What is the role of online support from the perspective of facilitators of face-to-face support groups? A multi-method study of the use of breast cancer online communities ☆

Jacqueline L. Bender [a,b,c,*], Joel Katz [e], Lorraine E. Ferris [a], Alejandro R. Jadad [a,b,c,d]

[a] Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada
[b] Centre for Global eHealth Innovation, University Health Network, Toronto, ON, Canada
[c] ELLICSR: Centre for Health, Wellness and Cancer Survivorship, University Health Network, Toronto, ON, Canada
[d] Department of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada
[e] Department of Psychology, York University, Toronto, ON, Canada

ARTICLE INFO

ABSTRACT

Objective: To explore the role of online communities from the perspective of breast cancer survivors who are facilitators of face-to-face support groups.
Methods: Seventy-three attendees (73% response rate) of a Canadian support group-training program completed a questionnaire examining when and why they used online communities. A purposive sample of 12 respondents was interviewed on how they used them in comparison to traditional supportive care. Survey responses were analyzed using descriptive statistics, and interview transcripts using a descriptive interpretive approach.
Results: Online communities were used by 31.5%, mostly during treatment (73.9%), daily or weekly (91.3%), primarily for information (91.3%) and symptom management (69.6%) and less for emotional support (47.8%). Reasons for non-use were lack of need (48.0%), self-efficacy (30.0%), trust (24.0%), and awareness (20.0%). Respondents used online communities to address unmet needs during periods of stress and uncertainty. A multi-theory framework helps to explain the conditions influencing their use.
Conclusion: Online communities have the potential to fill gaps in supportive care by addressing the unmet needs of a subgroup of breast cancer survivors. Further research is required among typical cancer survivors.
Practice implications: Online communities could play an important role as a supplemental resource for a sub-group of breast cancer survivors.

1. Introduction

Peer support groups have shown great promise in meeting the supportive care needs of people with cancer and are considered an important complement to the formal health care system [1–3]. However, practical barriers such as time, mobility and geography limit their use [4]. Online support groups, also known as online communities, have the potential to overcome many of the barriers to in-person support, while reaching a wider segment of the population [5–7]. They provide additional advantages such as 24-h accessibility from the convenience of home, anonymity, similarity of experiences and diversity of resources [8].

Breast cancer support groups ranked third (after chronic fatigue and diabetes) in frequency of postings in an evaluation of disease support groups on the Internet [9]. Although there is limited empirical evidence concerning their impact [7,10], several qualitative studies have shown that such groups provide breast cancer survivors with important benefits. These include: reassurance and hope for the future [11–13]; reduced feelings of isolation and uncertainty [12–15]; validation of concerns not dealt with by health professionals [11]; and enhanced understanding of the disease [11,13,16] and ability to cope [15].

Although breast cancer survivors appear to be one of the more active illness groups online [9], little is known about the proportion who use online communities. A 2010 Pew survey of 3001 U.S. found that Internet users living with one or more chronic

conditions such as cancer were more likely to report using online communities [17]. Specifically, 37% read someone else's experience of a health issue on an online group, website or blog compared to 31% of those reporting no chronic conditions. A hospital-based survey of 679 Dutch patients with breast cancer, rheumatoid arthritis or fibromyalgia published in 2009 found that 15% of the patients surveyed had used an online community [18].

Similarly, we know little about the individual, social or contextual factors that influence people to seek online support, or how participation in online communities compares to traditional forms of support. According to research by Davison et al. embarrassment, stigma and disfigurement motivate patients to seek both online and offline forms of support, while online support occurs at higher rates for those whose conditions are poorly understood or overlooked by the medical community [9]. A survey of 1039 Japanese breast cancer survivors demonstrated that those who used both online communities and face-to-face support groups received the most benefit [19]. Online communities were used immediately after diagnosis, whereas face-to-face groups were used after beginning or completing treatment, suggesting that they may serve different purposes.

This study focuses on breast cancer survivors who are facilitators of face-to-face support groups. Several studies indicate that the success of support groups is largely dependent on the group leader [20–22]. Our goal was to leverage their expertise in providing support, to better understand the role of online support, including how it compares to face-to-face support, and whether it could complement traditional supportive care services. Hence, the study purpose was twofold: (1) to identify the extent to which this unique sample of breast cancer survivors used online communities including their timing, frequency and reasons for use; and (2) to explore the conditions under which they used online communities, and how they compare to traditional sources of supportive care. Lastly, as the results were being analyzed it became apparent that theories of social support, technology adoption and health behavior could help to explain the study findings. Therefore, we used selected theories to frame the findings.

2. Methods

2.1. Study design

We used a multi-method study design involving a cross-sectional survey followed by qualitative interviews. This study was approved by the University of Toronto Research Ethics Board [23].

2.2. Participants

The sample for the survey was drawn from the 2008 and 2009 attendee list of a support group facilitator-training program offered by Willow Breast Cancer Support Canada, a national non-profit support agency (www.willow.org). This program is attended by breast cancer survivors at least one-year post diagnosis, seeking to enhance their skills as support group facilitators. The survey was restricted to program attendees who had used the Internet to send and receive email; and could read and speak English. A purposive sample [24] of survey respondents who had used an online community was recruited for a follow-up interview. The sample size for the qualitative study was determined by the saturation point of the data [25], which occurred after 12 participants were recruited.

2.3. Data collection

Program attendees were notified of the study through a Willow newsletter. One week after the mail-out of the newsletter, each attendee was sent, by postal mail, a survey package (a letter of invitation, questionnaire and a pre-paid postage return envelope). Non-responders were sent up to two follow-up letters (with another survey package). Participants were also given the option to complete and submit the questionnaire online. Survey respondents who answered on their questionnaire that they were willing to be interviewed, were contacted by telephone. Each agreeable participant took part in one 60–90-min semi-structured interview, conducted face-to-face (n = 1) or by telephone (n = 11) depending on the preference of the participant. The same investigator (JLB) conducted all interviews to ensure consistency and trustworthiness of data collection. Interviews were audio-recorded and fully transcribed.

2.4. Survey instrument

The survey requested information on demographic and disease characteristics, use of the Internet, social media and online communities. Socio-demographic characteristics included age, ethnicity, highest level of education completed, total household income and approximate size of town or city of residence. Use of online communities was assessed with the question: "Have you ever visited (e.g. read or posted a message) 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 asked to indicate 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 they had used them, when they most frequently used them, and the reasons they used them (selected from a list). The survey was pilot-tested with seven of Willow's staff members.

2.5. Interview guide

Interview participants were asked to talk about how they became aware of online communities; what motivated them to seek support from an online community; what was going on in their lives when they used them; what motivated them to continue or stop using them; how, in their opinion, online communities compared to traditional sources of supportive care; and what role they played for them personally. Clarification probes and follow-up questions were used to explore issues in greater depth and to verify understanding of the information being collected [26].

2.6. Data analysis

Survey data was analyzed using the statistical software package SPSS version 17 (IBM Corporation, Somers, NY, USA). Descriptive statistics were used to describe respondent characteristics, Internet, social media and online community use. Transcribed interviews were analyzed using a qualitative descriptive interpretive approach combining thematic content analysis [26] and constant comparison methods [27] facilitated by QSR NVIVO 8.0 data management software. Transcripts were coded in an iterative manner using codes derived from the data. A second team member coded three randomly selected transcripts, resulting in minor modifications to the coding scheme. The coded data was re-arranged with accompanying text into comparative tables to contrast the participants' views and experiences, and identify common themes. Social comparison theory [28], Transactional Model of Stress and Coping [29], Technology Acceptance Model [30], and the Theory of Planned Behavior [31] were used to frame the findings.