a different identity, or assume a number of different personas in one online community; potentially increasing the number of supportive responses they receive Pulman & Taylor (2012).

There are various theories used to explain an individual's motives for feigning illness. One of these theories, which could apply to the person in this case study, refers to a longing for nurturance and a need for distraction from authentic life stressors Parker (1996). There is also the view that a person who practises online deception is either a narcissist who enjoys the responses and attention they receive from others online or a troll who posts or sends messages, to annoy others or disrupt an online community Pulman & Taylor (2012).

The prevalence of MBI is difficult to determine because it relies on the ‘outing’ or ‘confronting’ of the online community member, by other members or the moderator of the community, the admission of deceptive behaviour and the subsequent reportage of those instances. Pulman & Taylor (2012) have noted that new cases are identified regularly, but do not say where, and by whom, the cases are identified or if there is a regulatory body recording statistical data of those cases.

While there is only a small number of well documented cases Cunningham & Feldman (2011), it is likely that there is a much larger number of individuals with MBI who have remained undetected because the instances of outing have occurred in isolation and are unknown to others, unless the case is widely publicised or brought to the attention of someone who is an expert in the field Swains (2009). In the United Kingdom, a list of the names of individuals with a factitious disorder has been compiled and distributed to clinics and emergency departments Dyer & Feldman (2007). Whether this list includes details of MBI cases could not be determined, but in any case, such a list would be viewed as a breach of the person’s privacy and confidentiality if the person concerned has not given written consent for their name to be included on the list Dyer & Feldman (2007).

Often detection of the deception falls upon other members of the group or community to determine and take appropriate action. With MBI it would be necessary for the moderator(s) to be aware of MBI and of Feldman’s clues to FIBI, to compare the member’s behaviour with those clues, confront the offending member with their deceptive behaviour and to manage the member without disrupting the harmony of the community. To illuminate this, a ‘real-life’ scenario follows involving Diana* (pseudonym), a member of the Click community.

A “Real-Life” Scenario

The Click online community had just formed, with six active members, known as Clickers, plus the research team, engaged in long weekly Click Chat sessions and frequent pop-up or instant chats. The main protagonists in this scenario were Diana and the SBCN. Diana was aged in her late thirties, married with one young daughter. Her

user photograph showed a plump woman sporting a very short hairdo (which may have been a rubber cap) and gold-framed glasses.

The SBCN received 227 requests for chats from Diana over a five-week period, and chatted with Diana on 36 occasions with each chat lasting between 15 minutes and two hours. These chats indicated that Diana was a very 'needy' Clicker who consumed a considerable amount of the SBCN's limited work time. The chat text is used to illuminate Diana's online behaviour.

Diana's online behaviour was initially focused on the learning disability she referred to, but over time it became evident that Diana's description of her breast cancer and her many other health and family issues that occurred almost simultaneously were physically, logistically and medically impossible, raising doubts about her authenticity as a person with breast cancer.

The Click research team had no knowledge of MBI, although the idea of Munchausen Syndrome had been discussed as a way of explaining her unusual online behaviour. It was only when Diana's textual data were seen as a gestalt, after she had left the Click, that a review of MS literature was conducted. MBI and FIBI were subsequently discovered using Feldman's clues to FIBI. The likelihood that in the future more nurses would be employed to moderate and/or provide advice and support for members of illness-focused online communities was a driver of this research.

The Study

Aim

The aim of this focused study was to determine whether the content of Diana's online textual data (her online behaviour) conformed to the clues of FIBI offered by Feldman, Bibby and Crites (1998).

Design

This is a small, focused, qualitative research study and the methodology used was ethnonetnography, which sits in the centre of the netnography continuum devised by (Kozinets, 2010). Netnography is a qualitative participant-observational research methodology based in online fieldwork in online communities and groups. The

researcher was a member and moderator of the Click, and ideally placed to participate with the members through online text and to observe and analyse the text of other members.

Three months of online transcripts of the personal messages and chat sessions between the SBCN and Diana were placed in chronological order from January 1 2012 to March 31 2012. The content was then compared with Feldman's clues to FIBI (1998) and matched accordingly.

Data Collection

Data collection included the totalling of chat requests and compilation of the Click Chat; pop-up chat sessions and personal message transcripts between the SBCN and Diana. Diana's online photograph was examined for congruence with the information she provided and an offline interview with the SBCN was conducted to clarify and validate the researcher's understanding of the interactions between the SBCN and Diana. All of the data were stored on a password-protected computer.

Data Analysis

The interview transcript was checked by the SBCN for content accuracy. All authors of this paper crosschecked the verbatim data for consistency of understanding, accurate attribution and congruency with Feldman's clues.

Reliability and dependability

Triangulation of the data occurred through the review of the online transcripts, personal interviews and member checking with other Clickers including the research team members. The researcher remained in the online setting until information saturation was reached, in this instance until Diana left the online community. The detail provided in this research study can facilitate others to repeat the study, thereby confirming its dependability Lincoln & Guba (1985).

Ethical considerations

This research is part of the research outcomes of a larger project, which was approved by the University's Research Ethics Committee.

Authenticity

The Click member application process does not prevent people from providing incorrect information, whether by mistake or design. Members are asked for correct information such as postcodes, all email addresses are verified and obviously fabricated names are automatically invalidated.

Honesty

There were no ethical concerns around what Kozinets (2010) refers to as, *entrée* where the researcher must decide how they are going to enter an already well-established online community, because the researcher was a founding member of the Click and all members were provided with the research information before joining the community.

Informed consent.

The Click membership process required the individual to read the research information and website term and conditions and agree to be a part of the research project, by selecting the submit button on the website. The relevant research and website information was available at the bottom of each web page. Hard-copy informed consent was obtained for the interviews.

Trust

Click membership was based on trust. If improbable membership data were entered, then a personal message querying the content was sent, and if no response was received the member was deleted.

Anonymity

The name of the online community is given, but online pseudonyms, names and other means of identifying the person such as locality and family members' names are altered to protect participant anonymity in the study Kozinets (2010). Direct verbatim quotes are used in the research, but no details that might be harmful to the community or individual participants are provided.

Findings and Discussion

Feldman's clues to FIBI were used to examine the online and offline data and this information is summarised in Table.1. All Diana's posts are quoted verbatim to demonstrate the similarity in content and grammar and therefore dismiss the possibility that multiple people were posting. These quotes also serve as a practical guide for nurses and other health professionals who practice online, to help them identify deceptive behaviour in online community members.

Table 1. Diana's Behaviour Compared with Feldman's (2011) Clues to Factitious Illness Behaviour on the Internet (FIBI)

FIBI CLUES	Diana's Behaviour (including verbatim quotes)
The posts consistently duplicate material in other posts, in textbooks, or online health-related websites	Posted the same or similar information with the same username to three BC support sites. 1. "a mother of daughter Michaela 8 years old with breast cancer stage 2 grade2." 2." im a mum with breast cancer stage 2 grade 2
The length, frequency, and duration of the posts do not match the claimed severity of the illness e.g. a detailed post from someone claiming to be in septic shock).	Chatted with the SBCN at length, from hospital, shortly after a miscarriage and hysterectomy then after surgery for a brain tumour only on this occasion used her sister as a 'sock puppet'.
The characteristics of the supposed illness and its treatment emerge as caricatures based on the individual's preconceptions.	Changes her BC stage and grade from one chat to the next Refers to oral chemotherapy that is given at the hospital and that she has to stay in hospital for so that "... they can keep watch on me" and "i am bedridden still for another week or so" "daily tablets hospital said spoke to oncology" frequently refers to feeling tired and nauseated and food "...tasting funny..."
Near-fatal exacerbations of illness alternate with miraculous recoveries.	Recovers from brain and other major surgeries almost overnight yet continues to chat. "Meningitis under control now but had total hysterectomy last night 2.30am long needle in arm and 6 drips!"
Personal claims are fantastic, contradicted by later posts, or disproved.	Claims to have a learning disability so her child was taken away at birth to live with her mother. States she is in one location then another, in a timeframe that is impossible. Claims to have lost her hair due to chemotherapy timeframes prove this to be unlikely. Claims her mother was killed and her daughter seriously injured in a car accident
There are continual dramatic events in the person's life especially when other group members have become the focus of attention.	As more people joined the Click and made claims on the SBCN's time Diana introduced more health conditions and underwent several surgeries while coping with the treatment for diabetes, asthma, breast infection due to cut from a mammogram, meningitis, breast cancer and cervical cancer, coeliac disease and a urinary tract infection plus the death of her mother and the serious injury of her daughter in a car accident.
The individual complains that other group members are not sufficiently supportive and warns that this insensitivity is undermining his/her health	Diana did ensure that a major part of any Click Chat session was taken up by her comments by pretending to leave the session, then staying in the chat room and interrupting other members' discussions with her claims to feeling nauseated and upset.
The individual resists telephone contact, sometimes offering odd justifications	One telephone contact is known to have occurred therefore the behaviour does not comply with this clue.
There is feigned blitheness about crises (e.g. a cardiac arrest) that will predictably attract immediate attention.	Reports that her father had a stroke then when asked for further information about his condition, comments on a sporting event. Turns the conversation back to herself with "oh i had to get another scan for my cervical check as bleeding strated [started] again" but then asks "what's for dinner"
Others ostensibly posting on behalf of the individual have identical patterns of writing, such as grammatical errors, misspellings, and stylistic idiosyncrasies	SBCN Comment: "Pauline [Diana's sister] speaks in exactly the same fashion as Diana, and is in [A] one moment and with Diana in [B] the next! I am now doubtful 'Pauline' is sending any messages...she may exist but I am not convinced she is 'sending' messages!). I have also had a nurse, social worker & specialist breast care nurse all 'send' me messages - they all speak in same fashion as Diana and many things do not add up - I suspect it is all just Diana ..."

Diana's online behaviour in the Click community was congruent with the behaviour described in nine out of 10 of Feldman's clues. The one clue that didn't apply to Diana's behaviour was the avoidance of telephone contact. Diana did have one telephone conversation with Beryl and although the content is unknown, this could be viewed as another way of telling her 'stories' and reinforcing her need for support.

Diana Leaving and Re-Joining the Click.

Diana left and re-joined the Click five times without explanation, resulting in five different member numbers and two different usernames: Diana and Diana1. This behaviour indicated that she either hoped to mislead the other Click members into believing she was a new member or she was genuinely confused about the site processes due to her "learning disability".

Photograph

Diana claimed to have lost her hair due to chemotherapy and posted a user photograph purporting to show her without hair. The SBCN commented: "I believe Diana was wearing a rubber cap to simulate a bald head."

Distress score

On joining the Click, Diana's distress score relative to breast cancer was 0, which was unusual when compared to the scores of 6 or 8 registered by other members newly diagnosed with breast cancer.

Treatment Inconsistencies

Diana initially referred to an oral chemotherapy medication she was taking for her newly diagnosed primary breast cancer. SBCN commented: "This oral medication is used to treat cancer metastases and is not the first line of treatment for the early breast cancer stage" (SBCN). Diana's chemotherapy medication then became intravenous therapy and she referred to common side effects, such as nausea, lack of appetite, mouth sores and "food tasting strange". This information can easily be gleaned from comments made in the Click forum or from other breast cancer support sites.

The grade of breast cancer changed from grade one (in her first Click Chat session) to grade two in her online signature, Diana also referred to staging of breast cancer that the SBCN noted: "...is not generally used in this (country name deleted)".

Effects on Other Click Members

Most of the interaction between the SBCN and Diana was invisible, except for Click Chat, but only by those Clickers who joined the chat session. If posted to the forum or home page it could have caused the disruption described by UridgeRodan and Green (2012) in which online community members became openly divided over the veracity of posts, left the community or logged off immediately when the suspected false posters came online.

The Click Chat sessions were without incident and members were generally sympathetic and supportive of Diana. However, one member, Beryl, became weary of Diana's seemingly constant need for support and her monopoly of Click Chat. Beryl had engaged in a lengthy phone call from Diana that caused her to comment as follows:

Diana is in hospital for a few days, and I hope she is being linked in with some local supports. She can be very very needy and quite demanding. Not sure how the chats will go with her, she seems to see them as her personal time and no one else gets much of a look in. I've seen her in the [other] site and she gets up their noses real fast lol

Diana's incessant chat requests showed self-absorption and further fed her apparent insatiable need for attention, nurturance and sympathy. She showed little regard for the chat needs of other Clickers. She may also have felt gratified by her ability to engage the SBCN in chats, thus monopolising her attention and limiting her online behaviour with others (Day & Moseley, 2010).

Confrontation

The SBCN had expressed doubts about the authenticity of Diana's stories and, being aware of Diana's offline location, had conducted an online newspaper search to determine whether the car accident that resulted in the death of Diana's mother and serious injury to her daughter had been reported. She was able to verify that no accident or deaths had occurred in that location, so took the opportunity to confront Diana asking her if she had been "telling lies" and "stories" about her life. Diana insisted she did have breast cancer and questioned where the SBCN "...got her information" and was "...worried" [that the SBCN] "...has spoken to the family, because mums too old...do i need a lawyer?" This confirmed the SBCN's suspicion that Diana's mother and

daughter were still alive and well. When asked if she knew the treatment for breast cancer, Diana responded “I’m sorry but ... im trapped [*sic*] in all four walls all day long my marrage [*sic*] fell apart over lying ...can you help me ask gp about my sore breast stuff then as [mammogram] came back ok”, thereby acknowledging that she did not have breast cancer. The SBCN offered Diana the opportunity of an interview to discuss her behaviour and to help her get some treatment. Diana agreed to the interview and then withdrew, after advising the SBCN that she and her mother had sorted everything out with the GP. Diana later left the Click of her own accord.

The following is an excerpt from the interview with the SBCN:

Have you had any particularly difficult challenges since you’ve been doing this job?

Yes, Diana was an enormous challenge mostly because it was extremely demanding, not that it was challenging in the types of things she was raising, because nothing is too confronting, but I did know right from the start that it [she] wasn’t your traditional [member] but I did think to begin with that it was more her understanding rather than necessarily anything else. Then the challenge was how to act upon my suspicions.... I will never confront someone without being absolutely certain. That is the most important thing on an online site – you don’t have anything other than your words popping up on a screen, and therefore the risk of harm if you take a wrong angle is too great, so I could never do that....

The SBCN took a cautious approach in confronting Diana and her online posts were always supportive of Diana’s feelings.

Lurking

Although Diana left the Click, her membership remains and she can login and ‘lurk’ on the site if she chooses. (Schneider, von Krogh & Jager, 2013) argue that 90% of online community members are ‘lurkers’; that is, passive members who read rather than write and post text. Whether Diana is a ‘lurker’ is unknown because the Click moderators are not logged in constantly to see who is online and the site’s posting statistics do not show who logs in and how often. Lurking is not necessarily a harmful activity, and although Diana did not have breast cancer, she had developed a friendship,

albeit based on untruths, with the SBCN, so she may want to lurk out of curiosity about her friend's life (Schneider, von Krogh & Jager, 2013).

Factitious Illness and the Law

It is very easy for the online user, once their factitious behaviour is discovered, to logout and leave the online support community without any consequences and/or without knowing they have a disorder for which there is treatment (Dyer & Feldman, 2007). One individual did attempt to sue the organisers of a large online community for defamation of character, after they had challenged him and banned him from the community for his deceptive behaviour. His case was unsuccessful because he refused to allow the judge to examine his medical records. The judge believed that those records lay at the heart of the matter because the litigant had personally posted information about his health crises to the Internet (Feldman & Peychers, 2007).

This case would not prevent someone who genuinely suffered life-threatening illnesses and had been unjustly accused of deceptive online behaviour from suing for defamation. In Diana's case, although she did query whether she needed a lawyer, she did not post that she had or was going to seek legal advice and her reference to a learning disability would seem to preclude any such action occurring.

Other Health Professionals

The diagnosis and treatment of Diana's real and/or imaginary illnesses involved numerous health and hospital personnel and resources. If Diana was exhibiting signs of factitious illness offline, then her behaviour resulted in an unnecessary consumption of scarce health resources and highlighted the fact that the health professionals were unaware of the signs and symptoms of a factitious disorder and how to manage the patient (Eisendrath & Federer, 1996). Feldman's book 'Playing Sick' (2004) provides guidelines for managing individuals with MS, which would assist health professionals both on- and offline.

Limitations of this Study

This study focused on one member of a particular online support community, therefore it is difficult to extrapolate the findings to other communities, however given the plethora of online support communities in existence, the clues for identifying MBI or a less serious factitious disorder on the Internet will be useful for nurses and other health professionals who choose to practice online.

Conclusion

Feldman's clues to FIBI led to the conclusion that Diana was suffering from a factitious illness disorder and because Diana's behaviour included fantastic stories and online peregrination, it could conceivably be Munchausen by Internet (Turner & Reid, 2002). However, Diana's behaviour also had troll-like and narcissistic aspects to it; troll-like because of the constant harassment of the SBCN with personal messaging and chat requests and narcissistic because she may have enjoyed the volume and supportive content of the responses she received each time she reported on her worsening health status. Diana's online behaviour ultimately reached a nadir, when she posted on her mother's demise and daughter's serious head injury, which stretched the SBCN's credulity and resulted in the confrontation and exposure of her deception.

Fortunately, Diana's online behaviour and the subsequent exposure of her deception had little effect on the trust and supportive relationships developed within the Click community, because the majority of the textual interaction was between the SBCN and Diana and therefore invisible to other Clickers.

Of the rapidly increasing number of Internet users worldwide, many will seek information, support and advice in online support communities and not all of them will be truthful about their condition or their life circumstances, therefore it is important for members of online support communities, in particular nurses and other health professionals who provide online support and advice, to be aware of FIBI and MBI and its management.

Acknowledgements

Thank you to the Clickers for their willing participation in this research.

Conflicts of Interest

The authors declare, "There is no conflict of interest".

The final paper in this chapter has been prepared and submitted for publication to International Journal of Nursing and Clinical Practices. The paper addresses the use of a Distress Thermometer (Donovan, Grassi, McGinty, & Jacobsen, 2014) a brief screening tool, which has been used in other cancer scenarios to detect stress levels of those with cancer; and, the use of a Structure Written Emotional Expression (SWEE), on distress

levels within the Click community. The role of the SBCN in the identifying of distress and management of that distress is described.

Witney, C., Hendricks, J., Cope, V., (2015) The specialist breast care nurse's role in the identification and minimisation of distress in a members' only, breast cancer focused online support community. Submitted to the *International Journal of Nursing and Clinical Practices*.

Abstract

Objective

To explore the use of the distress thermometer (DT) together with structured written emotional expression (SWEE) in a breast cancer focused, online support community that employs a specialist breast care nurse (SBCN), to identify and deal with problems causing the distress. Does the level of distress diminish as a result of writing a SWEE and/or interaction with the SBCN?

Method

Each member recorded a DT score during the membership process then again in an online survey, six months after the specialist breast care nurse, had joined the community. Survey respondents, who had received personal messages from the SBCN and written a SWEE, were identified and the content examined.

Results

N=30 of 385 members completed the survey, of these ten had completed a SWEE, been personal messaged by the SBCN and had declared that the information and advice they received had been instrumental in decreasing their distress score.

Conclusions

The SBCN used the Distress Thermometer tool online to screen for distress in members of an illness focused online support community and followed up that initial distress score to identify the problems causing the distress, and depending on the level of distress, to provide advice and support or refer the member on, to appropriate care services. The SWEE is an important way in which problems causing distress can be identified but it wasn't possible to determine whether it had any on the member's distress level.

Key Words

Cancer, oncology, distress, community, blogs, nursing

Introduction

Background

Internet use is an integral part of daily life today and has radically changed the way people communicate, inclusive of how they seek information about health, wellness and disease (BakshyRosennMarlow & Adamic, 2012). Internet users now have access to information in real time, which creates a new milieu for nursing and other support services (Bottorff, Struik, Bissell, Graham, Stevens, & Richardson, 2014; Ferguson, Inglis, Newton, Cripps, Macdonald, & Davidson, 2014). This information is often sought in order to self-diagnose or to diagnose the medical condition of someone else (Fox & Duggan, 2013). However, this online information should be treated with scepticism if the source is unknown, as health information not based on scientific evidence can pose increased risk, fear and distress (Lane, 2010). The quality of information on health care websites varies, so it is also difficult for individuals to decide whether or not, to trust the information (CorritoreWiedenbeckKracher & Marble, 2012; LaCoursiereKnobf & McCorkle, 2005).

Individuals in the process of seeking illness information online also gain knowledge about the ways to access health professionals for support, or have found others who share their illness concerns (Fox & Duggan, 2013). An online support community (OSC) that focuses on their particular disease or illness is one place where they can tell their story to others in a similar situation, and find information, advice and support (Chuang & Yang, 2010; E. Kim, Han, Moon, Shaw, Shah, McTavish, & Gustafson, 2012). There are numerous OSCs, some that focus on a specific condition such as fibromyalgia or diabetes (Chen, 2012) and others that focus on a category of disease such as cancer (Han, Shah, Kim, Namkoong, Lee, Moon, Cleland, Bu, McTavish, & Gustafson, 2011; Portier, Greer, Rokach, Ofek, Wang, Biyani, Yu, Banerjee, Zhao, Mitra, & Yen, 2013).

Individuals with breast cancer have indicated satisfaction with their ability to access the online stories of others, (Overberg, Otten, de Manl, Toussalne, W'estenbrtnk, & Zwetsloot-Schonk, 2010) particularly if the other person was in the same stage of the illness, had opted for similar treatment or had told a story of long-term survival (Shaw, Han, Hawkins, McTavish, & Gustafson, 2008). Caregivers or supporters of those with

breast cancer have also benefited from reading the narratives of others, as well as writing about their own thoughts and feelings concerning their burden of caregiving or the effect(s) of the disease on their family member or friend (Butcher, 2003). Those with breast cancer stated that they felt better able to cope with their illness because their online interactions reduced uncertainty and anxiety, (Overberg et al., 2010), major contributors to their distress (National Comprehensive Cancer Network, 2010).

A direct link between a cancer diagnosis and distress has been widely acknowledged in the literature, to the extent that distress has been referred to as the 'sixth vital sign' (Bultz & Johansen, 2011; Howell & Olsen, 2011) that should be assessed by health professionals caring for a person with cancer. Significant psychological distress is suffered by half of all adults with cancer and much of this distress goes unrecognised and untreated (Jacobsen & Ransom, 2007). Nurses who work closely with cancer patients are in an excellent position to screen for distress using the Distress Thermometer (DT) tool, and to provide timely intervention or referral to appropriate treatment providers (Mahendran, Chua, Peh, Lim, Ang, Lim, & Kua, 2014).

Distress is described as

“...a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (National Comprehensive Cancer Network, 2010, p. 2).”

Distress may result from the person's struggle to adjust to or cope with the impact of cancer on their physical, emotional, and social well-being (Head, Schapmire, Keeney, Deck, Studts, Hermann, Scharfenberger, & Pfeifer, 2012). What is known is that support from others, particularly family and friends, helps to decrease the negative effects of cancer's symptoms and treatments, and that it is important for health professionals to continue to assess for symptom distress and the adequacy of personal support throughout the cancer trajectory (Manning-Walsh, 2005). If the offline support

of family and friends is not forthcoming, then the person may turn to the Internet and an OSC to find this advice and support. The supporter of someone with breast cancer may also seek information and support online through an online support group or community (Klemm, Hayes, Diefenbeck & Milcarek, 2014).

This paper focuses on the results of a survey to determine what effect membership of the breast cancer OSC known as ‘the Click’ had on members’ (known as Clickers) DT scores. A specialist breast care nurse (SBCN) was employed to provide online emotional support, evidence-based information and advice for Clickers, and this innovative extension to her offline practice has had positive effects on the Click OSC members (Witney, Hendricks & Cope, In Press). The SBCN was able to read and respond to all text-based communication on the Click and use this to gain a deeper understanding of members’ concerns and how to deal with them (Witney, Hendricks & Cope, In Press). This study adds to the body of literature concerning specialist healthcare support and to the identification of distress via the Distress Thermometer (DT) within an online support community.

Methods

Research Question(s)

Can the distress thermometer score of members of a breast cancer focused online support community be influenced by the information, advice or support provided by a Specialist Breast Care Nurse (SBCN) and the written expression of their emotions (SWEE)?

Study Design

Ethnonetnography is participant-observational fieldwork in an online community, whereby data collection means observation and collection and analysis of the text-based communication between members of an online culture or community (Kozinets, 2010). The researcher was a Clicker and participated in and/or observed the interaction on of the Click. This particular study also included an online survey.

All Clickers were required to enter a Distress Thermometer (DT) score, per the Click membership process, then again in response to a survey question. The survey was posted six months after the SBCN had joined the Click. Once the individual had joined the Click, they were welcomed and encouraged to complete a 'structured written

emotional expression' (SWEE) exercise in their Click blog space.

For the purposes of this paper, only the survey questions and responses related to the DT score, the SBCN support and the SWEE are used.

Research Participants

Clickers with breast cancer, herein referred to as Clicker (BC) and supporters Click (S), participated in this research study. The Clickers (BC) were in various phases of their breast cancer trajectory, some newly diagnosed and some undergoing active or palliative treatment or maintenance therapy.

Data Collection

Data were obtained through an online survey and from the textual data on the Click website.

Survey

The survey was an online opt-in survey, which was posted to the Click home page six months after the part-time SBCN had been employed. Survey participants were asked to give their Click username so that their Click text could be identified.

Distress Thermometer

The Distress Thermometer (DT) is a very brief screening tool consisting of a self-rating visual analogue scale with 11 points of measurement (0 = no distress and 10 = extreme distress) and a list of problems used by the self-rater to identify possible causes of their distress. The DT is used to measure psychosocial distress and related problems in cancer patients (see Appendix 1). The National Comprehensive Cancer Network (NCCN) developed the DT and it is an important part of the routine cancer care recommended in their good practice guidelines [25, 26, and 21]. Permission was given by the NCCN for the use of the DT tool in this research project.

A DT thermometer score of four or greater than four indicated moderate to severe distress and alerted the SBCN to the fact that the Clicker needed help from other health professionals. This involved suggesting to the Clicker to contact their treating medical practitioner for assistance and referral to an appropriate health care practitioner as necessary. A score of less than four indicated mild distress or 'expected distress' and this could be investigated and managed by the SBCN or the breast cancer team (Head et al., 2012). The DT score of four was chosen because this score was used in a community-based telephone helpline for cancer patients and their carers, which is

similar to online contact in that the assessor and the patient are not meeting face-to-face (Hawkes, Hughes & Chambers, 2010).

SWEE

The SWEE formed a supportive intervention and avenue for Clickers to vent their feelings and relieve some of their distress. It also provided the SBCN with further information about the causes of the Clickers' distress and the information, advice and support they required. On joining the Click, members were invited to write a SWEE, which, according to the literature, can benefit their psychological and physical health (Davison, Pennebaker & Dickerson, 2000; Owen, Giese-Davis, Cordova, Kronenwetter, Golant, & Spiegel, 2006; Shim, 2008). A SWEE requires participants to write for 15 – 30 minutes for 3-5 consecutive days, expressing their deepest thoughts and feelings about their or their family member/friend's breast cancer experiences (Butcher, 2003, 2008). Offline this would be written in a journal or diary; online it was in their Click blog space. It could not be determined whether a Clicker had followed this particular process to complete their SWEE, but if the content provided insight into how the Clicker was feeling about their breast cancer experiences, it was considered to be a SWEE.

Reliability and Validity

The DT has been used in psycho-oncology research in many countries, and has been recommended as a clinical tool that routinely detects clinically significant distress in individuals with cancer (Donovan, Grassi, McGinty & Jacobsen, 2014). A systematic review of research studies to test the validity of the DT showed that the DT "...maintains good psychometric properties across countries and cultures; the values for sensitivity and specificity, and for positive and negative predictive value, are largely in the range typically characterized as representing good overall accuracy" (Donovan, Grassi, McGinty & Jacobsen, 2014). DT cut-off scores have ranged from 3-5, with the cut-off score of four being the most commonly used score (Donovan, Grassi, McGinty & Jacobsen, 2014). Reliability of the data were ensured by the triangulation of the data from three different sources: member posts, the survey and member checking.

Ethics

The university's human research ethics committee approved the research project and all procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the *Helsinki Declaration of 1974*, as revised in 2005 (World Medical Association, 2013).

For Click membership, each person was required to acknowledge that they had read the research information and to give online consent to their participation in the research project. Consent to participate in the online survey was sought within the survey process, whereby the participant had to click "Yes" if they understood the purpose of the survey and agreed to participate. If they did not click "Yes" then they were not able to proceed any further in the survey. The respondent clicked on the submit button at the end of the survey and this showed implicit consent to participate (Friedman, Felten & Millett, 2000). The privacy and anonymity of the participants was protected by referring to those who have been quoted as Clicker (BC), Clicker (S) and SBCN.

Results and Discussion

Thirty-six Clickers completed the survey, which was a positive response rate because this group included the foundation online community members, even though the overall member response rate was ten per cent of the Clicker population. It is not unusual for only a small number of OSC members to actively participate in an online community at any one time, with active participation of only two per cent in some online communities (Nonnecke, Andrews & Preece, 2006). A large majority of OSC members can participate by reading what is posted and not posting or entering a chat room and not posting any text, therefore they are largely invisible (Nonnecke, Andrews & Preece, 2006). Sometimes referred to as 'lurkers', research has shown that these people still consider themselves to be members of the OSC (Nonnecke, Andrews & Preece, 2006). It is also possible that some members join an OSC and never return to participate either visibly or invisibly (Han et al., 2012).

Of the thirty-six Clickers who completed the survey, one was a health professional whose response was discarded from the results. All 36 participants completed the DT at membership and 30 participants completed the second DT in the survey six months later.

Ten participants, including eight females with breast cancer and two supporters (one female and one male), gave their usernames to enable the identification of their membership DT scores and SWEEs. Therefore, only 10 data sets were analysed in the results presented in Table 1.

Table 1. Survey participant demographic and treatment data

Click Member Category	Gender M=Male F=Female	Treatment Phase	Length of Click membership	Click membership inclusive of SBCN
Clicker BC	F	Maintenance	13 months	6 months
Clicker BC	F	Maintenance	13 months	6 months
Clicker BC	F	Active	6 months	6 months
Clicker BC	F	Active	3 months	3 months
Clicker BC	F	Active	5 months	5 months
Clicker BC	F	Active	5 months	5 months
Clicker BC	F	Active	9 months	6 months
Clicker BC	F	Active	1 week	1 week
Clicker S	M	x	14 months	6 months
Clicker S	F	x	2 weeks	2 weeks

The changes in the distress thermometer scores of the ten Clickers scores recorded on joining the Click compared with the distress score recorded in the survey, conducted six months later, are presented in Figure 1. below.

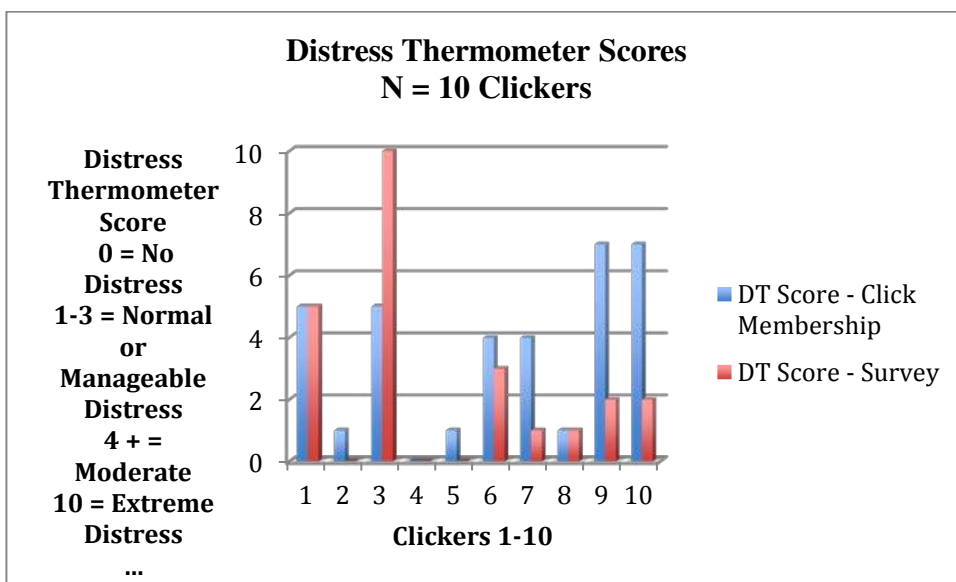


Figure 1. Comparison of Distress Thermometer Scores

Decrease in DT score

When the two DT scores were compared, six Clickers, five with breast cancer and one supporter showed a decrease in their DT scores. Of the six, five had been Clickers for six to 14 months and all five indicated that the SBCN’s information, advice and support had been instrumental in decreasing their DT scores.

The Clicker (S) in the above group of five had a DT score of seven on joining the Click, which is the second highest recorded, but after 14 months membership she recorded a DT score of two in the survey. This score reflects research showing that supporters of people with cancer have a higher DT score than the person with the cancer. While in this instance the DT score of the supported person was not known, this Clicker did have a membership score higher than the Clickers’ (BC) in this survey group. (Hawkes, Hughes & Chambers, 2010).

To the survey question: What was the advice that helped decrease your Distress Thermometer score? The Clicker (S), (verbatim) response, was:

“what cancer is as when my wife was told I did not know a lot about what may happen I just was think of the word Cancer and what I knew it to mean as in Death.”

Notably, this Clicker was also a lurker, who read the online information but had only posted once, thereby confirming the notion that lurkers can learn as effectively as those who visibly and actively participate in an OSC (Preece, Nonnecke & Andrews, 2004). Lurking online could also have prevented or minimised any distress that can be caused by difficulties in accessing or using the website facilities, referred to later in this paper.

DT score remained the same

Three Clickers' DT scores remained the same as their membership DT scores, and none of these were higher than three. One Clicker (BC) scored zero on both DT scores and this could be attributed to having completed her breast cancer treatment some seven years prior to joining the Click. All three indicated they had benefited from the SBCN's support and advice.

DT score increased

One Clicker said their score had increased from five to ten. This Clicker had been a member for one week and indicated that she had not actively participated other than completing the survey. Her survey comment was: “I have just had diagnosis, a mastectomy and reconstruction all in 3 weeks ...I was very stressed when I tried to get into the chat room but I wasn't really ready for it and it made my distress worse. Too busy dealing with the process of operation. I received a message from one of the members [the SBCN] who gave support.” The factors contributing to her distress could not be ameliorated to any great extent because of her brief time on the Click, which was further escalated by the difficulty she had accessing the chat room. However, a prompt supportive response was provided by the SBCN, which could, depending on its content, lead to a decrease in the Clicker's distress level. If the Clicker is not computer-savvy or has difficulty accessing the website, then this can further escalate distress as shown by one Clicker's survey comment: “I would like to see the usability improved; especially when it is a place I have turned to while distressed and seeking support/help”. These

comments prompted the Click research team to review the useability of the site and post clearer instructions for website and chat room access (de Souza & Preece, 2004).

The following are verbatim examples of the SBCN personal messages to Clickers. Firstly, a message to a Clicker with a high distress score and secondly, a message to a Clicker who initially recorded a very low distress score and subsequently became extremely distressed

SBCN: Hi [...] I've noted you have a very high distress score – please contact your local support services or GP if not already receiving support.

SBCN: Oh [...] I'm so sorry to hear it's a big struggle ... yet not surprised! You ARE Wonderwoman, but not beyond all aspects of being human!!! No-one could deal with all you do. Several options: 1) Breast Cancer Clinical Psychology Service (free). Fantastic ladies - qualified Clinical Psychologists specialising in breast cancer and associated aspects. I know them and they are great. However they do get booked up so may not get an appointment for a few weeks (I can contact them/send referral for you and find out). **Also depends if you want the psychological approach ... discussing coping styles / strategies. [...] Will do phone consultations. Ph: [...] (message machine - leave your contact details) 2) Breast Cancer Care WA (free) - have several counsellors ... Look more into imagery / thought patterns / tools for coping, etc. Ph: [...] - ask to speak to a counsellor. Are flexible with services. 3) See GP or contact Cancer Council 131120 - who may be able to recommend a counsellor locally. Likely to be a fee involved. May be eligible for Medicare rebate (not for full amount) under 'mental health care plan' for a series of sessions. I will try to ring you tomorrow (am in clinic but will find time somewhere!). Sending hugs & talk soon! xxx

SWEE

Four Clickers (BC) in the survey stated they completed a SWEE; of these, three showed a decrease in their DT score and one DT score remained the same. The Clickers (BC) who had a decrease in their DT score and who had written a SWEE were stalwarts of the Click community, as was the Clicker whose score remained the same. Each of the

four Clickers responded positively when asked if the advice and information that the SBCN provided them with, was instrumental in decreasing their DT score. A typical comment follows:

Clicker (BC)

“Support regarding my fears of tests and treatments that I was due to have. It was good to have the SBCN to interpret the medical jargon).”

One Clicker (BC) wrote in capitals, which is referred to as online ‘shouting’ to emphasise her point: “WRITING A BLOG (SWEE) - THAT REALLY HELPED” but did not give any details.

The following is an example of a SWEE written by one of the four Clickers mentioned above and responded to by the SBCN and other Clickers:

What? It's Monday already? How did that happen & who got the number of the road train that hit me? Every muscle is aching & every noise reverberates through the head like a banshee. [...] I thought I had this covered.. Friday was a good day! Day 1 after 1st treatment & I was feeling really good - great in fact! [...] I did go in to work (and stayed until 7pm) perhaps that was my mistake. But I felt great & didn't want to lose momentum. Progress was made. That's good right? Saturday a bit slower resting on & off. Just tired from the 1st treatment day marathon & the day of work? [...] Sunday..slower still surely I should be over the tiredness the culmination of the past 7 weeks. Apparently not. Monday & yes - I'm looking for the driver of that road train. I anticipated being able to go in to work this afternoon but that's just not going to happen. A quick chat to S... before the nausea decided to threaten & I learn I have been tricked! Damn you 'roids! Giving a false sense of everything. Right now this minute I feel ok again but I know that's the pain meds. In 30 seconds I'll probably have another hot flash & my head will start aching again. My mouth feels like it's packed with cotton wool & I need water. Should I go to bed? Yes. Do I want to? No. This feeling of not being in control I hate it. Looking forward to tomorrow...

The Clicker who writes a SWEE can make it public or for friends and family only, to read. Selecting friends and family provides the Clicker with a way of letting their supporters know how they are feeling without the stress of talking about their illness face-to-face. In turn, supporters become aware of their loved one's thoughts and feelings and learn how best to support them (Chung & Kim, 2007). If the SWEE is made public, all Clickers can read the SWEE, identify how that particular Clicker is feeling and provide advice and support. Alternatively, the Clicker who reads the SWEE may recognise someone in the same situation as themselves, and so commences a private online dialogue with them. Either way, there is potential for a decrease in the distress felt by those involved.

Writing a SWEE has been shown to have positive effects on the physical and psychological health of those with an illness and their supporters (Baikie & Wilhelm, 2005; Butcher, 2003) but it was not the aim of this project to determine the extent of these benefits. Rather, the objective was to provide the Clicker with an written avenue for expressing their distress. The examples provided demonstrate the expression of this distress and the support and advice received.

Nurses have played a pivotal role in the conduct of research into the use of the DT in cancer patient care (Hammonds, 2012) and the DT has been utilised in various stages of a person's cancer trajectory. The use of the DT by a nurse in her online practice can be seen as an innovative, yet natural, extension of their offline nursing practice.

Although research studies have shown that the DT has primarily been used in face-to-face situations, for example in hospital and outpatient clinics (Carlson, Waller & Mitchell, 2012; Jacobsen, Donovan, Trask, Fleishman, Zabora, Baker, & Holland, 2005) it has also been administered via the telephone in a community-based cancer helpline service to assess the distress of both patients with cancer and their supporters/carers (Hawkes, Hughes & Chambers, 2010). Online administration of the DT can be viewed as similar to this because the individuals do not meet face-to-face, however online use could prove to be superior because the user has time to read and understand the information, whereas the telephone method is reliant upon the person understanding what is said to them at the time of the phone call.

Limitations

Only four Clickers, in this survey, indicated they used the SWEE technique in their blog space.

Conclusion

The DT can be used online to assess the distress level of members of a breast cancer-focused OSC and that the evidence-based information, advice and support provided by the SBCN can result in a decrease in this distress level. DT scores should be sought more than once, perhaps before and after each phase of treatment, in order to minimise or prevent a high level of distress from occurring.

Although a direct connection between the writing of SWEEs and their effect on the Clicker's distress score could not be made, research indicates that distress does decrease when people write about their traumatic experiences offline in a journal or diary (Pennebaker, 1993). It follows that taking this structured writing online should have a similar effect, provided the website is easy to access and use.

It is anticipated that in the future, more expert nurses will be employed to practice online in an advice, support and referral capacity. The DT could be easily incorporated into this practice.

Acknowledgements

Many thanks to the Clickers who participated in this study

Conflict of Interest

The authors acknowledge and declare no conflict of interests. The corresponding author has full control of all primary data and agrees to allow the journal to review the data if requested

Summary of Chapter Four

This chapter provided three papers detailing varied aspects of the value of the SBCN's contribution to the Click community through online and offline nursing practice and her role as a link between the stages of the breast cancer diagnosis and the treatment continuum of care.

The papers discussed the value of online nursing practice for those nurses who are experts in their field. The presence and active participation of a SBCN, as both a

member and health professional in an online support community may have positive effects on the knowledge, understanding and supportive care of those online community members who have been diagnosed with breast cancer and their supporters. The nurse in this instance is a SBCN however; other specialist nurses could undertake a similar role within other illness specific online support communities.

Next the use of the SBCN, as a health expert, used Feldman's clues (2000) to identify factitious illness behaviour on the Internet (FIBI) the online behaviour of one member of the online breast cancer support community as being Munchausen by Internet (MBI). The relevance of these findings were discussed in relation to the effects this behaviour can have on other community members, the attendant legal ramifications and the necessity for nurses and other health professionals, who are employed or who participate in online support communities, to be aware of this behaviour and how to recognise it.

Last, via the use of a Distress Thermometer and of SWEEs that membership of an online support community for breast cancer patients and their supporters, particularly if a specialist breast care nurse is employed, can result in a decrease in the distress felt by the members.

Although a direct connection between the writing of SWEEs and their effect on the members' distress scores could not be made, research indicates that distress does decrease when people write about their traumatic experiences offline; in a journal or diary (Smyth & Pennebaker, 1999) therefore taking this structured writing online should have a similar effect.

It is anticipated that more nurses will be employed to practice online in an advice, support and referral capacity in the future where the DT can be easily incorporated into their online practice to assess and assist members of illness focused online communities to diagnose and deal with their distress.

Overview of Chapter Five

Chapter Five, provides an overview of the study, the conclusions drawn, implications for nursing, the limitations of the research study, recommendations for further research and elementary guidelines for those who choose to design and develop an illness focused, online support community.

CHAPTER FIVE

Conclusion

Introduction

This chapter revisits this ethnonetnographic study illuminating the role of an expert nurse, in a purpose-built, breast cancer specific online support community, in significantly allaying the anxiety of those with a breast cancer diagnosis and their supporters. This study has demonstrated how an expert nurse, in this instance a Specialist Breast Care Nurse (SBCN), may extend nursing practice to an online community, thereby making an important communicative contribution to the patient's cancer care continuum. The papers contained in this study have charted the successful development of an online breast cancer support community, the Click, and revealed the ways in which the SBCN's online nursing practice resulted in the Clickers' enhanced understanding of their disease and treatment, and the consequential diminution of the distress caused by this personally catastrophic occurrence in their lives.

Ethnonetnography was the research method employed in this study. This method was deployed in order to study online communities and cultures; it occupies mid-position of Kozinets (2010) netnographic research continuum. The research steps in this study were a variation on those used by (Kozinets, 2010) in that, the online community was purpose built and data collection commenced prior to formation of the online community whereby the researcher was not required to gain entrée to an already established online community. The focus of the investigation concerned the employment of an SBCN, an expert nurse, to explore this role as a dynamic of an online community in terms of providing support, evidence-based information and advice. The researcher was an integral member and moderator of the online community from its inception, and therefore had an insider position within the Click. Immersion in the

online community occurred through interaction with the Clickers and also with the observation of the members' and the SBCN's interactions with each other.

In order to meet the requirements of the study, three interrelated research phases with iterative data collection and analysis were undertaken. In the first phase, the researcher explored the style and format of similar online support communities in terms of their interactive affordances and the use of a health expert online and as discussed in the literature. Individuals with breast cancer and their supporters were interviewed and surveyed regarding breast cancer information, support and advice needs and their Internet use to find support, advice and information. These insights provided valuable information of this study population's needs, a website built, based in part by these insights and to the user specifications of the researcher by an information technologist. The website was then tested for ease of use and accessibility by potential members prior to launch with the anticipation that members of a previously formed social network, the Purple Boot Brigade, would join and 'seed' the online support community. Although the latter did not eventuate, the Click membership base attracted over 400 members, maintaining an active membership of 20 plus constant members who formed a bonding relationship throughout their breast cancer trajectories. This development complied with the descriptions of an online community by Kozinets (2002) and Rheingold (2000). Thus, the Click was clearly recognised as an online support community because regular, weekly Click Chat sessions attracted a cohort of Clickers who interacted regularly with each other in the weekly chat sessions, in the forum and personal blogs.

The second phase of the study involved active online interaction of the Clickers and encouragement of interaction between Clickers and the SBCN, which provided information, education, advice and support to members. The third phase focused on the collection and analysis of offline interview data, online usage, the opt-in survey and Clicker interaction data pertinent to the SBCN's online role and practice. The Clickers comprising the online community responded to the survey and were also interviewed in relation to the role of the SBCN in providing support, advice and information to allay personal fears and anxiety related to experiencing a breast cancer diagnosis.

The essential findings drawn from the data were obtained concurrently throughout the three phases of this study. The conclusions were then drawn, and

implications and limitations of the study together with recommendations for future nursing practice, education, management and research recorded.

Conclusions

The building of an online community was not quickly or easily achieved. This was demonstrated through the researcher's unsuccessful attempt to attract PBB members to the newly launched support website, the Click. The intent was to use the PBB website members as the nucleus of the new Click online community. In hindsight this is not surprising because although each of these website had complementary objectives the member would decide which one suited their individual needs. PBB was designed to educate the public about breast cancer and advertise 'purple work boots' and fundraising activities which contributed funds towards the offline activities of breast cancer care whereas the Click was designed to foster online interaction between members that engenders support and advice for those with breast cancer and their supporters. An online community is only built through this regular warm and caring interaction between members, so even though a cohort of PBB members may have joined the Click, they may not have interacted in a manner that demonstrated online community, thus obviating the benefits presumed by the researcher, to be inherent in the provision of a ready-made membership base. The online promotion of the Click through the complementary websites PBB and BCCWA plus the Google adword campaign attracted almost 200 Clickers and of these 24 members interacted regularly with a concomitant warmth in their communication. This demonstrated the formation of an online community which conformed to Keim-Malpass's (2014a) suggested cohort numbers and to both Kozinets' (2010) and Rheingold's (2000) description of an online community.

The Click provided significant therapeutic benefits for members from the first budding of the online community. The members were able to express themselves about their bodily changes and the way they dealt with them in a supportive, private online milieu that assisted them to envisage their bodies in a different yet positive way. The Click also provided Clickers with a space they could use to create their breast cancer stories, SWEES or poems and use this creativity to help them deal with their sometimes traumatic treatment experiences.

While the majority of member interaction took place online it was also the offline meeting of Clickers that provided therapeutic benefits for Angel through her prompt referral to counselling and the immediacy of the support offered. The Click continued to grow and membership relationships developed but it was not until the SBCN was introduced to the Click that the online community consolidated as a therapeutic community where prompt, accurate, information, advice and support could be found.

The SBCN's online nursing practice has been described as the 16th moment of cancer care for patients with breast cancer. The SBCN made a significant difference to the quality of Click communication regarding the evidence-based information provided. The depth and warmth of online interaction indicated a substantial contribution was had enabling individual Clicker's better understanding of their disease and treatment. The SBCN through online and offline clarification of medical terms, explanation of treatment options, emotional support and advice, was vital to membership well-being. The online and offline aspects of the SBCN's practice illustrated this new approach for addition to the terms and conditions of nursing practice. In effect, the expert nurse through incorporating this online aspect into her patients' care became the communicative and supportive 'linchpin' in their care continuum (see Figure 14.).

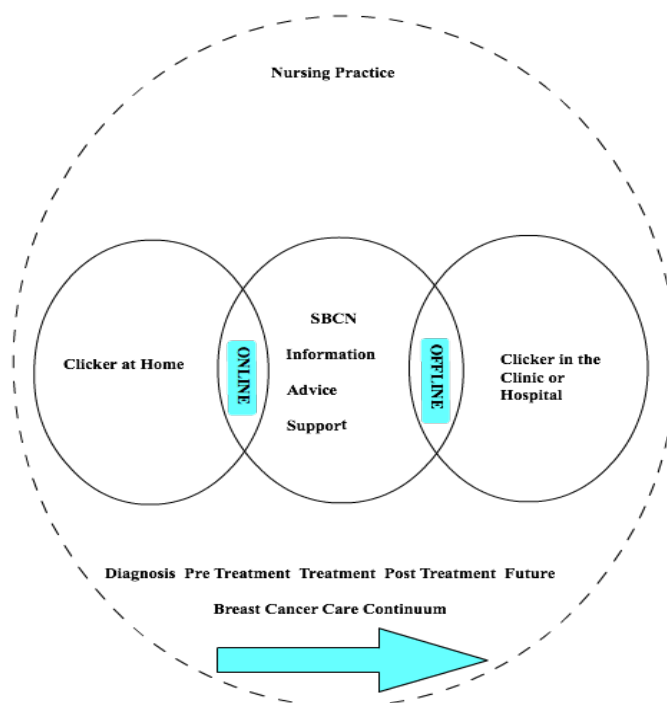


Figure 14. Breast Cancer Care and Communication Continuum utilising the expertise of a Specialist Breast Care Nurse

This model demonstrates the manner in which the SBCN contributed to the individual's breast cancer continuum of care offline and online, through her employment within the Click and in the breast care clinic. The three interconnecting circles represent the bond that can develop between the Clicker and SBCN as the Clicker proceeds into the maelstrom of distress, pain and isolation that breast cancer and its treatment brings. The spaces between, where the online or offline connection occurs, signify the SBCN's metaphorical arms embracing the Clicker with accurate information to help them take the next steps in their breast cancer continuum with confidence. The outermost circle is representative of the wider nursing world in which nurses, particularly expert nurses, may choose to extend their practice beyond the confines of purely face-to-face nursing practice, and incorporate online practice into their nursing repertoire thereby emulating the role and practice forged by the SBCN in this study which, in effect, had elements of a pilot study.

In this research, the Clicker may have met the SBCN personally in the offline clinic during breast cancer treatment, then joining the Click, or alternatively, joined the Click when newly diagnosed with breast cancer, before meeting the SBCN in person during the offline clinic. In either situation, at any stage of the breast cancer continuum, the SBCN proved to be the linchpin in the care and communication continuum, able to advise and support the Clicker when needed, and, with the Clicker's permission, shared relevant information with the breast cancer care team that contributed to optimum patient care. The advent of mobile computer technology and the availability of Internet connections have signalled the potential for individuals' with breast cancer or their supporters to contact the SBCN whenever in need of advice and support from wherever located.

This study confirmed the breast cancer care and communication continuum model may be applied to the care of patients with other types of cancer or illnesses providing they are members of an online support community with an expert nurse employed under an extended model of care incorporating both on and offline practice. This study has shown that health care services should implement an online support

community as an extension of their patient care and support remit. However an assessment of potential sources of technological support in forming an online community and the provision of expert nurses is required.

The specific and important impacts of the SBCN's presence, and nursing practice in the online community revealed in this study, were demonstrated in several ways. The SBCN brought warmth of tone and content to membership communication. The previously semi-formal online interactions between the Clickers were extended to become warm and supportive communication links, concluding with virtual hugs or kisses. The warmth of the SBCN and Clickers' responses to each other's posts and blogs would most certainly have contributed to lessening the distress of individual Clicker's.

The SBCN's application of a Distress Thermometer determined the Clicker's level of distress, and coupled with an examination of the Clicker's forum posts, SWEEs, blogs or personal messages, problems or issues identified and provided the impetus for nursing interventions to alleviate or minimise Clicker's distress. This study found evidence of the SBCN's actions leading to a decrease in Clicker distress and the writing of a blog, or of using the SWEE format, assisted members in the management of their fears and anxieties when facing with a breast cancer diagnosis and its treatment.

The SBCN posted her evidence-based breast cancer information to the forum ensuring Clickers' were provided with accurate information when needed. These communicative actions, alone, were found to decrease the Clickers' distress levels because they were confident of the SBCN's knowledge and expertise. Also the researcher observed that, because of the SBCN's availability, Clickers found no need to spend time searching the Internet for information which may not prove to be current or correct. The uncommon nature of some of the Clickers' questions required the SBCN to research the answer, which had two positive outcomes: the amelioration of the Clicker's distress, and a new contribution to the SBCN's breast cancer knowledge base.

The SBCN in this investigation encouraged the Clickers to write a SWEE and promoted the use of blogs as an outlet for creative expression as a way of assisting members to navigate the chaotic mental reactions caused by the diagnosis of breast

cancer and its accompanying treatment modalities. In so doing, the SBCN further reinforced the notion that the Click provides a valuable 'blank canvas' for individuals to document their experience about breast cancer, this information being read and utilised by others to help them manage their emotions.

The SBCN made herself available for contemporaneous and synchronous discussion of treatment issues, which does not necessarily occur in the clinical care situation. The data collected showed the manner in which Clickers' variety of experiences with breast cancer gave rise to a new appreciation of their bodies which was shared with and confirmed by others in a similar situation. The Click provided a disembodied space where changes to breast cancer patients' bodies and appearance could be discussed. Thus a Clicker was empowered to move from thinking about the abnormality of these changes to previously held ideas of 'self' to an understanding that this 'who I am now'. Clickers were able to embrace their condition and develop new understandings of self-identity. It was also possible for them to explore and imagine their future responses to the effects of treatment on their bodies. Such considerations might include whether to wear a prosthesis or undergo a breast reconstruction with the expert advice and support of the SBCN.

The researcher observed not all Clickers to share their concerns online, for example, one Clicker chose an offline meeting to share innermost thoughts about their breast cancer situation and of the intention to commit suicide. In effect, this cry for help was not shown online and required an immediate offline response by the moderators/expert nurse. Therefore the researcher intuited that protocols and guidelines be developed immediately to protect the health and safety of all concerned after online support community members decided to meet with the SBCN in an offline venue. This particular Clicker chose an offline situation to reveal her strong response to a diagnosis of breast cancer, and the concurrent consequence of the diagnosis on her mental health. Another Clicker's mental health needs were evidenced by continually requesting chats with the SBCN, these chats eventually revealing what appeared to be a mental health issue. Following a lengthy discussion about breast cancer diagnosis and treatment inconsistencies, the Clicker confessed to the SBCN that her breast cancer diagnosis was fabricated. The SBCN advised the Clicker to discuss her health issues with her doctor and offered further support, but this was not availed of by the Clicker

who chose to leave the Click community. In these cases, the role and experience of the SBCN was central to the identification of health needs, which may have gone undetected in any other forum.

The member's departure from the Click raised awareness of the potential for fraudulent membership and further investigation of the member's online behaviour. Feldman's (2000) clues to factitious illness behaviour on the Internet revealed the Clicker's behaviour complied with nine out of his ten theoretical clues. In this case, the SBCN was unable to suggest treatment options however in itself the SBCN's extensive online advice and support would have provided this Clicker with some therapeutic benefit. However, the study demonstrated that expert nurses who practice online need to be aware of the potential for deceptive behaviour to occur and how this may be detected. Protocols regarding the management of vexatious behaviours were formulated as a result of this study.

Implications and practical applications

Online nursing practice has not featured prominently in nursing literature to date, nor have the positive aspects of this practice on patient care been documented. While the implications of the findings of this innovative study focussed on the role of an expert nurse in an online environment with recommendations pertinent to nursing practice and nursing education and employment, the findings are significant for many health care professional groups currently practising in the health care sector; this extended role may be applied in different illness-focused online support groups.

For expert nurses, practising in speciality areas, the findings reinforce the use of the Internet by patients seeking information, advice and support related to their illnesses; thus it is important for nurses to make patients aware of the dangers inherent in Internet-based information due to the potential for misinformation. The expert nurse who chooses to practise online must also be familiar with online modalities and the use of safe practices together with the potential for aberrant memberships to occur, in order to ensure communication is authentic.

This study has clearly demonstrated the benefits of an online, illness-focused, support community for patients. Thus, a health care organisation's consideration of this important extension to the continuum of care must consider the technological capabilities that allow the organisation to institute the service. The health professional, in this case the nurse, must have expert experience in the offline world to ensure it is commensurate with that required for such a senior and specialised role; the situation of the SBCN in this study exemplifies and establishes the basic requirements of an expert nurse who practises online.

Future nursing practice may incorporate the terms and conditions for nurses practising in an online support community. Eriksson and Salzman-Erikson (2013), emphasise the variable knowledge and skills base of nurses and their concern about their practising in an online support community. In view of this concern it is important for employers to articulate clearly the evidence-based knowledge and experience required in the job description, when employing expert nurses to practice online.

Experience in the study shows online employment hours should be flexible, although a certain number of hours of work are expected, when this work is directly related to the needs of online community members. Naturally 24 hours a day of nursing care by one expert nurse is not feasible, although in the future expert nurses may incorporate online support into their usual nursing duties and share the workload with others. Thus practising for the normal hours of their rostered shift will prevent stress that can develop from an unreasonable workload.

The findings of the study have implications for nurses' study curricula, in two ways: the Internet and an online illness/health-based support community is an innovative practice setting which may normalised in the future so nursing faculty must consider including appropriate information in the undergraduate nursing curricula; and the information found in online support communities can enhance the nurse's knowledge of a patient's condition, contributing to improved patient care so this improved paradigm must incorporate this new online facet of the care continuum in the undergraduate nursing curricula.

Limitations of the study

An uptake in new technology is continuous, but the role of the SBCN as an expert online healthcare professional is new and relatively untested. Therefore the study would have benefited from multiple testings in various settings with many SBCN's testing the veracity of the role's possibilities. However, as this was not part of the one SBCN's workload or employment position, several probing applications alone or concurrent were not possible.

Therefore the conclusions of the current research are not generalisable, but serve as the basis of a more widespread implementation to test this new provocative extension's potential for positive addition to the health care continuum supporting breast cancer patients.

Experience during the study had the researcher conclude that a screening tool for mental illness or the inclusion of the Mini Mental Examination or a variation would have added value to the use of the Distress Thermometer. The opt-in or not concession for the Distress Thermometer was found to be so helpful that it's deployment should be mandatory following the Clicker's initial completion of its use, which could then be used by online community members on a regular basis. Should identification of distress and anxiety, and behaviours that do not conform to the expected pathway of a breast cancer sufferer or supporter be apparent, formal mechanisms for referral should be in place

At the outset, the Click was linked to the Purple Boot Brigade website, but uptake was poor; thus raising the profile of the online health expert, or SBCN, must be marketed more strategically.

Recommendations

The following recommendations arising from this study are presented refer to the nursing profession only, including nursing practice, nursing management, nursing education and nursing research, and the construction of an online community. A basic assumption is that the advance of technological applications throughout the various societies comprising our and other nations needs to be recognised and implemented in all of our endeavours.

Nursing Practice

Recommendation One

Nursing practice in an online, illness-specific, support community must be recognised as a specialised form of nursing practice, either as a standalone online speciality practice or incorporated into the specialist nurse's practice.

Recommendation Two

Nurses who choose to practice in an online support community must ascertain whether the policies and guidelines relevant to offline meetings' with community members exist, before meeting with them offline.

Nursing Education

Recommendation One

Both undergraduate and post-graduate students must be informed the Internet is a major source of health information for individuals living with or supporting a person living with breast cancer. However, some Internet-based health information is not current or evidence-based; therefore any health information disseminated, online or offline, by the nurse, must be based on reliable, contemporary research outcomes.

Recommendation Two

A stand-alone post-graduate online nursing course must be developed, or the theory and practice of online nursing care included as a discrete unit in specialised nursing courses such as a post graduate certificate or diploma of cancer care, palliative care, diabetes management, or community health.

Recommendation Three

Nurses become familiar with online nursing practice and the potential for this communicative practice to fill gaps in the patient's knowledge of their treatment and provide advice and support for the patient throughout their care continuum.

Recommendation Four

Online, illness-specific support communities must be acknowledged as an extension to the continuum of care, and topics such as those listed below be included in courses or units covering online support communities and nursing practice:

- a. Munchausen by Internet and the clues to detection of fallacious illness behaviour on the Internet;

- b. The use of the Distress Thermometer or other short assessment tool, be mandated to monitor distress across the patient's care continuum; and
- c. The use of the SWEE technique and blogging by patients be encouraged to cope with their feelings of distress.

Nursing Management

Recommendation One

Nurse Managers, working in health care organisations, must investigate the establishment of online, illness-specific, support communities with expert nurses as health professionals and moderators within the community. The online support community should be promoted as a feature of the healthcare organisation's public website it should be a joint initiative between acute, post-acute and community health care organisations, thus improving each patient's potential for a smooth and well-understood continuum of care from home to hospital and return.

Recommendation Two

The expert nurse's online nursing practice must be standalone or incorporated into their regular working week, thereby avoiding any undue physical or mental fatigue occurring if the online nursing practice is added to their current full-time role. An ideal scenario would entail several expert or specialist nurses sharing the online practice load, across a 24-hour time period, thereby providing patients with necessary information and support in a contemporaneous manner and a range of personnel with which to bond.

Nursing Research

Recommendation One

Nurses must be encouraged and supported to use netnography, or a variant of netnography such as ethnonetnography, as the research methodology of choice, because this approach provides a new, written, perspective on how patients view their disease and the effect it has on their lives. The data is relatively easy to access and remains available online for evaluation; no offline storage is required. The information can then be used to enhance nursing practice relevant to that particular disease and its treatment.

Recommendation Two

A longitudinal study must be conducted of members of an online illness-specific support community to identify the specific impact(s) that membership has on the individual's continuum of care compared with that of a patient who is not a member of

such a support community. The days and times must be identified that the patient group is most likely to be online then the website trialled with several nurses sharing the workload and responsibilities as members/moderators.

Online Community Construction

Nurses, or other health professionals, who decide to design and develop an online support community with the assistance of an information technologist, should consider the following elementary guidelines:

Guideline One

Seek out an alliance or partnership with an organisation that already provides offline services and support for individuals with the particular illness, which the new online community will complement. The organisation in this study was a not for profit organisation but this does not preclude approaching other organisations such as hospitals and community health centres. Once a mutually supportive agreement is reached with the organisation, the promotion of the concept and identification of potential online community members would commence.

Guideline Two

Become familiar with the operation of similar online support communities, including their mission, vision, terms and conditions, in order to identify and choose the most appropriate milieu and interactive opportunities that will promote community development.

Guideline Three

Decide how the community will function, that is, will it be peer-to-peer only or will health professionals participate on a member basis? Will the health professionals, who moderate the community, be paid or volunteer their time?

Guideline Four

Ensure sufficient personnel with the appropriate expertise and time are available to continue regular interaction with the online community members; the intention being this will not be a short-term situation.

Conclusion

The Click remains an active and purpose-built, online community that used ethnonetnographic research, an innovative methodology at the forefront of research into the development of illness focused, online support communities.

The role of an expert nurse as peer, moderator and health professional with extensive knowledge and understanding of breast cancer and its treatment was created and found to be significant in reducing the distress of community members. The ground breaking aspect of this study was the employment of an SBCN to lead and extend the continuum of care into the online world of individuals with breast cancer, and their supporters. It was found that the role of the SBCN must be known to the membership for facilitating care, support and information. The dual online and offline aspects of Click SBCN's nursing practice has been demonstrated by this study to be a new approach to expert nursing practice, which focuses on the Internet. It will prove to be one way forward for nursing by offering a cancer care and communication continuum facilitated by an expert nurse, functioning as the linchpin for individuals to access, either online or offline, a reliable source for them to better understand and manage their care.

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Appendices

Appendix A

Research Information and Hard Copy Consent Form



This informed consent form is for the members of the social networking site and the online community site i.e. people diagnosed with breast cancer, their family members and friends, who take part in the online activities.

The Research Team consists of:

Supervisor: Professor Lelia Green from Edith Cowan University
Supervisor: Dr Leesa Costello from Edith Cowan University
Ms Vanessa Bradshaw from Breast Cancer Care of Western Australia
Researcher/PhD student: Ms Cynthia Witney from Edith Cowan University

Name of Project: A comparison of social network sites and online communities for the provision of advice, support and information: Guidelines for health professionals

This Informed Consent Form has two parts: 1. Information Sheet (to share information about the study with you)
2. Certificate of Consent (if you choose to participate: see below for signature)

PART I: INFORMATION SHEET

Introduction

The Breast Cancer Care of Western Australia (BCCWA) has formed a partnership with Edith Cowan University (ECU) to develop the exciting new research project referenced above. The project will aim to build an online community via Internet technologies that will provide professional advice, information and support for people who have been diagnosed with breast cancer their families, and friends.

You will be able to login to the secure, members only, website, to share your experiences with other people who understand the experience of breast cancer or who might benefit from your understanding. This unique site will enable you to participate in a way that suits you: you can chat online, participate in discussion groups, host blog pages, and listen to podcasts, and post videos or photos. During the research project a health care professional will be introduced to provide advice, information and support for a period of 3-6 months, and links to relevant breast cancer information sites will be available.

Purpose of the research

The research project aims to develop guidelines to support the integration of professional advice giving within an online community by comparing the engagement and interaction of members of a social networking site, Purple Boot Brigade (PBB) with that of members of an online community site, before during and after the introduction of the health care professional to the community. Both sites are websites for people who have been diagnosed with breast cancer their families and friends and are sponsored by BCCWA.

Type of Research Processes

The members of both websites (BCCWA Purple Boot Brigade (PBB) social network and the online community) will be invited to attend focus groups, interviews and to complete online surveys to inform all stages of the project. It is probable that not all people willing to be involved will be able to take part. None of these research activities is compulsory and invited participants can choose to take part in none, one or more of these research activities. Apart from your time spend online voluntarily; the interview and survey research components together should take no longer than 2½ hours. However, if you are willing to be involved in a focus group discussion then please allow another hour or so of your time.

Participant Selection

As a person diagnosed with breast cancer or a family member or friend who has used one or both of the sites, you have been invited to participate as you can contribute much to our understanding of the need for, valuing of and use of online professional information and support during your involvement with the breast cancer journey.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate or choose to participate then wish to withdraw at any stage please be assured that then you may do so then all of the services you receive through the organization and its websites will continue and nothing will change. Even so, if the interview or group discussion has already taken place, you can no longer 'stop' your participation' but you can request that the information provided by you is not used in the research study and we will withdraw it. A *Who to Contact* sheet is provided if you would like to speak to a counsellor for support during or following any of the research processes?

Procedures

We are asking you to help us learn more about online social networks and communities for those people diagnosed with breast cancer, their family and friends, in particular, about the inclusion of information from a health professional as part of community forums. We are inviting you to take part in this research project. If you accept, you will be a research participant in an online community supported by Breast Cancer Care of WA and/or in the Purple Boots Brigade social network. People who have agreed to be part of this online research project may also be asked to contribute to a survey or participate in a focus group and/or interview.

Risks

We are asking you to share with us some very personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion/interview/survey if you don't wish to do so, and it is fine to choose not to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in a survey, interview, or focus group.

Benefits

Participation in the online community, both before and during the period the Breast Cancer Nurse is onsite, will enable you to obtain information, advice and support to which you may not previously had easy access.

Your participation will help us find out more about online communities, and how professional advice giving can be integrated into such communities. This will benefit breast cancer survivors and their supporters, and other people with health problems, in the future.

Privacy and Confidentiality

The BCCWA and ECU respect your privacy and have embraced the national Privacy Principles; therefore, the identity of participants in this research will not be disclosed.

Focus Group - You must be aware that in a focus group we will ask you and others in the group not to talk to people outside the group about what was said in the group. We will, in other words, ask each of you to keep what was said in the group confidential. Maintaining this confidentiality of is very important. You should know, however, that we cannot stop or prevent participants who were in the group from sharing things that should be confidential.

People will not be identified in any published works. If the results of the research are to be published, code names (pseudonyms) will be used and any identifying details will be disguised. Interviews and focus groups will be audio recorded and the researcher will refer to your comments under your code name. The digital records will be kept under password (known only to the research team) on the researcher coordinator's university supplied computer hard drive. Paper records will be kept in a locked filing cabinet at the university and all records will be destroyed five years after the research is completed.

Sharing the Results

The knowledge that we get from this research will be shared with you and your community. Participants can request a summary of the results and we will also publish the results so that other interested people may learn from the research.

Who to Contact

This proposal has been reviewed and approved by Edith Cowan University Human Research Ethics Committee, whose task it is to make sure that research participants are protected from harm and that all research offers public benefit. If you have any concerns or complaints and wish to speak to an independent person, please contact:

Ms Kim Gifkins
Research Ethics Officer
270 Joondalup Drive
Joondalup
WA 2027
Phone (08) 6304 2170
Email research.ethics@ecu.edu.au

If you have any questions or wish to know more about the research project, please contact one of the following people:

<p>Cynthia Witney Project Coordinator/ PhD student Edith Cowan University (08) 9370 6560 c.witney@ecu.edu.au</p>	<p>Leesa Costello Supervisor Edith Cowan University (08) 6304 5459 l.costello@ecu.edu.au</p>	<p>Lelia Green Chief Investigator Edith Cowan University (08) 9370 6204 l.green@ecu.edu.au</p>	<p>Vanessa Bradshaw Partner Investigator Breast Cancer Care of WA (08) 9324 3703 vanessa@breastcancer.org.au</p>
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If you would like to speak to a counsellor during or following any of the research project activities please contact one of the following organisations:

Breast Cancer Care of WA
Support Services Coordinator/Counsellor
Phone: (08) 9324 3703

Royal Perth Hospital
Specialist Breast Nurse Counsellors
Phone: (08) 9224 3321

Breast Cancer Clinical Psychology Service
Phone: (08) 9224 1629

Lifeline WA
24 hour Telephone Counselling - Call 13 11 14
or
Phone: (08) 9261 4444
Email: lifeline@lifelinewa.org.au

PART II: CERTIFICATE OF CONSENT

The Breast Cancer Care of WA (BCCWA) has formed a partnership with Edith Cowan University (ECU) to develop this research project entitled “A comparison of social network sites and online communities for the provision of advice, support and information: Guidelines for health professionals”. The research involves the creation of a strong online community website that will provide advice, information and support for people who have been diagnosed with breast cancer and their families, friends and supporters.

As a member of this community you will be able to login to the secure, members only, website, to share your experiences with other people who understand the experience of breast cancer or who might benefit from your understanding. This unique site will enable you to participate in a way that suits you: you can chat online, participate in discussion groups, host blog pages, listen to podcasts, and post videos or photos.

During the research project a Specialist Breast Cancer Nurse will be introduced to provide advice, information and support for a period of 3-6 months, and links to relevant breast cancer information sites will be available.

As a website member, you may be invited to attend a focus group(s), interview(s) and/or to complete an online survey(s) during the project.

Statement by Participant

I have been invited to participate in research about online social networks and communities for people who have been diagnosed with breast cancer, their families and friends and the integration of professional information, advice and support giving.

I have read the foregoing information and I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Name of Participant:

Address:

Telephone:

Mobile:

Email address:

Signature of Participant:

This Day:

Month:

Year:

Appendix B

Online Consent Form



CERTIFICATE OF CONSENT

The Breast Cancer Care of WA (BCCWA) has formed a partnership with Edith Cowan University (ECU) to develop this research project entitled “A comparison of social network sites and online communities for the provision of advice, support and information: Guidelines for health professionals”. The research involves the creation of a strong online community website that will provide advice, information and support for people who have been diagnosed with breast cancer and their families, friends and supporters.

As a member of this community you will be able to login to the secure, members only, website, to share your experiences with other people who understand the experience of breast cancer or who might benefit from your understanding. This unique site will enable you to participate in a way that suits you: you can chat online, participate in discussion groups, host blog pages, and listen to podcasts, and post videos or photos.

During the research project a Specialist Breast Care Nurse will be introduced to provide advice, information and support for a period of 3-6 months, and links to relevant breast cancer information sites will be available.

As a website member, you may be invited to attend a focus group(s), interview(s) and/or to complete an online survey(s) during the project.

Statement by Participant

I have been invited to participate in research about online social networks and communities for people who have been diagnosed with breast cancer, their families and friends and the integration of professional information, advice and support giving.

I have read the foregoing information and I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Please Press the SUBMIT BUTTON to REGISTER YOUR CONSENT

Appendix C

Interview Information Sheet

INTERVIEW – INFORMATION SHEET

Dear

You are invited to take part in an interview. You are under no obligation to take part in this interview and there are no consequences if you decide not to do so. The interview will be conducted by me – Cynthia Witney – in a place, which is comfortable and convenient for you. This might be in a private room at BCCWA, ECU or in your own home. If you are uncomfortable with any of the questions asked, I will move on to the next question. I will be the only person present unless you would like someone else to attend with you. A *Who to Contact* sheet is provided if you would like to speak to a counsellor for support during or following the interview (See Attached).

The interview will take approximately 1.5 hours of your time. The place and time of the interview will be discussed and confirmed with you.

Before the interview commences, I will answer any questions that you might have about the research or about how the interview is to be conducted. You will then be given the opportunity to speak about your experiences of support and access to information with regards to breast cancer. You do not have to share anything that you are not comfortable sharing.

The entire interview will be audio recorded but the information you provide is confidential and only a codename will identify you when the recording is transcribed.

Information will be kept on a password protected, university owned computer hard drive, and will be accessed only by members of the research team. Paper records will be stored in a locked filing cabinet at the university and all records will be destroyed 5 years after the research project is completed.

Thank you for your participation in this project.

Kind regards

Cynthia Witney

Cynthia Witney
Researcher/PhD student
Edith Cowan University
(08) 9370 6560
c.witney@ecu.edu.au

Appendix D

Focus Group Information Sheet

FOCUS GROUP – INFORMATION SHEET

You have been invited to take part in a discussion with 8 - 10 other persons with similar experiences of living with breast cancer, or supporting someone who lives with breast cancer. This discussion will be guided by one of the researchers and take approximately 1.5 – 2 hours of your time.

The group discussion will start with the focus group facilitator making sure that you are comfortable and answering any questions about the research that you might have. Then we will ask you questions about how you seek out support and information about breast cancer. We will give you time to share your knowledge.

We will also talk about how community members support each other since this will give us a chance to understand how people seek out information about breast cancer in a different way. We will not ask you to share personal beliefs, practices or stories, and you do not have to share any knowledge that you are not comfortable sharing. A *Who to Contact* sheet is provided if you would like to speak to someone for support during or following the focus group. (See Attached)

The discussion will take place at the Breast Cancer Care or at Edith Cowan University and no one else but the people who take part in the discussion and the facilitator will be present. It is also very important that any information disclosed by other participants is kept confidential and not shared with other persons who are not part of the focus group.

The entire discussion will be digitally recorded, but no one will be identified by name on the recording. The information recorded is confidential, and kept on a university computer hard drive which is password protected: only the research team will have access. The digital recording will be deleted from the university's hard drive 5 years after the research project is completed.

Thank you for your participation in this research project

Kind regards

Cynthia Witney
Researcher/PhD student
Edith Cowan University
(08) 9370 6560
c.witney@ecu.edu.au

Appendix E

Information links embedded in each web page of the Click

Free from Cancer Council
Helpline on 13 11 20.

The screenshot shows the footer of the Breast Cancer Click website. It features a purple sidebar on the left with site statistics and copyright information. The main footer area is divided into three columns: 'Quick Access' with links to blog and album creation; 'Explore' with links to albums, blogs, chat, and forum; and 'About' with links to privacy, terms, support, and research. Below these menus are navigation options for 'Standard' and 'Touch' views, and a 'Proudly Sponsored by...' section with logos for ECU, Australian Government, Australian Research Council, breast cancer care wa, STEEL BLUE, and PURPLE BOOT BRIGADE.

breast cancer
click.com.au
12 groups
476 blogs
569 photos
© 2015 Breast Cancer Click
All rights reserved

Quick Access

- > Add to my Blog
- > Create Photo Album
- > Message The Nurse
- > Create New Account

Explore

- > Albums
- > Blogs
- > Chat
- > Forum

About

- > Privacy
- > Terms of Service
- > Contact Site Support
- > Code of Conduct
- > Certificate of Consent
- > Research Information

Standard — Touch

Breast Cancer Click is Proudly Sponsored by...

AUSTRALIA
ECU
EDITH COWAN
UNIVERSITY

Australian Government
Australian Research Council

breast cancer
care wa

STEEL
BLUE
100% COMFORT

PURPLE BOOT
BRIGADE

Appendix F

Membership Process

Personal Information *Required Fields

***First Name**

***Last Name**

***Gender**

***Postcode**

***Birthdate** This field is required for research purposes so we can report on the age demographics of our members as a statistic. Your birth date will not show on your profile, but your birthday will show to your friends. *Our minimum age is 18

***Site Agreements** Please review our site agreement requirements and confirm your consent by ticking the boxes below. All agreements can be found at the bottom right of this page - under the About heading. By ticking the boxes below you confirm that you have read and agree to the following :-

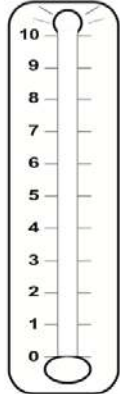
- Terms of Service
- Code of Conduct
- Certificate of Consent
- Research Information
- I agree to be part of the Research

***How did you hear about us?** How did you find out about the Breast Cancer Click website?

Referral by a health professional
Newspaper / Radio / TV / Magazine
Family / Friend / Colleague

Appendix G

Distress Thermometer

<p>NCCN Practice Guidelines in Oncology – v.1.2010</p>	<h3>Distress Management</h3>	<p>Guidelines Index Distress Management TOC Discussion, Reference</p>			
<p>SCREENING TOOLS FOR MEASURING DISTRESS</p>					
<p>Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.</p>					
<p>Extreme distress</p>		<p>No distress</p>			
<p>Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.</p>					
<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; vertical-align: top;"> <p>YES NO Practical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p> </td> <td style="width: 33%; vertical-align: top;"> <p>YES NO Physical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p> </td> <td style="width: 33%; vertical-align: top;"> <p>Family Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Ability to have children</p> <p>Emotional Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> Spiritual/religious concerns</p> </td> </tr> </table>			<p>YES NO Practical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p>	<p>YES NO Physical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p>	<p>Family Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Ability to have children</p> <p>Emotional Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> Spiritual/religious concerns</p>
<p>YES NO Practical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p>	<p>YES NO Physical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p>	<p>Family Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Ability to have children</p> <p>Emotional Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> Spiritual/religious concerns</p>			
<p>Other Problems: _____</p> <p>_____</p>					

Appendix H

Breast Cancer Terms

Abbreviations and Acronyms

As well as medical terms and conditions, forum users often use a lot of abbreviations and acronyms, which can be very confusing for new forum users (and sometimes even experienced ones).

So we have started to compile a list of the most commonly used acronyms and abbreviations.

If you've got suggestions for what should be added, please post them here.

Here they are so far:

(if you've post others, please be patient, as we might be chatting with our clinical team to make sure we have the correct wording for them)

FAMILY TERMS

YD = Youngest Daughter

ED = Eldest Daughter

MD = Middle Daughter

OH = Other Half (husband, wife, partner)

mil = mother in law

fil = father in law

bil = brother in law

sil = son in law or sister in law

dil = daughter in law

dh = darling husband

ds = darling son

dd = darling daughter

dgc = darling grandchild(ren)

FORUM TERMS

LOL = lots of love or laugh out loud

PM = private message

BREAST CANCER TERMS

BC = breast cancer

chemo = chemotherapy

Dx = Diagnosis

MX = Mastectomy

BCN = Breast Care Nurse

Onc = Oncologist

Rads = Radiotherapy

ANC = Axillary Node Clearance. Operation to remove all the lymph glands from under the arm.

Bisphos = Bisphosphonates (bone strengthening drugs). A group of drugs mainly used to manage secondary breast cancer in the bone by slowing down the process of bone breakdown. Also used to prevent and treat osteoporosis.

CMF = a regime of chemotherapy made up of 3 drugs:

- C: Cyclophosphamide
- M: Methotrexate
- F: 5 Fluorouracil (5FU)

DCIS = Ductal Carcinoma In Situ. This is a breast cancer that has stayed inside the ducts and not spread outside. Some doctors call this intraductal or non-invasive.

E-CMF = a regime of chemotherapy made up of 4 drugs:

- E: Epirubicin
- C: Cyclophosphamide
- M: Methotrexate
- F: 5 Fluorouracil (5FU)

GCSF = Granulocyte Colony Stimulating Factor. Injections to boost white blood cells especially neutrophils – a circulating hormonal substance that controls the growth of some of the white blood cells in the blood.

E = Oestrogen (Estrogen is the American spelling)

ER pos/+ Refers to breast cancers that have receptors on the cell surface that latch onto the female hormone oestrogen and help stimulate the cancer to grow.

ER neg/- Refers to breast cancers that do not have receptors on the cell surface that latch onto the female hormone oestrogen and so are not stimulated by oestrogen to grow.

FEC = a regime of chemotherapy made up of 3 drugs:

- F: 5 Fluorouracil (5FU)
- E: Epirubicin
- C: Cyclophosphamide

HER2 = Human epidermal growth factor receptor2. A protein found in small amounts on normal breast cells. It is made by a specific gene called the HER2/neu gene. It is one of the proteins involved in the growth of cells.

HER2 pos/+ = Breast cancers that have a higher than normal level (called over expression) of the HER2 protein.

HER2 neg/- = Breast cancers that do not have a higher than normal level of the HER2 protein.

Hormone Receptor Positive – refers to breast cancers that have receptors on the cell surface that latch onto the female hormones oestrogen or progesterone and help stimulate the cancer to grow.

Hormone Receptor Negative – refers to breast cancers that do not have receptors on the cell surface that latch onto the female hormones oestrogen or progesterone and so are not stimulated by hormones to grow.

IBC = Inflammatory Breast Cancer. A type of breast cancer, so called because the skin of the breast often looks red and swollen (similar to some breast infections).

IDC = Invasive Ductal Carcinoma. A cancer that originates/starts in the breast ducts and has the ability to spread sometimes called No Special Type.

ILC = Invasive Lobular Carcinoma. A cancer that originates/starts in the breast lobes and has the ability to spread

LCIS = Lobular Carcinoma in Situ or Lobular cancer in situ (LCIS). Condition where cells in the lobules of the breast look different and multiply differently from normal cells. Although the word carcinoma is included in the term this is misleading as it is not cancer, so it is often referred to as Lobular Neoplasia. However, having LCIS does mean that you have an increased risk of getting breast cancer in the future, even though most women with LCIS will not get breast cancer.

Neuts = Neutrophils. Type of white blood cell that is very important in fighting infection. Regularly measured if you are having treatment with cancer drugs that lower the number of neutrophils made by your bone marrow (chemotherapy). If count too low, this may mean treatment is deferred until count is within acceptable range.

Onc refers to oncologist, the specialist treating your breast cancer

PR pos/+ Refers to breast cancers that have receptors on the cell surface that latch onto the female hormone progesterone and so are stimulated by progesterone to grow.

PR neg/- Refers to breast cancers that do not have receptors on the cell surface that latch onto the female hormone progesterone and so are not stimulated by progesterone to grow.

PS or p/s - Plastic surgeon

RFA = Radio Frequency Ablation. A treatment that uses radio waves to produce heat to kill cancer cells (ablation means killing completely). Used to treat secondary breast cancer cells in the liver.

SIRT = Selective Internal Radiation Therapy. High dose targeted radiation used to treat secondary breast cancer in the liver.

SNB = Sentinel Node Biopsy. This is a method to detect whether any cancer has spread to the lymph nodes.

Tam = Tamoxifen. Also known as Nolvadex, it is a drug used to treat hormone sensitive breast cancer.

TAX = taxanes. A group of chemotherapy drugs (sometimes referred to as taxoids) that includes Taxol (paclitaxel) and Taxotere (docetaxel).

TN = Triple Negative. Breast cancer cells which do not possess Oestrogen receptors (ER) Progesterone receptors (PR) or HER 2 receptors.

WLE = Wide Local Excision (operation to remove a breast cancer with a small amount of surrounding healthy tissue. Sometimes called breast conserving surgery, or lumpectomy.)

Please post any other acronyms/abbreviations you think should be included in this list

Appendix I. Getting Started on the Click

GETTING STARTED

Our online services are perfect for those who don't want to talk face-to-face or on the phone. They're easy to use, whether you want to join the discussion, read through the postings on our forums or come to one of our live chat sessions.

Now you have registered here is a guide to getting you started.

THE FORUM is available 24 hours a day and offers a chance to exchange information and connect with people who share similar experiences.

Posting on the Forum

Category

You need to find the right category to ask your question. For example, if you want to share your worries while you're waiting for test results, you'll want to find the section headed "waiting for test results".

In the column on the left hand side of the page is a list of categories and the topics within them. Categories include:

- Worried
- Diagnosis
- Treatment & side effects
- Living with breast cancer
- The Young and the Breastless
- Living with secondary breast cancer
- Click Chat

Topic

Find the topic you want. In this example, you would choose "Worried" then "waiting for test results". You will then see a page with the latest conversations on your chosen topic.

New Topic

To post a new topic, look in the top right-hand corner of the page. In the purple bar, you should see "Post a new topic". Click this link.

You should now see an empty box. In the subject box write the topic for the post. Try to make the topic clear, so that people will know what the post is about when they see it in the list of latest posts.

When you've added the title of the topic, click in the big box below to start writing your post.

You might find it helpful to draft your post in a Word document and save it there before copying & pasting it into the box on the forum. This has two main benefits spellchecker

and if the site crashes or you lose Internet connection, you won't lose your post forever (because you'll still have a version saved in Word).

When you've finished writing your post, click the "Submit" button.

All new forum members must have their first few posts approved by a moderator before they go live (can be seen by other members), so there might be a short delay before your post goes live.

If you want to edit or delete your post, you can do this by clicking the links at the end of your post.

LIVE CHAT Allows you to interact in real time with others, and in the future we will have hour-long live chat sessions or virtual support sessions hosted by professionals. Each hour-long session offers a private and safe place where anyone affected by breast cancer can talk in depth about issues that are important to them.

If a general chat session isn't for you, you can join one of the specialist sessions we set up from time to time for people in similar circumstances. E.g. Secondary breast cancer discussion.

Smileys Emoticons

These are some of the keyboard symbols to express emotion. If you have any others you would like included on the list please post them as I am happy to add them to the list and I am also <:-l Cynthia

:)) laughing
:) happy
:(sad
;) winking