The Web of Care: A Multi-Method Study Examining the Role of Online Communities as a Source of Peer-to-Peer Supportive Care for Breast Cancer Survivors

By

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A thesis submitted in conformity with the requirements

for the degree of Doctor of Philosophy

Dalla Lana School of Public Health

in the University of Toronto

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2011

Abstract

This dissertation uses a multi-method approach to examine the role of online communities as a source of peer-to-peer supportive care for breast cancer survivors. A collection of four studies is presented.

Study 1) A systematic search of the Internet identified 111 active online communities for breast cancer survivors with extensive archives of personal health experiences (one third had over 100,000 posts each as of 2010-10-26). More than one-third (36.0%) were initiated by breast cancer survivors or loved ones, and more than two-thirds (69.5%) were maintained with little or no professional input.

Study 2) An analysis of Facebook (www.Facebook.com) identified 620 public breast cancer groups containing a total of 1,090,397 members as of 2008-11-23. The majority of groups were created for fundraising and awareness purposes (92.6%), rather than supportive care (7.4%).

Study 3) One hundred breast cancer survivors, known to provide peer support were surveyed on their supportive care needs and use of online communities. Two-thirds (68.6%) of the 73 respondents reported at least one unmet need, most frequently (30 to 40%) concerning sexual problems, stress, survivor identity, fear of recurrence, and ongoing symptoms or side effects. About one-third (31.5%) used online communities predominantly during and while recovering from treatment. Reasons for non-use included lack of need, self-efficacy, trust and awareness.

Study 4) Twelve breast cancer survivors who participated in the previous study were interviewed on how and why they used online communities. Unmet needs drove use, particularly during periods of stress, uncertainty or insufficient local support. Online communities served as a unique supportive care resource due to their quality of information, reassurance from similar others, availability, anonymity, and limited commitment. Social support, technology adoption and health behaviour theories help to explain use.

Online communities have the potential to fill gaps in health care services by addressing the supportive care needs of breast cancer survivors in a way that may not be available elsewhere, and survivors may play an increasingly important role as care providers. Future research must focus on overcoming barriers to use, and identifying factors that enhance their effectiveness among diverse groups.

Acknowledgments

First and foremost, I would like to extend my sincere gratitude to the breast cancer survivors who were involved in this research as participants, as well as those who were involved as supporters and friends. I thank you for sharing your time, candor and personal experiences with me. I would especially like to thank Virginia Yule, Executive Director of Willow Breast Cancer Support Canada, and Marina Englesakis, librarian extraordinaire of the University Health Network, for their insight and instrumental support.

A very special thank you is necessary for Alex Jadad, my thesis supervisor and mentor. Thank you for inspiring me with your vision, passion and enthusiasm. Thank you for the freedom to explore, to try new things and to make mistakes, and for encouraging me to push the envelope. Working with you and learning from you has been an exceptional, transforming, and invigorating experience, for which I am eternally grateful.

I owe a debt of gratitude to my thesis committee advisors, Lori Ferris and Joel Katz. I am certain that I had *the best* thesis committee! Thank you for your critical and insightful feedback, which helped shape this dissertation, and for your guidance and encouragement throughout the research process. It has been an honour and pleasure working with you and learning from you.

This thesis would not have been possible were it not for the collaboration of several colleagues and friends. I am deeply grateful for the time, energy and support provided by Carolina Jimenez in helping to locate, assess, and code the hundreds of online communities analyzed in this dissertation, and for teaching me Spanish along the way. *Muchas gracias por todo.* I am grateful to Hans Oh for the time and energy he devoted to the role of 'second coder' of the qualitative data. I am grateful to Mingyang Li for providing statistical support

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Glossary of Abbreviations

CaSUN	*Cancer Survivors Unmet Needs*
CCS	*Canadian Cancer Society*
CMC	*Computer-Mediated Communication*
IARC	*International Agency for Research on Cancer*
IOM	*Institute of Medicine*
ICT	*Information and Communication Technology*
IT	*Information Technology*
PCP	*Presidents Cancer Panel*
RCT	*Randomized Controlled Trial*
REB	*Research Ethics Board*
SCT	*Social Comparison Theory*
SC&T	*Stress & Coping Theory*
TAM	*Technology Acceptance Model*
TPB	*Theory of Planned Behaviour*
TCPS	*Tri-Council Policy Statement*
WHO	*World Health Organization*
Willow	*Willow Breast Cancer Support Canada*

Glossary of Terms

The terms found in this dissertation are defined as follows:

Blog: A type of website commonly used as an online diary, journal or news publication, and maintained by individuals or groups to share commentary on a particular topic, usually on a regular basis (Blood, 2002).

Cancer survivor: "An individual is considered a cancer survivor from the point of diagnosis through the balance of his or her life" (Mullan, 1985).

Cancer survivorship: A distinct phase of the caner journey, which generally refers to the period after active treatment has ended (Institute of Medicine [IOM], 2005).

Chat room: Also known as synchronous message boards or discussion forums, these are web-based applications that permit one-on-one or group communication in real-time, typically with a restricted membership (Preece, 2000).

eHealth: "An emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" (Eysenbach, 2001).

Late effects of cancer treatment: Any unrecognized toxicities that are absent or sub-clinical at the end of therapy and that manifest later (Aziz & Rowland, 2003).

Long-term effect of cancer treatment: Any side effects or complications of treatment for which a cancer patient must compensate; they typically begin during treatment and continue beyond the end of treatment (Aziz & Rowland, 2003).

Long-term breast cancer survivors: People who are five or more years past a cancer diagnosis (Gotay & Muraoka, 1998).

Mailing list: Also known by the popular commercial term LISTSERV, this is an email-based distribution list that enables communication between subscribers (Preece, 2000).

Message board: Also known as bulletin boards or discussion forums, these are web-based applications that support asynchronous group discussions in the form of posted messages (Preece, 2000).

Peer support: Social support provided by and for individuals who share something in common (Hegleson & Gottlieb, 2000).

Peer support provider: Individuals who provide social support to people with whom they share something in common (Hegleson & Gottlieb, 2000).

Social media: "A group of Internet-based applications that build on the ideological and technological foundations of **Web 2.0**, which allows the creation and exchange of **user-generated content**" (Kaplan & Haenlein, 2010).

Social network site: Web-based services that "allow 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" (Boyde & Ellison, 2008).

Social support: The functional provisions of relationships, such as emotional, instrumental and informational assistance, or the health benefits accrued from simply belonging to a group (Cohen, Gottlieb, & Underwood, 2000).

Supportive care: "The provision of the necessary services *as defined by* those living with or affected by cancer to meet their physical, social, emotional, informational, psychological, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement" (Fitch, 2000).

User-generated content: Forms of media content that are publicly available and created by end-users (Kaplan & Haenlein, 2010).

Web 2.0: "A set of economic, social and technological trends that collectively form the basis for the next generation of the Internet – a more mature, effective medium characterized by participation, openness, and network effects" (Musser & O'Reilly, 2006).

Wiki: A web-based application that permits the creation and editing of content by anyone (or in some cases a restricted membership), without the need for other software applications. The term wiki originated from the Hawaiian phrase "wiki wiki", meaning quick (Cunningham, 2002).

Online community: "A virtual social space where people come together to get and give information or support, to learn or to find company" (Preece, 2001).

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Introduction

Research Problem

There are close to one million cancer survivors living in Canada, with breast cancer survivors forming the largest group (Canadian Cancer Society [CCS], 2008). While these numbers are a testament to the many advances in preventing, screening and treating cancer, the period after active treatment brings its own set of unique, and in some cases poorly understood challenges (Alfano & Rowland, 2006). For many, cancer has become a chronic disease. The current heath care system is not equipped to deal with the needs of the growing population of cancer survivors, and despite calls for a comprehensive, integrated cancer care delivery system, there has been little progress. There is a pressing need to identify cost-effective, sustainable strategies to meet the long-term health care needs of breast cancer survivors. Online peer-to-peer support communities present one possible option.

Rationale

Breast cancer is the most common female cancer worldwide (World Health Organization [WHO], 2011). Globally it accounts for 22% of all new cancer diagnoses in women (International Agency for Research on Cancer [IARC], 2002). Breast cancer rates in Canada are among the highest in the world. In Canada, breast cancer accounts for 29% of all female cancers, which corresponds to 23,2000 new cases per year (CCS, 2010). Fortunately, breast cancer mortality rates have been steadily declining across North America, the United Kingdom and Australia since the mid-1980s largely due to increases in mammography screening and advances in adjuvant treatment (CCS, 2010). The age-adjusted 5-year survival rate for women diagnosed with breast cancer in Canada is 86% (CCS, 2007). Approximately

one in every 100 women in Canada has a history of breast cancer, which corresponds to about 1.0% of the female population (CCS, 2007).

Two seminal reports *Lost in Transition: From Cancer Patient to Cancer Survivor* by the Institute of Medicine's Committee on Cancer Survivorship (IOM, 2005) and *Living Beyond Cancer: Finding a New Balance* by the Presidents Cancer Panel (PCP, 2004) served to firmly established the need for comprehensive and coordinated follow-up care for all cancer survivors. Many cancer survivors struggle with long-term or chronic effects of cancer and its treatment (e.g., pain, fatigue, distress, body image, infertility) without much professional help or support, and worry about adverse late effects (e.g., second cancers, cardiovascular disease). Addressing the long-term health care needs of the growing population of cancer survivors has been identified as supportive care's next challenge (Alfano & Rowland, 2006). To meet this challenge, the IOM report offered ten recommendations, one of which emphasized the need to explore innovative strategies and delivery methods to overcome barriers that cancer survivors face in obtaining timely and effective supportive care, particularly as they transition from treatment to long-term follow-up.

There is considerable international interest in leveraging the potential of information and communication technology systems – often referred to as eHealth (Eysenbach, 2001) - to enhance the quality, safety and efficiency of care (Black et al., 2011; Catwell & Sheikh, 2009). eHealth interventions, which could overcome practical barriers to clinic-based services such as time, mobility and geography, while reaching a wider segment of the population at reduced personnel costs (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006; Strecher, 2007) offer a promising means of addressing the needs of the growing

population of cancer survivors. Specifically, online peer-to-peer support communities, which have been described as the single most important aspect of the web with the greatest potential impact on health outcomes (Eysenbach, 2005; Ferguson, 2002; Jadad, Enkin, Glouberman, Groff, & Stern, 2006), warrant further examination. While a number of studies have examined the use and impact of professionally initiated online support groups among breast cancer survivors, less is known about consumer-driven, self-help communities, which attract the bulk of online traffic (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

Purpose and Objectives

The purpose of this dissertation is to examine the role of online communities as a source of peer-to-peer supportive care among breast cancer survivors. The specific objectives are:

- To identify and describe the general characteristics and patterns of use of English language online communities for breast cancer survivors.
- To describe the supportive care needs and online community use of breast cancer survivors who are peer support providers.
- To explore how, why and under what conditions breast cancer survivors who are peer support providers use online communities as a source of supportive care and the usefulness of theory in explaining use.

Organization

This dissertation is organized into nine chapters based on the multiple papers thesis format. This thesis option allows the candidate to build the PhD thesis around a collection of

papers that are considered to be of publishable quality by the student's thesis committee. The first four chapters introduce the goals, literature, theory and methodology that guided the present program of research. The next four chapters (i.e., chapters 5 to 8) present the four studies that comprise the core of this dissertation. The final chapter (chapter 9) summarizes the findings and offers recommendations for research and practice.

Chapter Overview

Chapter 2 presents a narrative review of the literature on the supportive care needs of breast cancer survivors, sources of supportive care and the unique role and needs of cancer peer support providers. The benefits and limitations of online communities are discussed, as well as the evidence on their use and effectiveness among breast cancer survivors. The chapter concludes with a summary of the gaps in the literature, which this dissertation attempts to fill. The search strategy used to identify relevant articles for this review of the literature is presented in Appendix 1.

Chapter 3 provides an overview of the social support, health behaviour and technology adoption theories used to illuminate the support seeking behaviour of breast cancer survivors and frame the interpretation and, in some cases, the re-presentation of the study findings.

Chapter 4 describes the overall research design and the methods used in each of the four studies, and reflects on the strengths, limitations and ethical considerations of the approaches taken.

The four studies are presented in **Chapters 5, 6, 7 and 8.** They have been written in the standard manuscript format requested by peer-reviewed biomedical journals (i.e.,

Abstract, Introduction, Background, Methods, Results, Discussion, References). Chapter 5 presents the systematic review and synthesis of online communities for breast cancer survivors. Chapter 6 presents the content analysis of breast cancer groups on Facebook. Chapter 7 presents the cross-sectional survey of the supportive care needs of breast cancer survivors known to provide peer support, and their patterns of online community use. Chapter 8 describes the qualitative interviews of selected survey respondents concerning the conditions under which they used online communities as a source of supportive care.

Lastly, **Chapter 9** provides a general discussion of the findings from the four studies, addresses some outstanding topics for which there was little room in the preceding papers, and suggests some implications for research and practice.

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2

Review of the Literature

Supportive Care Needs of Breast Cancer Survivors

Numerous studies have documented a good or above average quality of life among breast cancer survivors two or more years post diagnosis (Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Ganz et al., 2002; Ganz et al., 2003). However, many breast cancer survivors experience considerable long-term physical and psychosocial morbidity. Psychosocial distress has been reported in about 30% of breast cancer survivors (IOM, 2004), fatigue in about 33% (Bower et al., 2006), lymphedema in 12 to 25% (IOM, 2005), body image concerns and problems with sexual functioning in about 20 to 30% (Kornblith et al., 2003), and cognitive dysfunction in a range of 20 to 61% of breast cancer survivors (Wefel, Saleeba, Buzdar, & Meyers, 2010). Younger breast cancer survivors (under age 50) and those who received adjuvant systemic therapy (chemotherapy, tamoxifen or both), are at greater risk of sexual dysfunction (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999) and poorer physical, social and emotional functioning (Ganz et al., 2002; Ganz et al., 2003). In addition, late effects, the prevalence and mechanisms of which are still poorly understood, can include second malignancies, cardiovascular disease, neurotoxicity, nephrotoxicty, pulmonary toxicity, and metabolic syndromes (for a complete review of late effects associated with breast cancer and its treatment see (IOM, 2005).

Despite the growing evidence of long-term and late effects of breast cancer and its treatment, only a few researchers have investigated the supportive care needs of long-term breast cancer survivors. A Canadian interview study of 70 'well' breast cancer survivors four or more years after diagnosis revealed ongoing emotional and physical effects of the illness, fears of recurrence, and information needs that were not met by physicians and oncology teams (Gray et al., 1998). The ongoing impact of the disease was felt most strongly when

survivors' experienced aches and pains related to post-treatment effects, which many feared were indicative of disease recurrence. Similar types of unmet needs were reported by a focus group study in the United States involving 128 women one to 32 years post diagnosis (Wilson, Andersen, & Meischke, 2000). Women with late-stage disease reported more unmet needs and less satisfaction with the supportive care provided by the formal health care system than women with early stage disease. In particular, they reported a lack of: treatment information; support to manage symptoms and side effects; and, problems with insurance and finances.

A Canadian focus-group study of 65 women diagnosed with breast cancer at or before the age of 45 years, highlights the unique needs of younger breast cancer survivors (Gould, Grassau, Manthorne, Gray, & Fitch, 2006). The psychosocial issues identified by the participants who were one to five years post-diagnosis included early menopause, loss of sexuality and fertility, financial concerns, increased emotional distress due to competing demands for self, partner and family, and instrumental support such as meal preparation, house cleaning and child care. Participants explained that the accessed information and services did not fit or match their age or life-stage. They stressed the need for tailored, life-stage specific information and services, as well as support for their children and partners.

More recently, an Australian group documented high rates of anxiety and supportive care needs among a sample of 117 disease-free breast cancer survivors two to 10 years post diagnosis (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, & Wain, 2007), using a newly developed multidimensional supportive care measure (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, Lo, et al., 2007). Nearly two-thirds of respondents reported at least one unmet need, most frequently concerning fear of recurrence, access to up-to-date information,

an ongoing case manager, access to complementary and alternative therapy, and help to cope with their new identity as a cancer survivor. In addition, breast cancer survivors who experienced significant anxiety or depression reported having two to three times as many unmet supportive care needs.

Professional Sources of Supportive Care

Growing recognition of the issues that exist in coping with the effects of cancer and its treatment has led to the development of supportive care services for cancer survivors. Supportive care services that exist as part of the formal health care system are typically offered by two broad groupings of health professionals: those specializing in psychosocial oncology and palliative care (e.g., pain experts, psychologists, social workers), or those with a primary focus on disease control (e.g., oncologists) (Gray et al., 2000). Such services could include, but are not limited to, personalized care from a health care professional such as a pain expert, dietician or psychologist, integrated interdisciplinary care from an oncology team, or specialized educational programs such as professionally moderated psychotherapy groups (Kash, Mago, & Kunkel, 2005).

In reality, the types and availability (and sometimes costs) of professional supportive care services for cancer survivors in Canada vary tremendously from one health care setting to another, and tend to be personnel and leadership dependent (Fitch, 2000, 2008). Despite calls for improvements in supportive care delivery, there has been little progress. Numerous barriers at the level of the patient, health professional and health system have contributed to this lack of progress. Health care systems lack funding, relevant data on the patterns of survivors' supportive care needs over time and resultant utilization of services, and

consensus concerning models of appropriate follow-up care (Fitch, 2000, 2008; IOM, 2005).

Health care professionals lack the knowledge and tools to provide appropriate supportive

care (e.g., clinical guidelines) and system supports such as information technology that could

help them manage increasing patient caseloads (Fitch, 2000, 2008; IOM, 2005). Cancer

survivors, confronted with a fragmented and poorly coordinated cancer care delivery system

lack awareness of what type of help is available and how to access it (Fitch, 2000, 2008).

These limitations might in part explain the low utilization of specialized professional

supportive care services by Canadian women with breast cancer (Gray et al., 2000).

Supportive Care from Peers

Support from family, friends and other survivors is recognized as an important

alternative or complement to supportive care provided by the formal health care system

(Fitch, 2000; Vivar & McQueen, 2005). Family caregivers often serve as the primary source

of support (Gass, Weitzen, Clark, & Dizon, 2007). However, support from family caregivers

typically drops significantly within the first year of diagnosis (Arora, Finney Rutten,

Gustafson, Moser, & Hawkins, 2007). Support from people in similar circumstances is highly

valued by breast cancer survivors (Rozmovits & Ziebland, 2004), even for those who report

high levels of support from family members (Arora et al., 2007). Support form peers can

provide a unique sense of community, reassurance and practical information that cannot be

gained from other supportive relationships and can improve relations with family and friends

by relieving their burden of care (Ussher, Kirsten, Butow, & Sandoval, 2006).

Peer support can take many forms including one-on-one or in a group, face-to-face or

mediated by the telephone or the Internet, all forms of which are typically offered by

community-based cancer organizations at the regional and national level. Peer support programs are typically organized by community agencies and run by peer volunteers (Owen, 2003). Evidence on the effects of cancer peer support programs is favourable, but limited by methodological shortcomings. A review of 17 evaluations of cancer peer support programs, documented improved coping skills, confidence, reassurance, sense of normalcy, understanding of the disease and reduced isolation (Campbell, Phaneuf, & Deane, 2004). A more recent review of 43 studies, documented a high level of satisfaction with peer support programs and similar informational, emotional and instrumental benefits as the earlier review, but inconsistent psychosocial effects (Hoey et al., 2008). However, most of the studies lacked a theoretical framework, adequate program descriptions, details on participants who dropped-out and validated instruments. While neither review compared the relative benefits of the different peer support models, Hoey et al. documented consistently improved psychosocial functioning for one-on-one support, and for face-to-face and Internet-based support groups.

Supportive Care Needs of Peer Support Providers

Although little is known about the relative benefits of the different peer support models, there is growing evidence of the pivotal role of the support provider or group leader in producing positive outcomes (Butow et al., 2007; Butow et al., 2005; Owen, Bantum, & Golant, 2009). A survey of 476 cancer support group members indicated that the most important features of such groups were having a leader who allowed everyone to talk, and who was empathic and qualified to understand what the group members were experiencing (Butow et al., 2007). In addition, the survey revealed that respondents further from diagnosis

preferred to have a cancer survivor as a support group leader rather than a health professional.

Researchers, primarily from Australia and the United Kingdom, have begun to document the training and support needs of leaders of face-to-face (Butow et al., 2005; Stevinson, Lydon, & Amir, 2010) and Internet-based cancer support groups (Owen et al., 2009) in order to support and sustain them in their roles. Surprisingly little attention has focused on the supportive care needs of cancer peer support providers as long-term survivors. In fact, there is only one known study (Matthews, Baker, Hann, Denniston, & Smith, 2002) of the health status and quality of life of 586 breast cancer survivors who were on average five years post-diagnosis and who were also peer support volunteers. Respondents had higher physical functioning, emotional well-being and vitality than population norms. However, they expressed greater dissatisfaction with their sexual ability, physical strength, and bodies compared to the general population.

Virtual Peer-to-Peer Supportive Care

In the short time that the Internet has been available to the general public, its use for the finding and sharing of information about health has increased exponentially. Surveys (conducted in 2008) indicate that at least 80% of North American adults used the Internet regularly, and that at least six in 10 have looked online for health information (Canada, 2010; Fox, 2009). "E-patients" as they have been called (Ferguson & Frydman, 2004), are not looking for just any kind of information online. Sixty percent of e-patients in the United States have reported accessing some form of user-generated health information (e.g., posts in a discussion forum or blog about personal health experiences, reviews of physicians or

hospitals) to aid in their health decision making including, and 41% specifically reported reading someone's description about a health issue in an online community (Fox, 2009).

The popularity of user-generated health information can be attributed to a number of technological advances and cultural trends. These include: growing societal appreciation of the complexity and uncertainty of modern life, resulting in a loss of faith in traditional figures of authority (Giddens, 1994); an economic trend toward a free market model and consumerism in health care (Lupton, 1997); and, increasing availability of information facilitated by advances in information and communication technology (Nettleton, 2003). Together, these factors have led to a more active and informed public making demands for better information and care (Mechanic, 1998).

However, people have been using electronic media to communicate and support each other in groups long before the evolution of the public Internet. The first known computer-mediated community was the USENET discussion system (Lueg & Fisher, 2003). Created in 1980, USENET relied on a decentralized network of global news servers to propagate messages built on ARPANET, the precursor to the Internet (Lueg & Fisher, 2003). USENET forums were therefore known as 'newsgroups', which are similar in function to asynchronous message boards, where messages posted to the forum appear in sequential threaded order.

More recently, online communities have formed around blogs, wikis and social network sites (Bender, O'Grady, & Jadad, 2008), also known as Web 2.0 software applications or social media (Kaplan & Haenlein, 2010). While web 2.0 may simply represent new jargon for what the web was meant to achieve at the outset (Berners-Lee & Fischetti, 1999), the applications it has become known to represent are markedly different than earlier websites whose static content was governed by webmasters and broadcast

through hypertext links (Deshpande & Jadad, 2006). Web 2.0 applications are designed to support the creation and exchange of content by anyone in an open and collaborative fashion, providing people with the tools to engage with each other and with health care in ways that were almost unimaginable a decade ago (Fox, 2010; Strecher, 2007).

Scope of Research on Online Communities

Research on online communities for health purposes is largely limited to studies of the use and impact of professionally moderated electronic mailing lists or asynchronous message boards. Less is known about the use of synchronous technologies such as chat rooms as health resources, and non-professionally moderated, self-help online communities created by and for consumers (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). In addition, there are only a handful of studies that have examined the use of popular social media resources (e.g., Facebook, YouTube, MySpace, Twitter) for health purposes (Chew & Eysenbach, 2010; Farmer, Bruckner Holt, Cook, & Hearing, 2009; Keelan, Pavri, Balakrishnan, & Wilson, 2010; Keelan, Pavri-Garcia, Tomlinson, & Wilson, 2007; Scanfeld, Scanfeld, & Larson, 2010) none of which focused on breast cancer.

Moreover, most of this research has focused on characterizing the use and impact of one or a few online communities using a single medium such as message boards (Preece & Maloney-Krichmar, 2005); less is known about the scope of online communities for breast cancer survivors or their levels of use. One known study characterized the scope of online cancer communities, highlighting those that were designed for ethnic minority groups (Im, Chee, Tsai, Lin, & Cheng, 2005). However, this study did not document their levels of use, and was conducted in 2003 before the emergence of social media and social network sites.

Two studies that investigated the quality of health information in breast cancer websites (Hoffman-Goetz & Clarke, 2000; Meric et al., 2002) documented the type of communication software that the sites provided, but they did not describe or evaluate their use. Meric et al. (2002) investigated the popularity of breast cancer websites based on their link popularity or Google rank, but also did not directly investigate use. Both studies were conducted in the early 2000s, well before the emergence of web 2.0 and the subsequent social media revolution.

Benefits of Online Communities

Online communities can overcome many of the practical barriers to face-to-face support, while providing additional advantages such as 24-hour accessibility from the convenience of home, anonymity, similarity of experiences and diversity of resources (Wright, 2000). Content analysis of message posts, and interviews with group members of professionally and non-professionally moderated mailing lists, message boards and chat rooms has revealed a number of potentially empowering effects. Such groups have been shown to enable the disclosure of sensitive and potentially stigmatizing topics; to provide reassurance, a sense of community and hope for the future; to reduce feelings of stress and uncertainty, and validate concerns ignored by health care professionals; and enable breast cancer survivors to become better informed and able to cope with their condition and prepared for their interactions with the health care professionals (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Rogers & Chen, 2005; Sharf, 1997; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; Vilhauer, 2009).

Van Uden Kraan and colleagues (2008) provide direct evidence of the effects of online communities on patient empowerment. Beginning with a qualitative interview study involving 32 participants of breast cancer (n = 10), fibromyalgia (n = 11) and arthritis (n = 11) online support groups, the authors identified both empowering processes and outcomes (van Uden-Kraan et al., 2008). Empowering processes included: exchanging information; encountering emotional support; finding recognition; sharing experiences; helping others; and, amusement. Empowering effects included: being better informed; feeling confident in their relationship with their physician, their treatment, and social environment; improved acceptance of the disease; enhanced self-esteem and social well-being and social action. A subsequent survey involving 214 participants of seven different online communities for breast cancer survivors revealed that the most common empowering outcomes, experienced by more than 50% of the sample were: being better informed (74%); knowing what questions to ask their physicians (68%); knowing how to manage their disease (60%); and, being better prepared for their consultation with their physicians (60%) (Smit et al., 2007).

Evidence on the effects of online communities on health outcomes has primarily focused on professionally initiated and moderated groups. One of the most extensively studied online support communities is the Comprehensive Health Enhancement Support System (CHESS), which includes a professionally moderated asynchronous message board. Two randomized controlled trials (RCT) of the CHESS program resulted in higher perceived social support, information and health care competence among samples of 226 and 249 newly diagnosed breast cancer survivors (Gustafson et al, 2001, 2005). The greatest benefits were observed among African-American women, the uninsured and those with less

education. The discussion group was the most extensively used service, leading the authors to tentatively conclude that it could be in large part responsible for the effects.

Although these results are promising, the multidimensional nature of the program, limit the generalizability of findings. However, research on stand-alone online communities has demonstrated similar psychosocial effects. An RCT of three separate e-mailing discussion lists, involving a total of 108 breast cancer survivors (36 in each mailing list) that were moderated by a health professional following Spiegel's supportive-expressive therapy (Spiegel & Classen, 2000) resulted in significant reductions in measures of depression, perceived stress and a nearly significant ($p = 0.045$) reduction in post-traumatic growth (Winzelberg et al., 2003).

Very few studies have evaluated the effects of peer-to-peer online communities that are not professionally led (Eysenbach et al., 2004). A pre-post study of five un-moderated asynchronous message boards involving 91 breast cancer survivors demonstrated significant improvements in depression, quality of life and post-traumatic growth (Lieberman & Goldstein, 2005). However, an RCT comparing an un-moderated mailing list to an Internet-based control condition among 78 newly diagnosed breast cancer survivors produced conflicting results (Salzer et al., 2010). Participants in the intervention condition experienced a non-significant increase in distress and decreased emotional well-being over time, compared to those in the control condition. Paradoxically, 60% of the intervention participants felt supported by the mailing list and reported high levels of satisfaction, a sub-group of which created a mailing list of their own at the end of the study. These findings suggest that online communities may not be universally beneficial. The authors hypothesized

that the homogeneous nature of the group and the lack of opportunity to learn from others who were in remission could have limited the potential benefit of the group.

Prevalence of Online Community Use

Surveys of the American public indicate that 41% of online health consumers have read someone else's commentary or experience about a health or medical issue in an online community and one in five have posted information about their health condition in online communities (Fox, 2009). When other demographic factors are held constant, having a chronic disease increases an Internet user's likelihood to use or contribute to an online community that helps people with personal issues or health problems (Fox & Purcell, 2010). There is only one known study of the prevalence of health-related online community use among a sample of patients. In a cross-sectional hospital-based study of 679 Dutch patients with breast cancer, rheumatoid arthritis or fibromyalgia, 52% of the patients surveyed reported using the Internet, in general, as a health resource, and 15% reported specifically using an online patient community (van Uden-Kraan et al., 2009).

Conditions that Influence Online Community Use

Similarly, little is known about the conditions under which people use online communities for health purposes, and how they compare to other sources of supportive care. People typically use a variety of offline and online health resources to meet their needs (Eysenbach & Kohler, 2002; Rozmovits, Ziebland, Rozmovits, & Ziebland, 2004). However, most researchers have studied the use of online communities in isolation. There is only one known study of the comparative uses and support functions of face-to-face support groups

versus online communities. A survey of 127 Japanese breast cancer survivors who participated in online communities, 538 who participated in face-to-face support groups and 374 who participated in both types of support groups, demonstrated that those who used both resources received the most support (Setoyama, Yamazaki, & Nakayama, 2010). Users of online communities scored higher for emotional expression and advice, while users of face-to-face groups scored higher for emotional support/ helper therapy and insight/universality. Interestingly, online communities were used immediately after diagnosis, whereas face-to-face groups were used after beginning or completing treatment. The results of the study by Setoyama et al. suggest that online communities may serve as a different source of support for breast cancer survivors. A better understanding of the context of use is central to understanding the significance or role of these technologies in the everyday lives of breast cancer survivors (Henwood, Wyatt, Hart, & Smith, 2003).

Limitations of Online Communities

Online communities are not without their limitations. Most studies of online communities for health purposes (Eysenbach et al., 2004) and Internet-based health interventions in general (Bender, Radhakrishnan, Diorio, Englesakis & Jadad, 2011; Cuijpers, van Straten, & Andersson, 2008; Rosser, Vowles, Keogh, Eccleston, & Mountain, 2009) report high dropout rates. A qualitative investigation with breast cancer survivors who withdrew from of an online community suggests that high the dropout rates might be due in part, to the challenge of 'fitting-in' (Sandaunet, 2008). Study participants explained that they either felt that their circumstances were too different from other community members or they were not able to establish a legitimate position in the community.

Most online communities also report low participation rates. Although participation rates vary, it has been estimated that the percentage of "lurkers" (people who read but do not post) in mailing lists and message boards is on average 90% (Nonnecke & Preece, 2000). There are various explanations for lurking including not understanding how the software or the community (social norms) operates, feeling as though one has nothing to contribute, concerns over whether questions will solicit a response or not liking the dynamics of the community (Preece, Nonnecke, & Andrews, 2004).

Research suggests that online cancer communities are also predominately used by white cancer survivors. A review of the evidence on online cancer communities conducted in 2003 revealed that most studies involve college-educated, high-income whites (Klemm et al., 2003). A survey of online communities for cancer survivors also conducted in 2003 identified 546 different groups, only 24 of which were ethnic- specific; eight were for African Americans, eight were for Asian Americans and eight were for combined ethnic minority groups (Im et al., 2005). In addition, the CHESS discussion group was used 68% of the time by white women and only 38% of the time by African-American women (Gustafson et al., 2005). The possible reasons for the under-presentation of ethnic minorities in online cancer communities include differences in how ethnic groups make use of the Internet, differences in preferences for support (Fogel, Ribisl, Morgan, Humphreys, & Lyons, 2008; Im & Chee, 2008), and a North American bias in online breast cancer spaces (Orgad, 2006).

Research has also demonstrated that online communities may not be a space for suffering. Several researchers (Orgad, 2006; Pitts, 2004) have observed a discourse of 'restitution' in online health communities, which privileges positive experiences and coping with illness (Frank, 1995). Even breast cancer survivors with metastatic disease and poor

prognosis report having difficulty discussing concerns related to death and dying in online communities (Vilhauer, 2009). Being confronted with the negative aspects of the disease in online communities can have disempowering effects (van Uden-Kraan et al., 2008), and has caused breast cancer survivors to drop out of online communities (Sandaunet, 2008).

Lastly, there is enduring concern about the potential for harm resulting from deception and misinformation in online health communities (Broom, 2005), and from the use of the Internet in general (Gagliardi & Jadad, 2002; Jadad & Gagliardi, 1998). However, there is little evidence to support the claim (Crocco, Villasis-Keever, & Jadad, 2002). Moreover, research suggests that the self-organizing nature of online communities may enable its members to identify and correct potentially harmful information (Jadad, Enkin, Glouberman, Groff, & Stern, 2006). Esquivel et al (2006) analyzed 4600 postings of the Breast Cancer Mailing List during the first quarter of 2005 and found only 10 containing false or misleading information, seven of which were identified by members of the list and corrected, on average, less than 5 hours after they appeared.

Summary

It is clear, from the literature to-date, that online communities hold promise as an alternative or complementary supportive care resource for breast cancer survivors. What remain unclear are which communities, to what extent, under what conditions and for whom. In addition, despite the abundance of observational studies that suggest breast cancer survivors benefit from participating in online communities, higher quality studies are needed to assess the net health effects of non-professionally moderated online communities and the

conditions or factors that influence positive outcomes, particularly in diverse survivor groups.

As a first step, research is needed to characterize the scope of non-professionally moderated online communities that currently exist for breast cancer survivors, as well as their levels of use in order to build an evidence base to guide future resource development. The use and effects of popular social media resources, such as Facebook, warrant special attention. Given the pivotal role of cancer peer support providers, who have been described as "the frontline of psychosocial care for cancer survivors" (Owen et al., 2009), a better understanding is needed of their unique supportive care needs, and use of online communities. Cancer peer support providers are in a unique position to provide rich, experientially based insight on the conditions that influence use of online communities as a supportive care resource and their role in comparison to other sources. This dissertation attempts to address these gaps in knowledge and contribute to the rapidly growing fields of online communities and cancer survivorship.

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3

Theoretical Underpinnings

Theoretical Framework

The field of online communities is at the crossroads of multiple disciplines. Not surprisingly, research in this field has drawn upon numerous theoretical perspectives from a variety of disciplines; namely, sociology, anthropology, social psychology, and linguistics (Preece & Maloney-Krichmar, 2005). No particular theory or set of theories has dominated the field. In most cases, researchers have drawn from, and adapted, theories from traditional disciplines that reflect their training (Preece & Maloney-Krichmar, 2005).

This dissertation employed a multi-theory perspective, drawing on theories from the fields of social support, health behaviour and technology adoption, to illuminate the context of online support seeking by breast cancer survivors. Thoughtful combinations of theories are hypothesized to result in a more robust understanding of particular health behaviours (Rimer, 2002). Rather than directing and guiding the inquiry process, theory was used to frame the interpretation and, in some cases, the re-presentation of the findings. These interpretations are discussed in detail in the discussion sections of Chapters 5, 6, 7 and 8 and Chapter 9 of this dissertation. This chapter describes the theories that underlie the present program of research.

Social Comparison Theory
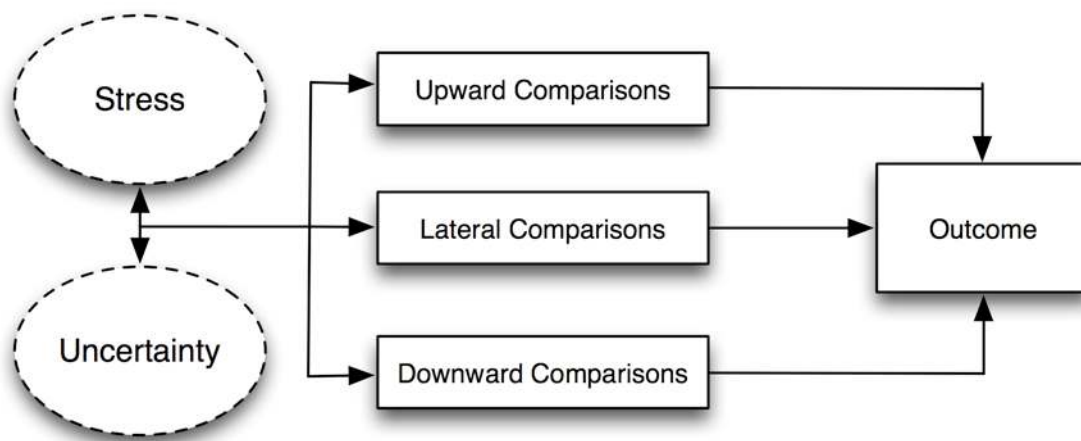
Figure 1: Illustration of the Social Comparison Theory (author's interpretation).

The two major explanations for why individuals decide to join support groups involve social comparisons (Buunk, Gibbons, & Reis-Bergan, 1997). The first explanation is that in times of stress and uncertainty, people make social comparisons to reduce their anxiety. The second explanation is that participation in support groups reduces feelings of uniqueness or deviance thereby enhancing self-esteem. Both of these explanations gain import from the Theory of Social Comparison (Festinger, 1954) which asserts that under conditions of threat, people seek similar others in order to compare the appropriateness of their thoughts, feelings or behaviours.

The experience of breast cancer is plagued by ambiguous physical symptoms and an unclear prognosis (Bender et al., 2008). Studies suggest that women experience feelings of uncertainty for years after breast cancer treatment has ended (Gill et al., 2004) and that it is often associated with new aches and pains (Hsu, Lu, Tsou, & Lin, 2003). Uncertainty can negatively influence the experience of cancer and reduce coping efforts (Shaha, Cox,

Talman, & Kelly, 2008). Uncertainty, optimism, perceived seriousness of the illness and control over physical symptoms are important predictors of psychosocial adjustment to cancer (Mishel, 1984). While there are no published studies examining whether uncertainty influences people to join online communities, Shaw et al. (2000) found that communicating with other breast cancer survivors in an online community served to reduce uncertainty about ambiguous painful symptoms.

As illustrated in Figure 1, people in stressful situations make upward, downward and lateral comparisons with similar and dissimilar others depending on whether their goals are self-evaluation, validation, self-enhancement, self-improvement or modeling (Hill, 2003). A review of the social comparison literature (Taylor & Lobel, 1989) revealed that while cancer patients frequently make downward comparisons to enhance their self-esteem, they prefer to associate with others who have either overcome threatening circumstances or adjusted well to them, avoiding those who are doing poorly. The authors found that affiliating with other cancer patients who were doing 'well' provided useful cues to successful coping, as well as hope for the future. Similar findings have been reported in studies of online communities used by cancer survivors (Davison, Pennebaker, & Dickerson, 2000; Sharf, 1997).

However, the effects of social comparisons are not always positive, which might, in part, explain why breast cancer survivors drop out of online communities. As suggested by Buunk et al. (1990), learning that there are others who are doing better provides two pieces of information: that you are not doing as well as everyone, and that it is possible for you to be better than you are at present. Conversely, learning that there are others who are worse off suggests that: you are not as badly off as everyone, and it is possible for you to get worse. A longitudinal investigation of the social comparisons made by women with breast cancer who

participated in face-to-face peer support groups (Bogart & Hegleson, 2000) revealed that low-self esteem, high illness uncertainty and low internal locus of control were associated with making negative comparisons. Negative downward comparisons were associated with increases in uncertainty about the illness, and negative upward comparisons were associated with decreases in perceptions of control.

The Transactional Theory of Stress and Coping
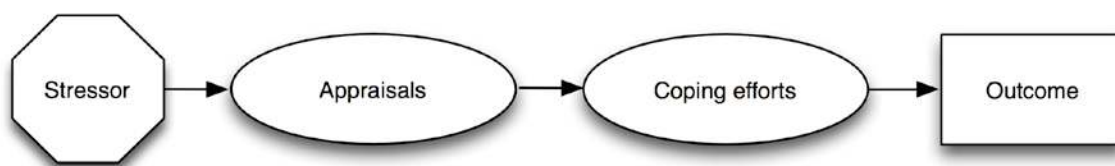
Figure 2: Simplified Illustration of the Transactional Theory of Stress and Coping adapted from Cohen, Underwood & Gotllieb (2000).

The second theoretical perspective that informed the present research was the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), which postulates that the impact of a stressful event is mediated by 1) an individual's appraisal of the event, and 2) the coping resources at his or her disposal (Figure 2). Support from peers is hypothesized to promote coping efforts and lessen negative appraisals of events, which in turn reduce or buffer anxiety. Joining an online community to seek support from peers or make social comparisons reflect coping strategies. Specifically, seeking information and making upward comparisons with others who are doing well, have been described as active or problem-focused coping strategies, while seeking emotional support and making downward comparisons with others who are worse off, reflect emotion-focused coping strategies (Folkman & Lazarus, 1980). The predominance of one coping style over the other

depends on the context, the personality characteristics of the individual and how the event is appraised.

Several researchers have confirmed that cancer survivors who participate in face-to-face support groups tend to be more depressed, more anxious and use active coping strategies compared to those who do not (Edgar, Remmer, Rosberger, & Rapkin, 2003; Grande, Myers, & Sutton, 2006). Although no known studies have explicitly examined the coping styles predictive of the use of online communities, content analyses of the communication occurring in those used by breast cancer survivors demonstrate a greater frequency of information-oriented *versus* emotionally-supportive exchanges which is suggestive of more problem-focused coping strategies (Gooden & Winefield, 2007). According to the theory of stress and coping, problem-focused coping is most effective when the stressor is controllable whereas emotion-focused coping is more useful when the situation is not, as is the case with many health conditions. However, research by Taylor (1983) suggests that coping strategies that enhance perceptions of control are an important element in the process of adjustment to cancer regardless of the actual "controllability" of the outcome.

Several researchers have successfully used the Theory of Stress and Coping to explain the effects of online communities. Gustafson and colleagues (2001, 2005) demonstrated increases in perceptions of support among users of a multi-dimensional support community for breast cancer survivors. Lieberman and Goldstein (2005) reported reductions in perceived stress among users of online breast cancer discussion lists. Although neither study examined the relationship between perceptions of support and stress, a survey of 103 users of 30 different online cancer communities demonstrated a modest positive correlation between perceptions of emotional support and global measures of perceived stress (Wright,

2002). Earlier research involving 148 users of 24 different health-related online communities revealed that the amount of time spent in online communities was directly related to satisfaction with the support received (Wright, 2000). Satisfaction with online support correlated with reduction in perceived stress, and satisfaction with online support was predictive of the use of both information- and emotion-focused coping strategies.

The Theory of Planned Behaviour
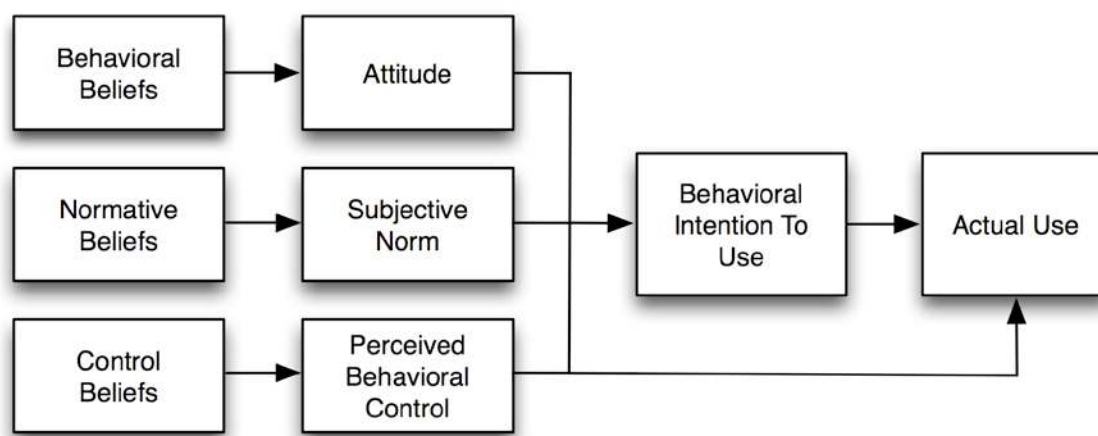
Figure 3: Illustration of the Theory of Planned Behaviour adapted from Ajzen (2006).

Whether or not an individual chooses to use online communities as a method of coping depends on their beliefs about online communities. As shown in Figure 3, the Theory of Planned Behaviour (TPB) (Ajzen, 1991) maintains that intentions to perform a health behaviour are influenced by: *attitudes* toward performing the behaviour; *subjective norms* associated with the behaviour; and *behavioural control* to perform the behaviour. The more favourable the attitude, perceived social pressure, and perceived ability to perform the behaviour, the stronger should be the individual's intention to perform the behaviour in question. The TPB is an extension of the theory of reasoned action (TRA), which was first

developed by (Fishbein, 1967) in an effort to understand how attitude affects behaviour. Both theories are concerned with individual motivational factors as determinants of the likelihood of performing a specific behaviour, and emphasize intention as the most important determinant (Montano & Kasprzyk, 2002).

Ajzen (1991) introduced the TPB as an extension to the TRA to address behaviours over which individuals have incomplete volitional control. Specifically, Ajzen added *perceived behavioural control* to account for beliefs about the presence of factors that may facilitate or impede performance of the behaviour, and the perceived power or impact of these factors. Ajzen's construct of perceived behavioural control is similar to Bandura's construct of 'self-efficacy', which is defined as the belief in one's ability to perform a particular behaviour despite impediments (Bandura, 1997). The TPB maintains that perceived behavioural control is an independent determinant of intention along with attitude and subjective norms and, similar to self-efficacy, is also a direct determinant of behavior. The relative importance of these factors in determining intention varies according to the behaviour and population of interest (Montano & Kasprzyk, 2002).

The TPB has been successfully used to predict a wide range of health and non-health related behaviours (Ajzen, 1991). Of particular relevance, the TPB was used to investigate factors associated with the use of face-to-face support groups by cancer patients as a method of coping. Using the TPB, Grande, Myers and Sutton (2006) demonstrated that beliefs about face-to-face support groups, important others' beliefs about face-to-face support groups, less perceived difficulty in joining a face-to-face support group and lack of support from a special person were associated with cancer support group membership, independent of demographic and clinical characteristics. This finding lends partial support to the proposition that

demographics and external factors operate through the model and do not independently contribute to explaining the likelihood of performing a behaviour.

The Technology Acceptance Model
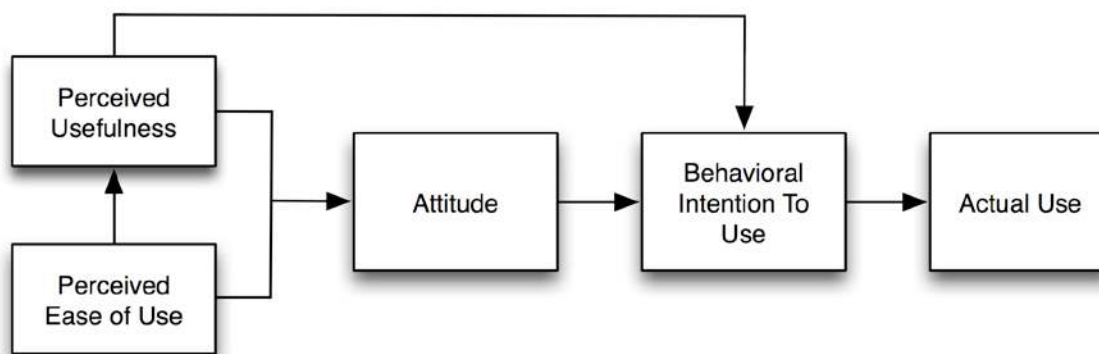
Figure 4: Illustration of the Technology Acceptance Model adapted from Holden & Karsh (2010).

Within the information technology literature, ideas regarding individual motivational factors that affect behaviour have taken shape in the form of the Technology Acceptance Model (TAM). The TAM (Davis, 1989) is perhaps the most widely used theory to explain the relationship between attitudes and use of information technology. [See (Holden & Karsh, 2010) for a recent review of the use of TAM in health care.] Although the TAM is an adaptation of the TRA, in its original form it emphasizes attitude as the primary determinant of behavioural intention (subsequent revisions of the theory include the subjective norms; (Venkatesh & Davis, 2000). The TAM asserts that attitude toward using IT systems is determined by two types of beliefs: *perceived usefulness*, defined as the extent to which using a system will enhance an individual's job, and *perceived ease of use*, defined as the extent to which an individual believes that using the system will be free of effort. The TAM

also departs from the TRA by maintaining that *perceived usefulness* is a direct determinant of both attitude and intention, as opposed to being mediated through the attitude construct. When compared to the TRA as a predictor of intention to use a computer system in a work place, the TAM explained 47% of the variance in intention and 51% of the variance in use, compared to 32% and 26% for the TRA respectively (Davis, Bagozzi, & Warshaw, 1989).

The TAM has been adapted and extended by numerous researchers in an effort to increase its explanatory power (Holden & Karsh, 2010). One important variant is the combined TAM-TPB model. While several studies have shown that TAM has reasonable predictive power, the relationship between perceived ease of use and intention has been less consistent and to a large extent mediated by perceived usefulness (Taylor & Todd, 1995b). Likewise, the TPB has also demonstrated good predictive power, but has been criticized for having uniform antecedent belief constructs that are difficult to interpret (Taylor & Todd, 1995a). Therefore Taylor and Todd decomposed the model's core constructs into specific types of beliefs and added *perceived usefulness* as an indirect measure of attitude. When compared as a predictor of the use of a computing facility in a school setting, the TAM explained 52% of the variance in intention, the TPB explained 57%, and the decomposed TAM-TPB explained 60%, suggesting that the decomposed TAM-TPB might provide a more robust understanding of behavioural intention to use IT systems.

Online communities are similar to IT systems in that they provide technology-mediated access to information that can impact decision-making. However, online communities differ in one very important way, the information they contain is created through the collaborative efforts of the community. The success of an online community is therefore dependent on its *sociability* – the ability to support social interactions (Preece,

Abras, & Maloney-Krichmar, 2004). One key aspect of sociability is *credibility*, which is the believability of a source or message (Flanagin & Metzger, 2008). Drawing from recent theoretical advances in understanding IT usage, Lin (2006) created a decomposed version of the TAM-TPB model tailored to the online community context with the addition of *perceived trust* as determinant of attitude along with perceived usefulness and ease of use. Based on a survey of online communities users, Lin demonstrated that attitude and perceived behavioural control were significant predictors of intention to use general-purpose online communities, while subjective norms were not. In addition, all hypothesized paths between the antecedent beliefs and the model's core components were significant.

Summary

Although some of these theoretical perspectives have been used previously to examine the use of online communities, this work is limited to investigations of the effects of online communities used by breast cancer survivors (Gustafson et al., 2001, 2005; Lieberman et al., 2003; Wright, 2000, 2002) and the motivations to use general-purpose online communities (Lin, 2006). No known studies have examined the application of these theoretical perspectives in combination to understand how and why online communities are used by breast cancer survivors, or any other illness-specific group for that matter. In fact, most theoretical work in the field of health information technology has focused on the adoption and use of health technology systems by clinics, hospitals and clinicians relying primarily on the TAM (Holden & Karsh, 2010), which was developed for use in business environments for behaviours over which individuals have relatively incomplete volitional control (i.e., where use of an IT system may not be mandatory but is certainly expected).

Thus determining whether these theoretical perspectives are useful in understanding how and

why online breast cancer communities are used voluntarily requires critical examination.

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4

Methodology

Research Design

This dissertation employed a *multi-method research design* to explore the role of online communities as a source of peer-to-peer supportive care among breast cancer survivors.

Multi-method research designs have been defined as "qualitative and quantitative projects that are relatively complete but that are used together to form essential components of one research program" (Morse, 2003). A major research question drives the research program, and different studies are planned and conducted to answer particular sub-questions or objectives. These studies can be conducted simultaneously to supplement each other, or sequentially to resolve problems/issues uncovered by the first study or to provide a logical extension from the findings of the first study. The results of each study are not usually dependent on each other, and unlike 'mixed method study designs' qualitative and quantitative data are not integrated with each other, but rather are used to inform a greater conceptual understanding of the phenomenon under study.

Multi-method research designs are a form of mixed method research. Mixed method research is considered ideal for the investigation of complex social phenomenon, which many believe "cannot be fully understood using either purely qualitative or quantitative techniques" (Teddlie & Tashakkori, 2003). eHealth interventions are inherently complex social phenomena. Although ehealth interventions are developed in a technical and scientific world, they are dependent on personal, social, political, and ideological factors for their success (Greenhalgh & Russell, 2010). The collection and analysis of both quantitative and qualitative data can lead to findings that confirm, complement or challenge each other,

"illuminating these complexities" (Greenhalgh & Russell, 2010) and in doing so, provide a more complete and useful understanding of their role and potential impact.

Brief History of Mixed Method Research

Mixed method research arose from the notion of 'triangulating' information from different data sources, a technique that emerged from psychology and sociology but that gained prominence in the applied disciplines of evaluation and nursing (Teddlie & Tashakkori, 2003). It is recognized as the third methodological movement in the social and behavioural sciences (Teddlie & Tashakkori, 2003). The first methodological movement, which dominated the 20th and the first half of the 21st century, was quantitative methods and the positivist paradigm. Postivitism is a deterministic, reductionist philosophy that is based on the notion of a universal truth, and an objective, measurable reality (Lincoln & Guba, 2000). Dissatisfaction with the central tenets of positivism led to the evolution of the second methodological movement - qualitative methods and the constructivist paradigm, which gained popularity in the 1970s and 1980s. Constructivism claims that reality is pluralistic and that knowledge is socially and historically constructed (Lincoln & Guba, 2000). Mixed methods emerged as a distinct methodological orientation in the 1990s in response to the 'paradigm wars' between the quantitative and qualitative scholars, and the ensuing 'incompatibility thesis', which claimed, "it was inappropriate to combine quantitative and qualitative methods due to the incompatibility of the paradigms underlying the methods" (Teddlie & Tashakkori, 2003).

Several scholars have discredited the incompatibility thesis, noting among other things that researchers have been successfully employing multiple diverse methods in

combination to answer research questions since the beginning of the 20th century (Teddlie & Tashakkori, 2003). However, the incompatibility thesis has had an enduring effect in the form of continued disagreement regarding the appropriate use of paradigms in mixed methods research. The range of positions can be best characterized by three over-arching perspectives: *the a-paradigmatic stance* which maintains that methods can be separated from the epistemology out of which they emerged (Patton, 1990); *the single paradigm thesis* which proposes the use of a new paradigm, namely pragmatism (Howe, 1988); and, *the multiple paradigms thesis* which includes a number of perspectives ranging from the dialectic stance which views mixed methods as engaging a multiple set of paradigms and their assumptions (Greene & Caracelli, 2003) to the complementary strengths thesis which suggests that multiple paradigms should serve as the foundation of mixed method research.

Philosophical Orientation

This dissertation is guided by pragmatic underpinnings. Pragmatism emerged as a philosophical movement in the late 19th century through the work of American philosophers Charles Sanders Pierce, William James, John Dewey, George Herbert Mead and Arthur Bentley (Maxcy, 2003). Dissatisfied with the singular notion that the scientific method could adequately access the "real word", these early pragmatists searched for a more meaningful philosophy of inquiry that was based on ordinary experience (Maxcy, 2003). Pragmatism faded following World War I with the financial depression during the 1930s, but experienced a revival during the late 1960s led by neo-pragmatist thinkers such as Richard Rorty and Hilary Putnam, who fueled a new way of thinking about pragmatism, and cemented its place as a philosophy and method of research (Maxcy, 2003).

Since its inception in the late 19th century, pragmatic views have become broad and diffuse resulting in multiple strands and variants. Despite this multiplicity, pragmatism is associated with certain basic characteristics. Essentially, it contends that a researcher should use whatever philosophical or methodological approach works best for a particular research problem or issue. Instead of methods being important, the problem is considered most important and researchers are encouraged to use pluralistic approaches to derive knowledge about the research problem (Creswell, 2003). Pragmatism supports the use of both qualitative and quantitative research methods in the same study and within multi-stage research programs (Teddlie & Tashakkori, 2003). It also rejects the notion that positivism and constructivism are incompatible, and instead embraces both points of view (or a position between the two viewpoints) (Teddlie & Tashakkori, 2003).

With applied research objectives, multiple research questions that cross post-positivism and constructivism, and a complex social phenomenon under study, a pragmatic philosophy was well suited to investigate the role of online communities as a source of supportive care for breast cancer survivors. Accordingly, this dissertation is informed by the basic tenets of pragmatism, which include the value-ladenness of inquiry (research is influenced by the values of the researcher), the theory-ladenness of facts (research is influenced by the theory that an investigator uses), and the belief that reality is pluralistic, and that facts can be supported or explained by more than one theory (Robson, 2002).

Research Methods

The present program of research had three main objectives. As shown in Table 1, four studies were conducted to address these objectives, and each study is based on a different

core research method. Each method, including its advantages and disadvantages, is discussed in the following sections. A detailed description of the data collection and analysis techniques used in each study is provided in Chapters 5, 6, 7 and 8.

Table 1: Objectives, Studies and Methods

Objective	Study	Method
1) To identify and describe the general characteristics and patterns of use of English language online communities for breast cancer survivors.	Study 1: Synthesis of online breast cancer communities	Systematic review Content analysis
	Study 2: Analysis of breast cancer groups on Facebook	Content analysis
2) To describe the supportive care needs and online community use of breast cancer survivors who are peer support providers.	Study 3: Identification of the supportive care needs, and patterns of online community use of breast cancer survivors known to provide peer support	Cross-sectional descriptive survey
3) To explore how, why and under what conditions breast cancer survivor peer support providers use online communities as a source of supportive care and the usefulness of theory in explaining use.	Study 4: Examination of how breast cancer survivors from the preceding survey used online communities	Qualitative descriptive study using semi-structured interviews

Systematic Review

Systematic review methodology was used in Study 1, to guide the collection and characterization of English language online communities. The results of this effort are presented in Chapter 5.

Systematic reviews attempt to synthesize all empirical evidence that relates to a specific research question using explicit and systematic methods that are selected to minimize bias (Oxman & Guyatt, 1993). They are based on: a clearly stated set of objectives with an explicit, reproducible methodology; a systematic search that attempts to identify all studies that would meet the eligibility criteria; an assessment of the validity of the findings of included studies; and, systematic presentation and synthesis of the characteristics and

findings of the studies (Moher, Liberati, Tetzlaff, & Altman, 2009).

Similarly, Study 1 involved a systematic search strategy using explicit objectives and methods to identify all English language online communities for breast cancer survivors that met certain eligibility criteria. In order to minimize bias, two members of the research team independently selected the websites for inclusion based on explicit criteria, and extracted the relevant characteristics using a common data extraction form. Lastly, the characteristics of the websites were collated in evidence tables, and a balanced summary was produced.

Unlike the classic systematic review of effectiveness that summarizes the evidence from RCTs on the impact of health care interventions, neither the quality of websites, nor their 'effectiveness' per se, were assessed. Although there are numerous website quality criteria and rating instruments (Deshpande & Jadad, 2006), none exist for online communities, and it remains to be seen whether it is possible, or even useful, to measure the quality of content in dynamically evolving, user-generated resources (Deshpande & Jadad, 2006). However, the effectiveness of the online communities identified in the search was indirectly assessed by comparing their activity, as measured by the total number of posts at a given time point.

One of the limitations of systematic reviews is the time and resources required to complete each of its steps, and keep the contents up-to-date. It has been estimated that new relevant information is available within two years of publication of 23% of systematic reviews (Shojania et al., 2007) and yet only 18% of reviews are cited as updated versions (Moher, Tetzlaff, Tricco, Sampson, & Altman, 2007). It is likely that syntheses of online resources expire at a significantly more rapid rate.

Content Analysis

Content analysis was used to code and analyze the information extracted from the breast cancer online communities in Study 1, as well as the breast cancer groups on Facebook in Study 2. The results of these efforts are presented in Chapters 5 and 6, respectively.

Content analysis offers a flexible and pragmatic method for systematically collecting and analyzing text data from verbal, print or electronic media (Kondracki, Wellman, & Amundson, 2002). Not surprisingly, it has become a popular method to study the user-generated content in online communities. It represents a family of approaches that involve both qualitative and quantitative techniques, and has been described as "a technique that lies at the crossroads of qualitative and quantitative methods" (Smith, Heady, Hamilton, & Phillips, 1996). The specific type of content analysis varies depending on the theoretical and substantive interests of the researcher and the problem being studied.

An inductive form of quantitative content analysis was used. *Quantitative* content analysis involves the systematic coding of text into categories that are then described or summarized using statistics (Hsieh & Shannon, 2005). Codes are developed inductively (i.e., derived from the data) or deductively (i.e., pre-determined). *Qualitative* content analysis, on the other hand involves the subjective interpretation of the content of the text (usually both manifest and latent content) through a systematic process of coding and identifying themes, codes are usually developed inductively and data is summarized in narrative form (Hsieh & Shannon, 2005). Both approaches require a similar analytic process that involves formulating the research question to be answered, selecting the sample to be analyzed, defining the categories to be applied (inductively, deductively or a combination of both), outlining the coding process and coder training, implementing the coding process, determining

trustworthiness, and analyzing the results of the coding process.

One of the limitations of content analysis is that it can be a time-consuming and laborious method. For example, the content analysis of Facebook groups was limited to the content displayed on the first page of the group (based on the page layout of Facebook groups in 2008). Further analysis of the discussion and wall posts is needed in order to understand the nature and utility of supportive exchanges occurring in breast cancer groups on Facebook, and a more qualitative form of content analysis would be best suited to meet this goal. This workload could be offset by the use of qualitative data analysis or automated text analysis computer software programs.

Cross-Sectional Survey

A cross-sectional descriptive survey was used in Study 3 to identify the supportive care needs of breast cancer survivors known to provide peer support, and to determine the prevalence, timing, and extent to which they used online communities, as well as the reasons that motivated use, and non-use. The findings from the survey are presented in Chapter 7.

Surveys are a useful and efficient tool for learning about people's characteristics, opinions and behaviours. They offer a classic method of collecting information from a small proportion of the population to estimate the views of many (Dillman, Smyth, & Christian, 2009). Surveys can be descriptive, analytic (i.e. explanatory) or both, and can be categorized as cross-sectional or longitudinal depending on the time period covered (Abramson & Abramson, 1999). They have evolved considerably since their inception nearly 75 years ago, "from a comfortable face-to-face conversation to a highly impersonal experience that with increasing frequency is mediated by an electronic device" (Dillman et al., 2009). Nowadays

the use of different survey modes (e.g., face-to-face, telephone, postal mail or the Internet) is increasingly viewed as the norm in design (Dillman et al., 2009). Similar to the principle behind mixed-method research, mixed-mode surveys offer the potential to compensate for limitations inherent in any single method.

A well-done survey provides the ability to estimate with known statistical precision the characteristics of all members of a carefully defined and selected population. It also uses multiple techniques to minimize the four types of survey error – coverage, sampling, non-response and measurement (Dillman et al., 2009). One of the main limitations of cross-sectional surveys is that they provide a snapshot of peoples' views and behaviours at one point in time. In addition, if they are retrospective as was Study 3, they involve some recall bias. Therefore cross-sectional surveys cannot be used to determine causality. Longitudinal, repeated measure studies are required to assess the nature, timing, intensity and predictors of supportive care needs which are known to change over the course of the disease and beyond (Fitch, 2000).

Semi-Structured Interviews

Finally, semi-structured interviews were used to examine how breast cancer survivors used online communities as a source of supportive care. These interviews formed the basis of the fourth and final study of this dissertation, which is presented in Chapter 8.

Initially, the objective of Study 4 was to produce a comprehensive descriptive account of breast cancer survivors' experiences using online communities as a source of supportive care that was rich in context. Therefore, a qualitative method called "fundamental qualitative description" (Sandelowski, 2000) was chosen, which has as its central goal a

comprehensive summary of a phenomenon in the everyday terms of that event. Qualitative descriptive studies seek to achieve a thorough understanding of the "facts" of an event (i.e., who, what and where), as well as the meaning participants give to those "facts". They have been described as the least interpretive of qualitative research designs, as there is no requirement to analyze or view the phenomenon in terms of a specific conceptual or theoretical framework.

However, it became apparent during the analysis of the interview transcripts that a number of different theories could be used to explain the conditions under which breast cancer survivors used online communities as a supportive care resource. Although, some qualitative methods such as grounded theory require you to suspend a priori theoretical commitments in order to generate new theory from the data, theory can also enter a qualitative project from the outside (Sandelowski, 1993). Some qualitative researchers use a theoretical lens or perspective to guide their study, others use theory to provide a context or interpretive framework with which to organize, analyze, and interpret the study findings.

Drawing from grounded theory methodology, a constant comparison method of analysis was used to build an interpretive framework with which to examine the relationships among key themes and concepts (Charmaz, 2000). To avoid theoretical tunnel vision, which is a potential limitation of this approach (Sandelowski, 2000), theory was used to frame and re-present the data only after a descriptive account of the findings had been produced. The theoretical rendering of the study findings thus represents a secondary analysis of the data. This study therefore departs from pure qualitative descriptive approaches in its use of theory. The use of multiple techniques is in keeping with philosophical underpinnings of qualitative research, which has been described as "not produced from any pure method, but from the use

of methods that are variously textured, toned and hued" (Sandelowski, 2000).

One of the main limitations of qualitative studies is their use of typically small, non-probability samples, which limit the generalizability of their findings. Although qualitative researchers do not aim to generalize research findings to a wider population, it is common practice to provide sufficient descriptive detail to enable the reader to judge whether or not the findings apply in other settings (Mays & Pope, 2000). This concept is commonly referred to in qualitative research as "transferability" (Graneheim & Lundman, 2004).

Quality of Findings

Assessing the quality, reliability and validity of the findings in mixed-method research is a controversial undertaking because there is not one set of terms, criteria or prescribed methods that transcend the quantitative and qualitative traditions. Moreover, there is considerable debate as to whether quantitative and qualitative research can and should be assessed according to the same criteria given that they are informed by a different set of philosophical assumptions. Some mixed methodologists advocate a bilingual nomenclature, where terms and criteria from both research traditions are used as appropriate; others recommend the creation of a new nomenclature that transcends the quantitative and qualitative orientations (Teddlie & Tashakkori, 2003).

Given that this dissertation used a multi-method study design, and each study is a separate, stand-alone piece of work that is based on one particular research method, techniques that are appropriate for each method were used to ensure the quality of the findings. This position is consistent with the pragmatic orientation, which is not committed to any one system of philosophy or reality (Creswell, 2003). A number of well-recognized

techniques were used to ensure the trustworthiness of the results that relate to how the study participants or units of analysis were selected, the methods used to generate the data, the comprehensiveness of data collection, and the procedures for analyzing the data and corroborating the research findings. These are described in detail in each of the four studies of this dissertation and in brief in Table 2.

Table 2: Techniques Used to Ensure Trustworthiness

Method (Study)	Guide	Techniques
Systematic review (1)	QUOROM – Moher et al (1999) PRISMA – Moher et al (2009)	- Explicit objectives, inclusion and exclusion criteria, data collection and analysis methods to ensure transparency - A thorough search using multiple, complementary strategies and sources to ensure coverage and representativeness - Independent selection of websites and extraction of data from websites by two reviewers to reduce investigator bias and enhance coder reliability - Missing data was sought from website administrators
Content analysis (1,2)	Kripendorf (1980) Kondracki, Wellman & Amundson (2002)	- Analysis of all known breast cancer groups on Facebook and breast cancer online communities, to ensure coverage and representativeness - Inductive development of the coding scheme to ensure relevance - Pilot testing of the coding scheme to reduce measurement error - Independent application of coding scheme by two reviewers to enhance reliability
Cross-sectional survey (3)	Dillman, Smyth & Christian (2009)	- Survey restricted to all members of a known and bounded sample, to ensure coverage and representativeness - Pilot testing of the survey to reduce measurement error - Multi-modes (e.g., postal and web survey), multiple contacts and reminders, and personalized contact to reduce sampling and non-response error
Semi-structured interviews (4)	Lincoln & Guba (1985) Mays & Pope (2000) Giacomini & Cook (2000)	- Thick description of data collection and analysis methods to ensure transparency and transferability - Purposive sampling to ensure maximum variation sample - Clarification probes and follow-up questions during interviews to ensure participants viewpoints were faithfully captured - Iterative process of data collection and analysis to confirm emerging themes and interpretations - Inductive development of coding scheme to ensure relevance - Three transcripts were independently coded by a second reviewer to ensure consistency of coding procedure and reduce investigator bias

Ethical Considerations

Ethical Review

Ethics approval to conduct this research was granted on April 21, 2009 by the Office of Research Ethics of the University of Toronto (Appendix 2). It should be noted that both the systematic review of online communities and content analysis of Facebook groups met the exclusion criteria of the (Canadian) Tri-Council Policy Statement (TCPS2, 2010) as to what studies require review by an institutional research ethics board, because all information was publicly available (Appendix 3). However, the Tri-Council Policy Statement further elaborates that "Researchers may need to consider other factors when using this information, such as copyright, dissemination restrictions, privacy and intellectual rights." In keeping with these guidelines, the use policies for all included websites were reviewed to ensure that the proposed research was in accordance with the websites terms of service.

Risks

The only foreseeable risks associated with participating in this research were fatigue due to the time involved in completing the survey and participating in the interview, and the potential for issues of a sensitive and personal nature to arise during the interviews. It was anticipated that some individuals might find it difficult to discuss aspects of their illness, or reveal how much they did not know about online communities or what reasons they used online communities. Interview participants were informed that they had the choice to decline discussing issues that they found uncomfortable, to decline to have their interviews or portions of their interviews audio-recorded, and to stop the interview at any time without affecting their treatment or care.

Free and Informed Consent

Full informed consent procedures were followed. Research participants were recruited from Willow Breast Cancer Support Canada (Willow), a national charitable organization that provides targeted information and support to anyone affected by breast cancer, free of charge (http://www.willow.org/). The student investigator informed survey participants in writing (Appendix 7) and interview participants by telephone (Appendix 12) and in writing (Appendix 13): what would be involved should they choose to participate in the study; the type of data collected and the purpose for which the date will be used; that the informed collected from them would be treated confidentially; that their participation is voluntary; and that their decision to participate or not would not have any negative consequences, and would not be shared with Willow. Consent to participate in the survey was assumed based on completion of the questionnaire. Consent to participate in the interview was obtained from study participants in writing, by postal mail, prior to the interview (Appendix 13).

Privacy and Confidentiality

Research participants were informed of the measures that would be taken to protect their privacy and to ensure confidentiality of the information collected from them. Privacy in this context refers to the freedom of research participants to decide for themselves, the time, circumstances, and extent to which their attitudes, beliefs, behaviours, and opinions are to be shared with or withheld from others (Kosseim, 2003; TCPS2, 2010). Survey participants were informed that they had the right to skip a question in the questionnaire and stop completing it any time. Interview participants were given the choice to decide when the

telephone interview was conducted, and informed that they could refuse to answer any questions and to stop the interview any time. All research participants were informed that their decision to participate or not would not be disclosed to Willow.

Confidentiality refers to how private information is managed and shared (Kossiem, 2003; TCPS2, 2010). Measures taken to ensure security and confidentiality included the removal of all identifying material and replacement with unique study identification numbers. Research participants were assured that the information collected would be shared and reported in a way to ensure that it could not be identified with a particular research participant. Access to research materials was restricted to the student investigator, the supervising investigator and appropriate members of the research team (Appendix 16). When not in use, all electronic data were stored on a secure computer network, and all non-electronic data (e.g., consent forms, questionnaires, audiotapes, hand-written notes, and interview transcripts) were stored in a locked, fireproof cabinet at the Centre for Global eHealth Innovation, a research division of the University Health Network located at the Toronto General Hospital and to be kept for a maximum of seven years following the first publication resulting from the study and then destroyed.

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5

Systematic Review of Online Communities

for Breast Cancer Survivors

Abstract

Background: Online communities have been heralded as one of the most promising health resources on the Internet, however little is known about their levels of use.

Objective: To identify the general characteristics and levels of use of online communities for breast cancer survivors.

Methods: Using Google (accessed 2009-12-23) websites were identified with: a string of computer-mediated communication terms combined with the keyword 'breast cancer'; and individual queries of three to five words that reflected a particular type of online community. This was complemented by a review of website resource lists and personal libraries. Two reviewers independently extracted information on their general characteristics, and number of members and message board posts. We developed a coding scheme to guide content analysis.

Results: The search yielded 111 websites. Most (n = 64, 65.8%) had a broad focus (e.g., health, cancer or general purpose). One third (n = 38, 34.2%) were exclusive to breast cancer. The majority were American (n = 79, 75.2%) and contained message boards (n = 102, 92%) that were moderated by site staff or community members (69.5%). Greater than one-third (n = 40, 36%) were initiated by breast cancer survivors or affected loved ones. Thirty of the breast cancer specific sites (78.9%) contained a total of 4,186,275 message board posts, with 10 sites displaying more than 100,000 posts each.

Conclusion: There is a wide range of active and thriving online communities available for breast cancer survivors with extensive archives of personal illness experiences. Future efforts should focus on identifying the factors that determine their effectiveness.

Background

The Internet is changing the way people seek and engage with health information. Although health professionals, family and friends remain the preferred sources of health information, an increasing number of people are turning to peers in un-moderated, self-help communities on the Internet to address their health related concerns (Fox, 2009). The latest estimates indicate that about half of American Internet users between the ages of 18 and 49, and one-third of users 50 and older have read someone else's description about a health or medical issue in an online community (Fox, 2009).

Online communities have been defined as "virtual social space(s) where people come together to get and give information or support, to learn or to find company" (Preece, 2001). However, the terms online, virtual, Interned-mediated- group, community or network are used interchangeably in the literature to refer to the same concept. Initially online communities were supported by mailing list and message board software. More recently they have formed around blogs, wikis and social network sites, known as Web 2.0 software applications (Bender, O'Grady, & Jadad, 2008).

Breast cancer survivors have been shown to be one of the groups most likely to join online communities (Davison, Pennebaker, & Dickerson, 2000). Numerous descriptive studies indicate that such groups can: provide reassurance, a sense of community and hope for the future; reduce feelings of stress and uncertainty; validate concerns ignored by health care professionals; enable breast cancer survivors to become better informed and able to manage their condition; and prepared for their interactions with the health care professionals (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Rogers & Chen, 2005; Sharf, 1997; Smit et al., 2007; Vilhauer, 2009).

Very few studies have attempted to evaluate the effects of unstructured online communities that are not professionally led (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). The only known RCT of an unstructured, un-moderated mailing list produced conflicting results and is limited by a small sample and effect sizes. Participants, who were newly diagnosed breast cancer survivors, experienced a non-significant increase in distress and decreased emotional well-being over time, however the majority also reported feeling supported by the intervention, a sub-group of whom created their own mailing list at the end of the study (Salzer et al., 2010). These findings suggest that online communities may not be universally beneficially.

A better understanding is needed of the online communities that are most popular, in order to identify the factors that determine their effectiveness. However, the characteristics and levels of use of online communities have not been systematically studied. One study characterized the scope of online cancer communities available for ethnic minority groups (Im, Chee, Tsai, Lin, & Cheng, 2005), but did not document their levels of use or characterize them by cancer type. Two studies that attempted to evaluate the quality of information in a cross-section of breast cancer websites (Hoffman-Goetz & Clarke, 2000; Meric et al., 2002) documented the type of communication software that the sites provided, but also did not report on their levels of use. Furthermore, all of these studies were conducted in the early 2000s, well before the emergence of web 2.0 and the subsequent social media revolution.

One way to assess the popularity of an online community is to determine its activity, as measured by the number of user-generated posts (Preece, 2001). Therefore, in this study we attempted to identify all known resources that provide English language online

communities for breast cancer survivors and synthesize their general characteristics (e.g., purpose, country of origin, initiator, affiliation, communication features, moderation, and launch date) and patterns of use (e.g., total number of members and posts).

Methods

Study Design

This study is based on systematic review methodology. Systematic reviews attempt to synthesize all empirical evidence that relates to a specific research question using explicit methods that are selected to minimize bias (Oxman & Guyatt, 1993). Instead of synthesizing the findings from a body of research studies, we used systematic review procedures to identify all relevant websites that offered online communities and synthesize their characteristics and patterns of use.

Data Sources

Websites were identified through a search of Google (www.google.ca) accessed on December 23, 2009. We choose Google as the main data source because it represented the leading search engine used by 85% of global search engine market share at that time (MarketShare.com, 2009).

Inclusion Criteria

Websites were included if they:

- Included communication technology (e.g., mailing list, message board, chat room, blog, wiki) that served as a forum for group discussion (i.e., where any registered user could contribute content) of breast cancer related topics;

- Contained content (including that contributed by users) in English;

- Were active, as defined as more than one post contributed by members from the date the search was conducted (December 23, 2010) to the date the total number of the members and posts was documented (October 26, 2010); and

- Were publicly available.

Excluded Websites:

- Single author blogs (as opposed to sites that provided facilities for any visitor to create and sustain a personal blog);

- Websites that contained wikis as the only form of computer-mediated communication if they were not being used for breast cancer themed discussion;

- Website aggregators (i.e., websites that pool and publish other websites).

Search Strategy

We used two complementary online search strategies (Appendix 2). The first approach was modeled after a typical academic literature database search using Boolean operators (e.g., "AND" and "OR") and relevant phrases (words enclosed in quotations to search for web pages where they appear together). It included a search string of the most common communication technology terms (e.g., *mailing list*) combined with the term *breast cancer*. We reviewed all accessible search results for eligibility. The second approach was

modeled after a typical Google query, which consists of an average of four words (Ussery, 2008). Nine separate searches were conducted, each consisting of a combination of three to five words that reflected a particular type of online support community or communication technology (e.g., *breast cancer message boards*). We reviewed the first 100 search results from each search after it was concluded from the first round that there would likely be around 100 relevant sites in total. Both search strategies were applied to "anywhere on a page", rather than restricting the queries to certain fields on a web page (e.g., the hyperlink or anchor text on a page). In addition, one of us (JLB) reviewed the resource lists of retrieved websites, as well as personal libraries for other potentially eligible websites to include in the review.

Data Collection and Analysis

Two of us (JLB and MCJM) independently extracted information on:

- General characteristics (e.g., URL, launch date, purpose, country of origin, initiator, affiliation and moderation);

- Number and type of communication technologies (e.g., mailing list, asynchronous message board, chat room, blog, wiki)

- Social networking features (e.g., ability to construct a public profile and view the profiles and networks of other members); and

- Total number of registered users and posts as of October 26th, 2010, (11 months after the sites were identified and their general characteristics were extracted for analysis).

We developed a coding scheme to guide the extraction and description of the general characteristics of the websites. The purpose of the sites was characterized based on whether they provided a discussion forum for people with breast cancer exclusively, cancer, any health issue, or any general topic. The sites were further classified as providing a forum for the discussion of breast cancer in general, or a specific type (e.g., triple negative) or experience (breast reconstruction) of breast cancer, or demographic of breast cancer survivor (e.g., young). Sites were categorized as being affiliated with a commercial entity (e.g., pharmaceutical or device manufacturer), a non-profit organization (if they reported a charity registration number), a university or health care organization, or an unaffiliated individual or group. We categorized the initiators of the sites, as being a former cancer survivor or family caregiver, a health professional, a health research, or a charity and unknown. Lastly, sites were classified as moderated if they claimed to be so, or contained evidence of moderation from site administrators or suggestive activities in the message board (e.g., posts that welcomed new members, individuals who responded to member requests or questions, or who stimulated discussion).

We contacted the administrators of the included websites, where possible, to obtain permission to register as members, if required, or to request the information regarding the total number of registered members, posts and date of launch, for use in the present review if it was not clearly posted on the site or not publicly available. We obtained permission from site owners to publish any information that was not publicly available on the site. The total number of registered members and message board posts is summarized from breast cancer specific sites only because this information was not consistently available from multi-

purpose sites. (Only 21.9% of multi-purpose sites disclosed the total number of posts, and only 2.7% disclosed their membership numbers.).

Evidence tables were produced to summarize the information extracted from the websites and obtained from the site administrators. Descriptive statistics were calculated using the software package SPSS version 17 (IBM Corporation, Somers, NY, USA).

Results

The total yield from the Internet search was 1,714 (900 + 814). [Although the first search strategy yielded 35,700,000 hits, the actual number of accessible results was only 814 because Google omits search results in order to provide the most relevant hits]. In total, 153 websites were subjected to preliminary analysis, and 111 were included in the final analysis.

Figure 1: Flow Diagram of Included Websites
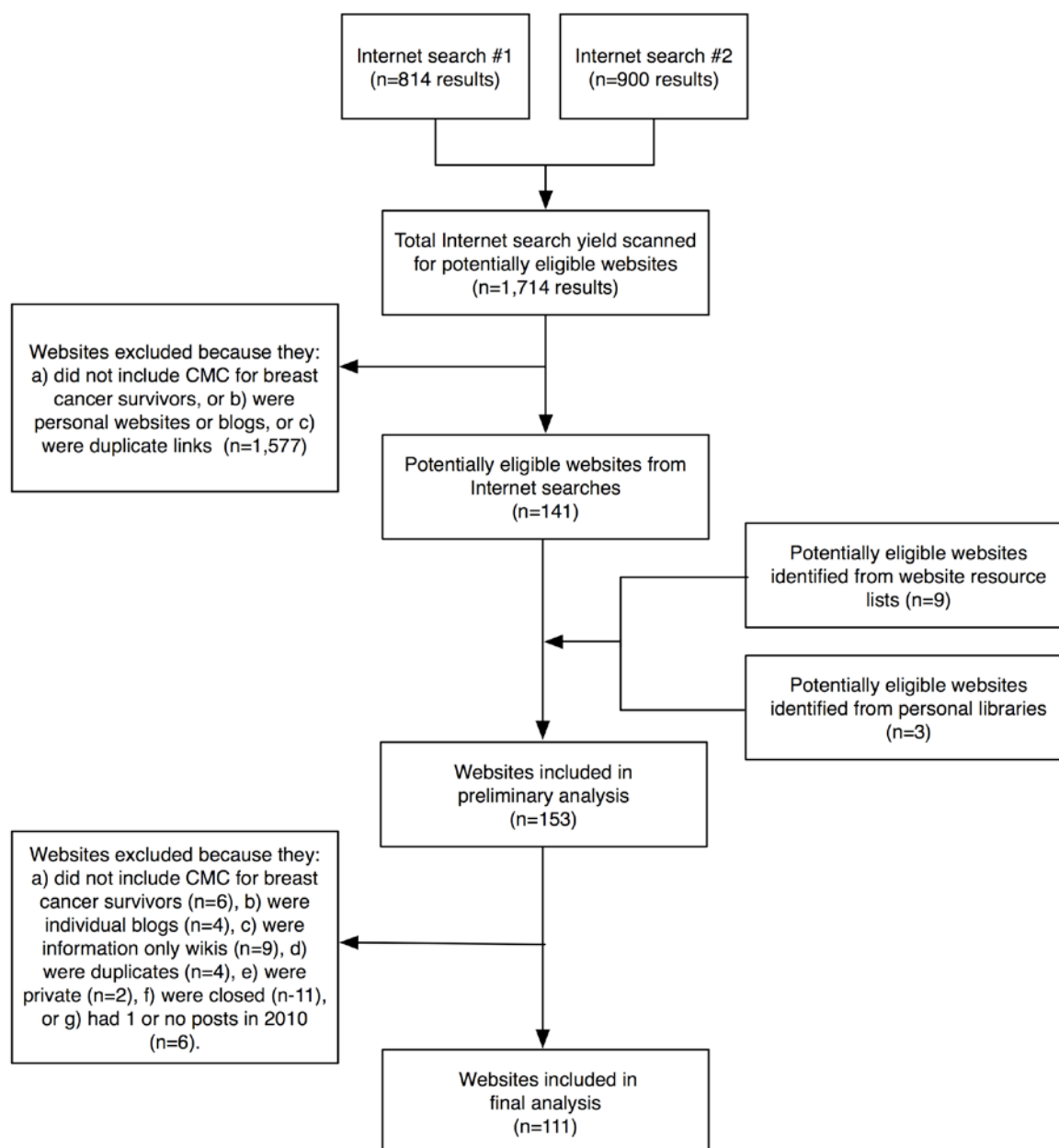
Characteristics of Included Websites

General Purpose and Specialization

Characteristics of the websites are summarized in Table 1. The majority of sites (n = 64, 65.8%) were multi-purpose with discussion forums for breast cancer, as well as other topics. These included: health sites (n=36, 34.2%) such as MD Junction (www.mdjunction.com); cancer sites (n=21, 18.9%) such as the Association for Cancer Online Resources (www.acor.org); and general purpose sites (n=16, 14.4%) such as Facebook (www.facebook.com). About one-third of sites (n = 38, 34.2%) were exclusively for people with breast cancer, and of these, 11 catered to certain types or experiences of breast cancer or demographics of breast cancer survivors. Selected characteristics of the breast cancer specific sites are shown in Table 2.

Table 1: Characteristics of Included Websites

Characteristic	n (%)
Purpose (n = 111)	
Breast cancer exclusively	38 (34.2)
Breast cancer forum on a health site	36 (32.4)
Breast cancer forum on a cancer site	21 (18.9)
Breast cancer forum on a general site	16 (14.4)
Niche breast cancer communities (n = 11)	
Young women	4
Breast reconstruction	2
Hereditary breast cancer	1
Her2 positive breast cancer	1
Inflammatory breast cancer	1
Metastatic breast cancer	1
Triple negative breast cancer	1
Country of origin (n = 105)	
USA	79 (75.2)
United Kingdom	9 (7.6)
Canada	8 (7.6)
Australia	4 (3.6)
South Africa	2 (1.9)
India	1 (0.9)
Ireland	1 (0.9)
New Zealand	1 (0.9)
Affiliation (n = 108)	
Commercial	50 (45.0)
Non-profit organization	32 (29.6)
Individual or Group	19 (17.6)
University or health care institution	7 (6.5)
Initiator (n = 58)	
Former patient or caregiver	40 (69.0)
Health care professional	10 (17.2)
National Charity	6 (10.3)
Patient and health care professional	1 (1.7)
Health researcher	1 (1.7)
Communication Features (n = 111)	
Message boards (asynchronous)	102 (91.9)
Blogs (multi-user)	42 (37.8)
Chat rooms (synchronous)	21 (18.9)
Mailing lists	5 (4.5)
Wikis	3 (2.7)
SNS features	
Profiles (n = 110)	91 (82.7)
Create and view friend lists (n = 105)	47 (44.8)
Moderation (n = 111)	
Yes	77 (69.4)
Moderator (n = 77)	
Website staff or volunteers exclusively	66 (85.7)
Website staff and health care professionals	8 (10.4)
Health Care professionals exclusively	3 (3.9)

Table 2: Selected Characteristics of Breast Cancer Specific Online Communities

Name	URL	Origin	Affiliation (Creator)	Focus	Features	Official Moderation	Other Services	Date	Members	Posts
Aussie Breast Cancer Forum	www.bcaus.org.au	AU	Individuals (BC survivors)	General	Message board Chat room	Volunteer members (BC survivors)		2005	1,171	119,679
Avon Breast Cancer Crusade Survivors Forum	http://avoncompany.com/scripts/discussionforum/discus.pl	US	Commercial	General	Message board	Staff/ volunteers		2001*	NA	13,279
B-Mail	http://www.bci.org.au/index.php/support/online-support-groups/b-mail	AU	University or medical centre	General + Young + Metastatic	Mailing lists	Staff/ volunteers (BC survivors)		1995	NA	NA
BC Advisor	www.bcadvisor.com	US	Non-profit (BC survivor)	General	Message board SNS features	Staff/ Volunteers (BC survivors)		2006	NA	5,142
BC Mets	www.bcmets.org	CAN	Individual (Family caregiver)	Metastatic Disease	Mailing list	Un-moderated	Site blog	2000	1,429	132,609
BC Pals	www.bcpals.org/uk	UK	Individual (BC survivors)	General	Message board Chat room	Staff/ volunteers (BC survivors)		2004	813	105,594
BC Support	www.bcsupport.org/	USA	Non-profit (BC survivors)	General	Message board Chat room	Staff/ volunteers (BC survivors)		1998	NA	NA
BeBright Pink	www.bebrightpink.org	USA	Non-profit (BC survivor)	High Risk Young Women	Message board	Staff/ volunteers	Book Series Workshops One-on-One support Ask a Genetic Counselor Outreach activities Expert led teleconference	2007	NA	1,159
Bosom Buddies	http://bosombuddies.cfsites.org/	AZ	Non-profit (Breast Health Foundation)	General	Message board SNS features	Un-moderated		2005	22	14
Breast Buddies	http://www.breastbuddies.co.za/forum/	AZ	Unknown	General	Message board	Staff/ volunteers (BC survivors)	Information	2008*	142	26,060

Name	URL	Origin	Affiliation (Creator)	Focus	Features	Official Moderation	Other Services	Date	Members	Posts
Breastcancer	www.breastcancer.org	USA	Non-profit (MD)	General	Message board Chat room	Staff/ volunteers	Information Booklets Site blog Stories of Hope Ask the Expert Online Conferences Care Navigation Coach Drug Glossary Diagnosis Guide IPhone App	1999	78,931	1,502,513
Breast Cancer Awareness Forums	www.breastcancerawareness.com	USA	Commercial	General	Message board Multi user blogs	Un-moderated	Information	NA	1312	317
Breast Cancer Care	www.breastcancercare.org.uk	UK	Non-profit (BC survivor)	General	Message board Chat room	Staff moderate message board Nurses moderate chat room	Information (FAQ) Publications Telephone helpline Info & Support Workshops Telephone support groups Support services for health care professionals	2001	NA	440,860
Breast Cancer Mailing List	www.bclist.org	CAN	Individual (MD)	General	Mailing List	Un-moderated		1994	NA	308,160
Breast Cancer Network of Strength	www.networkofstrength.org/	USA	Non-profit (BC survivors)	General	Message board SNS features	Staff/ volunteer	Information Brochures 24 Peer support telephone line Survivor match program Partner match program Wig & Prosthesis bank	2007	NA	33,803

Name	URL	Origin	Affiliation (Creator)	Focus	Features	Official Moderation	Other Services	Date	Members	Posts
Breast Cancer Now What	www.breastcancernow what.ca	CAN	Non-profit (BC survivors & Rethink Breast Cancer Charity)	Young women	Message board Chat room SNS	Staff/ volunteer	Information Site blog Special guest chat	2007	558	1,065
Breast Cancer Support New Zealand	www.breast.co.nz/	NZ	Non-profit	General	Message board	Staff		2002*	NA	NA
Breast Cancer Support UK	www.breastcancersupp ort.co.uk	UK	Individuals (BC survivors)	General	Message board	Volunteer members		2006	NA	NA
Breast Friends	www.breastfriends.org	USA	Non-profit (BC survivor)	General	Message board	Staff/ volunteer	24 Telephone Support line Transportation to treatment Cancer support groups in the workplace Workhops	NA	10	40
Breast Reconstruction	www.breastreconstructi on.org/	USA	Individuals (BC survivors and Heath care professionals)	Breast reconstructi on	Message board	Staff/ volunteer	Information Survivor Stories	2006*	301	201
DIEP Breast Reconstruction	http://www.diepbreastre construction.org/forum/	NA	NA	Breast reconstructi on	Message board	Staff/ volunteer		NA	1066	1639
FORCE	www.facingourrisk.org	USA	Non-profit (BC survivor)	Hereditary Breast and Ovarian Cancer	Message board Chat room	Staff/ volunteers	Information Telephone help line Ask a genetic counselor service Annual Conference Webinars Outreach events	1999	4266	276,091
Friends in Needs	www.friendsinneed.co m	AU	Individual (BC survivor)	General	Message board Chat room Listserv	Volunteer members	Survivor Stories Member Bios Tips from survivors	1996	NA	NA

Name	URL	Origin	Affiliation (Creator)	Focus	Features	Official Moderation	Other Services	Date	Members	Posts
Friends in Touch	www.friendsintouch.net	USA	Individual (BC survivors)	General	Message board	Staff/ Volunteer members		2001	197	4088
Her2Support	www.her2support.org	USA	Non-profit (BC survivor)	Human Epidemral Growth Factor Recptor-2 Positive	Message board	Staff/ volunteers	Information Launching telephone support program	2001*	4411	185,302
IBC Support	www.ibcsupport.org/	CAN	Individual (Family caregiver)	Inflammatory Breast Cancer	Mailing List	Un-moderated	Information Patient Stories	1996	604	64,330
Living Beyond Breast Cancer	www.lbbc.org	USA	Non-profit (MD)	General	Message board	Staff/ volunteers	Telephone helpline Ask the Expert Email service Survivor Stories Teleconferences Annual Conference	NA	2056	2,111
National Breast Cancer Foundation	www.nationalbreastcancer.org	USA	Non-profit (BC survivor)	General	Message board SNS	Staff/ volunteers	Information Beyond the Shock diagnosis guide	2007	14,241	NA
No Surrender Breast Cancer Foundation	www.nosurrenderbreastcancersurvivorforum.org/	USA	Non-profit (BC survivor)	General	Message board Chat room	Staff/ volunteers	Information	2007*	NA	50,323
Pink Link	www.pink-link.org	USA	Non-profit (BC survivor)	General	Message board Blogs SNS	Staff/ Health care professionals	Information	2006	138	63
Pink Ribbon	www.pinkribbon.org	USA	Non-profit (Family caregiver)	General	Message board Multi-user blog SNS?	Staff/ volunteers	Information Magazine Awards	2008*	NA	349
Pink Ribbon Girls	www.pinkribbongirls.com	USA	Non-profit (Friends of BC survivor)	Young women	Blogs	Un-moderated	Information	NA	NA	NA

Name	URL	Origin	Affiliation (Creator)	Focus	Features	Official Moderation	Other Services	Date	Members	Posts
Sharing Strength *(Closed Down)*	www.sharingstrength.ca	CAN	Commercial	English and French Canadian Women	Message board	Staff	Resource Library Editors blog Survivor stories French language message boards	2007	NA	3,308
Susan G. Komen Breast Cancer Foundation	apps.komen.org/Forums	USA	Non-profit (Family caregiver)	General	Message board SNS?	Staff/ volunteers (BC survivors)	Information Fundraising events Grant programs	NA	21,463	317,620
The Breast Cancer Site	www.thebreastcaresite.com/tbcs/CommunitySupport/DiscussionForum/	USA	Commercial	General	Message board	Un-moderated	Information Ask the expert email service	2007*	NA	NA
Triple Negative Breast Cancer Foundation	www.tnbcfoundation.org	USA	Non-profit (Friends of BC survivor)	Triple Negative	Message board	Staff/ volunteers	Telephone helpline Professionally moderated online support group Clincal trials matching service Site blog	2005*	4,185	67,129
Willow Breast Cancer Support	www.willow-talk.org	CAN	Non-profit (BC survivors)	General	Message board	Un-moderated	Peer support telephone helpline Information Support group facilitator training	2008	545	623
Young Survival Coalition	www.youngsurvival.org	USA	Non-profit (BC survivor)	Young women	Message board SNS?	Staff/ volunteers	Information Ask the expert email service Survivor stories Outreach events	2005*	NA	522,804

* Approximate launch date based on first message board post. NA= not available.

Affiliation and Initiator

A minority of sites (n = 7, 6.2%) was affiliated with a university or health care institution, and of these only two were affiliated with a cancer treatment centre: www.caringvoices.ca, a resource of the University Health Network (Princess Margaret Hospital site) in Toronto, Canada, and the Cancer Survivor Online Support Group, based at the MD Anderson Cancer Centre in Houston, USA. Of the sites that included information on the individual or group that spearheaded its creation (n = 58, 52.0%), the majority (n = 40, 69.0%) reported that they were initiated by or on behalf of a breast cancer survivor or informal caregiver (e.g., spouse, partner, child or friend).

Communication Technology Features

The majority of websites contained message boards as their main communication tool (n = 102, 91.9%), and provided their users with the ability to construct a public or semi-public profile (n = 91, 82.7%). Nearly half (n = 47, 44.8%) allowed their users to make visible their social networks, and thus could be classified as a social network sites. The majority (n = 27, 57.4%) of social network sites had an explicit commercial affiliation.

Moderation

The majority of websites (n = 77, 69.4%) were described as moderated or contained evidence of moderation by a site administrator, and most (85.7%) were moderated by website staff alone or in combination with volunteers from the community, many of whom were breast cancer survivors. A minority of sites contained message boards that were moderated by health care professionals alone or in combination with website staff (n = 11; 14.3%).

Fifteen sites (13.5%) contained additional features that were moderated or led by health professionals such as a synchronous chat or an 'Ask the Expert' message board service. Three websites employed a 'notice and take down' policy, also known as 'reactive moderation' relying on the members of the site to alert the site administrators of inappropriate use. For example, one website explained: "we do not screen content before it is posted and we rely on our members to alert us to any inappropriate content or behaviour". Only one website (Cancer Chat UK) claimed to screen the accuracy of message board posts before being publishing them on the site.

Launch Dates

Forty-three of the multi-purpose sites (58.9%) provided their launch date. Of these, roughly 37% were launched between 1994 and 1999, 25.5% were launched between 2000 and 2004, and another 37% were launched between 2005 and 2009 (data not shown).

Twenty-two of the breast cancer specific sites (57.9%) provided their launch date. The approximate start date of the message board was obtained from an additional 11 sites by scanning the message boards for the date of the first post.

As shown in Figure 2, the majority of these sites (n = 20, 60.6%) were launched within a span of four years between 2004 and 2008.

Figure 2: Launch Dates of Breast Cancer Specific Online Communities (N = 33)
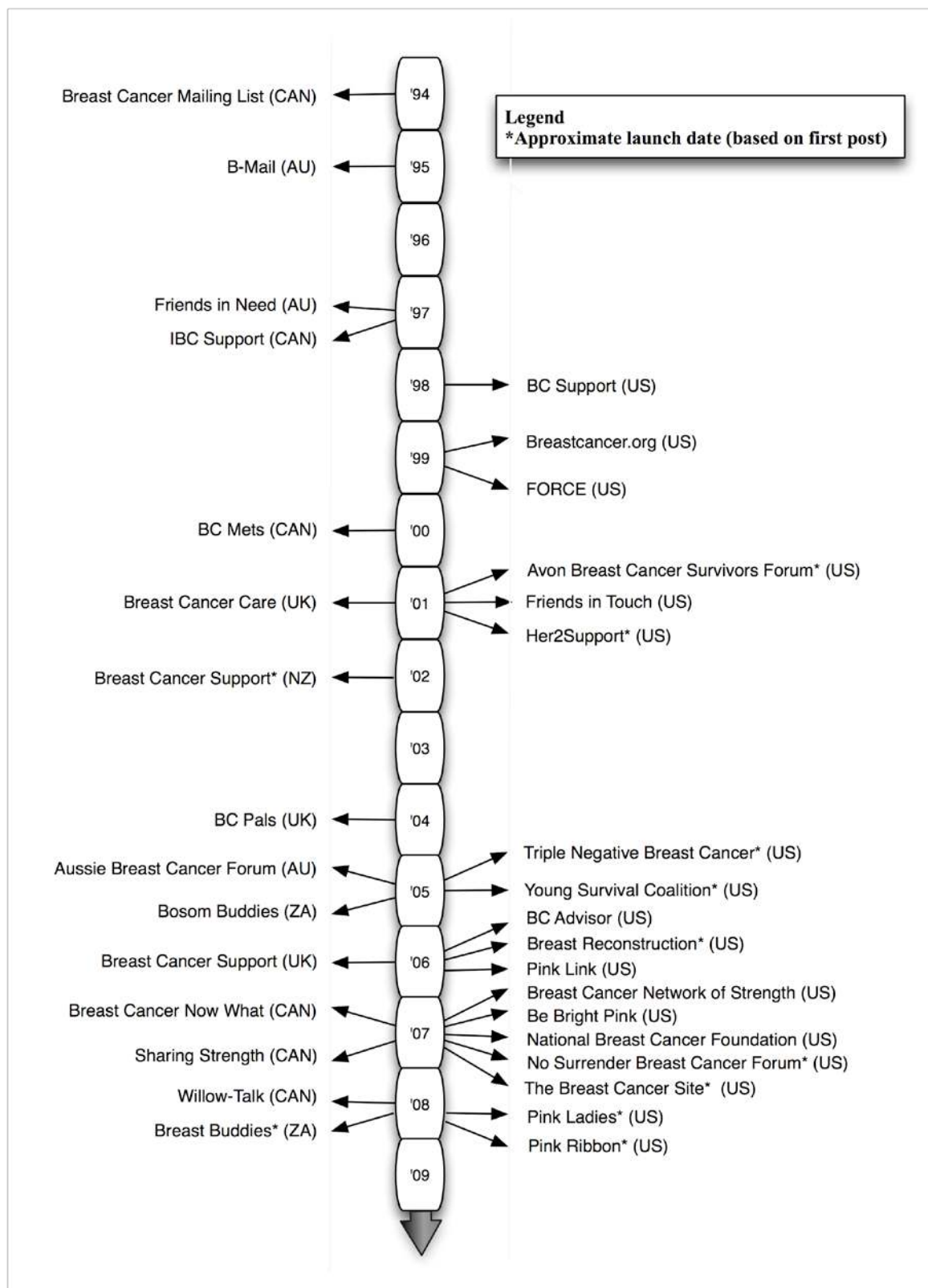
Membership size and Message Board Posts of Breast Cancer Specific Sites

As shown in Table 3, 22 of the 38 (63.2%) breast cancer specific sites provided information on the size of their membership. (In four cases, this information was obtained from the site administrators.). In total, these sites reported 140,162 registered members. Three sites had memberships that exceeded 10,000. These were, in order of largest membership: Breastcancer.org with 78,931 members; Susan G. Komen Foundation with 21,463 members; and National Breast Cancer Foundation with 14,241 members.

Table 3: Activity Level of Breast Cancer Specific Online Communities

	N*	Total	Min	Max	Median	IQR
Total Members	22	140,162	10	78931	1118.5	3930.2
Total Posts	30	4,186,275	14	1,502,508	19,669.5	144,827.7

*Twenty-two of the 38 breast cancer online communities that were exclusive to breast cancer survivors provided information on the total number of registered members, and 30 provided information on the total number of posts.

Thirty of the 38 (78.9%) breast cancer specific sites reported the total number of posts contained in their message boards. These communities contained a total of 4,186,275 posts. One third of breast cancer specific online communities (n = 10) contained the majority of posts. Each of these 10 online communities reported more than 100,000 posts, four of which catered to a specific breast cancer type or experience as shown in Table 4.

Table 4: Top Ten Most Active Breast Cancer Specific Online Communities

Rank	Online community (URL)	Total posts
1	Breastcancer.org (www.breastcancer.org)	1,502,508
2	Young Survival Coalition (www.youngsurvival.org)	522,804
3	Breast Cancer Care UK (www.breastcancercare.org.uk)	440,860
4	Susan G. Komen Foundation	317,620
5	Breast Cancer Mailing List (www.bclist.org)	308,160
6	FORCE -Facing Our Risk of Cancer Empowered (www.facingourrisk.org)	276,091
7	Her2Support (www.her2support.org)	185,302
8	BC Mets Mailing List (www.bcmets.org)	132,609
9	Aussie Breast Cancer Forum (www.bcaus.org.au)	119,679
10	BC Pals (www.bcpals.org/uk)	105,594

Discussion

This study has generated the first known systematic review and characterization of online breast cancer communities. In doing so, it has revealed that breast cancer survivors have at their disposal a wide range of websites with peer-to-peer support communities. The proportions of online communities identified in this review are an underestimation of the total number of online communities that exist for breast cancer survivors given that we analyzed websites as whole entities. Many websites have multiple communities. In a separate study we identified over 600 breast cancer groups on Facebook alone (Bender, Jimenez-Marroquin, & Jadad, 2011). Likewise, a review conducted in 2003, identified a total of 546 different online cancer communities, 150 of which were mailing lists offered by the Association of Online Cancer Resources (Im et al., 2005), a website that was included in our review. The authors of the previous review did not report the total number, names or URLS of unique websites included in their review, limiting further comparisons.

The results of the present study confirm anecdotal reports which have suggested that patients, and their loved ones, are taking a major role in creating health resources on the Internet (Bass, 2003; Fox, 2010; Fox & Purcell, 2010; Walther et al., 2005). At least 36% of the online communities identified in our search, and 68% of those that were exclusive to breast cancer survivors, were initiated by a breast cancer survivor or affected loved one, whereas only seven were affiliated with university or health care organization. A recent qualitative study with 23 webmasters of patient-initiated breast, fibromyalgia and arthritis online communities suggests that patients create such resources for altruistic (desire to help others and promote awareness of the disease) and intrinsic (hobby) reasons, because existing resources do not meet their needs (e.g., they were not satisfied with their mindset, activity

level or focus of existing resources) (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2010).

Contrary to some reports which have described online communities as "ad hoc, self-organizing, organic discussions with no particular oversight or administration" (Walther et al., 2005), the majority of online communities in our sample were described as or contained evidence of moderation by site administrators. However, the sites also relied on particularly helpful or knowledgeable community members, as well as the self-organizing nature of the community as a whole to monitor and facilitate the discussion. The qualitative study of webmasters of patient-initiated online communities also revealed that, promoting the group, facilitating participation and moderating messages were key to ensuring its success, but were onerous activities consuming on average 10-15 hours per week (van Uden-Kraan et al., 2010) –findings which confirm previous research (O'Grady, Bender, Urowitz, Wiljer, & Jadad, 2010). A study comparing the tasks involved in facilitating online versus face-to-face support groups identified a number of challenges that were unique to the online medium including decreased commitment to the group and social pressure to participate, and uncertainty regarding how to interpret silence and convey emotions (Owen, Bantum, & Golant, 2009)

Many health professionals and patients alike have expressed concern about the potential for deception and misinformation on the Internet (Gagliardi & Jadad, 2002; Jadad & Gagliardi, 1998), particularly in consumer-led online communities (Broom, 2005a). This study may serve as a further cause for concern, given that only one community in our sample claimed to screen the accuracy of posts before they were published on the site. However, studies indicate that users of online health communities feel competent deciphering 'good' from 'bad' information (Broom, 2005b) and that they put effort into ensuring that the

information shared is accurate, often including original sources (Sullivan, 2003). In addition, there is evidence to suggest that online communities can effectively self-regulate the accuracy of their content (Jadad, Enkin, Glouberman, Groff, & Stern, 2006). Content analysis of the un-moderated Breast Cancer Mailing List (which was included in our sample) revealed that of 4,600 postings, only 10 were found to be misleading or false, and of these seven were corrected by the community within five hours of the original posting (Esquivel, Meric-Bernstam, & Bernstam, 2006).

Many of the breast cancer specific online communities in our sample were active and thriving, with extensive repositories of user-generated content. Vibrant online communities are also more likely to produce richer and more accurate information quickly - a process known as emergent credibility that arises from the self-regulating and coordinating efforts of the community (Flanagin & Metzger, 2008). High levels of activity can also confer credibility to an online community by implying the site is popular and liked by others (Flanagin & Metzger, 2008). Interactivity is another important indicator of the health of an online community, which can be measured by the number of messages over a period of time, the thread depth (e.g., number of posts within a sub-discussion) or number of contributors to a thread (Preece, 2001). However, this information is rarely provided by websites in summary form, and obtaining estimates can be quite a futile without access to the site's log files.

The level of activity of an online community although crucial to its success says nothing about the caliber or relevance of the posts or social interactions it contains. One previous study (Meric et al., 2002) concluded that the popularity of breast cancer websites (as determined by Google rank) was correlated with type rather than quality of content.

Interestingly, the most popular sites were those that contained among other things, a message board service. While the most popular breast cancer online community identified by our search, (as measured by the total number of posts) contained a message board as its main communication tool, it was not possible to determine whether sites with message boards were overall more popular or more actively used than those with mailing lists, blogs, wikis or social network features due to inadequate reporting of usage statistics.

Practice Implications

The inventory of online communities produced by this review could serve as a guide for health care professionals and a resource for patients. Given that one-third of the breast cancer specific sites have over 100,000 posts each, it is highly possible that breast cancer survivors could use the existing online communities to address their concerns with out needing to post a question. Before developing another online community for breast cancer survivors, interested parties would be advised to assess whether their needs could be met by one of the existing online communities identified in this review, and if not, engage breast cancer survivors as collaborators to new resources that address unmet needs or gaps in supportive care services. The inventory of English language online communities for breast cancer survivors generated by this review will be published online so that the public can participate in keeping it relevant and up-to-date.

Limitations

The search results are dependent on the terms included in the strategy and on the search engine used. We attempted to overcome this limitation by choosing common search

terms, two complementary search strategies and the search engine with the greatest market share. It is possible that our search did not retrieve all English language online communities in existence, however once the information becomes available online, others could complement the list. In addition, a significant proportion of the online communities included in this review did not provide information on the date the site was launched or the usage statistics. Moreover, the launch dates reported in this paper should be regarded as estimates, given that it was not clear in all cases whether the communication feature (e.g., message board) was included on the site when it was first launched or if it was an add-on feature.

Research Implications

More studies are needed to understand the factors that contribute to the popularity of online communities, and how they relate to one another. By understanding what breast cancer survivors want from online communities and which sites they most actively use, we may be able to identify the elements that offer the most promise and effectiveness. Future researchers may want to consider the influence of moderation, and archived posts, in addition to the anonymity, homophily, interactivity, presence and interaction management of the site as suggested by others (Preece, 2001; Walther et al., 2005). Lastly, there is a need to explore in detail the types of needs these sites might be able to meet, and the proportion and effectiveness with which they complement, enhance or replace in-person interactions.

Conclusion

There is a wide range of active and thriving online communities available for breast cancer survivors with extensive archives of personal illness experiences. The scope of online

peer support options for breast cancer survivors will inevitably increase due to the growing popularity of social media applications that provide lay members of the public with the tools to create the support resources that they need. Future efforts should focus on identifying the factors that determine their success and effectiveness.

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6

Seeking Support on Facebook: A Content

Analysis of Breast Cancer Groups[1]

Abstract

Background: Social network sites have been growing in popularity across broad segments of Internet users, and are a convenient means to exchange information and support. Research on their use for health-related purposes is limited.

Objective: This study aimed to characterize the purpose, use, and creators of Facebook groups related to breast cancer.

Methods: We searched Facebook (www.Facebook.com) using the term breast cancer. We restricted our analysis to groups that were related to breast cancer, operated in English, and were publicly available. Two of us independently extracted information on the administrator and purpose of the group, as well as the number of user-generated contributions. We developed a coding scheme to guide content analysis.

Results: We found 620 breast cancer groups on Facebook containing a total of 1,090,397 members. The groups were created for fundraising (n = 277, 44.7%), awareness (n = 236, 38.1%), product or service promotion related to fundraising or awareness (n = 61, 9%), or patient/caregiver support (n = 46, 7%). The awareness groups as a whole contained by far the most members (n = 957,289). The majority of groups (n = 532, 85.8%) had 25 wall posts or fewer. The support oriented groups, 47% (27/57) of which were established by high school or college students, were associated with the greatest number of user-generated contributions.

Conclusion: Facebook groups have become a popular tool for awareness-raising, fundraising, and support-seeking related to breast cancer attracting over one million users. Given their popularity and reach, further research is warranted to explore the implications of social network sites as a health resource across various health conditions, cultures, ages, and socioeconomic groups.

Introduction

Online communities present a convenient means to exchange information and support with people in similar circumstances and are increasingly being used for health purposes (Fox, 2009), particularly by breast cancer survivors (Davison, Pennebaker, & Dickerson, 2000). One of the most popular and perhaps most successful online communities, if success is based on sheer numbers of registered users, is the social network site Facebook (www.Facebook.com). Just over 5 years since its launch, Facebook became the second most visited website in the world (second only to Google) (Alexa, 2010), with over 500 million active users (those who returned to the site within the last 30 days) worldwide (Facebook, 2010). While young adults are still more likely to use social network sites (Lenhart, 2009), the fastest growing demographic of Facebook users is women 55 years and older (Smith, 2009), which corresponds to the average age of onset of breast cancer (CCS, 2010). Although recent studies indicate that Facebook groups are used for health purposes (Farmer, Bruckner Holt, Cook, & Hearing, 2009) little is known about how this resource is used by people affected by breast cancer.

Online communities are "virtual social space(s) where people come together to get and give information or support, to learn or to find company" (Preece, 2001). They tend to be characterized according to the activity (e.g., support) or the people that they serve (e.g., breast cancer survivors), or the communication technology that supports them (e.g., message board) (Preece & Maloney-Krichmar, 2005). Initially, online communities were supported by mailing lists, and asynchronous and synchronous message boards. More recently online communities have formed around blogs, wikis, and social network sites, commonly referred to as Web 2.0 social media applications (Bender, O'Grady, & Jadad, 2008). Social network

sites are differentiated from other online communities based on their ability to enable users to display their social networks. Their backbone consists of visible user profiles that display an articulated list of friends who are also users of the system (boyde & Ellison, 2008). While other online community platforms enabled users to create a list of friends, these networks were not displayed or accessible to other users. This unique feature of social network sites is hypothesized to result in connections between individuals that would not otherwise have been made (boyde & Ellison, 2008).

Research on online communities for health purposes has primarily focused on the use and effects of mailing lists and message boards by breast cancer survivors, who have been shown to be one of the groups most likely to seek support from peers on the Internet (Davison et al., 2000). Qualitative studies have revealed that these types of online communities provide breast cancer survivors with a safe, relatively anonymous space to communicate about sensitive and potentially stigmatizing topics (Sharf, 1997) reduce feelings of isolation and uncertainty regarding prognosis and ambiguous painful symptoms (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005) and enable them to become more informed and better prepared for their interactions with the health system (Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). Randomized controlled trials have shown that professionally moderated mailing lists and message boards for breast cancer survivors can reduce depression, stress, and cancer-related trauma, and enhance social support (Gustafson et al., 2001; Gustafson et al., 2005; Winzelberg et al., 2003).

Relatively little is known about the use of social network sites for health purposes. Keelan and colleagues (Keelan, Pavri, Balakrishnan, & Wilson, 2010; Keelan, Pavri-Garcia, Tomlinson, & Wilson, 2007) examined the use of YouTube videos and Myspace blogs as a

source of information on immunization and found a sub-community of users critical of or with divergent views about vaccines. Research by Scanfeld and colleagues has demonstrated that Twitter has been used to share information on the use and side effects of antibiotics (Scanfeld, Scanfeld, & Larson, 2010). To our knowledge, there is only one study of the use of Facebook for health purposes. Farmer et al (2009) examined non-communicable disease groups and found a considerable number of patient and caregiver support groups related to malignant neoplasms. Surprisingly, breast cancer groups were notably absent from their analysis.

Breast cancer is the most common cancer among women worldwide (WHO, 2009) and thanks to advances in detection and treatment, women affected by this disease form the largest group of female cancer survivors (Surbone & Peccatori, 2006). However, the post-treatment period carries numerous physical and psychosocial needs that often go unaddressed by professional health care services (Surbone & Peccatori, 2006). Addressing the needs of this growing population of cancer survivors has been identified as supportive care's new challenge (Alfano & Rowland, 2006; Surbone & Peccatori, 2006). Social network sites could provide breast cancer survivors with a convenient means to connect with a diverse network of peers, thus facilitating access to a wider array of supportive information and services. In fact, some have questioned the utility of government-funded personal health care solutions, when social network sites provide users with the tools to create and share health resources on their own (Kidd, 2008). Little is known about how people affected by breast cancer use social network sites. This study attempted to fill some of the gaps by presenting a characterization of the purpose, patterns of use, and creators of Facebook groups related to breast cancer.

Methods

Search Strategy

On November 19, 2008 we searched Facebook using the platform's built-in search engine and the keyword breast cancer (Figure 1). We restricted our analysis to Facebook groups that were related to breast cancer, operated in English, and were publicly available to anyone with a Facebook account to view and join. Pages for individual members, organizations, events, and applications were excluded.

Figure 1: Sample Facebook Search Result Restricted to Group Pages
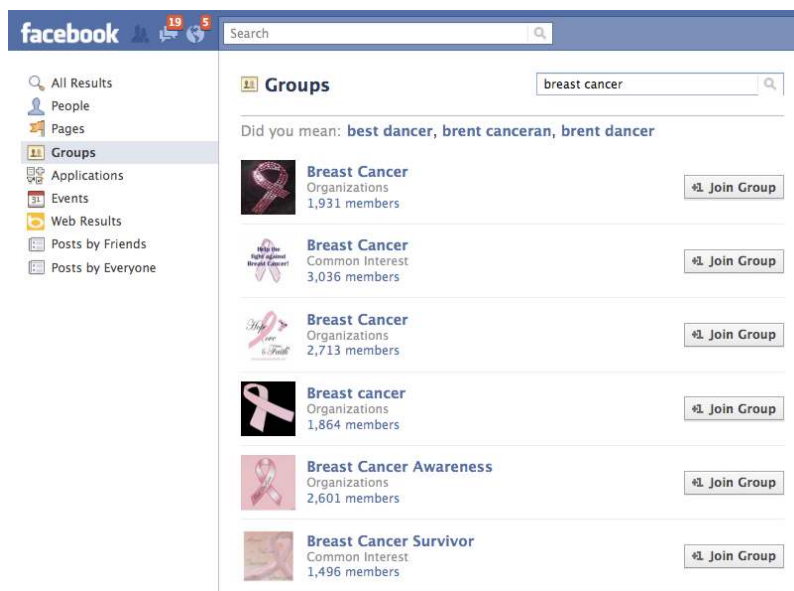
Data Extraction

Two of us (JLB and MCJM) independently reviewed the resulting set of eligible groups and extracted information on the following: (1) general characteristics (e.g., group name, purpose, creator, and URL), and (2) membership and user-generated content (e.g., number of members, discussion posts, wall posts, photos, and videos).

Data Analysis

We determined the purpose of each group based on a content analysis of, and in order of priority (if available), the title of the group, the description of the group, the information in the Recent News section, the discussion posts, and the wall posts. (The content analysis of the discussion and wall posts was restricted to those displayed on the main page of the group.)

We began by analyzing the content of the first 100 groups to develop a coding and classification scheme that could be applied to the entire set. This initial step led to the identification of four main types of breast cancer groups:

- Fundraising groups: created to attract financial resources for breast cancer through an event, product, or service. Visitors to these groups were asked to donate money, or to purchase a product or ticket to an event. Instructions were typically provided regarding how or where to donate the funds.

- Awareness-raising groups: created to bring attention to the importance of breast cancer in general, or to promote a charitable organization, a fundraising event, or screening or research program.

- Support groups: created to meet the informational and emotional needs of breast cancer survivors or affected family members or friends.

- "Promote-a-site" groups: created to increase the prominence of an external website raising funds or awareness for breast cancer through the sale of products or services.

After independently classifying the general purpose of the groups using the above coding scheme, we resolved any differences. Next we generated a second-tier coding scheme to sub-classify and more specifically describe the purpose of each group.

We also developed and independently applied a coding scheme to classify the approximate age and geographic location of the creators of the support groups. We restricted our analysis of the creators to the support groups, because we were primarily interested in the role of Facebook groups as a source of supportive care.

Lastly, we calculated descriptive statistics using SPSS version 17 (IBM Corporation, Somers, NY, USA) to summarize and compare the size (in terms of number of members) and amount of user-generated contributions of each type of group (in terms of wall posts). Most data were expressed as medians with interquartile ranges (IQRs) because the number of group members and user-generated content varied considerably and did not follow a normal distribution. We used chi-square tests to compare categorical data across groups.

This study was a component of a larger research study for which ethical approval was obtained. However, it should be noted that this study met the exclusion criteria of the (Canadian) Tri-Council Policy Statement as to what studies require review by an institutional research ethics board, because all information was publicly available.

Results

The search of Facebook on November 19, 2008 yielded 637 groups. As shown in Figure 2, 620 groups were included in the final analysis. We excluded one group because it was not related to breast cancer, three groups because they were not in English, and 13 groups because they were "closed". Figure 3 shows an example of a breast cancer support group on Facebook at the time the study was conducted. Since then, the platform has undergone revision, including changes to the way information is displayed on the group

pages and the addition of new features (e.g., group chat). Figure 4 shows an example of the

current layout of a breast cancer awareness group on Facebook.

Figure 2: Flow Diagram of Group Selection Process
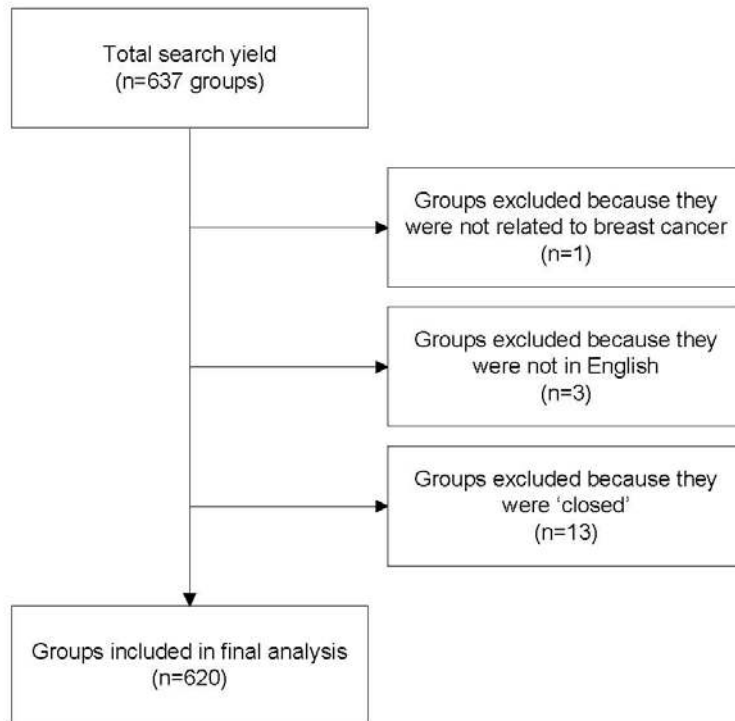
Figure 3: Sample Breast Cancer Support Group on Facebook in 2008

Figure 4: Sample Breast Cancer Awareness Group on Facebook in 2010

General Purpose

As shown in Table 1, the majority of groups (n = 513, 82.7%) were created for fundraising or awareness purposes. In total, 44.7% (n = 277) were created to raise funds for breast cancer, 38.1% (n = 236) to raise awareness about breast cancer and related events, 9.8% (n = 61) to promote an external website raising funds or awareness for breast cancer through the sale of products or services, and 7.4% (n = 46) to generate support for people affected by breast cancer. A minority of groups (n = 55, 8.9%) were classified as having an additional purpose, 34.5% (n = 19) of which related to fundraising or support, 27.3% (n = 15) to raising awareness, and 3.6% (n = 2) to supporting an external website. As shown in Table 2, the three most common types of breast cancer groups on Facebook, which comprised 69% of the total sample, were (1) groups created to raise funds for a fundraising walk associated with a charitable organization in the United States or Canada (n = 239, 38.5%), (2) groups raising awareness about a specific fundraising event (n = 95, 15.3%), or (3) groups promoting the importance of breast cancer in general (n = 94, 15.2%).

Group Size

We identified a total of 1,090,397 Facebook users who were members of one or more of the 620 breast cancer groups. The awareness groups contained by far the most members (n = 957,289, 87.8%), followed by the promote-a-site groups (n = 64,861, 5.9%), fundraising groups (n = 51,307, 4.7%), and support groups (n = 16,940, 1.5%). The groups ranged in size from 1 to 772,815 members and had a median of 196.5 members (IQR 214.7). Most groups (n = 612, 98.7%) contained 5000 or fewer members and 70.8% (n = 439) contained 101 to 500 members. On average, the promote-a-site groups had the greatest median number of members (median 373.5, IQR 932), followed by the awareness groups (median 270, IQR

389), support groups (median 235.5, IQR 237), and fundraising groups (median 151, IQR 92)

(Table 1).

Table 1: General Purpose and Size of Facebook Breast Cancer Groups

Group	Sample group description	n (%)	Members			
			Total	Median (IQR)[a]	Min	Max
Fundraising	*My mom is a 11 yr cancer survivor and i [sic] am walking for her and encouraging friends and family to join me in this walk for a cure for breast cancer.*	277 (44.7)	51,307	151 (92)	1	2623
Awareness	*October is Breast Cancer Awareness Month. Share Beauty...Spread Hope ...Think Pink!!*	236 (38.1)	957,289	270 (389)	2	772,815
Promote-a-site	*This doesn't cost you a thing. Their corporate sponsors/advertisers use the number of daily visits to donate a mammogram in exchange for advertising.*	61 (9.8)	64,861	373.5 (932)	116	16,769
Support	*For anyone who knows someone who has survived, is battling, or has died of breast cancer. For congratulations, hope and [in] memoriam.*	46 (7.4)	16,940	235.5 (237)	2	2995

[a] IQR: interquartile range.

Table 2: Specific Purpose and Frequency of Facebook Breast Cancer Groups

General purpose	Specific purpose	Primary purpose, n	Secondary purpose, n
Fundraising (n = 277)	1. Charity fundraising event	239	2
	2. Personal fundraising event	11	14
	3. Product promotion	17	0
	4. Charitable organization	7	2
	5. Non-charitable organization event	3	0
	6. Service promotion	0	1
Awareness (n = 236)	1. Breast cancer in general	94	7
	2. Fundraising event (egg, walk)	95	6
	3. Charitable organization	23	1
	4. Awareness event	10	1
	5. Research project	5	0
	6. Political advocacy	4	0
	7. Risk factors	3	0
	8. Planning an event	2	0
Promote-a-site (n = 61)	1. Product promotion	43	2
	2. Political advocacy	16	0
	3. Awareness	1	0
	4. Research recruitment	1	0
Support (n = 46)	1. For anyone affected by breast cancer	22	10
	2. For oneself or loved one with breast cancer	22	3
	3. For fundraisers	2	6
Total		620	55

User-Generated Contributions

A user can contribute content to a Facebook group in various ways, such as posting messages to the "wall," news section, or discussion board, or uploading multimedia such as photos or videos. As Table 3 shows, the most frequently used communication feature was the

wall. Although wall posts ranged in number from 0 to 8614, the groups contained a median of 5 wall posts (IQR 11). The majority of groups (n = 532, 85.8%) had 25 wall posts or fewer. The support groups had the greatest median number of wall posts (median 16, IQR 38), followed by the awareness groups (median 6, IQR 19), promote-a-site groups (median 4, IQR 9), and fundraising groups (median 4, IQR 7). The difference in median number of wall posts across the groups was statistically significant (χ^2 (3)=52.02, P < 0.001).

Table 3: User-Generated Content on Facebook Breast Cancer Groups, Median (IQR)

Group	Wall posts	Discussion posts	Photos	Videos
Support	16 (38)	1 (4)	3 (12)	0 (0)
Awareness	6 (19)	1 (3)	3 (11)	0 (0)
Fundraising	4 (7)	0 (1)	0 (6)	0 (0)
Promote-a-site	4 (9)	2 (2)	0 (1)	0 (0)

Support Groups

Nearly half (n = 32, 49.2%) of the support groups were created to generate support for anyone affected by breast cancer. A typical purpose statement for these types of groups was "For anyone who knows someone who has survived, is battling or has died of breast cancer. For congratulations, hope and [in] memoriam." An additional 38.5% (n = 25) of the support groups were established to obtain support for the creator of the group or a loved one affected by breast cancer and 12.3% (n = 8) were created as a forum for information sharing among people participating in a fundraising walk (Table 2). Interestingly, a minority of the groups that were created "for anyone" affected by breast cancer (n = 6, 18.7%) were initiated by individuals with an afflicted family member or friend, even though the explicit purpose of the group was not to gain support for the creator of the group or a loved one in particular. In the remaining 26 of these groups, the motivation of the group creator was not explicitly

described. A small percentage of the support groups (n = 5, 7.7%) were also serving in memoriam of a loved one who had died of breast cancer.

Support Group Creators

We also examined the creators of the support groups for anyone, oneself, or a loved one affected by breast cancer (excluding groups created as a support forum for people participating in a fundraising walk, because we were primarily interested in breast cancer-related support). All but one of the creators of the support groups (n = 57) restricted the visibility of their personal profile pages to members within their networks. However, in 47.3% (n = 27) of the support groups the academic institution of the creator and their expected graduation date either was included on the group page itself or was available in the search result content, and in 86% (n = 49) of the support groups the geographic location of the creator was also available. Of the groups with available information on the approximate age of the group creators, 55.6% (n = 15) were college students, 37% (n = 10) were high school students, and 7.4% (n = 2) were recent college graduates. None of the support group creators appeared to be health care professionals or associated with a health care organization. Of the groups with available information on the geographic location of the support group creators 57.1% (n = 28) were located in the United States, 40.8% (n = 20) in Canada, and 2% (n = 1) in Australia.

Discussion

We found a large number of breast cancer-related groups on Facebook (n = 620) with over one million members. Unlike most disease-specific online communities, the majority of breast cancer groups on Facebook were created for fundraising and awareness purposes, rather than supportive care. The awareness groups as a whole contained by far the most members (n = 957,289), while the support groups were associated with the greatest number of user-generated contributions. Many of the individuals who did create the groups for supportive care purposes were adolescents and young adults, and the majority appeared to be living in the United States or Canada. None of the support group creators appeared to be health care professionals or associated with a health care organization.

Unlike in our study, Farmer et al (2009) found patient (47.4%) and caregiver support groups (28.1%) to be more common than fundraising groups (18.6%). However, Farmer et al did not include breast cancer groups in their sample. Of relevance, the authors did include lung, stomach, and colorectal cancer as search terms, and found considerably fewer groups (n = 55) and members (n = 77,832) associated with these neoplasms, than we found associated with breast cancer (620 groups with 1,090,397 members). This difference is largely due to the greater number of fundraising and awareness groups we found associated with breast cancer, which is not surprising given that the breast cancer fundraising movement is one of the largest and most successful survivor-driven social movements, which other disease groups seek to emulate (Picard, 2009). However, we also found more support groups for breast cancer (n = 47) than Farmer et al found for lung, stomach, and colorectal cancer combined (n = 32). Although breast cancer is the most common neoplasm in women, lung, stomach, and colorectal cancers are the three neoplasms associated with the greatest

morbidity and mortality among both men and women worldwide (WHO, 2009). Hence, the difference in the number of support groups on Facebook associated with these cancers cannot be attributed to their relative prevalence, and may instead reflect a greater tendency for people affected by breast cancer to join online communities than people affected by other conditions (Davison et al., 2000).

In contrast to breast cancer-specific online communities, which are used primarily to meet treatment information, symptom management, and emotional support needs (Rimer et al., 2005), breast cancer groups on Facebook were not primarily used for supportive care purposes. One of the frequently reported advantages of breast cancer-specific online communities, which to date have focused on mailing lists and message boards, is the relative anonymity and privacy that they provide, which allows users to communicate about personal and socially stigmatizing topics (Sharf, 1997). Although Facebook groups provide facilities for discussion forums based on shared experiences, the visibility of user profiles and personal networks reduces the relative anonymity of the encounter and, if open to the public, which all groups in this study were, they have the potential to attract a much wider audience. This core functionality of social network sites, which gives users access to a more diverse and extensive network, makes them ideally suited for fundraising and awareness-raising purposes, as this study has demonstrated, but may make them less suitable for support-seeking related to topics that are embarrassing or socially stigmatizing (Davison et al., 2000).

Many of the individuals who did create the groups for supportive care purposes were adolescents and young adults, and the majority appeared to be living in the United States or Canada. These findings reflect the site's user demographics at the time study was conducted. In the fall of 2008, the largest demographic of Facebook users was 18 to 24 years old

(Lenhart, 2009), the United States reported more Facebook users than any other country, and Canada had the highest penetration of Facebook users per capita (Burcher, 2008). While some support groups were created for a loved one affected by breast cancer (perhaps a less technology-savvy parent), many young people established Facebook groups to obtain support for themselves.

Adolescents and young adults can experience significant distress when a loved one has cancer (Grabiak, Bender, & Puskar, 2007; Turner, 2004), and research suggests that their unique needs are often poorly met both within and outside the family (Kristjanson, 2004). Social network sites such as Facebook could provide this group with a convenient and familiar means to accumulate coping resources. Use of these sites is associated with greater levels of *bridging social capital,* or access to information and resources through a diverse set of acquaintances, and *bonding social capital,* or emotional support from close friends (Putnam, 2000). Both of these, according to the theory of stress and coping, can promote coping efforts and lessen negative appraisals of events, in turn reducing or buffering anxiety (Lazarus & Folkman, 1984). Furthermore, (Ellison, Steinfield, & Lampe, 2007) have shown that college students who are active on Facebook experience higher levels of both forms of social capital, and Burke and colleagues (Burke, Marlow, & Lento, 2010) have confirmed that these findings generalize to older users and English speakers outside the United States.

Notwithstanding the large number of members that the breast cancer groups attracted, there were relatively few user contributions overall, and in the fundraising, awareness, and promote-a-site groups in particular. These findings support the consistently reported observation that online communities attract significantly more lurkers (visitors who do not post messages) than posters (Nonnecke & Preece, 2000). However, the fundraising,

awareness, and promote-a-site groups were not created to stimulate discussion but rather to promote a message, event, product, or service. Although activity, which is often judged by the number of posts, is a key determinant of a successful online community (Preece, 2001), posting messages in online health communities is not necessary to obtain the empowering effects from participating in them (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). Likewise, it may be possible to benefit from joining a Facebook group without contributing content, depending on the purpose of the group or the motivation of the joiner. According to a study by Park et al (Park, Kee, & Valenzuela, 2009) college students join Facebook groups not just to socialize, but also to obtain information about events, to seek self-status, and to find entertainment. In addition, Park and colleagues found that those who joined Facebook groups for information purposes were more likely to participate in civic and political activities, suggesting that Facebook groups may play an important role in facilitating youth engagement.

Practice Implications

The findings of this study are valuable because they provide information on the health-related use of the most widely popular social network site in existence. They indicate that Facebook groups are being used by a considerable number of people affected by breast cancer for fundraising and awareness purposes, and to a lesser extent supportive care. That being said, our findings should not be interpreted to imply that Facebook is rarely used for supportive care purposes, given that several ways to solicit or provide support on Facebook were not examined in this study, including private messages, wall posts on personal profile pages, and status updates. These findings do suggest that Facebook may play an important

role in facilitating public engagement in health promotion and fundraising activities, particularly among youth.

Limitations

First, we were unable to collect demographic information on 52.6% (30/57) of the support group creators due to their use of privacy settings. However, this finding suggests that users of Facebook not only are becoming aware of the public nature of their online activities, but also are activating the privacy measures offered. In fact, all but one of the support group creators in our sample restricted their personal Facebook profiles to their networks, whereas a study of Facebook users conducted in 2005 found that only 0.06% of college students restricted the visibility of their profiles to members within their networks (Gross & Acquisiti, 2005). Since then, significant changes made to the platform and user base of Facebook might in part explain the increased use of privacy settings by this sample, such as the launch of the NewsFeed feature, which provides updates on the activities of friends (boyde, 2008), the introduction of third-party-developed applications (Novak, 2009), and the expansion of registration to anyone.

Another related limitation was our reliance on user self-reported data (that were available on the group page itself or in the search result content) to infer the approximate age and geographic location of the support group creators. This information is possibly incorrect or fabricated. In addition, we could not determine the exact number of unique individuals affiliated with a particular type of breast cancer group on Facebook, given that a single user could be a member of multiple groups. Therefore, the total number of members affiliated with each type of breast cancer group could be inflated. At the same time, the total number of

breast cancer groups identified in this study is likely only a portion of the total number of breast cancer groups on Facebook, given that we restricted our study to groups in English, while Facebook is available in more than 70 different language versions (Facebook, 2010).

Lastly, we encountered numerous challenges while investigating the nature of breast cancer groups on Facebook that were primarily related to its limited functionality as a search tool. The search bar yields an imprecise yield (egg, ">500 groups"), the order of the search results is inconsistent and unclear, and the search is limited to the title of the group. Since the time we conducted our study the search tool has been enhanced but, to our knowledge, these specific issues have yet to be resolved. We contacted Facebook to notify them of these technical issues and obtained an encouraging response. Collaboration with platform owners would certainly facilitate future research in this area.

Research Implications

Further research is warranted to understand the implications of participating in health-related groups on Facebook. While other researchers have examined site activities that lead to higher levels of social capital (Burke et al., 2010; Ellison et al., 2007), no known studies have examined the impact of participating in a health-related group on Facebook. It is also unknown whether general social network sites such as Facebook are as effective as disease-specific online communities in providing health-related information and support, and for whom. Given the importance of anonymity in facilitating disclosure in online breast cancer communities (Sharf, 1997), research is warranted to examine breast cancer survivors' perceptions of social network sites as a source of supportive care in comparison to other sources. Lastly, a better understanding is needed of the privacy implications of sharing

personal health information on public social network sites, which has raised concern (Kidd, 2008), leading some to advise against disclosing personal information on these sites (Farmer et al., 2009).

Conclusion

Facebook groups have become a popular tool for awareness-raising, fundraising, and support-seeking related to breast cancer, attracting over one million users by the end of 2008. Given their popularity and reach, further research is warranted to explore the implications of social network sites as a health resource across various health conditions, cultures, ages, and socioeconomic groups.

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7

**Supportive Care Needs and Online
Community Use of Breast Cancer
Survivors who are Peer Support Providers**

Abstract

Background: Group leaders are critical to the success of cancer peer support programs. Yet, little is known about their supportive care needs or their use of online peer support resources.

Objective: To identify the supportive care needs of breast cancer survivors known to provide peer support, and their use of online communities.

Methods: We surveyed the attendees of a support group facilitator-training workshop provided by a national non-profit breast cancer support agency in Canada from September 2008 to May 2009 inclusive. The total response rate was 73% (n = 73).

Results: Respondents were a mean of 56 years of age (SD 9.52) and a median of 5.9 years (IQR 7.3) post-diagnosis, with no evidence of current disease. Two-thirds (68.6%) reported at least one and a median of 4 (IQR 13) unmet needs; most frequently (30 to 40%) concerning sexual problems, stress, survivor identity, fear of recurrence, and ongoing symptoms or side effects. Online communities were used by nearly one-third (n = 23, 31.5%) of the sample, on a daily or weekly basis (91.3%), most often during (73.9%) and shortly after (60.9%) breast cancer treatment to obtain information about breast cancer and its treatment, symptom management, and emotional support. Reasons for non-use (reported by n = 50) included lack of need (48.0%), self-efficacy using online communities (30.0%), trust in Internet resources (24.0%), self-efficacy using computers (20.0%) and awareness (20.0%).

Conclusion: Given the unique and pivotal function of peer support, breast cancer survivors may play an increasingly important role as supportive care providers. Efforts should be made to address their supportive care needs and overcome barriers to their use of online peer support resources.

Introduction

There are close to one million cancer survivors living in Canada, with breast cancer survivors forming the largest group (Canadian Cancer Socieyt [CCS], 2008). Unfortunately, many breast cancer survivors struggle with long-term physical and psychosocial needs without much professional help or support (Insitute of Medicine [IOM], 2005). Peer support groups are an important source of supportive care for breast cancer survivors (Davison, Pennebaker, & Dickerson, 2000) and group leaders are critical to their success (Price, Butow & Kirsten, 2006), however practical barriers limit their use (Owen, 2003). Online communities could provide a convenient means to address the needs of this population. Research is needed to identify the supportive care needs of breast cancer survivors known to provide peer support and their use of online communities.

Some of the more common long-term effects of breast cancer and its treatment include: psychosocial distress, reported in about 30% of breast cancer survivors (IOM, 2005); fatigue in about 33% (Bower et al., 2006); lymphodema in 12 to 25% (IOM, 2005); body image concerns and problems with sexual functioning in about 20 to 30% (Kornblith et al., 2003); and cognitive dysfunction in a range of 20 to 61% (Wefel, Saleeba, Buzdar, & Meyers, 2010). Younger breast cancer survivors (under 50 years), as well as those who received adjuvant systemic therapy (chemotherapy, tamoxifen or both) have been shown to have poorer physical, social and emotional functioning (Ganz et al., 2002; Ganz et al., 2003).

A handful of studies have investigated the supportive care needs of long-term breast cancer survivors. A Canadian interview study (Gray et al., 1998) of 70 'well' breast cancer survivors four or more years after diagnosis documented ongoing emotional and physical effects of the illness, fears of recurrence, and information needs. Similar findings were

reported by a United States focus group study (Wilson, Andersen, & Meischke, 2000) involving 128 women one to 32 years post-diagnosis, with women with late-stage disease, reporting more unmet needs. A Canadian focus-group study of 65 breast cancer survivors, diagnosed at or before the age of 45, documented unique age and life-stage specific needs related to early menopause, fertility and sexuality, financial concerns, and family responsibilities (Gould, Grassau, Manthorne, Gray, & Fitch, 2006). An Australian study (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, & Wain, 2007) documented high rates of anxiety and supportive care needs related to fears of recurrence, up-to-date information, an ongoing case manager, complementary and alternative therapy, and survivor identity in a sample of 117 breast cancer survivors two to 10 years post-diagnosis.

Surprisingly, little is known about the supportive care needs of breast cancer survivors who provide peer support to others. Peer support groups are increasingly recognized as an effective form of psychosocial support for cancer survivors (Campbell, Phaneuf, & Deane, 2004; Davison, Pennebaker, & Dickerson, 2000; Hoey et al., 2008), and there is growing evidence of the critical role of the group leader in producing positive outcomes (Price, Butow & Kirsten, 2006). Unfortunately, many group leaders experience burnout, which has contributed to the demise of many groups (Butow et al., 2005). A few researchers have investigated the training and support needs of cancer support group leaders (Butow et al., 2005; Price et al., 2006; Stevinson, Lydon, & Amir, 2010). Only one known study has examined, albeit indirectly, the supportive care needs of cancer peer support providers. Matthews and colleagues (2002) examined the quality of life of 586 breast cancer peer support providers five years post-diagnosis. Respondents reported higher physical

functioning, emotional well-being and vitality than population norms, but greater dissatisfaction with their sexual ability, physical strength and bodies.

An increasingly popular (Fox, 2009) and convenient way to obtain support from peers is from online communities. Online communities are "virtual social space(s) where people come together to get and give information or support, to learn or to find company" (Preece, 2001). Current estimates indicate that at least 41% of American Internet users have read someone's description of a medical issue in an online community to aid in their health decision-making (Fox, 2009). There is only one known study of the prevalence of online community use among patients. Van Uden-Kraan et al. (2009) conducted a cross-sectional, hospital-based study of 679 Dutch patients with breast cancer, rheumatoid arthritis or fibromyalgia. In total, 52% of the patients surveyed reported using the Internet, in general, as a health resource, and 15% reported specifically using an online patient community. However, sub-group analysis was not conducted.

In an effort to advance understanding of the supportive care needs of cancer peer support providers and the potential role of online communities in meeting their needs, we surveyed a sample of breast cancer survivors known to provide peer support. The purpose of the study was to explore their met and unmet supportive care needs, as well as their use of online communities for support related to their illness.

Methods

Study Design

The study, which was reviewed and approved by the University of Toronto Research Ethics Board, used a cross-sectional survey design.

Setting and Participants

Participants were recruited from Willow Breast Cancer Support Canada (Willow), a national charitable organization that provides targeted information and support to anyone affected by breast cancer, free of charge (http://www.willow.org/). This survey was restricted to individuals who attended a Willow support group facilitator training workshop during September 2008 to May 2009 inclusive, and who: had received a diagnosis of breast cancer; had used the Internet to send and receive email; and could read English. The program is promoted widely across Canada *via* a series of channels (e.g., hospitals, cancer centres, community based support programs) and attended by current facilitators seeking to enhance their skills and facilitators-in-training who are planning to start a support group. Attendees must be at least one year post-diagnosis to participate.

Recruitment Strategy

Support group program attendees were notified of the study through a Willow newsletter in May 2009. One week following the mail-out of the newsletter, each attendee was sent, by postal mail, a survey package (a letter of invitation, questionnaire and return addressed envelope). Non-responders were sent up to two follow-up letters (with an additional copy of the questionnaire and return addressed envelope). Participants were given the option to complete the questionnaire on paper and return it via a pre-paid postage envelope, or to complete and submit the questionnaire online. Participants were surveyed from May to July 2009 inclusive. Informed consent to participate in the survey was assumed based on completion of the questionnaire.

Survey Instrument and Measures

The questionnaire contained information on respondent demographic, disease and social characteristics, supportive care needs, use of the Internet and online communities. It was pilot-tested with seven of Willow's staff members who were breast cancer survivors. The findings from the pilot-test were used to refine the clarity of the wording and comprehension of the questions; they were not included in the study findings.

Demographic and disease characteristics. Socio-demographic characteristics considered included age, ethnicity, highest level of education completed, total household income and approximate size of town or city of residence. Ethnicity was determined using questions taken from the Canadian census (Statistics Canada, 2006). Total household income and place of residence were determined using response categories adopted from a Statistics Canada report on Internet use in rural and small towns (McKeown, Noce, & Czerny, 2007). Three variables were used to measure disease status characteristics including: date of breast cancer diagnosis, recurrence of breast cancer, and treatment status.

Social support and social network integration. The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet , Dahlem, Zimet, & Farley, 1988) was used to assess perceptions of support adequacy from family, friends and a special person. The MSPSS is a 12-item scale with three subscales and uses a seven-point Likert response format ranging from 1 ("very strongly disagree") to 7 ("very strongly agree"). All three subscales have been shown to have high internal consistency (α = 0.89 to 0.91) (Canty-Mitchell & Zimet, 2000). The Social Network Index (SNI) (Berkman & Syme, 1979) was used to measure social

network integration. It is a composite measure of four types of social connection: relationship status (married or in a steady relationship/not); sociability (number and frequency of contacts with close relatives and close friends); participation in religious or spiritual groups or activities (yes versus no); and, participation in social groups or activities (at least once per week versus less than once per week). The measure has been shown to have satisfactory internal consistency (α = 0.57 to 0.68) (Kang et al., 2007).

Supportive care needs. The Cancer Survivors Unmet Needs instrument (CaSUN) (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, Lo et al., 2007) was used to measure supportive care needs. It is a 35-item measure with one open-ended question. Need items were scored as 0 (no need), 1 (met need) or 2 (unmet need), and total scores involved summing responses in each category. The measure has been shown to have high internal consistency (α = 0.96) (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, Lo et al., 2007). One item was added to the instrument to measure needs related to pain management specifically. Individuals who had active disease at the time of survey completion were excluded from this particular analysis.

Use of the Internet and online communities. Respondents were asked to describe how often they used the Internet, whether they had a personal profile on a social network site (e.g., Facebook) and whether or not they used the Internet to search for information on breast cancer. Use of breast cancer online communities was measured with the question: "Have you ever visited a breast cancer website that allows you to communicate with other women diagnosed with breast cancer, such as an online discussion forum or chat room?" Individuals

who responded 'no' were instructed to choose from a list, the reasons they had not used an online community for breast cancer related purposes. Users of breast cancer online communities were asked to indicate how often in the past three months they had used them, when they most frequently used them, the reasons they used them (selected from a list), the ways in which they used them (e.g., read or posted messages), and which ones (selected from a list) they had used.

Statistical Analysis

Data analysis was performed using the statistical software package SPSS version 17 (IBM Corporation, Somers, NY, USA). Descriptive statistics were calculated using sample means and standard deviations for continuous variables, and proportions were calculated for categorical variables. Bivariate analyses were used to examine whether differences existed between sub-scale values of the MSPSS scale using Mann Whitney U tests.

Results

Of the 113 individuals surveyed, 13 self-reported as non-Internet users and were removed from the sample, leaving a potentially eligible sample of 100. In addition, two individuals declined to participate due to family circumstances and 25 individuals did not respond. In total, 73 individuals returned a completed questionnaire (6 of whom submitted the questionnaire online) resulting in a response rate of 73%. Of the 73 respondents, 68 were current or previous facilitators of a support group and five were soon-to-be facilitators and considered themselves active contributors to their current support group.

Sample Characteristics

Demographic and Disease Characteristics

Respondents were middle-aged (mean of 56 years), a median of 6 years post-diagnosis, had completed primary treatment for breast cancer (51.4%) or were receiving a form of adjuvant hormone therapy (44.4%). Characteristics of the full sample are shown in Table 1.

Table 1: Demographic Characteristics and Disease Status

Characteristic	Total (n = 73)
Age in years, *mean (SD) (N = 70)*	56 (9.52)
Place of birth, *n (%) (N = 73)*	
Canada	64 (87.7)
Ethnicity, *n (%) (n = 73)*	
White	71 (97.3)
Relationship Status, *n (%) (N = 73)*	
Single, divorced, widowed	14 (19.2)
Married or in a relationships	59 (80.8)
Education, *n (%) (N = 70)*	
Secondary school or less	13 (18.3)
College or Technical school	33 (46.5)
University	24 (35.2)
Total Household income, *n (%) (N = 64)*	
Less than $40,000	18 (28.1)
$40,001 to $80,000	28 (43.8)
$80,001 +	18 (28.1)
City Size, n *(%) (N = 73)*	
Fewer than 10,000 people	27 (37.0)
10,001 to 99,999 people	32 (43.8)
100,000 or more people	14 (19.2)
Years since diagnosis, *median (IQR) (N = 73)*	5.92 (7.3)
Recurrence, *n (%) (N = 73)*	12 (16.4)
Treatment Status, *n (%) (N = 72)*	
Undergoing treatment	3 (4.2)
Completed, but on HRT	32 (44.4)
Completed all treatment	36 (51.4)
Social Support (7-point scale)	
Friends, *mean (SD) (N = 71)*	6.04 (0.11)
Special person, *mean (SD) (N = 70)*	5.92 (0.15)
Family, *mean (SD) (N = 71)*	5.66 (0.17)
Total, *mean (SD) (N = 70)*	5.88 (0.12)
Social Network Index, *n (%) (N = 69)*	
Socially isolated (I, 11)	25 (35.7)
Socially integrated (III, IV)	45 (64.3)

Social Support and Social Network Integration

As shown in Table 1, the majority of respondents were socially integrated (64%) with relatively high perceptions of social support (median of 5.8 on a 7-point Likert scale) Respondents reported receiving significantly greater perceived support from friends (Z=2.94, p=0.003) or a special person (Z=2.26, p=0.024) than from family members as a whole.

Supportive Care Needs

Respondents had more met than unmet needs in the past month as a result of having breast cancer. Overall, 81.4% (n = 57) of the respondents reported at least one and a median of 8 (IQR 7) met needs. (Of the 13 respondents who reported no met needs, 6 had no needs and 7 reported unmet needs for some items and no needs for others.) While, 68.6% (n = 48) of respondents reported at least one, and a median of 4 (IQR 13) unmet needs (data not shown). The top ten met and unmet needs are reported in Tables 2 and 3. No additional needs were reported in the open-response question, suggesting that the tool was comprehensive.

Table 2: Met Needs based on the CaSUN Measure of Supportive Care Needs

Rank	CaSUN Item	n (%)
1	I need to feel like I am managing my health together with my health care team (N = 66)	37 (56.0)
2	I need the very best medical care (N = 64)	32 (50.0)
3	I need any concerns regarding my care to be properly addressed (N = 66)	33 (50.0)
4	I need to talk to others who have cancer (N = 66)	32 (47.5)
5	I need local health care services that are available when I require them (N = 66)	30 (45.4)
6	I need to know that all my doctors talk to each other to coordinate my care (N = 67)	27 (40.3)
7	I need emotional support to be provided to me (N = 67)	24 (35.8)
8	I need information provided in a way that I can understand (N = 66)	23 (34.8)
9	I need help to manage my concerns about the cancer coming back (N = 65)	22 (33.8)
10	I need up to date information (N = 65)	22 (33.8)

Table 3: Unmet Needs based on the CaSUN Measure of Supportive Care Needs

Rank	CaSUN Item	n (%)
1	I need help to address problems with my/our sex life (N = 66)	26 (39.4)
2	I need help to reduce stress in my life (N = 66)	23 (35.0)
3	I need help to cope with others not acknowledging the impact that cancer has had on my life (N = 65)	22 (33.8)
4	I need help to deal with my own and/or others expectations of me as a "cancer survivor" (N = 66)	22 (33.3)
5	I need help to manage concerns about the cancer coming back (N = 65)	21 (32.3)
6	I need help to adjust to changes to the way I feel about my body (N = 66)	21 (31.8)
7	I need help to manage ongoing symptoms and side effects (N = 67)	20 (30.0)
8	Due to the cancer, I need help getting life or travel insurance (N = 66)	17 (25.7)
9	I need an ongoing case manager to whom I can go to find out about services when needed (N = 67)	17 (25.4)
10	I need help to try to make decisions about my life amidst uncertainty (N = 67)	17 (25.4)

Use of the Internet and Online Communities

Prevalence and Type of Internet Use

As shown in Table 4, the majority of respondents used the Internet daily (n = 53, 72.6%), and over 40% (n = 32) were registered users of Facebook. Nearly one-third of respondents (n = 23, 31.5%) had used a breast cancer online community, 60% (n = 13) of whom were 'active users' or posters.

Timing and Frequency of Online Use

Users of online breast cancer communities reported that they visited them most frequently during (n = 17, 73.9%) or after (n = 14, 60.9%) breast cancer treatment, or while on adjuvant hormone therapy (Table 4). During this peak use period, most (91.3%) reported visiting them on a daily or weekly basis. Over time, respondents reported visiting online communities less frequently. At the time the survey was conducted, which was when survey respondents were a median of 6 years post-diagnosis, most users (72.7%) reported visiting online breast cancer communities once per month or less.

Table 4: Prevalence, Frequency and Nature of Online Community Use

Characteristic	n (%)
Frequency of general Internet use (N = 73)	
At least once a day	53 (72.6)
At least once a week	16 (21.9)
At least once a month	1 (1.4)
Less than once a month	3 (4.1)
Breast cancer related Internet use (N = 73)	65 (89.0)
Use of Facebook (N = 73)	32 (43.8)
Use of Facebook for breast cancer (N = 32)	13 (40.6)
Use of online breast cancer communities (N = 73)	23 (31.5)
Frequency of use of online breast cancer communities in the last 3 months (N = 22)	
At least once a day	2 (9.1)
At least once a week	4 (18.2)
At least once a month	6 (27.3)
Less than once a month	10 (45.5)
Period of most frequent use of online breast cancer communities (N = 23)	
During diagnostic testing	5 (21.7)
After diagnosis but before treatment	12 (52.2)
During treatment	17 (73.9)
After treatment, but while on hormone therapy	14 (60.9)
After all treatment	11 (47.8)
Frequency of use during peak use of online breast cancer communities (N = 23)	
At least once a day	9 (39.1)
At least once a week	12 (52.2)
At least once a month	2 (8.7)
Less than once a month	0 (0.0)
Postings to online breast cancer communities (N = 23)	13 (59.1)

Reasons for Use and Non-Use

The top three reasons reported for *using* online breast cancer communities were to address informational, physical and emotional needs. In total, 91.3% (n = 21) of users reported that they visited online communities to obtain information about breast cancer or its treatment, 69.6% (n = 16) to learn how to manage symptoms and side effects, 47.8% (n = 11) to get emotional support, 43.5% (n = 10) to prepare for a medical appointment, 39.1% (n = 9) to help others, 34.8% (n = 8) to address fears, 30.4% (n = 7) to address feelings of depression, 26.1% (n = 6) following a medical appointment, 21.7% (n = 5) to address

feelings of anxiety or loneliness, and one person reported using online communities for spiritual reasons (data not shown).

The top reasons for *not using* online breast cancer communities related to lack of need, trust, self-efficacy and awareness. Specifically, 48.0% (n = 24) of non-users reported that their needs were being met by their offline breast cancer network; 30.0% (n = 15) reported not being confident using online communities, 24.0% (n = 12) reported not having trust in Internet security, and not trusting information from strangers on the Internet, 20.0% (n = 10) reported not being comfortable using computers in general, and another 20% (n = 10) reported that they had never heard of online communities for breast cancer survivors.

Online Communities Used

From a list of 20 online breast cancer communities, users reported using a median of 4 (IQR 4.2). The top ten online communities that the survey respondents reported using are shown in Table 6. Two respondents reported using online communities that were not in the list (www.ibcsupport.org and www.bcmets.org), and one respondent provided the following comment: "I didn't know about a lot of these sites before this questionnaire".

Table 5: Top Ten Online Communities Used

Rank	Online breast cancer community	n (%)
1	Breastcancer.org (www.breastcancer.org)	18 (81.8)
2	Willow Breast Cancer Support Canada (www.willow.org or www.willow-talk.org)	17 (77.3)
3	Breast Cancer Action Nova Scotia (www.bca.ns.ca)	9 (40.9)
4	Caring Voices (www.caringvoices.ca)	7 (31.8)
5	Living Beyond Breast Cancer (www.lbbc.org)	7 (31.8)
6	Canadian Breast Cancer Forum (www.breastcancerforum.ca)	7 (31.8)
7	Breast Cancer Awareness (www.breastcancerawareness.com)	5 (22.7)
8	Triple Negative Breast Cancer (www.tnbcfoundation.org)	5 (22.7)
9	Breast Cancer Now What (www.breastcancernowwhat.ca)	4 (18.2)
10	Sharing Strength (www.sharingstrength.ca)	4 (18.2)

Discussion

This study represents the first known investigation of the supportive care needs and online community use of breast cancer survivors who are peer support providers. Overall, the respondents reported more met than unmet needs, which suggests that the health care system, in its traditional form, worked for them. However, approximately two-thirds reported at least one unmet need most notably related to sexual problems, stress, survivor identity, fear of recurrence, and ongoing symptoms or side effects.

The proportion of met and unmet needs reported by the respondents in this study is similar to an Australian study of general breast cancer survivors (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, & Wain, 2007). In addition, both samples reported nearly the same top 10 met needs, sharing eight in common, with the exception that respondents in the present study reported having access to other breast cancer survivors to talk to, and receiving emotional support, as would be expected. The two samples differed considerably in terms of their top 10 unmet needs, sharing only five in common. Specifically, the respondents in the present study reported unmet needs related to sexual problems, stress, body changes, ongoing symptoms and side effects, and decisional uncertainty that were not reported by the sample studied by Hodgkinson et al. (2007).

The unmet needs reported by the respondents in the present study reflect the deficits in functioning documented in a sample of breast cancer survivor peer support providers in the United States (Matthews et al., 2002) with the exception of stress and uncertainty. In comparison to other samples, the respondents in this study reported levels of perceived support similar to breast cancer survivors who participated in face-to-face of support groups (Grande, Myers, & Sutton, 2006) and levels of social network integration similar to breast

cancer survivors in general (Kroenke et al., 2006). It is unknown why they were unable to address some of these needs through their existing social networks, including their own support group. Perhaps they required a different source of supportive care for certain issues, such as a health professional or an online community. It is also possible that being a peer support provider contributed to some of their needs, given the demanding nature of the role (Price et al., 2006).

Nearly one-third of study respondents reported using online communities to address breast cancer related issues. The prevalence of online community use found in this sample is similar to that reported in a survey of online health consumers aged 50 or older in the United States (33%) (Fox, 2009). However, it is greater than the prevalence of use documented in a mixed sample of breast cancer, rheumatoid arthritis and fibromyalgia patients in the Netherlands (~21%, when calculated as a proportion of the study's online health consumers) (van Uden-Kraan, Drossaert, Taal, Smit et al., 2009).

Interestingly, the majority of survey respondents used online communities most frequently during and while recovering from treatment, prior to becoming a facilitator of a cancer support group. Online communities were used less frequently to address survivorship issues, and only 39.1% of survey respondents used online communities to help other survivors. It is unclear why online communities were less used frequently for these purposes. Perhaps as a result of the time involved in helping others, they neglected their own needs, or maybe online communities did not offer the right match of support. According to the Optimal Matching Theory (Cutrona & Russell, 1990), the effects of social support will be greatest if matched to the demands of the stressor and the profile of the support seeker. Although there

are numerous online communities for breast cancer survivors, there are no known online communities specifically for cancer survivors who are peer support providers.

The majority of respondents used online communities to meet their information and symptom management needs, and less so for emotional support. These findings confirm previous reports of the primarily informative as opposed to emotionally supportive role of online communities (Meier et al., 2007; Rimer et al., 2005). Perhaps more importantly, this study has identified the reasons breast cancer survivors may not use online communities. Beyond a lack of need, these included a lack of self-efficacy using Internet resources, trust in Internet resources, and self-efficacy using computers in general, or awareness of online breast cancer communities. These findings reflect many of the individual motivational factors that have been shown to influence Internet use for health information more generally (e.g., a positive outcome expectancy, previous use of health websites, positive Internet self-efficacy) (Mead, Varnam, Rogers, & Roland, 2003).

Many of the reasons for not using online communities identified in this study are consistent with the Technology Acceptance Model (TAM) (Davis, 1989) - the most widely used theory to explain the adoption and use of information technology (Holden & Karsh, 2010). The TAM asserts that attitudes toward using IT systems are determined by *perceived usefulness* and *perceived ease of use* of the system (Davis, 1989). The barriers to use of online communities identified in this study also reflect a lack of eHealth literacy – the ability to find, appraise and use health resources on the Internet (Norman & Skinner, 2006). An assumption underlying many eHealth resources is that consumers have the skills to use them optimally (Strecher, 2007). However, online health consumers may need support to find,

evaluate and apply information gained in online environments toward solving health problems (Norman & Skinner, 2006).

Practice Implications

The study provides specialized knowledge about the unmet supportive care needs of an understudied category of breast cancer survivor whom many might mistakenly assume are sufficiently well supported and without needs, given their role as support providers. The findings provide an impetus for the development and testing of interventions tailored to the unique supportive care needs of long-term breast cancer survivors who are providers of peer support. An Internet-based peer support intervention may be a useful strategy to consider given the high rate of Internet use for health purposes among this sample, the significant portion of individuals who reported using online communities, and that these individuals clearly value peer support and are often quite geographically disperse. In addition, the finding that 60% of users of online communities were active contributors (e.g., posters) holds promise for the success of such a resource, considering that the success of an online community is largely dependent on its activity (Preece, 2001). The main barriers to online community use identified in this study - namely a lack of awareness and limited eHealth literacy, could be remedied through support, outreach and education designed to enhance self-efficacy towards online resources.

Study Limitations

Support group facilitators and people who have actively sought support from a local agency (in this case Willow) are not necessarily typical of breast cancer survivors. Previous

research suggests that they may be better educated, include fewer minority groups and better adjusted (Matthews et al., 2002). These trends were reflected in the current sample, which was nearly all white, and college or university educated. In addition, their experiences likely differ from those who want peer support but do not know where to find it, or who do not seek it out for whatever reason, or who wish to be peer support providers but do not seek out the experience or opportunity. However, a comparison with other studies suggests that this sample is representative of cancer peer support providers in terms of their average age (56 versus, 59 and 60 years), years since diagnosis (5 or more), education (college-educated) and ethnicity (white) (Matthews et al., 2002; Stevinson et al., 2010). A significant proportion (37%) of study respondents lived in small towns with fewer than 10,000 people, which may have predisposed them to having greater support needs given the limited supportive care resources typically available in rural areas (Gray, James, Manthorne, Gould, & Fitch, 2004). Lastly, one might assume that since these individuals were associated with a national support agency that had its own online community, they may have more likely than the average breast cancer survivor to be exposed to online communities as a resource. However, the analysis revealed that the majority used online communities during treatment for breast cancer, which would have been before they attended a facilitator-training workshop (e.g., breast cancer survivors must be at least one year post-diagnosis to attend).

Research Implications

Research is needed to better understand the contextual and individual motivational factors that facilitate or discourage the use of online communities as a health resource, the relative importance of each of these factors and strategies to address them. This information

could improve the design and function of online health communities, potentially attracting a larger user base. At the same time, a better understanding of the role of online communities as one potential source of supportive care among many is needed. In this era of cost cutting, the potential for Internet-based resources to reduce the transaction cost of heath system encounter may motivate health system administrators to choose Internet-mediated care delivery options as a substitute for more traditional methods. However, online support resources are likely not for everyone. Understanding who uses which online communities, for what purposes and under what conditions is essential in order to tailor supportive care resources to the needs and preferences of individual breast cancer survivors.

Conclusion

Given the unique and pivotal function of peer support, breast cancer survivors may play an increasingly important role as supportive care providers. This study has demonstrated that two-thirds of long-term breast cancer survivors, known to provide peer support have ongoing needs most commonly related sexual problems, stress, survivor identity, fear of recurrence, and ongoing symptoms or side effects. Online communities were used as a source of supportive care, particularly around treatments for nearly one-third of respondents. Efforts should be made to address the supportive care needs of peer support providers and overcome barriers to their use of online peer support resources.

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Post-Script

Originally, this dissertation also planned to examine the factors associated with online community use. Specifically, the goal was to examine the relative importance of key demographic characteristics (e.g., age, education, income, size of city of residence), disease status (e.g., years since diagnosis), support variables (perceived social support and social network integration) and attitudes toward using online communities based on a decomposed Technology Acceptance Model/ Theory of Planned Behaviour (TAM/TPB) model in regards to online community use.

To address this objective, the following procedures were planned: 1) examination of the differences between users and non-users using t-tests for continuous variables and χ^2 tests for categorical variables; 2) assessment of the reliability and validity of the TAM/TPM model, that was tailored to examine attitudes toward use of online communities which had not been done previously; and 3) examination of the relative importance of the potential predictor variables using multivariate logistic regression. However, it soon became apparent that this was not the appropriate sample with which to conduct these types of statistical analyses, due to its size and composition.

Firstly, the sample was very homogenous, which would have made it difficult to detect differences if indeed they existed, increasing the likelihood of committing a type II error (i.e., failing to observe a difference when there in fact is one).

Secondly, the sample was small (n = 73), which limited the type and extent of statistical analysis possible. Previous research has confirmed that a total of 30 representative participants (Johanson & Brooks, 2010) or 25 people per group (Hertzog, 2008) are required for preliminary internal consistency testing. However, these samples are recommended when

checking the performance of an existing instrument with a new population. If the goal is to evaluate a new instrument, such a sample size may be inadequate due to the likely imprecision (e.g., large confidence intervals) of the correlation estimates. Confirmatory factor analysis is the recommended technique for investigating the internal structural and construct validity of a theory-based instrument (Di Iorio, 2005). However, reliable confirmatory factor analysis typically requires samples of at least 10 subjects per instrument item, and 200 subjects at minimum (Norman & Streiner, 2008). Multivariate logistic regression, which is the recommended technique to investigate the relative importance of predictor variables for a dichotomous outcome, also requires at least 10 subjects per predictor variable and 100 subjects at minimum (Norman & Streiner, 2008).

Thirdly, the TAM/TPB instrument was designed to measure intention to perform a particular behaviour. However, the majority of the sample did not need to use online communities or was not aware of online communities as a potential resource. For example, 48% of non-users reported that they had not used online communities because they had no need to do so, as their needs were sufficiently being met by other sources, and 20% of non-users reported that they had never heard of online communities. The majority of users reported that they used online communities most frequently during (74%) and shortly after (61%) treatment, and only 39% still used online communities at the time the survey was conducted. It may be more appropriate to examine the applicability of the decomposed TAM/TPB instrument as a tool to predict intention to use online communities as a supportive care resource among a sample of breast cancer survivors undergoing treatment who would have a greater need for supportive care resources in general, or a sub-group of long-term breast cancer survivors with greater supportive care needs.

Pilot studies can produce relatively imprecise and sometimes seriously biased estimates when based on inadequate sample sizes (Hertzog, 2008). Given the important limitations discussed, it was deemed not advisable to make conclusions based on this sample alone. Therefore, the preliminary internal consistency (reliability) analysis of the TAM/TPB measure and the comparative analyses of users *versus* non-users of online communities are included in Appendix 17 and 18 of this thesis as reference material only.

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8

Conditions that Influence Breast Cancer Peer Support Providers to Use Online Communities: A Qualitative Study

Abstract

Background: Online communities offer a convenient way to obtain supportive care from peers. Cancer peer support providers are in a unique position to provide insight on their role in relation to other sources of support.

Objective: To explore how, why and under which conditions breast cancer survivors who are peer support providers use online communities as a source of supportive care.

Methods: We conducted semi-structured interviews with a purposive sample of 12 breast cancer peer support providers recruited from a training program provided by a non-profit breast cancer support agency in Canada. Participants were on average 56 years of age and 6 years post-diagnosis, with diverse disease characteristics. Interview transcripts were analyzed using a descriptive, interpretive approach involving constant comparison methods and thematic content analysis.

Results: Online communities were used mainly as a problem-focused coping strategy to prepare for or decide on a course of treatment and to cope with symptoms and side effects. Participants turned to them during times of stress and uncertainty or because of insufficient local support specific to their condition. They were regarded as a unique resource due to their quality of information, reassurance from similar others, availability, anonymity, and limited commitment. Social support, health behaviour and technology adoption theories help to explain the conditions that influence their use.

Conclusion: Online communities may have the potential fill gaps in supportive care services by addressing the unmet needs of breast cancer survivors, particularly during periods of stress and uncertainty. Targeted, peer-led strategies are required to promote awareness of the usefulness of online communities as supportive care resources.

Introduction

Cancer survivors are rapidly increasing in number due to advances in screening and adjuvant treatment, with women with breast cancer forming the largest group of survivors (Rowland, Aziz, Tesauro, & Feuer, 2001). Addressing the needs of this growing population of cancer survivors has been identified as supportive care's new challenge (Alfano & Rowland, 2006; Surbone & Peccatori, 2006). Psychosocial interventions, particularly group-based therapy and peer support groups have shown great promise in meeting the supportive needs of cancer survivors (Gottlieb & Wachala, 2007; Hoey, Ieropoli, White, & Jefford, 2008). However, practical barriers such as time, mobility and geography limit their use (Owen, 2003).

Online communities can overcome many of these practical barriers, while providing additional advantages such as 24-hour accessibility, anonymity, diversity of resources and access to a greater number of people with similar disease experiences (Wright, 2002). Online communities are "virtual social spaces where people come together to get and give information or support, to learn or to find company" (Preece, 2001). They are supported by web-based software such as electronic mailing lists and message boards, and more recently, blogs, wikis and social network sites (Bender, O'Grady, & Jadad, 2008), and they can be consumer or professionally led.

Numerous qualitative studies have revealed that online communities can enable the disclosure of sensitive and potentially stigmatizing topics; provide reassurance, a sense of community and hope for the future; reduce feelings of stress and uncertainty, and validate concerns ignored by health care professionals; and enable breast cancer survivors to become better informed and able to cope with their condition and prepared for their interactions with

the health care professionals (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Rogers & Chen, 2005; Sharf, 1997; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; van Uden-Kraan et al., 2008; Vilhauer, 2009).

Research on the effects of online communities among breast cancer survivors has produced mainly positive results. Two randomized controlled trials (RCTs) of a professionally-led, message board-based multi-dimensional support system resulted in higher perceived social support, information and health care competence (Gustafson et al., 2001; Gustafson et al., 2005). One RCT of three separate professionally moderated, e-mailing discussion lists resulted in reductions in depression and perceived stress (Winzelberg et al., 2003). The only known RCT of an unstructured, un-moderated mailing list produced conflicting results (Salzer et al., 2010). Although participants experienced a non-significant increase in distress and decreased emotional well-being over time, the majority reported feeling supported by the intervention, a sub-group of whom created their own mailing list at the end of the study.

It is clear from these studies that online communities could be a useful resource for breast cancer survivors with numerous empowering and psychosocial benefits. However, they also suggest that online communities may not be universally beneficial. A better understanding is needed of how and why people use online communities as a health resource and how they compare to traditional sources of supportive care. The findings from one study that examined the support gained from online communities compared face-to-face support groups among a sample of 1,039 breast cancer survivors in Japan (Setoyama, Yamazaki, & Nakayama, 2010), suggests that online communities may function as a different and complementary source of support. Users of online communities scored higher for emotional

expression and advice, while users of face-to-face groups scored higher for emotional support and insight/universality, and those who used both resources reported receiving the most support overall.

Understanding the context of use is central to understanding the significance of online resources among specific user groups (Henwood, Wyatt, Hart, & Smith, 2003), and could shed light on the factors that lead to their effectiveness. Cancer peer support providers are in a unique position to provide insight on the role of online communities in comparison to traditional sources of supportive care. As the "frontline of psychosocial care for cancer survivors", understanding their perspectives is key to creating effective supportive care services (Owen, Bantum, & Golant, 2009). Therefore, the purpose of this study was to explore how, why and under which conditions breast cancer survivors who are peer support providers use online communities as a source of supportive care, and to explore the usefulness of theory in explaining use.

Methods

Study Design

This study draws from multiple research designs. It is based on the approach "fundamental qualitative description" (Sandelowski, 2000), which aims to produce a comprehensive summary of a phenomenon in the everyday terms of that event. Qualitative descriptive studies seek to achieve a thorough understanding of the "facts" of an event (e.g., who, what and where), as well as the meaning participants give to those "facts". This study departs from pure qualitative descriptive studies in its theoretical interpretation and discussion of the findings. Using constant comparison methods of analysis commonly used in

grounded theory (Charmaz, 2000) we examined the utility of social support, health behaviour and technology adoption theories in explaining the relationships among key themes and concepts. The use of multiple methods is in keeping with philosophical underpinnings of qualitative research, which has been described as "not produced from any pure method, but from the use of methods that are variously textured, toned and hued" (Sandelowski, 2000). This study is therefore both empirically and theoretically driven.

The study was reviewed and approved by the University of Toronto Research Ethics Board. Full informed consent procedures were followed.

Participants

Study participants were recruited from the preceding survey examining the supportive care needs of breast cancer survivors and their use of online communities. The sample for the survey was drawn from the 2008 and 2009 contact list of the attendees of a support group facilitator-training program conducted by Willow Breast Cancer Support Canada, a national non-profit support agency. Willow provides free workshops for breast cancer survivors to help them start and sustain support groups in their local communities. The program is promoted widely across Canada *via* a series of channels (e.g., hospitals, cancer centres, community based support programs) and attended by current facilitators seeking to enhance their skills and facilitators-in-training who are planning to start a support group. Attendees must be at least one year post-diagnosis to participate.

Participants recruited for the present study were survey respondents who had used an online breast cancer community and who agreed to participate in a follow-up interview. We aimed to achieve a maximum variation sample of individuals with different

sociodemographic, disease and treatment characteristics, levels of experience with Internet technology and who had used online breast cancer communities as a source of supportive care to varying extents. The sample size for this study was not fixed or predetermined, but rather determined by the saturation point of the data. Recruitment ceased when the information collected from a sufficiently variable sample became repetitive across individuals, and new themes no longer emerged (Lincoln & Guba, 1985). This occurred after 12 participants were recruited.

Data Collection

Each participant took part in one 60 to 90 minute semi-structured interview, conducted face-to-face (n = 1) or by telephone (n = 11), and completed a survey online (n = 4) or by postal mail (n = 8). The interviews were audio-recorded, transcribed verbatim and conducted by the same investigator (JLB) to ensure consistency and reliability of the information collected.

Interview participants were asked to talk about how they became aware of online communities, what motivated them to seek support from an online community and what if anything they felt they had gained from participating in them. They were asked to talk about what they liked or disliked about online communities, and what motivated them to continue or discontinue using them. Lastly, participants were asked to discuss how, in their opinion online communities compared to other sources of supportive care (such as their in-person support group, their health care professionals, or other types of online resources such as Facebook) and what role they played for them personally.

The interviewer took detailed notes during the interviews about how the participants

described using online communities, paying particular attention to any discussion of contextual, personal or website features that may have encouraged or discouraged their use. Clarification probes and follow-up questions were used to elucidate and explore issues in greater depth and to verify understanding of the information being collected (Graneheim & Lundman, 2004). As appropriate in qualitative research, new questions were developed and included in successive interviews as new issues and themes emerged (Giacomini & Cook, 2000; Mays & Pope, 2000). Data collection and analysis were simultaneous and iterative lending further credibility to the data.

Data Analysis

Data from the transcribed interviews were analyzed using a qualitative descriptive interpretive approach combining thematic content analysis (Graneheim & Lundman, 2004) and constant comparison methods (Miles & Huberman, 1994) facilitated by QSR NVIVO 8.0 data management software. Each transcript was carefully read, and re-read, a provisional coding scheme was constructed based on emergent concepts derived from the data and the transcripts were subsequently coded in an iterative manner using these codes and adding new ones as new data was encountered. Three randomly selected transcripts were independently read and coded by a team member experienced in qualitative research methods (HO) to ensure consistency and reliability of the coding procedure (Giacomini & Cook, 2000; Mays & Pope, 2000). Independent coding results were compared, resulting in minor modifications to the coding scheme, which were applied to the entire data set. Codes were sorted into categories and the underlying meaning of the categories was formulated into a theme in consultation with the second coder to ensure consistency of interpretation (Graneheim &

Lundman, 2004). The coded data was subsequently re-arranged with accompanying text into comparative tables (Miles & Huberman, 1994) to contrast the participants' views and experiences (this allowed for the examination of concepts and themes across the whole data set and in the context of each person's interview). The use of comparative tables also allowed for the examination of descriptions or events that run counter to emerging propositions or hypotheses (e.g., negative cases), and can be used to refine them. Lastly, the selected theories were used as conceptual frameworks to guide the interpretation and discussion of the study findings.

Results

Participant Characteristics

As shown in Table 1, the sample comprised women with a range of disease characteristics, but relatively similar sociodemographic status. Seven participants reported having less common disease characteristics, three of whom were diagnosed with a hereditary form of breast cancer (e.g., BRCA gene mutation), one with triple negative breast cancer, one with inflammatory breast cancer, and two reported having co-morbidities (e.g., Paget's disease).

Although participants reported using the Internet daily (as shown in Table 1), the interviews revealed that the majority did not consider themselves experienced computer users. More than half (n = 7) had not used an online community for any reason prior to being diagnosed with breast cancer. Those who had used online communities previously (n = 5) did so for work, academic or leisure reasons, but not for personal health reasons.

Table 1: Participant Characteristics

Characteristic	n (%)
Age	
40-49	4 (33.3)
50-59	4 (33.3)
60-69	3 (25.0)
70+	1 (8.3)
Place of birth	
Canada	11 (91.6)
Ethnicity	
White	12 (100.0)
Relationship status	
Single	2 (16.7)
Married, in a relationship	10 (83.3)
Education	
College/ technical degree	6 (50.0)
University degree	6 (50.0)
Household income	
$40,000 or less	3 (25.0)
$40,001 to $80,000	5 (41.7)
$80,001 or more	4 (33.3)
City Size	
Fewer than 10,000 persons	4 (33.3)
10,001 to 99,999 persons	5 (41.7)
100,000 or more persons	3 (25.0)
Years since diagnosis	
Less than 5 years	7 (58.3)
5 to 9 years	4 (33.3)
10 or more years	1 (8.3)
Recurrence	1 (8.3)
Treatment status	
Undergoing treatment	1 (8.3)
Completed treatment, but on HRT	5 (41.7)
Completed all treatment	5 (41.7)
Internet use	
At least once per day	10 (83.3)
At least once per week	2 (16.7)
Use of Facebook	7 (58.3)

Factors that Influenced First Time Use

The majority of participants (n = 7) discovered breast cancer online communities accidentally, while in the process of searching for information on the Internet to address a specific need. Most of these individuals were not seeking peer support per se, either because they were not aware that it existed online or because they had not formulated the type or

source of support that they preferred. For example, participant F204 explained:

> Well I didn't really know about them. I just sort of Googled some of the symptoms that I was having and one of the sites that came up happened to be a chat line. There isn't really anything out there that says these support groups are online. I didn't know where to get them, I just, like I said, stumbled upon it.

The remainder (n = 5) learned about online communities through an unsolicited recommendation from a member of their informal support network, most often a family member, fellow breast cancer survivor or support group member. Only one person reported learning about breast cancer online communities from a health care professional.

Perceptions of their Trustworthiness

The majority of participants expressed concerns about the quality of information on the Internet, and the potential for deception and threats to their privacy when engaging in online activities. However, participants viewed breast cancer online communities as trustworthy based on the content, quality, currency and empathic nature of the postings and the belief that people who used breast cancer online communities were likely to do so for genuine reasons. A few women described being uncertain about the trustworthiness of online communities when they first contributed a post. Receiving a supportive response from another community member reassured them that "these are good people" and motivated them to post again. For example,

> F108: When I did put something in, somebody wrote back. They were really supportive and I was like well this isn't so bad. This is kind of nice. And I got that good feeling and then I thought well okay I could try this out again.

At the same time, participants acknowledged that not all information contained in online communities was of the same quality, and that the onus was on the individual to judge its credibility and relevance. However, all women perceived themselves as a capable of deciphering good from bad information in online communities. Some women described this as akin to what would be required in a face-to-face support group. For example:

> F75: You know what. I see it as just as valid… or just as credible or not credible as talking to somebody, or going to a support group. I kind of lump them all together. Like you are getting personal experience and testimony. So you sort of never really know. You have to be the judge in the end of what you think is good. Although I have to say that the quality of information that I found has been pretty high.

Extent of Use and Context of Use

Participants turned to online communities as a source of support to address an unmet need, in many cases during times of stress and uncertainty, or because local support, specific to their condition was lacking or insufficient. They were described as a major source of support for five participants, a temporary gap-filler for four participants, and a minor resource for three participants. Three typical use case scenarios are depicted in Table 2.

Table 2: Use Case Scenarios

Source	Description	Quote
Major	For participant F201, online communities became a major source of support primarily because she had an existing condition that put her at greater health risk from breast cancer treatment. As a result, her treatment course was not straight forward and she could not find anyone locally who shared her particular experience or condition.	"It was just such wonderful support for me at the beginning when I was wondering about whether I should even have the surgery or if I should go on the chemo route, um you know there was dispute about that because I had pancreatitis and a lot of the things that are recommended would probably kill me.... You know as time went on I needed that less. But when I needed it badly I had it."
Gap-filler	For participant F108, online communities were a gap filler. They were an important resource when she lacked access to local information or support. However, once she was introduced to sources of face-to-face support locally through a new treatment centre, she used online communities less often.	"I'd say about forty percent. I think um being actually at the clinic and talking with other patients was most helpful... and the women in the car pool... and the counselor in the clinic... I found that once I started that connection [with a new treatment centre] I would go online but not as often."
Minor	For participant F75, online communities were a minor source of support. They functioned to meet her needs in times of stress and uncertainty. In particular, she spoke extensively about the benefit and importance of being able to obtain an immediate response to an urgent need from online communities.	"I would say that only small piece of support that I got was through online social networking. The pattern would be around treatments that affected my appearance like loosing my hair or having a mastectomy, that were very anxiety provoking experiences."

Less Common Conditions or Experiences

All five participants who described online communities as a major resource had a particular type of breast cancer or condition that was less common (e.g., inflammatory breast cancer, triple negative breast cancer, BRCA mutation), or a particular treatment experience that was less common (e.g., significant side effects from chemotherapy and radiation treatment that required hospitalization). In addition, these five participants had found an online community that met their specific needs. This latter point differentiates these women from the two participants who also had a less common type of breast cancer or existing co-morbidity, but did not consider online communities to be a major source of supportive care.

Lack of Local Support including from Health Care Professionals

Many participants complained of a lack of attention paid to symptom management and to follow-up care, and were dissatisfied with the quality of information provided to them by their physicians. At the same time, several participants did not regard their physicians as the best source of information on how to prepare for treatment or manage symptoms and side effects. Several participants had the impression that physicians were not supportive of online patient communities; some had been told by their physicians not to trust them. However, the perceived negative physician view did not deter these women from using online communities as a source of supportive care.

Specific Reasons for Use and Needs Met by Online Communities

Participants described using online communities primarily for two specific reasons: to prepare for or decide on a course of treatment, and to learn how to manage or cope with symptoms and side effects. They described using online communities much less frequently once they had completed and recovered from treatment because they had less need for them.

Preparing for and Choosing Treatments

All but two participants reported seeking support from online communities to prepare for treatment. The two women who did not were introduced to online communities after they had completed treatment for breast cancer. In contrast, only those women who had an uncertain treatment course, or were averse to a particular type of treatment used online communities to decide on a course of treatment. All participants explained that they were

looking for highly detailed information that would help them understand exactly "what to expect" leading up to, during and after treatment:

> F75: Well, I remember going to FORCE and Hystersisters in anticipation of having a hysterectomy and oopherectomy. And wanting to find out like what is it really like, how can I prepare myself, what do I need to know and sort of going for that information.

Coping with Symptoms and Side Effects

Participants used online communities to help them understand why they were experiencing a particular symptom or side effect, and to learn how to manage it effectively. Many were seeking reassurance that theirs was a typical or normal experience and not indicative or something worse, such as a disease progression. For example:

> F203: I wanted to find out what bone metastases ... what that pain felt like... whether it was sharp or dull and if other people had experienced it after their radiation. I just wanted to know if I was heading down a road where I was going to look at bone metastases or whether it was just the recuperating from the radiation... if anyone else had felt the same way.

Beyond Cancer

During this new phase of cancer survivorship the main factors that motivated participants to use online communities were the experience of a new or worsening symptom, the need for subsequent treatment, to support other community members, or to obtain current information. Nearly all women described reaching a point at which they wanted to move beyond cancer, and this included distancing themselves from their online community. For example:

F77: Well actually I'm kind of in a place right now that I didn't anticipate after only five years. I'm realizing how my concerns, my focus is turning and I'm finding that I'm starting to pull away. I'm not quite ready yet to leave the [mailing] list because of the information... but um I didn't anticipate being here at this five year junction. But I'm finding that maybe it's a natural progression for most people.

Benefits in Relation to Other Sources of Supportive Care

Online communities seemed to play a distinct and important role for all because of their quality of information, reassurance from similar others, availability, anonymity, and limited commitment. As one woman described:

F203: It's a fabulous, incredible website with incredible support. In fact I think I was bragging to my doctor about that website. To him he thought it was ridiculous and um I was telling him you have no idea the support systems that women have... any question I had was answered, any fear I had was reassured, um and I didn't have to seek out as much help.

A Rich Source of Information

Online communities were differentiated from all other forms of supportive care, including face-to-face support groups and health care professionals, based on the breadth and quality of information that they provided which was described as extremely detailed, relevant and practical. In fact, many participants explained that they used online communities strictly to meet their information needs, and relied on face-to-face contacts or support groups for emotional support. Many women explained that they often did not have to post a question to get an answer from an online community, because other people had already asked that same question, and the answers were there for them to read. The extent and quality of information

provided in online communities was contrasted with that which was provided by health care professionals, which was described by many as insufficient and lacking detail. As one woman, explained "the doctors don't tell you everything... the women who have been through it… they can tell you a different kind of information". As participant F59 described:

> Originally I went to them because I found that there was a lot of information that you could get online from other women who were going through it.... It's just a different, um, quality of information... It's more personalized. It's more of a supportive sort of thing… say you have fatigue everyone's around saying that they hear you and that they have fatigue too um plus you can get tips that perhaps might not be on the medical site for a specific brand of uh perhaps a cream or something to use.

Reassurance from Similar Others

Nearly all participants described online communities as means to obtain reassurance and practical support from women who "had been through it and were on the other end of it". Many women explained that they were seeking others with as similar circumstances and experiences, as possible, as one woman [F75] put it, "As similar as I could get… I wanted to talk to someone who had the same type of surgery but also someone who had young kids". As one woman [F30] explained, "there is a tremendous gap between what people who haven't had it think they know and what actually happens to you". All women were seeking reassurance that their experiences were normal or typical and not indicative or something worse, such as a disease progression. For example:

> F202: A lot of the time you've got very panicky women that are on these sites and the older ones who might have been at a it for a few months reassure them so in a way I was being reassured even though they weren't talking to me but they were talking to people who were like me so that's why I never really needed to post or to tell my story personally because it was easy to find me uh there was always someone like me

and uh asking the same questions.

Availability

Nearly all participants commented on how useful it was to have a resource that they could use *when they most urgently needed it*, in the convenience of their home and at any time of day, as opposed to when or where it was convenient for someone else to provide it. Participants explained that face-to-face support groups usually meet only once per month, most support agencies provide services on a conditional basis or during certain time periods, and that it takes time to obtain an appointment with a physician, whereas one could get a response to a question from an online community almost instantly. For example:

> F34: Well, it's so accessible. If you have to book an appointment with someone and you can't deal with it when you're ready to deal with it you know what… I mean you have to wait… by going online it can be immediate.

Anonymity

Nearly all participants described online communities as offering a safe forum where they could discuss sensitive issues without risk of stigma or embarrassment, such as "really nasty side effects", sexuality and death --- topics that were difficult to discuss in face-to-face support group. Others explained that even disclosing a breast cancer diagnosis to one's personal support network could be difficult, as it could lead to negative consequences, and a loss of control over how other people viewed them or treated them. For example:

> F204: So what I liked about it was... it was safe to be talking to someone that doesn't really know you. Whereas I live in a small town, so to talk to friends, not that they would intentionally tell my secrets, but they might do something I didn't want them to do. This was safe... there was nobody going to get back to me if I didn't want them

to and I could be fully open and not worry about the consequences.

However, online communities were not regarded equally. Nearly all participants explained that they would be uncomfortable discussing breast cancer related issues on Facebook because of its perceived accessibility, popularity and lack of privacy.

Limited Commitment

Several participants explained that online communities offered a less emotionally demanding and low commitment form of support than face-to-face support groups. Participants explained that they could join an online group, obtain the information or support they needed and leave without having to reciprocate or incur any consequences. This was contrasted with face-to-face support groups and less anonymous online resources such as Facebook, which were perceived as affording them less control over the interaction. For example, it was explained that although one did not have to return to a face-to-face support group if one did not want to, members of the group would likely try to encourage the person to return and she could potentially run into them in public places. Likewise, if one disclosed her breast cancer diagnosis on Facebook, she could be at risk of unwanted contact from others. For example, F77 explained:

> Like the thing about going on a chat group is that I can get in, I can get out… there is no larger commitment. Other than me going online and typing a few sentences and if I don't want to do it anymore, I just leave. And nobody is going to keep emailing me or contacting me.

Limitations of Online Communities as a Source of Supportive Care

Not the Same Type of Connection

The majority of women described feeling more emotionally connected to women in their support groups than they did with the members of online communities. A few women suggested that it was easier to build relationships with people in their support groups because of the regularity of support group meetings and the continuity of membership, whereas online they could be speaking to a different person each time. A few women described becoming emotionally connected to members of their online communities. These participants used a specific online community regularly (e.g., daily), were able to find someone in that online community with whom they shared something in common, and shared personal information. One participant explained that some of the women in her support group with late-stage disease were able to develop more supportive relationships with women in online communities:

> F104: I have a couple of women in my group that are terminal right now that are still coming to the group meetings but they've said that they had uh developed some friendships online with women. Because they've talked to women that are uh that are also terminal and that have a lot of the same problems. So they can connect to those women.

Dependent on Empathic Communication

Some woman reported that not all communication in online communities was supportive and when it was not, it led to misunderstandings. However, one woman [F202] explained that, "for most people who posted... there were caring people that were ready to answer them". Many participants cited that a lack of visual cues caused misunderstandings since it limited their ability to understand the emotional tone underlying a post. The

participants explained that posts could be misconstrued as uncaring depending on the language the poster used. A few others described incidents where negative views or experiences triggered backlash from the community that aimed to silence the un-welcomed perspective. In some cases, this caused the poster to leave the community as participant F59 explained:

> When I got my first recurrence I wrote to them and I said you know triple negative isn't really great guys. It's got a fifty seven percent mortality rate after within five years and you know it does come back, and it came back to me and you know you should be aware of this. Anyway, I was seriously flamed... how could I possibly do this and I was scaring all these little newbies and we can't let them know about this and oh my god and so obviously I didn't get what I wanted from that site and I haven't gone back"

Not for the Disconnected

Although nearly half of the participants were experienced computer users, and those who were not, were able to learn how to use online communities with relative ease, many reported that a lack of computer skills would likely prevent other breast cancer survivors from using online communities. Many perceived online communities to be more suitable or preferred by "the younger ones", or those who were 50 years of age or younger, who were considered to be more technologically savvy and more regular users of the Internet. As participant F75 explained:

> You know I think some of it, or a lot of it has to with people's acceptance or like how comfortable they are with technology, support group aside. Like I think a lot of your acceptance or barriers or obstacles to it have to do the technology and not the support group itself.

Discussion

Online communities were used predominantly to prepare for or decide on a course of treatment and to cope with symptoms and side effects during and beyond treatment. Although used to varying extents depending on the individual's needs and circumstances, online communities were regarded as a unique and important supportive care resource by all because of their quality of information, reassurance from similar others, availability, anonymity, and limited commitment. They were considered limited in their ability to facilitate an emotional connection and their potential for misunderstandings due a lack of visual cues. These findings generally corroborate those of other studies that have identified the primarily information oriented role of online communities (Meier, Lyons, Fyrdman, Forlenza, & Rimer, 2007) and the advantages and disadvantages of the Internet as a communication tool (Hoybye, Johansen & Tjornhoj-Thomsen, 2005; Rosmovitz & Ziebland, 2004; Sharf, 1997; Shaw, McTavish, Hawkins & Pingree, 2000; Wright, 2002; Wright & Bell, 2003).

Perhaps most importantly this research has revealed the reasons (e.g., unmet information and support needs) and conditions (e.g., uncertainty and anxiety) that may influence breast cancer survivors to use online communities. These findings confirm recent research demonstrating that unmet information and support needs predicted time spent using a message-board based multi-dimensional support program (Lee & Hawkins, 2010). They also reinforce previous research that has implied that the use of online communities may represent an active coping strategy. A content analysis of the postings in 10 different cancer mailing lists over a five-month period revealed numerous examples of active coping behaviours, and encouragement from other community members to employ active coping

strategies (Meier et al., 2007). In addition, a recent survey with users and non-users of cancer online communities, demonstrated that lower socioeconomic status and cognitive avoidance, a form of passive coping was significantly associated with non-use (Hoybye et al., 2010).

Although previous studies have used stress and coping theories to explain the effects of online communities among breast cancer survivors (Davison, Pennebaker, & Dickerson, 2000; Gustafson et al., 2001, 2005; Meier et al., 2007; Winzelberg et al., 2003; Wright, 2002), and technology adoption theories to explain intentions to use non-health related online communities (Lin, 2006), no known studies have used these theoretical perspectives in combination for this purpose. In addition, the empirical research on the advantages and disadvantages of online health communities has been mainly atheoretical. Accordingly, four theories were purposefully selected with which to compare and explain the study results. Table 3 provides a list of the constructs from each of these theories, the corresponding findings from the interviews and practical implications.

Table 3: Theoretical Findings and Practical Implications

Construct (Theory)	Study Findings	Factors that influenced use:
Upward comparisons (SCT)	Participants described using online communities to gain guidance and reassurance from similar others particularly if local support, specific to their condition was lacking or insufficient.	-To find others who share specific characteristics -To find similar others who are doing well -To limit exposure to those doing poorly
Problem-focused coping (S&CT)	Participants described using online communities to address unmet needs particularly during times of stress and uncertainty.	-To obtain practical answers to questions -To obtain a timely, supportive responses -To reduce anxiety and uncertainty
Perceived usefulness (TAM)	Needs drove participants to use online communities, and they were described as useful based on the extent to which they addressed their specific needs in a safe and reassuring manner.	-To obtain detailed information on specific topics (e.g., treatment options and side effects) -To obtain reassurance from similar others -To obtain understanding and mutual support
Perceived ease of use (TAM)	Participants found online communities easy to use, despite having limited previous experience with social media. However, technological barriers were perceived as a potential barrier to use for other less experienced computer users.	-Easy to log-on and set up an account -Easy to navigate and find specific information -Easy to post a comment and view the response
Perceived trust (TAM/TPB)	Participants had concerns about the trustworthiness of information on the Internet. However, they regarded online communities as trustworthy based on their perceptions of the credibility of the message and the source.	-To find well written, accurate and current messages -To receive empathic and supportive responses -To be reassured of the credibility of the site owner -To protect privacy and confidentiality
Subjective norms (TPB)	The opinions of breast cancer survivors were an important factor that influenced use, while the opinions of health care professionals, which were generally regarded as negative, did not deter use.	-Opinions of relevant others (e.g., survivors) regarding their usefulness -Opinions of relevant others (e.g., survivors) regarding its credibility
Behavioural control (TPB)	Many participants described themselves as lacking technological know-how and computer skills. However, they described themselves as capable of identifying credible information and described incidents that would have facilitated the development of self-efficacy vicariously.	-Verbal persuasion from other survivors -Opportunities to observe how others use online communities (e.g., lurking) -Perceived ability to identify credibility information online

Social Comparison Theory

Social Comparison Theory asserts that under conditions of threat and uncertainty, people seek similar others in order to compare the appropriateness of their thoughts, feelings or behaviours (Festinger, 1954) Previous research has demonstrated that while cancer patients frequently make downward comparisons to enhance their self-esteem, they prefer to

make upward comparisons with others who have overcome threatening circumstances or adjusted well to them, avoiding those who are doing poorly (Taylor & Lobel, 1989). This study confirms these findings. Many of the participants sought support from online communities during times of stress and uncertainty, and they reported looking for practical information and reassurance from women who "had been through it and were on the other end of it". Reading stories of women who were worse off influenced some participants to withdraw from an online community, as has been reported in other studies (Sandaunet, 2008)

Stress and Coping Theory

The Transactional Theory of Stress and Coping suggests that support from peers can promote coping efforts and lessen negative appraisals of events, which in turn reduce or buffer anxiety (Lazarus & Folkman, 1984). Seeking information and making upward comparisons, have been described as active or problem-focused coping strategies, whereas seeking emotional support and making downward comparisons, reflect passive or emotion-focused coping strategies. As discussed, the participants mainly used online communities to obtain information, a common problem-focused coping strategy. Seeking information is considered a form of cognitive control and means to gain mastery or control over an event (Lazarus & Folkman, 1984). However, the availability, anonymity and low commitment afforded by the medium served to further enhance the participants' sense of control over their situations. Coping strategies that enhance perceptions of control are an important element in the process of adjustment to cancer (Taylor, 1983).

Technology Acceptance Model (TAM)

Whether or not an individual chooses to use online communities as a method of coping depends on their beliefs about online communities. The TAM asserts that attitudes toward using IT systems are determined by their *perceived usefulness* and *perceived ease of use* (Davis, 1989). In the present study, unmet needs drove the participants to seek support from online communities and this led to the resource as being described as beneficial based on their usefulness in meeting participants' specific questions or concerns. If a particular online community did not address participants' needs in a timely manner, many sought support elsewhere. The perceived usefulness of the online community was more critical than its ease of use, and a perceived lack of computer skills or Internet experience did not represent a barrier to use. Similarly, Sandaunet (2008) reported that breast cancer survivors' use of online support groups was contingent on their needs and was not influenced or limited by their perceived lack of Internet experience. These findings reflect the literature on technology adoption, which has shown that the relationship between perceived ease of use and intention is less consistent and to a large extent mediated by perceived usefulness (Taylor & Todd, 1995).

The Theory of Planned Behaviour (TPB)

The TPB maintains that intentions to perform a health behaviour are influenced by 1) *attitudes* toward performing the behaviour, 2) *subjective norms* associated with the behaviour and 3) *behavioural control* to perform the behaviour (Ajzen, 1991). Lin (2006) tested the application of a combined TAM/TPB model to explain the use of general-purpose online communities (not related to health), and found that attitude (decomposed *as perceived*

usefulness, ease of use and trust) and perceived behavioural control were significant predictors of intention, while subjective norms were not. Our findings suggest that perceived usefulness, trust, and the opinions of other cancer survivors are important factors that influence use while the dynamics of perceived behavioral control is less clear. All participants described themselves as capable of finding and appraising information in online communities. It is possible that some developed the confidence to use online communities through verbal persuasion from important referents, or by observing how others used them (e.g., two participants described lurking before posting to observe the dynamics of the community) -- two common ways to develop self-efficacy, or confidence in performing a particular behaviour (Bandura, 1997).

Practice Implications

These findings suggest that online communities have the potential to address many of the unmet supportive care needs of breast cancer survivors, in a way that may not be available elsewhere, even for the unfamiliar user. They also provide further evidence that breast cancer survivors are able to find the information that they need on the Internet, and that they have the skills to evaluate what they find (Eysenbach & Kohler, 2002; Rozmovits & Ziebland, 2004). Perhaps most importantly, this study highlights the reasons and conditions that motivate breast cancer survivors to use online communities. In doing so, this study provides both a framework to understand the context of online community use by patients, and strategies to improve their design and function, potentially attracting a larger user base.

Limitations

Support group facilitators or those who have actively sought support from a local agency are not necessarily typical of cancer survivors in general. Their views and experiences may differ from those of people who may want support but do not know where or how to find it, or do not seek it out for a variety of reasons, as well as those who choose not to give back. All participants in this study were recruited from the contact list of a local breast cancer support agency, which may have limited the range of participants. No participants in this study were from a visible minority, and the majority spoke English as a first language. In addition, the study design and method of data collection may have skewed the sample towards individuals who find it easer to talk about being a breast cancer survivor or who have had more positive experiences with online communities. Fortunately, given that we were seeking a maximum variation sample, the final sample comprised breast cancer survivors with a range of disease characteristics and experience with Internet technologies.

Research Implications

This research suggests that a multi-theory perspective may be required to understand the reasons behind the use of online communities as a supportive care resource. Further research is required to identify the relative importance and comprehensiveness of these theories in determining intentions to use online communities. This study could inform the development of measures to assess these constructs. Lastly, research is warranted to understand how online communities could be used to more effectively discuss bad news, hopelessness, despair and death. Although our findings provide evidence of the ability of online communities to address these sensitive issues, they also confirm previous research that

has observed a dominant 'restitution narrative' in online breast cancer spaces (Orgad, 2006) - one that emphasizes a positive attitude and outcome.

Conclusion

Online communities have the potential to fill gaps in supportive care services by addressing the unmet needs of breast cancer survivors in a way that may not be available elsewhere, particularly during periods of stress and uncertainty. Targeted, peer-led strategies are required to promote awareness of the usefulness of online communities as supportive care resources, and to overcome barriers to their use. Further research should examine the use of online communities among typical breast cancer survivors.

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9

General Discussion and Conclusion

Introduction

There is a pressing need to identify cost-effective, sustainable strategies to delivery timely, relevant and quality supportive care to the growing population of cancer survivors (Institute of Medicine [IOM], 2005). This dissertation has contributed to the advancement of existing knowledge on the role of consumer-driven, web-based approaches which have the potential to overcome the fragmented nature of cancer care, at reduced costs and without professional involvement (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006; Strecher, 2007). In doing so, it offers innovations in theory, practice and methodology that contribute to multiple research fields and sub-disciplines simultaneously, namely: psychosocial oncology and survivorship care; eHealth and consumer health informatics; and health behaviour and health education. This final chapter discusses the significance of this dissertation, and its implications. Study limitations, and directions for future research will be presented, followed by a concluding statement.

Major Findings

This dissertation adds to multiple bodies of literature in a number of important ways. The review of online peer support resources produced the first known systematic review and characterization of online community resources for patients. This study revealed that there are numerous and diverse peer support options available for breast cancer survivors on the Internet (n = 111), with extensive archives of personal health experiences (e.g., one third had over 100,000 posts each) that are predominantly (69.5%) moderated and maintained by site staff or volunteer community members with little or no professional input. It also identified the online breast cancer communities that are the most popular.

The content analysis of Facebook groups is the second known investigation of the health related use of the most popular social network site in existence. This study demonstrated that while Facebook groups have become a popular tool for awareness-raising, fundraising and support-seeking related to breast cancer attracting over 1 million members, a minority (7.0%) of the 620 groups were created for supportive care purposes.

The survey represents the first known examination of the supportive care needs of cancer peer support providers, their use of online communities, and barriers to use. This study demonstrated that approximately two-thirds had unmet needs, most frequently (30 to 40%) concerning sexual problems, stress, survivor identity, fear of recurrence, and symptoms or side effects. Online communities were used as a supportive care resource by nearly one-third (31.5%) most often during and while recovering from treatment. Reasons for non-use included lack of need, self-efficacy, trust and awareness.

Lastly, the qualitative study represents the first known investigation of the conditions that influence people to use online communities as a health resource, and the second known study of their role in relation to other sources of supportive care. This study demonstrated that online communities offer breast cancer survivors a unique source of supportive health information. Unmet needs drove the participants to use online communities particularly during periods of stress, uncertainty or insufficient local support.

As a collection these studies advance understanding of the scope and nature of online communities, their prevalence and nature of use, facilitators and barriers to their use, and function in relation to other sources of supportive care, from the unique and extremely insightful perspective of breast cancer survivors, who are peer support providers. The

significance and implications of these findings in the context of health care delivery are discussed in detail in subsequent sections of this chapter.

Theoretical Contributions

This dissertation offers important theoretical advances, particularly for the field of eHealth, and its sub-discipline, consumer informatics. As demonstrated in the qualitative study, when used in combination Social Comparison Theory (Festinger, 1954), Transactional Theory of Stress and Coping Theory (Lazarus & Folkman, 1984), Technology Acceptance Model (Davis, 1989) and the Theory of Planned Behaviour (Ajzen, 1991) provide a theoretical backbone for understanding the reasons behind the use of online communities as a source of supportive care, and the significance of the advantages and disadvantages of the medium in this context. None of the theories could alone account for the many individual, social, technical and contextual factors that affected their use. This dissertation suggests that multiple theories may be required to understand the acceptance and use of interactive health information technology by patients.

Figure 1 presents an integrated theoretical framework for understanding the conditions that influence breast cancer survivors to use online communities as a supportive care resource. This model is intended to illustrate the important role of online communities as a problem-focused coping strategy to obtain practical condition specific information to address an unmet need and in doing so reduce illness related anxiety and uncertainty, and enhance perceptions of control. Although online communities offer breast cancer survivors numerous opportunities to make social comparisons with similar others to judge the appropriateness of their thoughts, feelings and experiences, this dissertation suggests that

they are primarily used to make upward comparisons with breast cancer survivors 'who have been through it and are doing well'. Interview participants chose to use online communities as a coping strategy based on their beliefs about online communities, which were largely influenced by their perceptions of its credibility and usefulness, the opinions of other breast cancer survivors, and their self-efficacy to use them effectively.

Other researchers have concluded that multiple theories are required to understand the adoption, implementation and use of health technology systems by clinicians in clinical work environments (Karsh, Hamilton Escoto, Beasley, & Holden, 2006). As previously stated, there has been limited theoretically driven empirical work concerning the adoption and personal use of eHealth interventions by patients. This is the first known study to demonstrate the compatibility of multiple theories, specifically those from the stress and coping, and technology adoption literature in explaining the use of online communities for health purposes by patients. Further research is warranted to assess the efficacy, effectiveness and comprehensiveness of these theories in predicting and explaining the use of online communities, as well as other interactive health technology systems over which patients have volitional control. There are also other potentially applicable theories that warrant attention, particularly from computer-mediated communication theory. An example of which is The Uses and Gratification Theory of mass communication, which asserts that users are goal oriented in their media use and they seek media that best fulfills their needs (Blumer & Katz, 1974). [For a review of such theories and how they related to health related online communities, see (Wright & Bell, 2003).]

Figure 1: An Integrated Theoretical Framework for Understanding the Conditions that Influence Use of Online Communities as Supportive Care Resources
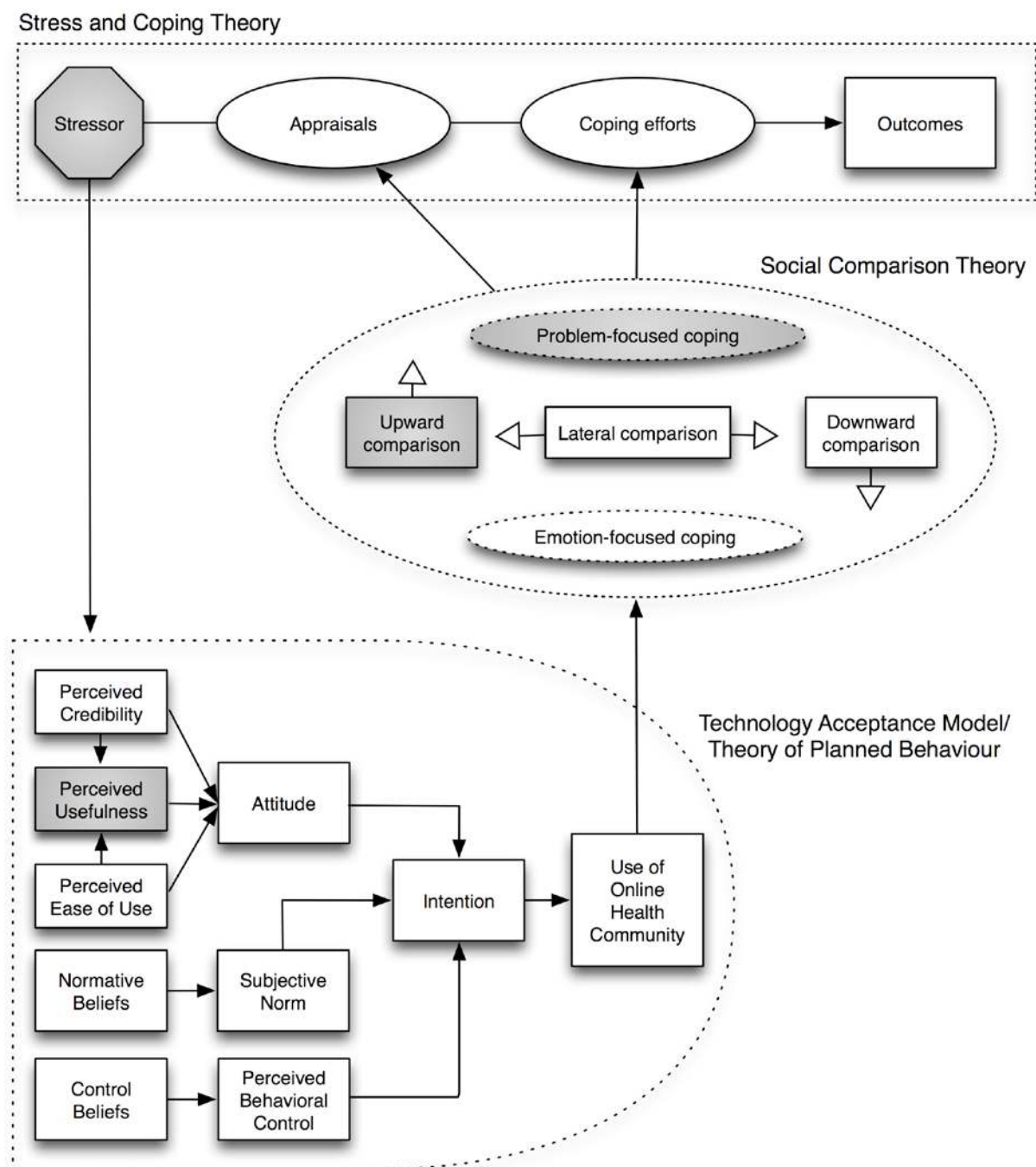
Methodological Contributions

This dissertation also offers important methodological contributions. Firstly, it represents the first known attempt to use systematic review methodology to identify, collate and assess online health resources. A recent series of papers published in PLoS Medicine called for a robust and scientific approach to the evaluation of eHealth applications (Bates & Wright, 2009; Catwell & Sheikh, 2009; Lilford, Foster, & Pringle, 2009). One argued for continuous and systematic methods to evaluate the effectiveness of eHealth interventions throughout their life cycle (Catwell & Sheikh, 2009). Developing rigorous methods to identify and characterize all relevant eHealth interventions is an important first step towards building an evidence base with which to assess their effectiveness. Although comprehensive, the inventory produced by this review is likely not exhaustive, and it is probably already out-dated given the rapid evolution of user-generated resources on the Internet. Both the inventory of online communities, and the method used to generate it should be regarded as a starting point for research and practice.

Secondly, this dissertation provides further evidence of the importance of using both quantitative and qualitative methods to achieve a more complete understanding of complex phenomena, such as the implementation and use of eHealth interventions. Different methods can address different questions and when used in combination can compensate for the limitations inherent in any single method (Creswell, 2003). Numerous eHealth researchers support this view, advocating iterative, multi-faceted and mixed methods throughout the life cycle of eHealth interventions (Catwell & Sheikh, 2009; Currie, 2005; Dansky, Thompson, & Sanner, 2006; Glasgow, 2007; Jadad & Delamothe, 2004; Kaplan, 2001; Lilford et al., 2009; Robinson, Patrick, Eng, & Gustafson, 1998).

Lastly, this dissertation confirms the critical role of qualitative methods for uncovering the individual and contextual factors that influence the use of eHealth interventions. If eHealth interventions are not "fit for purpose" (Car, Black, Creswell, & Pagliari, 2008) - that is if they do not fit the needs of end-users and their context of use, patients and health care professionals are unlikely to use them. Numerous reports of resistance, under-use, mis-use and abandonment of eHealth interventions support this claim (Catwell & Sheikh, 2009; Holden & Karsh, 2010). The inability of quantitative methods to adequately capture the human factors that determine their success has resulted in a move towards including more qualitative methods in eHealth evaluations (Currie, 2005; Lilford et al., 2009). Greenhalgh and Russell have gone one step further and proposed an alternative set of guiding principles for eHealth evaluation based on a critical-interpretivist approach that views evaluation as a social practice rather than merely scientific testing (2010). They argue that eHealth evaluations often fail to deliver because they fail to account for the complex, fast-moving, socio-political arena in which eHealth initiatives occur.

Discussion of Major Findings

To be effective supportive care must be tailored to the needs and circumstances of the individual (Fitch, 2000). This dissertation suggests that online communities could provide timely, relevant and personalized care to a broad range of breast cancer survivors, during and beyond treatment. As illustrated in Figure 9.2 online communities could serve as a source of general information about cancer and its treatment, which all survivors need; a source of peer support, which many desire; a source of personalized, condition-specific support, which

some survivors need; and they may facilitate access to specialized services which a minority

of survivors require.

Figure 2: Tiered Model of Supportive Care adapted from Fitch (2000) and Supportive Cancer Care Victoria (2011).
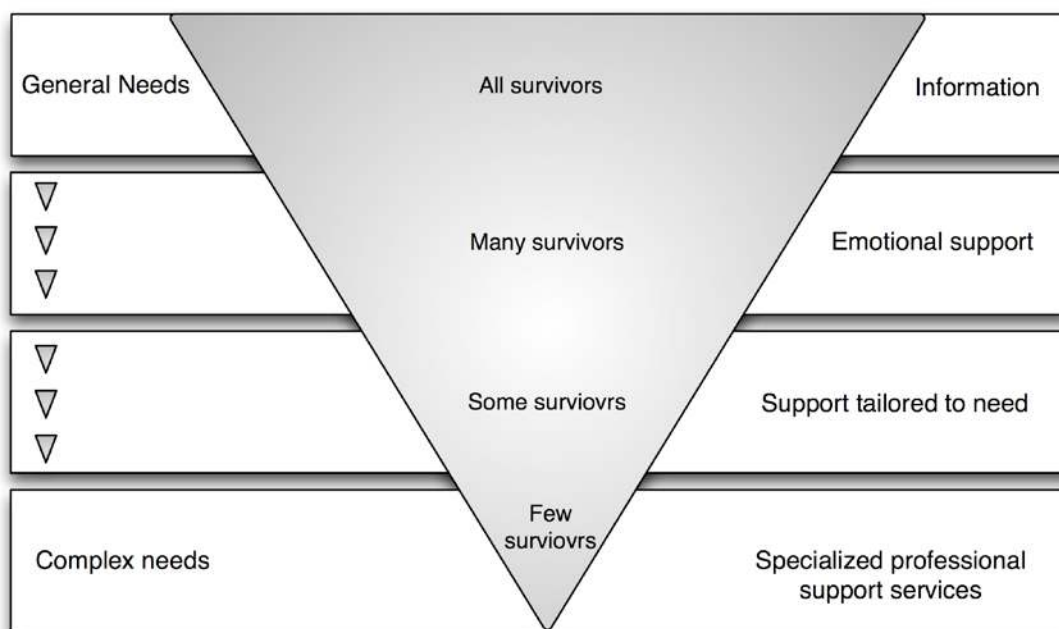
Benefits of Online Communities as Supportive Care Resources

Numerous Peer Support Options

The complexity of cancer survivors' supportive care needs necessitates breadth in

supportive care services. This dissertation demonstrates that breast cancer survivors have at

their disposal a wide variety of online communities to choose from with which to address

their supportive care needs. This is an important finding for several reasons. Firstly, online

health consumers typically triangulate information from several sources to establish the

credibility of what they learn online (Eysenbach & Kohler, 2002; Rozmovits & Ziebland,

2004). Secondly, according to the Optimal Matching Theory (Cutrona & Russell, 1990), the

effects of social support will be greatest if matched to the demands of the stressor and the profile of support seeker. Thirdly, the existence of niche online communities such as Her2support.org (for women with human epidermal growth factor receptor 2 positive breast cancer), demonstrates the ability of online communities to leverage the long-tail (Anderson, 2006) and meet the needs of people with less common conditions, who do not fit the model of the average patient and are thus poorly served by the traditional health care system (Bender, O'Grady, & Jadad, 2008; Deshpande & Jadad, 2006). Indeed the qualitative study confirmed that online communities were a major source of support for women with less common conditions or experiences.

Vast Repositories of Personal Illness Experiences

Online communities, similar to face-to-face support groups, suffer from low participation rates. It has been estimated that for every one person who posts a message, there are about 100 who read it but do not contribute further to the discussion (Preece, 2000). However, unlike face-to-face groups, interactions in online communities are archived in the form of message posts, and research indicates that people might gain the same empowering effects from simply reading them (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). The review of online resources revealed that many of the online communities exclusive to breast cancer survivors were active and thriving, with hundreds of thousands of archived posts about personal illness experiences with breast cancer. The breadth of content in online communities was so extensive, that many of the interview participants did not have to post a question, because other people had already asked the same question, and the answers were available for them to read. These findings have important implications not only

for lurkers, but also for breast cancer survivors seeking to benefit from the experiences of others without the emotional demand of having to reciprocate.

A Type of Information Unlike Any Other

Online communities offer breast cancer survivors a unique kind of health information that has been described as an "expert patient knowledge base" (Hoch & Ferguson, 2005). In comparison to the information offered by face-to-face groups which was described as emotionally supportive, and that provided by health care professionals, which was described as prescriptive, online communities offered highly detailed, relevant and personalized information. Interview participants explained that online communities offered information that they would have liked to obtain from their physicians, as well as information that they felt their physicians could not provide. As previously discussed, this finding confirms that online cancer communities are used for information-oriented purposes more so than emotional support (Meier et al., 2007; Rimer et al., 2005). However, this dissertation also suggests that online communities may in fact represent a new form of health care information rather than a different delivery method of more of the same. Based on their analysis of an online community for neurological conditions physicians Hoch and Ferguson (2005) concluded that the quality of information in online communities far surpassed anything that a patient might conceivably expect to receive from a physician; this dissertation suggests that patients might be of the same impression.

People Can Use Them However and Whenever They Want

Not only do online communities offer a different kind of information, they offer it in a way that may not be available elsewhere. Online communities offer 24-hour accessibility to peer-to-peer supportive care from the convenience and privacy of home. The survey revealed that when participants' needs were greatest, which occurred during and while recovering from treatments, the majority of them used online communities on a daily or weekly basis. This high frequency of use could not feasibly be met by professional supportive care services. In addition, interview participants explained that they valued the availability and anonymity of the medium because it allowed them to address their needs on their own terms.

Beliefs about mastery and control are central to many psychological theories of emotional wellbeing (Seligman, 1975), adjustment to major life events (Taylor, 1983). As previously discussed, seeking information is itself a means to gain mastery or control over an event. The main reasons cancer patients seek information are to gain a sense of control over their situation, to reduce feelings of anxiety, to change their behaviour and to predict and plan for the future (Henman, Butow, Brown, Boyle, & Tattersall, 2002). Seeking information from online communities may thus serve to further enhance perceptions of control due the characteristics of the medium that allow the participants the ability to control when and how they seek information. Cancer patients with a greater sense of overall perceived control tend to be better adjusted, less depressed and less anxious (Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993).

Useful Resources Even for the Unfamiliar User

There is the persistent impression among health professionals and patients alike that people who use the Internet to inform their health decision-making are technologically savvy. However, the majority of interview participants considered themselves inexperienced computer users - a finding that suggests that online communities may be useful resource even for the unfamiliar user. At the same time, many interview participants were of the impression that a lack of computer skills would prevent other breast cancer survivors from using online communities. The survey findings substantiate their claims. The main reasons for not using online communities reported by the survey respondents, beyond a lack of need were a lack of: self-efficacy using Internet resources; trust in Internet resources; self-efficacy using computers in general; and a lack of awareness of online breast cancer communities. Many of these barriers which reflect a lack of eHealth literacy (Norman & Skinner, 2006) could be remedied through support, outreach and education designed to enhance self-efficacy towards online resources. Self-efficacy can be developed through enactive mastery experiences where one learns to perform a behavior by actively performing it themselves; vicarious experiences where one learns a behavior by observing others perform it; verbal persuasion; and physiologic and affective states (Bandura, 1997). Given the tendency for people to make social comparisons with similar others under stressful circumstances and the important role that the opinions of peers play in influencing breast cancer survivors to use online communities, efforts to overcome barriers to use should focus on peer-led strategies to enhance eHealth literacy related self-efficacy.

Limitations of Online Communities as a Supportive Care Resource

Lack of Awareness

Online communities do not appear to be well known by the breast cancer survivors who participated in the survey. Twenty-percent of the respondents, who reported that they did not use online communities as a source of supportive care, were not aware that such resources existed, and all of the participants in the qualitative study reported that they stumbled on online communities accidentally. Lack of awareness of online communities will obviously limit their impact. This issue is not limited to online communities. Patients and families often describe not knowing where to turn for help, what help is available or how to access it, and health care professionals report a general lack of knowledge about resources in the wider community (Fitch, 2000, 2008). However, it may be more challenging to promote awareness and adoption of online communities as a resource than traditional resources such as face-to-face support groups, because they are novel. According to Shirky, "tools don't get socially interesting until they get technologically boring" (Shirky, 2009). This claim reflects the general principle of the Diffusion of Innovation theory, which suggests that the diffusion of an innovation in a society follows a five-step process (Rogers, 1962), which could be accelerated through the adoption of innovations by opinion leaders.

Not One in the Same

The conflicting findings produced by the only known RCT of an un-structured, un-moderated mailing list for breast cancer survivors suggests that online communities may not be universally beneficial (Salzer et al., 2010). Similarly, this dissertation suggests that online communities are not regarded as one in the same. The review of online communities

demonstrated that one third of breast cancer specific sites attracted most of the traffic. Groups on social network sites such as Facebook, although easy to create, were not commonly used for support-seeking related to breast cancer as demonstrated in the content analysis of Facebook groups. The qualitative study revealed that Facebook might not be the preferred venue to discuss personal or socially stigmatizing health issues because of its perceived lack of anonymity and privacy. The majority of the interview participants identified with one particular online community, which they relied on, almost exclusively to meet their needs. Lack of commitment is one of the major challenges of facilitating online communities and if not properly addressed can lead to the demise of the group (Owen, Bantum, & Golant, 2009). This might in part explain the recent closure of two online communities identified in the systematic review, and that were reported to be popular resources among the survey respondents, namely Breast Cancer Action Nova Scotia (www.bca.ns.ca), and Sharing Strength (www.sharingstrength.ca). As a collection, these findings have important implications for the sustainability of online communities as supportive care resources.

May Not Reach Those Most in Need

It has been suggested that those who are in the greatest need, likely have limited access to new technologies (Ziebland, 2004). This 'inverse information law' was evident in the interviews. Several participants spoke of breast cancer survivors living in remote communities who would benefit from online communities, but could not access them due to a lack of skills or poor quality Internet access. Although the digital divide on the basis of education, age and income is diminishing in Canada (Statistics Canada, 2010). The gap in the

rate of Internet use based on community size, which is likely reflective of a lack of broadband access (Fox, 2008) has persisted. Recent reports indicate that 83% of Canadians living in communities with a population of 10,000 or more used the Internet compared with 73% of those from communities with fewer people (Canada, 2010). Surveys of the American public indicate that individuals living with multiple chronic diseases are disproportionately offline due to a lack of access – 81% of adults reporting no chronic diseases go online compared with 52% living with two or more chronic disease (Fox & Purcell, 2010). However, they also indicate that once online people with chronic disease use the Internet more intensely as a health resource.

Dominated by Mainstream Discourses

Contrary to optimistic claims (Hardey, 1999), the relative anonymity offered by online communities has not created a liberating environment where people are free to explore and discuss diverse viewpoints and interests to the extent that was envisioned. Instead, there is evidence to suggest that online communities replicate and affirm powerful social norms and mainstream discourses about health and illness. The qualitative study confirms, as have others (Orgad, 2006; Pitts, 2004; Sandaunet, 2008a, 2008b; Vilhauer, 2009), that breast cancer spaces on the Internet are dominated by a restitution narrative, which emphasizes coping with illness, rebuilding the body and self, a positive attitude and outcome. Voices of despair, hopelessness and death are not welcome in most online communities, and if they are expressed they are marginalized, influencing people to withdraw from the group. While confirming these observations, the qualitative study also provides evidence to suggest that it is possible to find a space suffering. According to one interview participant, several women

in her face-to-face group with poor prognoses were able to obtain more effective support from an online community. This finding provides further evidence of the power of the Internet to leverage the long-tail, as discussed earlier. However, it also demonstrates that the onus is on the user to navigate Internet resources effectively (Strecher, 2007). Strecher cautions that requiring users to "navigate through a library of information… may be the least effective among individuals who are low in ability, perceive competence or prior knowledge" (2007).

A Threat to Medical Expertise

Hardey (1999) proposed over a decade ago that the Internet would form "the site of a new struggle over expertise in health that will transform the relationship between the health professions and their patients". The implications of Internet-informed patients on the control of medical knowledge and the de-professionalization of medicine have been extensively discussed (Blumenthal, 2002; Hardey, 1999, 2001). This dissertation suggests that the potential for the Internet to transform the relationship between health professionals and patients has yet to be realized. Several interview participants had the impression that their physicians were not supportive of online communities, and some had been advised by them not to trust them, confirming earlier research (Broom, 2005). However, the qualitative study also suggests that patients will continue to use online communities regardless of whether or not their health care professionals support the notion.

According to Broom (2005), the extent to which online communities can achieve their full impact might depend on their legitimization within health care profession. In his study of online community use among prostrate cancer patients, Broom demonstrated that

when confronted with Internet informed patients, specialists employed strategies to reinforce paternalistic dynamics and alienate patients who used the Internet, resulting in reduced patient control over decision-making. However, an analysis of the effects of a message-board based, multi-dimensional support system (CHESS), demonstrated an improvement in patients' appraisal of their relationship with their physician, suggesting that at least from the patients' perspective, online communities have the potential to improve the doctor-patient relationship (Shaw et al., 2007). If health care professionals had a better appreciation of the importance of online communities to their patients, and incentives to participate many of their fears might be alleviated.

Critical Role of Survivors as Care Providers

The Institute of Medicine report on Cancer Survivorship (IOM, 2005) identified a need to develop new models of survivorship care, including mobilizing community supports and involving cancer survivors as "informed care partners". This dissertation suggests that cancer survivors are taking a more active role in survivorship care, beyond being merely informed care partners. The systematic review and characterization of online community resources revealed that many cancer survivors and affected family members have taken the lead in creating and maintaining supportive care resources online. This observation reflects a growing trend of patients as both consumers and producers of health information (Fox, 2010). Although, cancer survivors have been acting in the capacity of informal health care providers in support groups long before the evolution of the Internet, the participatory nature of the new media landscape provides survivors with new tools to contribute to survivorship care in a more active, organized and collaborative fashion.

The findings from the qualitative study suggest that cancer peer support providers could play an important role as opinion leaders by promoting awareness of online communities as supportive care resources. Opinion leaders play a critical role in the diffusion of an innovation through a society (Rogers, 1962). They are defined as individuals who frequently influence the opinions and behaviour of others (Rogers & Kinkaid, 1981). According to research by Harkola and Greeve (Harkola & Greve, 1995) informal opinion leaders can be more influential than formal opinion leaders because they more accurately reflect the norms of a group. The findings from the qualitative study demonstrated that opinions of other cancer survivors influenced use of online communities.

This dissertation has also revealed that long-term breast cancer survivors who are peer support providers have ongoing supportive care needs that should not be neglected. Interestingly, the majority of survey respondents used online communities most frequently during and while recovering from treatment, prior to becoming a facilitator of a cancer support group. Online communities were used less frequently to address survivorship issues, and only 39.1% of survey respondents used online communities to help other survivors. It is unclear why online communities were less used frequently for these purposes. Perhaps as a result of the time involved in helping others, they neglected their own needs, or perhaps online communities did not offer the right match of support. Although there are numerous online communities for breast cancer survivors, there are no known online communities specifically for cancer survivors who are peer support providers.

Implications for Practice

Health care systems are not equipped to deal with the supportive care needs of the growing population of cancer survivors, and despite calls for a comprehensive and coordinated cancer care delivery system (Fitch, 2008; IOM, 2005), there has been little progress. Numerous service and program gaps remain (Fitch, 2008; IOM, 2005). This dissertation suggests that online communities could fill gaps in supportive care services and meet many of the supportive care needs of breast cancer survivors in a way that may not be available elsewhere, even for the less technologically inclined. They have the ability to meet the most common types of needs, and respond to individual patient choices and preferences. Health care professionals and systems would be remiss not to take advantage of the benefits of these free resources that provide supportive care to breast cancer survivors 24 hours a day.

The inventory of online communities generated from this dissertation could serve as a guidepost for breast cancer survivors seeking online peer support resources, and an educational resource for health care professionals and administrators interested in recommending online resources to their patients. While the determinants of popular online communities remain unclear, this dissertation has generated a theoretical framework for understanding the context of online community use by patients, and in doing so has highlighted important social, contextual and individual factors that may affect the use of online communities. These observations have important implications for the design of online communities, and could be used to enhance their effectiveness, potentially attracting a larger user base.

Some have questioned the utility of government-funded personal health care solutions, when social network sites provide users with the tools to create and share health

resources on their own (Kidd, 2008). This dissertation suggests that general social network sites may not be the preferred venue for breast cancer survivors to share sensitive and potentially stigmatizing information due to concerns about privacy and anonymity. However, Facebook and other social media have the potential to play an important role in promoting the awareness and adoption of other online community resources. Before developing another online community for breast cancer survivors, interested parties would be advised to assess whether their needs could be met by one of the existing online communities identified in this review, and if not, engage breast cancer survivors as collaborators to create a new resource that addresses an unmet need.

Perhaps most importantly this dissertation has demonstrated that the main barriers to the use of online communities by breast cancer survivors are lack of awareness and limited eHealth literacy. These barriers could be easily remedied through support, outreach and education. Targeted efforts are required to promote awareness of the existence and usefulness of online communities as supportive care resources, among breast cancer patients as well as health professionals involved in their care. Peer-led (e.g., other breast cancer survivors or clinicians) promotional strategies may be the most efficacious give the critical role that similar others play in influencing adoption and use of new knowledge and new technology. In addition, continued efforts are required to expand broadband services to reach patients living in remote and under-served communities.

Breast cancer survivors have the potential to play an increasingly important role in the organization and delivery of health care services, based on their increasing number, desire to give back and help others who are sick, and skill set as expert patients. Innovative strategies are required to leverage their intellectual and human resource capital. At the same

time, their needs as long-term survivors of breast cancer should not be neglected. This dissertation provides an impetus for the development of interventions tailored to the unique supportive care needs of long-term breast cancer survivors who are providers of peer support. An Internet-based peer support intervention may be a useful strategy to consider given the high rate of Internet use for health purposes among this sample, the significant portion of individuals who reported using online communities, and the extent to which these individuals value peer support and are often quite geographically disperse.

General Limitations

One of the major challenges of studying social media is keeping up with the pace of technology and its use by society. As a result of the rapid growth and evolution of resources on the Internet, the systematic review of online communities and content analysis of breast cancer groups on Facebook may be out of date. The first two studies of this dissertation should therefore be regarded as snapshots of the nature and use of online community resources at one point in time. In addition, although numerous strategies were undertaken to ensure the comprehensiveness of the inventories produced by these two studies, it is possible that our searches did not retrieve all English language online communities, or breast cancer groups on Facebook at that time.

A related limitation is the reliance on content analysis to infer the purpose, characteristics and use patterns of the online communities studied. Although the site content was independently extracted and coded by two reviewers to increase the reliability of the findings, the content analysis is only as good as the sample of text on which it is based. There were several categories of content that were incomplete or unclear. A significant proportion

of the online communities did not provide information on their date of launch or usage statistics. In many cases it was not clear whether the communication feature (e.g., message board) was included on the site when it was first launched or if it was an add-on feature. In addition, self-reported data (that were available on the group page itself or in the search result content) were used to infer the approximate age and geographic location of the Facebook group creators. This information is possibly incorrect or fabricated. Triangulating the content analysis with interviews with the site administrators, as well as analysis of the sites log files, could have enhanced the credibility of the findings.

Support group facilitators and people who have actively sought support from a local agency (in this case Willow) are not necessarily typical of breast cancer survivors. Previous research suggests that they may be better educated, include fewer minority groups and better adjusted (Matthews, Baker, Hann, Denniston, & Smith, 2002). These trends were reflected in the current sample, which was nearly all white, and college or university educated. In addition, their experiences likely differ from those who want peer support but do not know where to find it, or who do not seek it out for whatever reason, or who wish to be peer support providers but do not seek out the experience or opportunity. It is also possible that they may have been more likely to be exposed to online communities as a resource than the average breast cancer survivor. However, the analysis revealed that the majority of survey respondents used online communities during treatment for breast cancer, which would have been before they attended a facilitator-training workshop.

Lastly, the findings of the survey and qualitative study are limited by the methods used to recruit the sample and collect the data. Online communities provide a snapshot of people's views and their behaviours, and if they are retrospective, which this survey was,

they involve recall bias. The qualitative study recruited a purposive sample of users of online communities drawn from the survey, who expressed an interest in participating in a follow-up interview. This approach might have skewed the sample toward individuals who find it easy to talk about their illness, who felt well enough to participate, or who felt they had more positive or negative experiences to share about the role of online communities.

Implications for Research

As with most studies in new fields of research, the findings reported in this dissertation raise more questions than answers for researchers, clinicians and policy makers. First, there is a need to better understand the determinants of popular and effective online communities, and how they relate to one another. By understanding what breast cancer survivors want from online communities and which sites they most actively use, we might be able to identify the elements that offer the most promise and effectiveness.

Second, there is a need to understand the benefits and implications of using general social network sites, such as Facebook, for health purposes. It is unclear whether general social network sites are as effective as disease-specific online communities in providing health related information and support, and for whom, and a better understanding is needed of the privacy implications of sharing personal health information on public social network sites.

Third, this dissertation has provided a theoretical framework for understanding the use of online communities by breast cancer survivors. Further research is warranted to assess the efficacy and effectiveness of these theories in predicting and explaining the use of online communities by breast cancer survivors and among other illness groups.

Fourth, innovative methods and tools are needed to facilitate the process of collecting online health resources, characterizing their usefulness and keeping them up to date. Collaborative authoring tools such as wikis could be used to engage the public in building a shared knowledge base (Deshpande & Jadad, 2006) and collaborative filtering programs could be used to match users with resources that people who are similar to them have used (Strecher, 2007).

Fifth, research is warranted to understand how online communities could be used more effectively to discuss bad news, hopelessness, despair and death. This study has demonstrated that online communities met the unique and specific needs of breast cancer in the present sample including needs related to impending death, and yet it confirms previous research that has observed a dominant 'restitution narrative' in online breast cancer spaces.

Sixth, this dissertation, like most previous studies on online communities, has involved predominately college-educated, middle-income, white women. More research is needed to explore that use of online communities among breast cancer survivors of different socioecomic status and cultural backgrounds, and to explore if these findings hold true for individuals with other cancer types.

Lastly, more robust evidence is needed on the health benefits and implications of consumer-led online support communities. Specifically, there is need to explore in detail the types of needs these sites might be able to meet, and the proportion and effectiveness with which they complement, enhance or replace in-person interactions.

Conclusion

In order to achieve the vision of a comprehensive and coordinated cancer care delivery system, new models of service provision are needed, particularly those where professional care providers work in partnership with cancer survivors and community-based organizations to meet the needs of cancer survivors through the continuum of care. This dissertations shows, for the first time, that online communities have the potential to fill gaps in health care services by addressing the supportive care needs of breast cancer survivors in a way that may not be available elsewhere, even for the less technologically inclined. It also serves to underscore the increasingly important role that breast cancer survivors could play as providers of supportive care, while cautioning that their own needs must not be neglected in the process. These are exciting findings with important practical implications. However, we need to be ever mindful of the potential for abuses and misuses of online communities as supportive care resources, as well as who benefits and at what costs. Future research must focus on overcoming barriers to the use of online peer-to-peer support resources, and identifying factors that enhance their effectiveness among groups with diverse ethno-cultural and socio-economic characteristics.

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Appendices

Appendix 1: Literature Review Search Strategy

Databases
MEDLINE
PsychINFO
CINAHL
ACM

Searches
    1. **Online Communities X Neoplasms OR Breast Neoplasms**

Ovid MEDLINE(R) 1948 to March Week 2 2011		
#	Search	Results
1	internet*.mp.	44085
2	e-mail*.mp.	3188
3	email*.mp.	1218
4	(information adj2 highway*).mp.	96
5	electronic mail*.mp.	1801
6	world wide web*.mp.	2428
7	www.mp.	1176
8	(cyber* not cybernetic*).mp.	1333
9	web page*.mp.	907
10	webpage*.mp.	106
11	web bas*.mp.	7599
12	exp internet/	36059
13	exp electronic mail/	1311
14	web site*.mp.	4401
15	website*.mp.	5319
16	exp computer communication networks/	47421
17	webbas*.mp.	17
18	or/1-17	65546
19	exp support groups/	7862
20	support group*.mp.	3589
21	self-help*.mp.	12268
22	selfhelp*.mp.	13

23	discuss* group*.mp.	975
24	peer to peer*.mp.	262
25	peer support*.mp.	963
26	forum*.mp.	6847
27	p2p*.mp.	107
28	social support*.mp.	46548
29	exp social networks/	40484
30	(communit* adj2 (internet* or world wide web* or e-mail* or email* or electronic mail* or web page* or webpage* or web site* or website* or web base* or www or cyber*)).mp.	146
31	or/19-30	67699
32	discussion list*.mp.	74
33	listserv*.mp.	197
34	list serv*.mp.	77
35	chat room*.mp.	157
36	chatroom*.mp.	26
37	chat group*.mp.	19
38	chatgroup*.mp.	0
39	chat technolog*.mp.	2
40	e-bulletin board*.mp.	0
41	ebulletin board*.mp.	0
42	news group*.mp.	23
43	newsgroup*.mp.	102
44	instant messag*.mp.	74
45	mailing list*.mp.	351
46	virtual support*.mp.	15
47	electronic support*.mp.	30
48	internet group*.mp.	54
49	(internet adj2 group*).mp.	226
50	(internet adj2 support*).mp.	197
51	(internet adj2 communit*).mp.	74
52	(online adj2 group*).mp.	194
53	(online adj2 support*).mp.	239

54	(online adj2 communit*).mp.	118
55	(web adj2 group*).mp.	99
56	(web adj2 support*).mp.	140
57	(web adj2 communit*).mp.	75
58	(virtual adj2 group*).mp.	82
59	(virtual adj2 support*).mp.	66
60	(virtual adj2 communit*).mp.	116
61	newsgroup*.mp.	102
62	news group*.mp.	23
63	usenet*.mp.	22
64	bulletin board system*.mp.	26
65	mailbox*.mp.	54
66	mail box*.mp.	12
67	electronic group*.mp.	15
68	(electronic adj2 group*).mp.	136
69	e-communit*.mp.	11
70	messageboard*.mp.	0
71	message board*.mp.	57
72	or/32-71	2634
73	18 and 31	2619
74	72 or 73	4579
75	Neoplasms/	226653
76	74 and 75	143
77	Breast Neoplasms	178266
78	74 and 77	117

2. Web 2.0

Ovid MEDLINE(R) 1948 to March Week 2 2011		
#	Search	Results
1	blog*.mp.	352
2	collaborationwar*.mp.	1

3	connotea*.mp.	4
4	flickr.mp.	4
5	Facebook*.mp.	87
6	Folksonom*.mp.	4
7	friendster.mp.	2
8	(google adj2 collabor*).mp.	2
9	mashup*.mp.	15
10	Micro-blog*.mp	2
11	Microblog*.mp	11
12	myspace*.mp.	39
13	news feed*.mp.	6
14	newsfeed*.mp.	1
15	openlaszlo.mp.	1
16	open source application*.mp.	36
17	(open source adj2 application*).mp.	69
18	(participatory adj2 web*).mp.	2
19	(participatory adj2 internet*).mp.	1
20	Patientslikeme*.mp	9
21	rss feed*.mp.	19
22	really simple syndicat*.mp.	14
23	rich site summar*.mp.	3
24	secondlife.mp.	1
25	Second Life.mp.	75
26	semantic web*.mp.	200
27	(social adj2 bookmark*).mp.	16
28	(social adj2 book-mark*).mp.	0
29	(social adj2 software*).mp.	41
30	(sociable adj2 technolog*).mp.	1
31	(streaming adj2 media).mp.	9
32	tag cloud*.mp.	2
33	technocrati.mp.	0
34	Twitter*.mp	69

35	Tweet*.mp	51
36	(virtual adj2 collabor*).mp.	50
37	web api*.mp.	2
38	(web adj2 syndicat*).mp.	5
39	web-log*.mp.	34
40	weblog*.mp.	34
41	web tag*.mp.	1
42	webtag*.mp.	1
43	wikipedia.mp.	53
44	wiki*.mp.	219
45	youtub*.mp.	57
46	"Web 2.0"	175
47	Social media.mp	99
48	Social network site.mp	3
49	Social networking site.mp	13
50	User-generated content	11
51	Social networks	2209
52	Exp Internet/	36059
53	51 AND 52	62
54	Or/1-50	1439
55	54 OR 53	1501
56	Limit 55 to English language	1424

3. Supportive Care Needs of Breast Cancer Survivors

Ovid MEDLINE(R) 1995 to March Week 2 2011		
#	Search History	Results
1	Exp Breast Neoplasms/	179681
2	Social Support/	40484
3	Community Networks/	4121
4	Self-Help Groups/	6950
5	Needs Assessment/	18286

6	Social Environment/	32047
7	Adaptation, Psychological/	62734
8	Psychotherapy, Group/	10754
9	Counseling/	23965
10	Information Services/	14392
11	(information adj2 need?).mp	4369
12	"Quality of Life"/	88132
13	Health Servces/	16770
14	Patient care management/ or disease management/	9092
15	Or/2-14	295221
16	1 and 15	5492
17	supportive care.mp	6040
18	1 and 17	148
19	Survivors/	10420
20	survivor*.mp	52514
21	19 or 20	52514
22	1 and 21	2262
23	16 or 18 or 22	7092
24	Limit 23 to English language	6463
25	Limit 24 to yr="1995 to Current"	5565

4. Peer Leaders of Cancer Support Groups

Ovid MEDLINE(R) 1995 to March Week 2 2011		
#	Search History	Results
1	exp neoplasms/	2189632
2	cancer*.mp.	799966
3	onco*.mp.	262378
4	carcin*.mp.	625013
5	metasta*.mp.	293390
6	or/1-5	2461972
7	(peer* adj3 support*).mp.	1497
8	(survivor* adj2 support*).mp.	139

9	Self-Help Groups/	6958
10	self-help group*.mp.	7400
11	selfhelp group*.mp.	7
12	or/7-11	8839
13	6 and 12	1014
14	leader*.mp.	47372
15	facilitator*.mp.	9019
16	volunteer*.mp.	121378
17	mentor*.mp.	8214
18	moderator*.mp.	3288
19	or/14-18	187076
20	19 and 13	88
21	exp breast neoplasms/	179825
22	21 and 13	291
23	limit 22 to yr="1966 - 2009"	268

Appendix 2: Approval Letter from the University of Toronto

University of Toronto
Office of the Vice-President, Research

Office of Research Ethics

PROTOCOL REFERENCE #23818

April 21, 2009

Dr. Alejandro R. Jadad	Ms. Jacqueline Lorene Bender
Dalla Lana School of Public Health	Dalla Lana School of Public Health
Centre for Global eHealth Innovation	Centre for Global eHealth Innovation
190 Elizabeth Street R. Frazer	190 Elizabeth Street R. Frazer
Elliot Building, 4th Floor	Elliot Building, 4th Floor
Toronto, ON M5G 2C4	Toronto, ON M5G 2C4

Dear Dr. Jadad and Ms. Bender:

Re: Your research protocol entitled "Online Social Networks: Supportive Care for Breast
        Cancer Survivors?"

ETHICS APPROVAL	**Original Approval Date: April 21, 2009**
	Expiry Date: April 20, 2010
	Continuing Review Level: 1

We are writing to advise you that a member of the Health Sciences Research Ethics Board has
granted approval to the above-named research study, for a period of **one year**, under the REB's
expedited review process. Ongoing projects must be renewed prior to the expiry date.

The following consent documents (revised April 15, 2009) have been approved for use in this
study:
Study Advertisement on Willow Newsletter
Information Letter

**Any changes to the approved protocol or consent materials must be reviewed and
approved through the amendment process prior to its implementation. Any adverse or
unanticipated events should be reported to the Office of Research Ethics as soon as
possible.**

**Please ensure that you submit an Annual Renewal Form or a Study Completion Report at
least 30 days prior to the expiry date of your study.**

Best wishes for the successful completion of your project.

Yours sincerely,

Daniel Gyewu
Research Ethics Coordinator

Appendix 3: Email from the Office of Research Ethics

----- Forwarded message from rachel.zand@utoronto.ca -----
   Date: Wed, 9 Sep 2009 11:41:37 -0400
   From: Rachel Zand <rachel.zand@utoronto.ca>
Reply-To: Rachel Zand <rachel.zand@utoronto.ca>
 Subject: web-based research
    To: "'jackie.bender@utoronto.ca'" <jackie.bender@utoronto.ca>

Jackie,

As discussed, the Tri-Council Policy Statement states that: "Web-based research that uses exclusively publicly available information for which there is no presumption of privacy does not require REB review..." (Article 10.3)

The Application section further elaborates that "research that is non-intrusive, does not require direct interaction between the researcher and individuals through the Internet medium, and that draws its data primarily from postings on websites is not required to obtain REB review... Researchers may need to consider other factors when using this information, such as copyright, dissemination restrictions, privacy and intellectual rights. These, however, fall outside of the scope of the REB review."

I hope this helps.

Regards,
Rachel

Rachel Zand, Ph.D.
Director
Office of Research Ethics
University of Toronto

12 Queen's Park Crescent West
2nd Floor ** note the new office location **
Toronto, ON M5S 1S8
Tel: 416-946-3389
Fax: 416-946-5763

Appendix 4: Search Strategy for Online Communities

<u>Search Engine</u>
www.google.com

<u>Search Date</u>
2009-12-23

<u>Searches and Terms</u>

Search 1) String of terms

"breast cancer" OR community OR support OR network OR online-support-groups OR forums OR discussion OR discussion-forums OR discussion-boards OR message-boards OR chat OR chat-rooms OR blogs OR mailing-list OR wiki –hardcore –XXX -babes

Search 2) Individual queries

- breast cancer blogs
- breast cancer chat rooms
- breast cancer community
- breast cancer discussion forums
- breast cancer mailing list
- breast cancer message boards
- breast cancer online support groups
- breast cancer support network
- breast cancer wiki

Appendix 5: Letter of Support from Willow

December 4, 2008

To Whom It May Concern:

     Re: Jacqueline L. Bender, BSc, MSc

I am pleased to have the opportunity to write in support of Ms. Bender's thesis research for the PhD program in Health and Behavioral Science in the Dalla Lana School of Public Health at the University of Toronto, which will be conducted in collaboration with Willow Breast Cancer Support Canada.

Willow Breast Cancer Support Canada is a national, not-for-profit, charitable organization that provides information and support to Canadians affected by breast cancer. Willow's support services include: a) Peer Support Service, staffed by breast cancer survivors, b) Information Support Service, provided by a health librarian, c) Facilitator Training Program, which consists of workshops for breast cancer survivors who want to establish face-to-face support groups in their community, d) Face-to-face, peer-led support groups provided by Willow trained facilitators, and e) Web-based information and support services (http://www.willow.org/).

As the Executive Director of Willow and on behalf of the organization, I support Ms. Bender's proposal to explore the role of online support networks as a source of supportive care among Willow's membership of breast cancer survivors. I acknowledge that this research will require the assistance of Willow staff to conduct: 1) a cross-sectional survey to determine the characteristics and online support network use of a random sample of approximately 300 Willow community members, and 2) one-on-one interviews with a purposive sample of 10 to 15 community members who use online support networks to gain a better understanding of their perspectives of online support networks as source of supportive care.

This collaboration with Ms. Bender is timely as we are in the process of updating our web-based services to meet the needs of an increasingly Internet savvy membership. We look forward to Ms. Bender's doctoral research study to gain a greater understanding of our memberships' preferences regarding online support, as well as, increase our capacity for future research.

Sincerely

Virginia Yule

Virginia Yule
Executive Director

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20 Victoria Street, 5th floor   Toronto ON M5C 2N8   T: 1.888.778.3100   F: 416.778.8070   www.willow.org

Appendix 6: Survey Advertisement in Willow Newsletter

Upcoming Research Study about Online Peer Support for Breast Cancer!

Introducing…

Jackie Bender
PhD Candidate
Dalla Lana School of Public Health, University of Toronto

Health websites, where you can communicate with other people with breast cancer, are growing in number and popularity. A preliminary search of the Internet in July of 2008 yielded 85 such websites developed for or by breast cancer survivors in North America.

Willow has partnered with Jackie Bender a PhD student from the University of Toronto to gain a greater understanding of *your* support needs and preferences regarding these types of peer support resources on the Internet.

We are seeking the help of Willow-trained facilitators to complete a confidential questionnaire. This questionnaire should take approximately 20 to 30 minutes to complete. It will ask about your opinions and experiences using health websites, where you can communicate with other women diagnosed with breast cancer. Even if you have never visited these types of websites, we'd like to hear from you.

Beginning in May 2009 all individuals who participated in a Willow Facilitator Training Workshop between September 2008 and July 2009, will receive the questionnaire by postal mail. You will have the option to complete the questionnaire on paper and return it to Jackie in a pre-paid envelope. Or you can complete the questionnaire online at a secure website.

Jackie is conducting this research in partial fulfillment of a PhD at the University of Toronto. Her supervisor is Dr. Alex Jadad. The University of Toronto Research Ethics Board has approved the study. If you have any questions about this study, Jackie would be happy to hear from you at 416-340-4800 ext. 8116 or jackie.bender@utoronto.ca

Appendix 7: Letter of Invitation to Participate in the Survey

[Date]

[Name]
[Address]

Dear [Name],

Willow Breast Cancer Support Canada has partnered with Jackie Bender, a PhD student from the University of Toronto to conduct a research study to understand the role of online peer support for women diagnosed with breast cancer.

Health websites, where you can communicate with other people with breast cancer, are growing in number and popularity. We want to gain a greater understanding of the support needs and preferences of Willow's membership regarding these types of peer support resources on the Internet.

You have received this packaged because you have had a breast cancer diagnosis, and at some point, you have used Willow's services. If you have ever gone online to access the Internet or to send or receive email, then you are somebody we would like to participate in this study.

We are writing to ask if you would be willing to participate. We know your time is valuable and that you have many competing commitments, however, we hope you are able to assist us. If you agree to do so, we would ask you to complete a confidential questionnaire and return it to Jackie by **[Date]**, if possible.

There are <u>two ways</u> you can complete and return the questionnaire:

1) You can complete the enclosed questionnaire, and send it back to Jackie by postal mail in the enclosed pre-paid postage envelope.

OR

2) You can complete the questionnaire on the Internet. If you chose to complete the questionnaire on the Internet: just type the following web page address in your Internet browser, and then type in the questionnaire code to begin the survey:

URL:
Your questionnaire code: **[Code]**

The questionnaire should take you between 20 and 30 minutes to complete according the results of a pilot study.

We take privacy very seriously. The questionnaire is completely confidential but it is not anonymous. The questionnaire will be assigned a unique identification number that will be linked to your name in order to send thank you notes and reminders. However, only Jackie will know the identity of people who choose to respond or not.

No identifying information is returned with the completed questionnaire- except for those of you who choose to provide your contact information for a follow-up interview. You do not have to decide this now.

All information collected will be stored in a secure location accessible only to Jackie and her supervisor. Any identifying information will be removed from the questionnaire. The study results will be reported as aggregated data so that no identifying information can be inferred. You will not be named in any reports, publications, or presentations that may come from this study.

Your responses are voluntary. If you come to a question that you prefer not to answer, please skip it and go on to the next question.

If you have any questions about this study or if you have difficulties answering the questionnaire on the Internet, Jackie will be happy to help and can be reached by telephone at: 416-340-4800 ext. 8116 or by email: jackie.bender@utoronto.ca.

Jackie is conducting this research in partial fulfillment of a PhD at the University of Toronto. Her supervisor is Dr. Alex Jadad and is available by telephone at: 416-340-4800 ext. 6903 or by email: ajadad@ehealthinnovation.org. This study has been approved by the University of Toronto Research Ethics Board. If you have any questions about your rights as a research participant in this study, please contact Jill Parsons, Health Sciences Review Officer, Ethics Review Office, University of Toronto, by telephone at 416-946-5806 or by email: jc.parsons@utoronto.ca

The results of this study will be made available on the Willow website at www.willow.org in early 2010. Willow plans to make use of the study results to enhance their own services.

Many thanks,

Jackie Bender, MSc
PhD Student
Dalla Lana School of Public Heath
University of Toronto

Virginia Yule
Executive Director
Willow

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Appendix 8: Questionnaire

UNIVERSITY OF TORONTO
DALLA LANA SCHOOL OF PUBLIC HEALTH

SURVEY OF INTERNET USE & SUPPORT NEEDS OF BREAST CANCER SURVIVORS

This questionnaire is divided into 6 sections. It should take you approximately 20 to 30 minutes to complete according to the results of a pilot study.

We are interested in learning about your views. There are no right or wrong answers. Depending on your answers, you may be asked to skip certain questions. Skipping questions is our way of making sure we only ask you relevant questions. If you do not want to answer a question, please leave it and go to the next question. Thanks in advance for your participation.

START HERE

SECTION 1 The questions in this section confirm your eligibility for this study.

Q1. Have you been diagnosed with breast cancer?

☐ Yes
☐ No ⟶ If you have not been diagnosed with breast cancer, please do not complete this questionnaire. We would greatly appreciate it if you could please return the questionnaire.

Q2. Do you ever go online to access the Internet or to send or receive email?

☐ Yes
☐ No ⟶ If you never go online to access the Internet or to send or receive email, please do not complete this questionnaire. We would greatly appreciate it if you could please return the questionnaire.

SECTION 2 The questions in this section ask about your use of the Internet.

Q3. How often do you use the Internet?

☐ At least once a day
☐ At least once a week (but not every day)
☐ At least once a month (but not every week)
☐ Less than once a month

Q4. Have you ever used the Internet to search for information on breast cancer?

☐ Yes
☐ No

Q5. Do you have an account or personal profile on any social networking websites? Check as many as apply.

	Yes	**No**
Facebook............	☐	☐
MySpace.............	☐	☐
SecondLife..........	☐	☐
LinkedIn..............	☐	☐
Twitter…………..…	☐	☐
Other………………	☐	☐

If "other", please SPECIFY: _____

If "yes" to any of the above, have you ever used a social networking website to communicate with <u>other women diagnosed with breast cancer</u>?

☐ No

☐ Yes

If "yes", do you use a social networking website to: (Check as many as apply)

☐ Meet new people diagnosed with breast cancer

☐ Maintain connections with people diagnosed with breast cancer who you met offline

Q6. Have you ever visited (read or posted a message) a <u>breast cancer website</u> that allows you to communicate with other women diagnosed with breast cancer? We call these websites BREAST CANCER ONLINE SUPPORT NETWORKS.

☐ Yes ⟶ **If "yes", SKIP to Q8 in Section 3.**

☐ No

If "no", is this because you: (check as many as apply)

☐ Never heard of them

☐ Don't feel confident using them

☐ Don't feel confident using computers, in general

☐ Don't trust information from strangers on the Internet

☐ Don't trust Internet security

☐ Are not the kind of person who joins groups

☐ Don't need to because you have friends with breast cancer you can talk to

☐ Don't want to learn about the experiences of other women with breast cancer

☐ Don't know

☐ Other **(Please explain:**_____

Q7. If you have NEVER visited a breast cancer online support network, we would like to learn more about your opinions of participating (reading or posting messages) in them. Please select the box that best describes how you feel about each statement.

> **PLEASE READ: If you <u>HAVE VISITED</u> a breast cancer online support network DO NOT ANSWER this question. SKIP to Q8 in Section 3.**

	Very strongly agree	Strongly agree	Mildly agree	Neutral	Mildly disagree	Strongly disagree	Very strongly disagree
1. Participating in breast cancer online support networks would provide me useful information about breast cancer.	☐	☐	☐	☐	☐	☐	☐
2. Participating in breast cancer online support networks would provide me strategies to help me cope.	☐	☐	☐	☐	☐	☐	☐
3. Participating in breast cancer online support networks would provide understanding from others with similar experiences.	☐	☐	☐	☐	☐	☐	☐
4. Participating in breast cancer online support networks would make me feel depressed.	☐	☐	☐	☐	☐	☐	☐
5. Participating in breast caner online support networks would make me anxious.	☐	☐	☐	☐	☐	☐	☐
6. Participating in breast cancer online support networks would be risky because you cannot trust the information they contain.	☐	☐	☐	☐	☐	☐	☐
7. Learning how to operate breast cancer online support networks would be easy for me.	☐	☐	☐	☐	☐	☐	☐
8. My interaction with breast cancer online support networks would be clear and understandable.	☐	☐	☐	☐	☐	☐	☐
9. It would be easy for me to become skillful at participating in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
10. I would trust the information shared by other members of breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
11. The members of online support networks will do everything within their capacity to help others.	☐	☐	☐	☐	☐	☐	☐

	Very strongly agree	Strongly agree	Mildly agree	Neutral	Mildly disagree	Strongly disagree	Very strongly disagree
12. I would feel confident finding information in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
13. I would feel confident posting messages in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
14. I have the skills needed to evaluate the information posted in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
15. I have fast enough Internet connection to use breast cancer online support networks	☐	☐	☐	☐	☐	☐	☐
16. I have access to people who can help me use breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
17. Participating in breast cancer online support networks is a good idea.	☐	☐	☐	☐	☐	☐	☐
18. I like the idea of participating in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
19. Participating in breast cancer online support networks would be a positive experience.	☐	☐	☐	☐	☐	☐	☐
20. Participating in breast cancer online support networks would be a foolish idea.	☐	☐	☐	☐	☐	☐	☐
21. My family and friends would think that participating in breast cancer online support networks is a good idea.	☐	☐	☐	☐	☐	☐	☐
22. My doctors would think that participating in breast cancer online support networks is a good idea.	☐	☐	☐	☐	☐	☐	☐
23. I would be able to participate in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
24. I am in control of my participation in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
25. I intend to participate in breast cancer online support networks in the future.	☐	☐	☐	☐	☐	☐	☐

SECTION 3 The questions in this section are for people who HAVE VISITED breast cancer websites that allow you to communicate with other women diagnosed with breast cancer. Remember, we call these websites <u>BREAST CANCER ONLINE SUPPORT NETWORKS</u>.

> **PLEASE READ: If you <u>NEVER VISITED</u> a breast cancer online support network DO NOT ANSWER the questions in this section. SKIP to Q19 in Section 4.**

Q8. In the <u>past 3 months</u>, how often have you visited breast cancer online support networks?

- ☐ At least once a day
- ☐ At least once a week (but not every day)
- ☐ At least once a month (but not every week)
- ☐ Less than once a month

Q9. When did you <u>most frequently visit</u> breast cancer online support networks? Check as many as apply.

- ☐ During diagnostic testing (but before diagnosis)
- ☐ After diagnosis (but before treatment)
- ☐ During treatment (such as surgery, radiation, or chemotherapy)
- ☐ After treatment (but while on hormone therapy such as Tamoxifen or Arimidex)
- ☐ After all treatment for breast cancer (including Tamoxifen or Arimidex)
- ☐ Other **(Please specify**:_____

Q10. During the time you were <u>most frequently visiting</u> breast cancer online support networks, <u>how often were you visiting them</u>?

- ☐ At least once a day
- ☐ At least once a week (but not every day)
- ☐ At least once a month (but not every week)
- ☐ Less than once a month

Q11. What are the <u>reasons why you visit</u> breast cancer online support networks? Check as many as apply.

- ☐ When I have a question about breast cancer or its treatment
- ☐ When I feel lonely
- ☐ To learn about potential symptoms or side effects
- ☐ When I feel anxious
- ☐ To learn how to manage symptoms or side effects
- ☐ When I feel down or depressed
- ☐ To talk about my fears and concerns
- ☐ To get emotional support and understanding
- ☐ To help others
- ☐ After visiting a doctor to learn about what we discussed
- ☐ Before visiting a doctor to prepare for my appointment
- ☐ To talk people who share my spiritual beliefs
- ☐ Because other members expect me to be there
- ☐ To talk to people who share my cultural background

☐ Other **(Please explain:**_____

Q12. In what ways have you used breast cancer online support networks? Have you ever: (Check as many as apply.)

☐ Created a personal profile for others to see
☐ Read the profiles of other members
☐ Posted a message for others to read
☐ Read messages posted by others
☐ Added members to your friend list
☐ Browsed other members' lists of friends
☐ Sent a private message to another member

☐ Other **(Please explain:**_____

Q13. Have you ever visited (read or posted messages) any of the following breast cancer online support networks? Check as many as apply.

	Read messages	Posted messages
1. BC Advisor (www.bcadvisor.com)	☐	☐
2. Breastcancer.org (www.breascancer.org)	☐	☐
3. Breast Cancer Action Nova Scotia (www.bca.ns.ca)	☐	☐
4. Breast Cancer Awareness (www.breastcancerawareness.com)	☐	☐
5. Breast Cancer Network of Strength (www.networkofstrength.org)	☐	☐
6. Breast Cancer Now What (www.breastcancernowwhat.ca)	☐	☐
7. Breast Cancer Options (www.breastcanceroptions.org)	☐	☐
8. Breast Cancer Recovery Foundation (www.bcrecovery.org)	☐	☐
9. Canadian Breast Cancer Forum (www.breastcancerforum.ca)	☐	☐
10. Caring Voices (www.caringvoices.ca)	☐	☐
11. Force: Facing Our Risk Together (www.facingourrisk.org)	☐	☐
12. Living Beyond Breast Cancer (www.lbbc.org)	☐	☐
13. Lymphedema People (www.lymphedemapeople.com)	☐	☐
14. National Breast Cancer Foundation (www.nationalbreastcancer.org)	☐	☐
15. Pink Link (www.pink-link.org)	☐	☐
16. Sharing Strength (www.sharingstrength.org)	☐	☐
17. Triple Negative Breast Cancer Foundation (www.tnbcfoundation.org)	☐	☐
18. Willow Breast Cancer Support Canada (www.willow.org)	☐	☐
19. Willow-Talk (www.willow-talk.org)	☐	☐
20. Young Survival Coalition (www.youngsurvivor.org)	☐	☐
Other **(Please specify:** _____		

**Q14. Which breast cancer online support network(s) do you <u>most frequently visit</u>?
(Either from the list in Q13 above or other websites)**

_____

_____

**Q15. What do you like most about the breast cancer online support network that you most
frequently visit?**

_____

_____

_____

**Q16. Please rate how important it is for you to find women who are similar to you in
breast cancer online support networks based on the following characteristics:**

	Very Important	Important	Neutral	Somewhat not important	Not important
1.Age	☐	☐	☐	☐	☐
2.Relationship status	☐	☐	☐	☐	☐
3.Sexual orientation	☐	☐	☐	☐	☐
4.Caring for children	☐	☐	☐	☐	☐
5.Income level	☐	☐	☐	☐	☐
6.Education level	☐	☐	☐	☐	☐
7.Profession	☐	☐	☐	☐	☐
8.Time since diagnosis	☐	☐	☐	☐	☐
9.Treatments completed	☐	☐	☐	☐	☐
10.Treatments undergoing	☐	☐	☐	☐	☐
11.Breast cancer type	☐	☐	☐	☐	☐
12.Breast cancer stage	☐	☐	☐	☐	☐
13.Metastatic cancer	☐	☐	☐	☐	☐
14.Cancer recurrence	☐	☐	☐	☐	☐
15.Cultural background	☐	☐	☐	☐	☐
16.Spiritual beliefs	☐	☐	☐	☐	☐
17.Native language	☐	☐	☐	☐	☐
18.Country of origin	☐	☐	☐	☐	☐
19.Country of residence	☐	☐	☐	☐	☐
20.City of residence	☐	☐	☐	☐	☐
21.Treating hospital	☐	☐	☐	☐	☐
22.Treating doctor	☐	☐	☐	☐	☐
Other **(Please specify:**_____					

Q17. Have you stopped visiting breast cancer online support networks, for some reason?

☐ No
☐ Yes

If "yes", why did you stop?

_____

_____

_____

Q18. We would like to learn more about your opinions of participating (reading or posting messages) in breast cancer online support networks. Please select the box that best describes how you feel about each statement.

	Very strongly agree	Strongly agree	Mildly agree	Neutral	Mildly disagree	Strongly disagree	Very strongly disagree
1. Participating in breast cancer online support networks provides useful information about breast cancer.	☐	☐	☐	☐	☐	☐	☐
2. Participating in breast cancer online support networks provides strategies to help me cope.	☐	☐	☐	☐	☐	☐	☐
3. Participating in breast cancer online support networks provides understanding from others with similar experiences.	☐	☐	☐	☐	☐	☐	☐
4. Participating in breast cancer online support networks makes me feel depressed.	☐	☐	☐	☐	☐	☐	☐
5. Participating in breast cancer online support networks makes me anxious.	☐	☐	☐	☐	☐	☐	☐
6. Participating in breast cancer online support networks is risky because you cannot trust the information they contain.	☐	☐	☐	☐	☐	☐	☐
7. Learning how to operate breast cancer online support networks is easy for me.	☐	☐	☐	☐	☐	☐	☐
8. My interaction with breast cancer online support networks is clear and understandable.	☐	☐	☐	☐	☐	☐	☐
9. It is easy for me to become skillful at participating in breast cancer online support networks.	☐	☐	☐	☐	☐	☐	☐
10. I trust the information posted by other members of breast cancer online support networks	☐	☐	☐	☐	☐	☐	☐

	Very strongly agree	Strongly agree	Mildly agree	Neutral	Mildly disagree	Strongly disagree	Very strongly disagree
11. The members of online support networks do everything within their capacity to help others.	□	□	□	□	□	□	□
12. I feel confident finding information in breast cancer online support networks.	□	□	□	□	□	□	□
13. I feel confident posting messages in breast cancer online support networks.	□	□	□	□	□	□	□
14. I have the skills needed to evaluate the information posted by other members in breast cancer online support networks.	□	□	□	□	□	□	□
15. I have fast enough Internet connection to use breast cancer online support networks.	□	□	□	□	□	□	□
16. I have access to people who can help me use breast cancer online support networks.	□	□	□	□	□	□	□
17. Participating in breast cancer online support networks is a good idea.	□	□	□	□	□	□	□
18. I like the idea of participating in breast cancer online support networks.	□	□	□	□	□	□	□
19. Participating in breast cancer online support networks is a positive experience.	□	□	□	□	□	□	□
20. Participating in breast cancer online support networks is a foolish idea.	□	□	□	□	□	□	□
21. My family and friends think that participating in breast cancer online support networks is a good idea.	□	□	□	□	□	□	□
22. My doctors think participating in breast cancer online support networks is a good idea.	□	□	□	□	□	□	□
23. I am able to participate in breast cancer online support networks.	□	□	□	□	□	□	□
24. I am in control of my participation in breast cancer online support networks.	□	□	□	□	□	□	□
25. I intend to participate in breast cancer online support networks again in the future.	□	□	□	□	□	□	□

SECTION 4 These questions ask about the needs that you have faced as a result of having breast cancer and the people in your life that you may drawn upon for support.

Q19. We are interested in whether or not needs which you may have faced as a result of having breast cancer have been met. For every item listed below, indicate whether you have needed help with this issue in the LAST MONTH as a result of having cancer.

In the **last month…**	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
1. I need up to date information.	☐	☐	☐	☐	☐
2. My family and/or partner needs information relevant to them.	☐	☐	☐	☐	☐
3. I need information provided in a way that I can understand.	☐	☐	☐	☐	☐
4. I need the very best medical care.	☐	☐	☐	☐	☐
5. I need local health care services that are available when I require them.	☐	☐	☐	☐	☐
6. I need to feel like I am managing my health together with the medical team.	☐	☐	☐	☐	☐
7. I need to know that all my doctors talk to each other to coordinate my care.	☐	☐	☐	☐	☐
8. I need any concerns regarding my care to be properly addressed.	☐	☐	☐	☐	☐
9. I need access to complementary or alternative therapy services.	☐	☐	☐	☐	☐
10. I need help to reduce stress in my life.	☐	☐	☐	☐	☐
11. I need help to manage ongoing symptoms or side effects.	☐	☐	☐	☐	☐
12. I need help to manage pain	☐	☐	☐	☐	☐
13. I need help to adjust to changes in my quality of life as a result of the cancer.	☐	☐	☐	☐	☐
14. I need help with having a family due to fertility problems.	☐	☐	☐	☐	☐
15. I need assistance with getting and/or maintaining employment.	☐	☐	☐	☐	☐
16. I need help to find out about financial support or governmental benefits to which I am entitled.	☐	☐	☐	☐	☐
17. Due to the cancer, I need help getting life and/or travel insurance.	☐	☐	☐	☐	☐
18. Due to the cancer, I need help accessing legal services.	☐	☐	☐	☐	☐
19. I need more accessible hospital parking.	☐	☐	☐	☐	☐

In the **last month…**	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
20. I need help to manage my concerns about the cancer coming back.	☐	☐	☐	☐	☐
21. I need emotional support to be provided for me.	☐	☐	☐	☐	☐
22. I need help to know how to support my partner and/or family.	☐	☐	☐	☐	☐
23. I need help to deal with the impact that cancer has had on my relationship with my partner.	☐	☐	☐	☐	☐
24. I need help with developing new relationships after the cancer.	☐	☐	☐	☐	☐
25. I need to talk to others who have experienced cancer.	☐	☐	☐	☐	☐
26. I need help to handle the topic of cancer in social and/or work situations.	☐	☐	☐	☐	☐
27. I need help to adjust to changes to the way I feel about my body.	☐	☐	☐	☐	☐
28. I need help to address problems with my/our sex life.	☐	☐	☐	☐	☐
29. I need an ongoing case manager to whom I can go to find out about services whenever they are needed.	☐	☐	☐	☐	☐
30. I need help to move on with my life	☐	☐	☐	☐	☐
31. I need help to cope with changes to my belief that nothing bad will ever happen in my life.	☐	☐	☐	☐	☐
32. I need help to cope with others not acknowledging the impact that cancer has had on my life.	☐	☐	☐	☐	☐
33. I need help to deal with my own and/or others expectations of me as a "cancer survivor".	☐	☐	☐	☐	☐
34. I need help to try to make decisions about my life in the context of uncertainty.	☐	☐	☐	☐	☐
35. I need help to explore my spiritual beliefs.	☐	☐	☐	☐	☐
36. I need help to make my life count.	☐	☐	☐	☐	☐

Other **(Please specify:**_____

_____

Q20. We would like to learn about the kind of help and support you have available to you in coping with your life at present. Please indicate how your feel about each of the following statements

	Very strongly agree	Strongly agree	Mildly agree	Neutral	Mildly disagree	Strongly disagree	Very strongly disagree
1. There is a special person who is around when I am in need.	☐	☐	☐	☐	☐	☐	☐
2. There is a special person with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐	☐	☐
3. My family really tries to help me.	☐	☐	☐	☐	☐	☐	☐
4. I get the emotional help and support I need from my family.	☐	☐	☐	☐	☐	☐	☐
5. I have a special person who is a real source of comfort to me.	☐	☐	☐	☐	☐	☐	☐
6. My friends really try to help me.	☐	☐	☐	☐	☐	☐	☐
7. I can count on my friends when things go wrong.	☐	☐	☐	☐	☐	☐	☐
8. I can talk about my problems with my family.	☐	☐	☐	☐	☐	☐	☐
9. I have friends with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐	☐	☐
10. There is a special person in my life who cares about my feelings.	☐	☐	☐	☐	☐	☐	☐
11. My family is willing to help me make decisions.	☐	☐	☐	☐	☐	☐	☐
12. I can talk about my problems with my friends.	☐	☐	☐	☐	☐	☐	☐

Q21. What is your current relationship status?

☐ Divorced or separated
☐ Widowed
☐ Married
☐ In a steady and continuous relationship
☐ Single

Q22. How many <u>relatives</u> (not including your spouse) do you have, that you feel close to and that you can talk to about personal matters?

☐ None
☐ 1 to 2
☐ 3 to 5
☐ 6 to 9
☐ 10 +

Q23. How many <u>friends</u> do you have, that you feel close to and that you can talk to about personal matters?

     ☐ None
     ☐ 1 to 2
     ☐ 3 to 5
     ☐ 6 to 9
     ☐ 10 +

Q24. How many of these <u>close friends or relatives</u> do you see <u>at least once per month</u>?

     ☐ None
     ☐ 1 to 2
     ☐ 3 to 5
     ☐ 6 to 9
     ☐ 10 +

Q25. How often do you participate in any <u>religious or spiritual groups</u> or activities?

     ☐ More than once per week
     ☐ Once per week
     ☐ Less than once per week
     ☐ Less than once per month
     ☐ Never

Q26. How often do you participate in any <u>social groups or activities</u> (excluding breast cancer related group activities)?

     ☐ More than once per week
     ☐ Once per week
     ☐ Less than once per week
     ☐ Less than once per month
     ☐ Never

Q27. Do you participate in any <u>face-to-face breast cancer related groups or activities</u>, such as a support group, dragon boat group, running group, or fundraising event etc.?

     ☐ No
     ☐ Yes

     If "yes", do you use the Internet to stay connected to the women you meet in face-to-face breast cancer related group activities?

     ☐ Yes
     ☐ No

<u>SECTION 5</u> These questions ask about your breast cancer diagnosis and treatments.

Q28. When were you first diagnosed with breast cancer?

     Month:_____ **Year**:_____

Q29. Have you experienced a recurrence of breast cancer?

☐ No
☐ Yes

Q30. Are you: (Choose one)

☐ Recently diagnosis (but before treatment)
☐ Undergoing medical treatment (such as surgery, radiation, chemotherapy)
☐ Completed medical treatment (but on hormone therapy such as Tamoxifen)
☐ Completed all medical treatment for breast cancer (including hormone therapy)

☐ Other **(Please specify:**_____

SECTION 6 These final questions ask about your demographics such as age and background.

Q31. How old are you? _____

Q32. Where were you born?

☐ Canada
☐ Other country **(Please specify:**_____

Q33. What are the ethnic or cultural origins of your ancestors?
(An ancestor is usually more distant than a grandparent)

For example, Canadian, English, French, Chinese, Italian, German, Scottish, East Indian, Irish, Cree, Mi'kmaq (Micmac), Métis, Inuit (Eskimo), Ukrainian, Dutch, Filipino, Polish, Portuguese, Jewish, Greek, Jamaican, Vietnamese, Lebanese, Chilean, Salvadorean, Somali, etc.

Specify as many origins as applicable:

_____

Q34. Are you: (Check more than one or specify, if applicable.)

☐ White
☐ Chinese
☐ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
☐ Black
☐ Filipino
☐ Latin American
☐ Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.)
☐ Arab
☐ West Asian (e.g., Iranian, Afghan, etc.)
☐ Korean
☐ Japanese
☐ Other **(Please specify:**_____

Q35. What language do you speak most often at home?_____

Q36. Where do you currently live?

☐ Canada
☐ Other country **(Please specify_____**

If you currently live in Canada, which province do you live in:

☐ Nfld. Lbd
☐ P.E.I.
☐ N.S.
☐ N.B.
☐ Quebec
☐ Ontario
☐ Manitoba
☐ Saskatchewan
☐ Alberta
☐ British Columbia
☐ Yukon
☐ N.W.T.
☐ Nunavut

Q37. What is the name of the city or town in Canada that you live?

_____

OR, what is the approximate size of the city or town in Canada where you live?

☐ Less than 10,000 persons
☐ Between 10,001 and 99,999 persons
☐ Between 100,000 and 249,000 persons
☐ Between 250,000 and 1 million persons
☐ Greater than 1 million persons

Q38. What is the highest level of education that you have completed? Choose one.

☐ Preliminary or elementary school
☐ Secondary or high school
☐ College, technical school or other non-university certificate or diploma
☐ University – Bachelor's degree
☐ University- Master's degree
☐ University – Professional degree
☐ University – PhD or higher

Q39. What was your <u>total household income</u> from all sources before deductions in 2008?

☐ Less than $40,000
☐ $40,001 to $80,000
☐ $80,001 to $120,000
☐ $120,001 or more

REQUEST 1 **If you have visited a breast cancer online support network, would you be willing to be contacted for a <u>1-hour follow-up interview by telephone</u>? During this interview you would be asked to talk about the needs you've experienced as result of having breast cancer and your experiences using online support networks to meet your needs.**

If "yes", please provide your name and a contact telephone number with area code:

Name: _____

Area code and telephone number:_____

REQUEST 2 **If you currently facilitate a breast cancer support group in your community would you be willing to help us distribute the questionnaire to the members of your support group?**

If "yes", please provide your name and a contact telephone number with area code:

Name: _____

Area code and telephone number:_____

Your time is greatly appreciated. Please return the questionnaire to Jackie Bender, the study director in the pre-paid envelope included in your study package.

THANK YOU!

Appendix 9: Thank You Card for Survey Participation

Exterior

Interior

Dear [Name]

Thank you for completing a questionnaire for our research study investigating the role of online support networks for breast cancer survivors.

Your responses are important to us. The results of this study will be made available on Willow's website (www.willow.org) in early 2010. The findings will be used by Willow to enhance their services and will be published as widely as possible to make sure other groups benefit as well.

Sincerely,

Jackie Bender MSc
PhD Student
Dalla Lana School of Public Health, University of Toronto

Appendix 10: Survey Reminder/ Follow-up Letter

UNIVERSITY OF TORONTO
DALLA LANA SCHOOL OF PUBLIC HEALTH

[Date]

[Recipient's Address]

Dear [name],

In early **[date]** we sent you a letter asking you to respond to a questionnaire about your opinions and experience with the Internet as a source of information and support for breast cancer. To the best of our knowledge, you have not yet completed the survey.

We are writing again because we really want to hear from you! Your responses are important for us to get accurate results. It is only by hearing from nearly everyone in the sample that we can be sure that the results truly represent the opinions of the Willow community.

You have received this packaged because you have had a breast cancer diagnosis, and at some point, you have used Willow's services. If you have ever gone online to access the Internet or to send or receive email, then you are somebody that we would like to participate in this study.

We know your time is valuable and that you have many competing commitments, however, we hope you are able to assist us. If you agree to do so, **we would ask you to complete a confidential questionnaire and return it to Jackie as soon as possible.**

There are <u>two ways</u> you can complete and return the questionnaire:

1) You can complete the enclosed questionnaire, and send it back to **Jackie** by postal mail in the enclosed pre-paid postage envelope.

OR

2) You can complete the questionnaire on the Internet. If you chose to complete the questionnaire on the Internet: just type the following web page address in your Internet browser, and then type in the questionnaire code to begin the survey:

    http://
    Your questionnaire code:

The questionnaire should take you **between 20 and 30 minutes to complete according the results of a pilot study.**

We take privacy very seriously. The questionnaire is completely confidential **but it is not anonymous. The questionnaire will be assigned a unique identification number that will be linked to your name in order to send thank you notes and reminders. However, only Jackie will know the identity of people who choose to respond or not.**

No identifying information is returned with the completed questionnaire- except for those of you who choose to provide your contact information for a follow-up interview. You do not have to decide this now.

All information collected will be stored in a secure location accessible only **to Jackie and her supervisor.** Any identifying information will be removed from the questionnaire. The study results will be reported as aggregated data so that no identifying information can be inferred. You will not be named in any reports, publications, or presentations that may come from this study.

Your responses are voluntary. If you come to a question that you prefer not to answer, please skip it and go on to the next.

If you have any questions about this study or if you have difficulties answering the questionnaire on the Internet, Jackie will be happy to help and can be reached by telephone at: 416-340-4800 ext. 8116 or by email: jackie.bender@utoronto.ca.

Jackie is conducting this research in partial fulfillment of a PhD at the University of Toronto. **Her supervisor is Dr. Alex Jadad and is available by telephone at: 416-340-4800 ext. 6903 or by email: ajadad@ehealthinnovation.org.** This study has been approved by the University of Toronto Research Ethics Board. If you have any questions about your rights as a research participant in this study, please contact Jill Parsons, Health Sciences Review Officer, Ethics Review Office, University of Toronto, by telephone at 416-946-5806 or by email: jc.parsons@utoronto.ca

The results of this study will be made available on the Willow website at www.willow.org in early 2010. **Willow plans to make use the of the study results for their own services.**

We hope to hear from you soon!

Jackie Bender, MSc
PhD Student
Dalla Lana School of Public Health
University of Toronto

Appendix 11: Final Survey Reminder/ Follow-Up Letter

UNIVERSITY OF TORONTO
DALLA LANA SCHOOL OF PUBLIC HEALTH

[Date]
[Address]

Dear [Name],

In [Date] I mailed you a questionnaire about websites where you can communicate with other women diagnosed with breast cancer.

If you have completed and returned the questionnaire, please accept my sincere thanks. If you have not, I am writing one last time to let you know that your response is important to us, no matter what it is.

<u>I am hoping you might be willing to complete the enclosed questionnaire</u>, if you have been diagnosed with breast cancer and have used the Internet to send or receive mail. Even if you have never visited websites where you can communicate with other women with breast cancer, I hope you will consider completing the questionnaire.

<u>If you are not planning to complete the questionnaire,</u> could you take a few minutes to complete the enclosed post card and return it to me? It is very important to hear back from everyone, no matter what their response in order to get accurate results.

Completed questionnaires and post cards are needed by **[Date]**

If you have any questions about this study, please contact me at: 416-340-4800 ext. 8116 or by email: jackie.bender@utoronto.ca.

Thank you for considering this request. Your participation will provide valuable information to assist Willow Breast Cancer Support Canada in the development of future programs, and the findings will be published as widely as possible to make sure other groups benefit as well.

Sincerely,

Jackie Bender

Jackie Bender, MSc
PhD Student
Dalla Lana School of Public Heath
University of Toronto

Appendix 12: Final Participation Card

Participation Card

If you do not plan to complete the questionnaire, please let me know by completing this card. Please check as many as apply:

☐ I do not plan to complete the questionnaire.

    ⌐→

        ☐ I have not been diagnosed with breast cancer.

        ☐ I do not use the Internet

        ☐ Other reason

Please return this participation card in the pre-paid postage envelope included in the study package.

THANK YOU!

Appendix 13: Telephone Recruitment Script for Interview Study

Hello. May I speak to: [Name]

This is Jackie Bender from the University of Toronto.

I am the PhD student who is conducting a research study with Willow Breast Cancer Support Canada to understand the role of online peer support for women diagnosed with breast cancer.

Let me begin by thank you again for completing a questionnaire for our research study. You'll be receiving a brief summary of the study findings in a Willow newsletter; the full report will be posted on the Willow website in the coming months.

I am calling you now because you indicated in the study questionnaire that you would be willing to participate in a follow-up telephone interview. The purpose of this interview is to learn more about the needs you've experienced as a result of having breast cancer, your opinions of online support networks for breast cancer survivors, and your experiences using online support networks to meet your needs. I would also like to learn about how online support networks could support you in your role as a breast cancer support-group facilitator.

This interview can be conducted over the phone, at a time that is convenient for you and will take approximately 1-hour.

It is completely voluntary and confidential. You may choose not to participate, not to answer certain questions or stop the interview at any time. Your responses will be treated confidentially.

Q1. Are you still interested in participating in a telephone interview?
    ☐ Yes
    ☐ No   ⟶   Thank you for your time and consideration.

I will send you a study package that will include a consent form. I would ask you to please read and sign the consent form and return it to me. Once you have returned the signed consent form, we can conduct the interview.

What address should I use to send you the consent form? I can send it to you by email and you can fax it back to me. Or I can send it to you by postal mail with a return postage-paid envelope. Which method would you prefer? CONFIRM.
_____
_____
_____

Let's set up a tentative date and time within the next two weeks to conduct the interview. When would be a convenient time for you?
_____

Great. I will call you at the agreed upon date and time.

Thank you for your interest in this study.

Appendix 14: Consent Form for Interview Study

UNIVERSITY OF TORONTO
DALLA LANA SCHOOL OF PUBLIC HEALTH

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title: Online Social Networks: Supportive Care for Breast Cancer Survivors?

Study Investigator: Jackie Bender (416-340-4800 ext. 8116, jackie.bender@utoronto.ca)

Supervisor: Dr. Alex Jadad (416-340-4800 ext. 6903, ajadad@ehealthinnovation.org)

Introduction

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study investigators to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background and Purpose

Willow Breast Cancer Support Canada, in partnership with researchers at the University of Toronto are conducting a research study to understand the role of online peer support for women diagnosed with breast cancer. Health websites, where you can communicate with other people with breast cancer, are growing in number and popularity. We want to gain a greater understanding of the needs and preferences of breast cancer survivors regarding these types of peer support resources on the Internet.

You have been asked to participate in this study because you:
- Have had a breast cancer diagnosis;
- At some point, you have used Willow's services; and
- Have visited a website where you can communicate with other women diagnosed with breast cancer.

Study Procedures

If you agree to take part in the study you will participate in one telephone interview at a time that is convenient for you. The interview will take approximately 1 hour and will be audio-recorded. During the interview you will be asked about the needs you've experienced as result of having breast cancer as well as in role your as a support group facilitator (if relevant), your opinions regarding health websites, where you can communicate with other women diagnosed with breast cancer and your experiences using these types of peer support resources to meet your support needs. You will also be asked some basic information about the support group that you attend or facilitate, if relevant.

Voluntary Participation

Your participation is voluntary. You may choose not to participate, not to answer certain questions or stop the interview at any time without any negative consequences.

Risks and Benefits

There are no medical risks if you take part in this study. If you become tired or uncomfortable as a result of participating in this study, you can stop the interview at any time or continue later. You will not receive any direct benefit from being in this study. However, the information learned from this study may help others with breast cancer in the future.

Privacy and Confidentiality

Your responses will be treated confidentially. All identifying information will be removed and replaced with a unique identification code. All information collected will be stored in a secure location accessible only to the study team. Quotations from this interview may be included in the final report; however, you will not be named in any reports, publications, or presentations that may come from this study. The study results will be reported as aggregated data so that no identifying information can be inferred.

Questions About the Study

If you have any questions, concerns or would like to speak to the study team for any reason, please call Jackie Bender, the Study Investigator at 416-340-4800 x 8116 or Dr. Alex Jadad, the Principal Investigator at 416 340 4800 x 6903.

If you have any questions about your rights as a research participant or have concerns about this study, please contact Jill Parsons, Health Sciences Ethics Review Officer, Ethics Review Office, University of Toronto by telephone at 416-946-5806, or by email jc.parsons@utorontoc.ca.

Consent

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I voluntarily agree to take part in this study.

Study Participant's Name	Signature of Participant	Date

I consent to a follow-up interview in the event that clarification or elaboration is necessary:

Y ☐ N ☐

Appendix 15: Interview Guide

The purpose of this interview is to learn about your personal thoughts, opinions and experiences regarding online support networks as a source of support for breast cancer survivors.

1. Tell me about <u>why you decided to visit a breast cancer OSN?</u> *Probe: needs, timing, others*

2. Do you remember exactly <u>when</u> that was? For example, during or after breast cancer treatment?

3. Do you remember what you were thinking or feeling at that time? How would you describe the person you were then?

4. How did you <u>find out about</u> breast cancer OSNs? *Probe: search strategies, others, <u>first time user?</u>*

5. Do you have a <u>favourite</u> breast cancer OSN that you visit or visited most frequently? What do you <u>like most</u> about that site? *Probe: gains and technical features*

6. Is there anything that you feel that you <u>gained from participating</u> in OSNs at that time? Example?

7. Did participating in an OSN help you to address one or more of <u>the major needs</u> that you experienced during that time? If yes, did it help? How? Why or why not?

   Probe: emotional issues, health information needs, physical (symptoms and side effects), daily living, interpersonal relationships, sexuality, spirituality… etc.

8. Do you still visit OSNs now? What motivates you to visit them now as a breast cancer survivor?

9. Is there anything that you <u>dislike</u> about breast cancer OSNs? *Probe: technical features*

10. Do you feel comfortable using an OSN? *Probe: ease of use, posting frequency, profile use*

11. Some people don't trust OSNs… they don't think they are trustworthy or credible. Do you have these concerns? Why or why not? If yes, how did you overcome them? *Probe: search strategies for similar others*

12. What would cause you to <u>stop participating</u> in breast cancer OSNs? Or, why did you stop?

13. Do you think <u>sites like Facebook</u> could be a source of support for breast cancer survivors? Why or why not?

Now I'd like to ask you some questions about face-to-face breast cancer support groups.

14. What could be done to assist you in your role as a facilitator? What are some of the biggest challenges you face, and what type of support and from whom would help?

    Probe: Other facilitators? Online support networks? Would you be interested in an opportunity to communicate with other Willow facilitators... for example in a safe, protected forum on the new Willow website? What were you hoping to gain from the Willow facilitator training workshop?

15. In you experience, what role did <u>OSNs play for you in the context of all other sources of support</u> that were available to you? E.g., under what circumstances did you go to an OSN for support versus another source of support?
    Probe: advantages/disadvantages of online versus f2f support... under what conditions would you recommend them to others?

16. Based on your experiences, what advice would you give a woman newly diagnosed with breast cancer if she was seeking information or support about breast cancer or its treatment?

17. Is there anything else that you would like to add that could help me understand the role of online support networks for breast cancer survivors?

Thank you!

Appendix 16: Thank You Card for Interview Participation

Exterior

Interior

Dear [Name]

Thank you for participating in an interview for our research study investigating the role of online support networks for breast cancer survivors.

Your responses are important to us. The results of this study will be made available on Willow's website (www.willow.org) in early 2010. The findings will be used by Willow to enhance their services and will be published as widely as possible to make sure other groups benefit as well.

Sincerely,

Jackie Bender MSc
PhD Student
Dalla Lana School of Public Health, University of Toronto

Appendix 17: Preliminary Item Analysis of the TAM/TBP Instrument

Instrument Development

Items used to operationalize the constructs of the TPB and TAM were adapted from previous studies (Grand, Myers, & Sutton, 2006; Lin, 2006) and tailored for use in the context of online communities. Constructs were measured with two to four items using a 7-point Likert scale (1 = very strongly disagree to 7 = very strongly agree). The initial scale consisting of 24-items was pilot-tested and assessed by seven breast cancer survivors for clarity, wording and relevance resulting in the revision, elimination and addition of some items. The final scale consisting of 24-items and 9 sub-scales addressed the following constructs: beliefs about the perceived usefulness, ease of use and trust in online support networks, attitudes about outcomes of online support network participation (defined as reading or posting messages), affect towards online support network participation, beliefs about others' views about participating in online support communities, perceived self-efficacy and perceived behavioural control regarding participating in online support networks and facilitating conditions.

Preliminary Item Analysis

Methods

Item analysis and internal consistency reliability were assessed using Pearson's correlation coefficient and Cronbach's alpha. Item and sub-scale means, standard deviations and distribution characteristics (Skewness and Kurtosis) were calculated to ensure good variability and sufficient endorsement. Item-total, item-subscale and subscale-total correlations were calculated. Item correlations between 0.30 and 0.80 (Di Iorio, 2005; Hertzog, 2006), and Cronbach's alpha of more than 0.70 were considered acceptable (Norman & Streiner, 2008). Data analysis was performed using the statistical software package SPSS version 17 (IBM Corporation, Somers, NY, USA).

Results

Item - Total Correlations

Item-total correlations are shown in Table 17.1. Item analysis of the TAM/TPB measure indicated that the instrument had high internal consistency reliability ($\alpha = 0.91$). The corrected item-total correlations ranged from 0.22 (I have access to people who can help me use OSNs) to 0.72 (I like the idea of participating in OSNs). The item 'I have access to people who can help me use OSNs' had a weak correlation with the total score ($r = 0.22$), which suggests that this item might need to be eliminated or rephrased. It also produced a higher 'alpha value when deleted' ($\alpha = 0.92$) providing further indication of the item's weak association with total scale. In addition, items associated with the Perceived Affect subscale (Participating in OSNs make me feel anxious/ depressed) both produced higher alpha values when deleted although their item-total correlations were above 0.30, suggesting that they too might require further review.

Item - Subscale Correlations

Item-subscale correlations and reliability estimates are shown in Table 17.1. The majority of the reliability indices for the subscales were above the recommend minimum alpha level of 0.7 ranging from $\alpha = 0.71$ (Subjective Norms) to $\alpha = 0.89$ (Perceived Usefulness). Two subscales had reliability coefficients below 0.7, Perceived Self-efficacy ($\alpha = 0.64$) and Facilitating Conditions ($\alpha = 0.23$). The Facilitating Conditions subscale also had very low item-subscale total correlations ($r = 0.13$) suggesting that items within this subscale may not be measuring the same construct. Item-subscale correlations across the other subscales were acceptable ranging from $r = 0.42$ to $r = 0.91$. The findings from this stage of the analysis suggest that the Perceived Self-Efficacy subscale may have low internal reliability and the items within the Facilitating Conditions subscale might not be measuring the same constructs.

Table 17.1: Item Statistics and Reliability Indices

	Mean (SD)	Corrected item-total correlations	Corrected-item-subscale correlations	Cronbach alpha for subscales
Perceived Usefulness				0.89
Participating in OSNs would provide useful information about breast cancer	5.37 (1.05)	0.64	0.76	
Participating in OSNs would provide strategies to help me cope	5.18 (1.08)	0.60	0.77	
Participating in OSNs would provide understanding from similar others	5.51 (1.01)	0.68	0.80	
Perceived Ease of Use				0.87
Learning how to operate OSNs would be easy for me	4.81 (1.59)	0.50	0.77	
My interaction with OSNs would be clear and understandable	4.76 (1.32)	0.57	0.89	
It would be easy for me to become skillful at participating in OSNs	4.82 (1.52)	0.57	0.80	
Perceived Credibility				0.77
Participating in OSNs is risky because you cannot trust the info they contain	4.15 (1.59)	0.41	0.60	
I trust the information posted by members in OSNs	4.62 (1.29)	0.57	0.61	
The members of OSNs do everything within their capacity to help others.	5.24 (1.17)	0.55	0.65	
Perceived Affect				0.95
Participating in OSNs would make me feel depressed	4.96 (1.51)	0.32	0.91	
Participating in OSNs would make me feel anxious	4.91 (1.60)	0.37	0.91	
Attitudes				0.87
Participating in OSNs is a good idea	5.25 (1.20)	0.69	0.77	
I like the idea of participating in OSNs	4.95 (1.37)	0.72	0.80	
Participating in OSNs is a positive experience	4.93 (1.23)	0.77	0.82	
Participating in OSNs is a foolish idea.	5.38 (1.46)	0.44	0.52	
Perceived Self-Efficacy				0.64
I would feel confident finding information in OSNs	4.96 (1.19)	0.77	0.44	
I would feel confident posting messages in OSNs	4.22 (1.65)	0.51	0.48	
I have the skills needed to evaluate information posted by others in OSNs	5.19 (1.37)	0.48	0.45	
Facilitating Conditions				0.23
I have a fast enough Internet connection to use OSNs	5.51 (1.54)	0.47	0.13	
I have access to people who can help me use OSNs	5.01 (1.46)	0.22	0.13	
Subjective Norms				0.71
My family and friends would think that participating in OSNs is a good idea	4.69 (1.21)	0.46	0.55	
My doctors would think that participating OSNs is a good idea	4.51 (1.19)	0.60	0.55	
Perceived Behavioural Control				0.88
I would be able to participate in OSNs	5.07 (1.42)	0.70	0.79	
I am in control of my participation in OSNs	5.47 (1.48)	0.55	0.79	
Total alpha = 0.91				

Subscale - Total Correlations

Subscale-total correlations and reliability estimates are shown in Table 17.2. Analysis of the TPB measure at the subscale level indicated that the instrument had very good internal

consistency ($\alpha = 0.84$). The majority of the subscale-total correlations were within an acceptable range ($r = 0.48$ to 0.69) except for the Perceived Affect subscale, which had a weak association with the total scale ($r = 0.26$) below the recommended minimum level of 0.30. It also produced a higher 'alpha value when deleted' ($\alpha = 0.95$) providing further indication of the subscale's weak association with total scale. The findings from this stage of the analysis suggest that the Perceived Affect and Facilitating Conditions variables might need to be eliminated or revised.

Table 17.1: Sub-Scale Statistics and Reliability Indices

	Mean (SD)	Corrected Subscale-total correlation	Cronbach's alpha (α) if item deleted	Cronbach's alpha for instrument
Perceived Usefulness	5.35 (0.95)	0.63	0.81	
Perceived Ease of Use	4.80 (1.31)	0.55	0.82	
Perceived Credibility	4.67 (1.13)	0.52	0.82	
Perceived Affect	4.93 (1.52)	0.26	0.86	
Attitudes	5.10 (1.12)	0.69	0.80	
Perceived Self-Efficacy	4.79 (1.10)	0.74	0.80	
Facilitating Conditions	5.29 (1.13)	0.48	0.83	
Subjective Norms	4.60 (1.05)	0.56	0.82	
Perceived Behavioural Control	5.27 (1.37)	0.63	0.81	
Total				0.84

Interpretation

The extended TAM/TPB shows promise as a measure of intention to participate in online communities among breast cancer survivors. Overall, the measure had high levels of internal consistency at the item and subscale level. Two constructs warrant further review and refinement: the Perceived Self-efficacy and Facilitating Conditions constructs. In addition, further analysis is required to examine the role of Perceived Affect in relation to the internal structure of the overall instrument. Limitations of the study that affect the strength of these conclusions were the small sample size, the insufficient number of items per scale (some had less than the recommended three items) and the poor reliability of one item and two sub-scales. Therefore, future scale development efforts must consider refining and adding items to certain subscales, and even changes to the subscale structure. Future research should also focus on examining the validity of the scale in other populations.

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Appendix 18: Users versus Non-Users of Online Communities

Analysis

Data analysis was performed using the statistical software package SPSS version 17 (IBM Corporation, Somers, NY, USA). Univariate statistics were calculated using sample means and standard deviations for continuous variables and proportions for categorical variables. T-tests, Mann-Whitney U tests and χ^2 tests were used to analyze the differences between groups. All p-values <0.05 were considered to be significant.

Results

As shown in Table 18.1, users of breast cancer online communities were more likely than non-users to use the Internet to search for information about breast cancer. No significant differences were found in age, education, income, city size, length of time since diagnosis, frequency of Internet use, use of Facebook, perceived social support or social network integration.

Table 18.1: Differences in Sociodemographic and Disease Characteristics

	Total (n=73)	Non-users (n=50)	Users (n=23)	Test statistic	Significance
Age in years (mean, SD)	56 (9.52)	56.98 (9.98)	54.04 (8.74)	t= -1.25	p= 0.22
Education (%)					
Secondary school or less	18.3	18.8	18.2		
College or Technical school	46.5	45.8	50		
University	35.2	35.4	31.8	χ^2= 0.11	p= 0.94
Total Household Income (%)					
Less than $40,000	28.1	32.6	19		
$40,001 to $80,000	43.8	47.6	47.6		
$80,001 +	28.1	25.6	33.3	χ^2= 1.32	p= 0.52
City Size (%)					
Less than 10,000 persons	37	42	26.1		
10,001 to 99,999 persons	43.8	40	52.2		
100,000 or more persons	19.2	18	21.7	χ^2= 1.73	p= 0.42
Years since diagnosis (med, IQR)	5.92 (7.3)	6.3 (6.98)	3.7 (5.17)	Z= -1.93	p= 0.05
Frequency of Internet use (%)					
At least once a day	72.6	66	87		
Once per week or less	27.4	34	13	χ^2= 3.49	p= 0.06
Use of Internet for breast cancer (%)	89	84	100	χ^2= 4.13	p= 0.04
Facebook users (%)	43.8	36	60.9	χ^2= 3.96	p= 0.05
Social Support (7-point scale)					
Friends (mean, SD)	6.04 (0.11)	6.06 (0.89)	6.12 (0.97)	Z= -0.51	p=0.61
Special person (mean, SD)	5.92 (0.15)	5.81 (1.32)	6.18 (0.93)	Z= -0.75	p=0.45
Family (mean, SD)	5.66 (0.17)	5.63 (1.45)	5.55 (1.45)	Z= -0.17	p=0.87
Total (mean, SD)	5.88 (0.12)	5.83 (1.03)	5.99 (0.99)	Z= -0.65	p=0.51
Social Network Index (%)					
Socially isolated (I, 11)	35.7	36.7	33.3		
Socially integrated (III, IV)	64.3	63.3	66.7	χ^2= 0.74	p= 0.78

As shown in Table 18.2, users had significantly more positive beliefs regarding Perceived Usefulness, Ease of Use, and Credibility, overall Attitude, and Behavioural Control toward participating in online communities. Users also had significantly more positive overall mean scores for the extended TPB instrument compared to non-users. No significant differences were found in Perceived Affect, Self-Efficacy, Facilitating Conditions and Subjective Norms.

Table 18.2: Differences in TAM/TPB Sub-Scale Scores

	Total (n=73)	Non-users (n=50)	Users (n=23)	Test statistic	Significance
Perceived Usefulness	5.35 (0.95)	5.10 (0.88)	5.87 (0.86)	t=3.43	p<0.01
Perceived Ease of Use	4.80 (1.31)	4.53 (1.30)	5.32 (1.20)	t= 2.30	p=0.02
Perceived Credibility	4.67 (1.13)	4.47 (1.01)	5.06 (1.26)	t= 2.09	p=0.04
Perceived Affect	4.93 (1.52)	4.83 (0.23)	5.26 (0.31)	t=0.87	p=0.40
Attitudes	5.10 (1.12)	4.83 (1.08)	5.64 (1.00)	t=3.01	p<0.01
Perceived Self-Efficacy	4.79 (1.10)	4.64 (1.13)	5.07 (0.92)	t=1.57	p=0.12
Facilitating Conditions	5.29 (1.13)	5.12 (1.17)	5.63 (0.98)	t=1.77	p=0.08
Subjective Norms	4.60 (1.05)	4.43 (1.02)	4.93 (1.06)	t=1.89	p=0.06
Perceived Behavioural Control	5.27 (1.37)	4.97 (1.40)	5.87 (1.11)	t=2.68	p<0.01

Interpretations

Overall, the findings suggest that users of online communities may be more likely to use the Internet as a health resource than non-users. They also suggest that users may have more positive beliefs about the usefulness of online communities and their ability to use them. These findings confirm the potential utility of the TAM/TPB measure. They also reflect factors that have been shown to influence Internet use for health more generally. Based on data from a survey of 660 patients attending a general practice clinic in the United Kingdom, key predictors of the use of the Internet as health resource were (in order of importance), a positive outcome expectancy, previous use of health websites, positive Internet self-efficacy, higher education, positive attitude towards obtaining information from alternative sources, social deprivation and having school age children at home (Mead et al., 2003).

Interestingly three of the four TAM/TPMB subscales that were found to have poor reliability (See Appendix 17), namely Perceived Affect, Self-Efficacy and Facilitating Conditions were also not significantly different between the groups. As the results of the item analysis suggest, these constructs warrant further review and refinement.

The size and composition of the sample limit the strength of these conclusions. Future research should examine the reliability and validity of a refined version of the TAM/TPB in

larger samples of typical cancer survivors, and explore the relationship between the scale and sociodemographic factors known to influence patients' use of the Internet as a health resource (e.g., higher education, social deprivation and having school age children at home) (Mead et al., 2003).

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Appendix 19: Research Team Contributions

Research Team

Principal Student Investigator: Jacqeline L. Bender (JLB)

Thesis Supervisor: Alejandro R. Jadad (ARJ)

Thesis Committee Members: Joel Katz (JK), Lorraine E. Ferris (LEF),

Research Assistants: M. Carolina Jimenez-Marroquin (MCJM), Hans Oh (HO)

Contributions

Study 1) Systematic Review of Online Communities for Breast Cancer Survivors

JLB conceived and planned the study with support from ARJ. JLB and MCJM collected the data. JLB analyzed the data and wrote the manuscript. ARJ, LEF, JK and MCJM reviewed and contributed to the manuscript. JLB is guarantor.

Study 2) Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups

JLB conceived and planned the study with support from ARJ. JLB and MCJM collected the data. JLB analyzed the data and wrote the manuscript. ARJ, LEF, JK and MCJM reviewed and contributed to the manuscript. JLB is guarantor.

Study 3) Supportive Care Needs and Online Community Use of Breast Cancer Survivors who are Peer Support Providers

JLB conceived and planned the study with support from ARJ, LEF and JK. JLB collected and analyzed the data, and wrote the manuscript. ARJ, LEF, JK and MCJM reviewed and contributed to the manuscript. JLB is guarantor.

Study 4) The Conditions that Influence Breast Cancer Peer Support Providers to Use Online Communities: A Qualitative Study

JLB conceived and planned the study with support from ARJ, LEF and JK. JLB collected and analyzed the data, and wrote the manuscript. ARJ, LEF, JK and MCJM reviewed and contributed to the manuscript. JLB is guarantor.