Facebook support groups for ovarian cancer carers: a qualitative evaluation

Emergent Research Forum (ERF)

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Abstract

A cancer diagnosis takes a great toll on the health of both patients and their carers. Online cancer support groups, including cancer support Facebook groups, have evolved as new sources of support for cancer patients and their carers. However, little is known about how cancer carers make use of such online resources. Most research attention has been paid to Facebook support groups for cancer patients. This research is designed to determine the content of communication in Ovarian Facebook pages, and the impact of those communications on carers of ovarian cancer patients. The study will contribute to knowledge about how cancer patients' carers use Facebook cancer support groups and the impact of this use on their health and quality of life.

Keywords

Facebook cancer support group, cancer, carers, empowerment

Introduction

Social network sites (SNSs) are networked communication platforms in which users can create profiles and content, establish connections, develop interactions with their connections, and share content and consume content provided by their networks (Berger et al., 2014). These user-oriented sites have such as Facebook, have attracted cancer patients and their carers and have evolved as a new source of support for cancer patients and their carers (Bender et a.,2011; Erfani et al., 2017b).

A diagnosis of cancer is a life-changing event and takes a great toll on cancer patients and their carers' health (Hong et al., 2012; Moyer et al., 2014; Erfani et al.,2016). Many carers find providing care rewarding, but they and others still face multiple stressors that reduce their quality of life and health outcomes. This often leads cancer carers to search for health-related information and psychological support, and often to join cancer support groups (Erfani et al., 2018). With the advantages of convenience, 24/7 availability and anonymity, web-based cancer support resources have become viable alternatives to face-to-face support groups (Hong et al.,2012; Berger et al., 2014).

Facebook's popularity, its ubiquitous nature, its simplicity and cost-effectiveness, its unique features that support extensive aural and visual interactions, and its accessibility through various communication platforms and portable web-enabled devices has made Facebook-based cancer support groups popular with cancer carers (Erfani et al., 2016). However, little is known about how cancer carers make use of such online resources; most research attention has focused on Facebook support groups for cancer patients.

Accordingly, developing new knowledge and providing evidence of novel tools and technologies that can improve cancer carers' health outcomes would be a valuable advance.

The aim of this study is to add to knowledge about how cancer carers use Facebook cancer support groups and the impact of this use. To accomplish this aim, a content analysis was conducted on a large set of messages on Ovarian Cancer Facebook groups for carers. This research aimed to determine the content of communication and its impact among cancer cares.

The paper is organized as follows. Section 2 provides background and outlines the significance of the research and defines the research question. Section 3 explains the research methods. Section 4 presents the study results. Section 5 contains conclusions and plan for our future research (the second phase of this study).

Background and Significance

Consumers of health services, including patients and their carers, increasingly use web-based services to improve their ability to communicate with others, and to obtain health-related information, emotional support, products, and services (Hong et al., 2012; Erfani et al.,2016). Electronic health tools, such as static health-related web applications (apps) (Web 1.0), enable health service users to obtain health-related information (Nambisan 2011). Dynamic health-related, web-based apps (Web 2.0), such as SNSs, blogs, and forums, enable patients and their carers to exchange health-related information and experiences, make sense of the information they acquire, and promote changes in health-related behaviours (Hajli 2014; Laranjo et al., 2015;Erfani etla.,2017).

SNSs such as Facebook enables cancer carers to share cancer-related information by posting content on their own message board, called a wall, or commenting on posted contents on others' walls. Cancer carers can spread wall posts such as links to new findings; cancer-related events and new trials via in-formation distribution functionality such as "share," needing only a single click (Erfani et al., 2017). They also disseminate cancer-related information through tagging engagement. Facebook enables cancer carers to use various messaging services, including public and private messaging (Erfani et al., 2013). They use pubic messaging services for communication and making sense of data, and private messaging services for discussing sensitive issues that they might not be able to explore in a face-to-face environment (Erfani et al., 2017a).

Despite the understandably clear benefits of using Facebook cancer support groups for cancer carers health, research in SNS use lacks a clear theoretical basis and empirically derived evidence for integrating these tools and data into existing health programs for cancer carers. Although the effect of Facebook cancer support groups, on the health outcome and health outcome of cancer patients has been examined research on Facebook cancer support groups use by cancer carers is sparse (Erfani et al.,2017a; Erfani et al.,2018).

The purpose of this study was to gain an insight of Ovarian Cancer Facebook groups use by cancer carers. In this study, we addressed the fundamental questions: What is the content of communication among cancer cares on Ovarian Cancer Facebook groups and how dose this use impact cancer carers' health outcome?

Method

Subjects and data collection

Ovarian Cancer Facebook groups enable cancer cars to access cancer-related information, posts positive stories about staying healthy while living with cancer, and enables people affected by ovarian cancer and their carers to develop supportive interactions with others who have been similarly affected.

The data for this research were participant discussions collected from an Ovarian Cancer Facebook groups set up for cancer carers. Admins of Ovarian Cancer Facebook groups approved the use of Ovarian Cancer Facebook groups and observation of the communications between participants. All posts on public discussion threads over a three-month period from mid-February 2018 to mid-May 2018 were used. Data collection continued until theoretical saturation was achieved, meaning no new categories associated with

the content of the posts were generated. A total of 4323 posts were collected, including messages that began discussions and responses to them.

Qualitative data analysis

Qualitative analysis was performed to understand the content of communication in Ovarian Cancer Facebook groups communities and the impact of those communications and Ovarian Cancer Facebook groups use on cancer carers. Thematic analysis, the process of collecting candidate themes and creating relationships between these themes, was used to identify, analyze and report categories and themes found in the messages (Vais-moradi et al., 2013). We used NVivo 8, qualitative analysis software that facilitates the coding and sorting process. Messages were coded in six phases: familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final reports. The messages were divided into content areas based on theoretical assumptions derived from the literature (Shumaker and Brownell 1984; Braun et al., 2006). Within each content area, the text was divided into meaning units. The condensed meaning units were abstracted and labelled with a code. The various codes were compared and sorted into nodes in NVivo. Codes that were closely linked in meaning were formed into categories, creating the manifest content. Next, the underlying meanings – that is, the latent content – of these categories were formulated into themes. Themes were reviewed to compare and reconcile discrepancies, and themes with a similar meaning were combined.

To address rigor in this study the guideline proposed by Yin (2017) was applied. To confirm construct validity triangulation using multiple sources of evidence, including the authors' pervious study on web-based resources for cancer-affected people was applied. Internal validity was addressed by using sound data collection procedures, selecting the correct theories, and conducting a literature review. The instrument of reliability was intercoder agreement, two coders worked independently to identify the emergent categories and themes and arrived at a consensus about what is in a particular set of data for this study.

Results

Our analysis of the interview data revealed five major categories and three major themes. Note that many messages were categorized into multiple categories and themes, so the categories are not mutually exclusive, and the percentages below do not add to 100%.

Categories

Support: The most common category was support, with 3790 of the 4323 messages (87.6%) providing some measure of support. Informational support (advice-seeking, looking for experience-based information about caregiving, diagnosis, treatment, medications, tests) (48.1%) and emotional support (expressions of understanding and compassion) (39.5%) were the most common types. Most cancer carers went online to look for people in the same situation as themselves and were primarily looking for information about improving their care for their loved ones (cancer patients). Others were looking for emotional support for themselves, or information about the use of coping strategies.

Gratitude: The second category, covering 3020 messages (69.9%), was gratitude (information seekers expressed gratitude for what they had learnt from information providers through provided advice, stories of personal experience, and referrals to other sources of information). Carers also expressed their thanks to others who expressed sympathy.

Positive feelings: A total of 2743 messages (63.5%) contained text about positive feelings. There was acknowledgment that information obtained through Ovarian Cancer Facebook groups enabled carers to manage stressful situations effectively and achieve their desired outcomes, and that being cared for enabled them to feel less stress during caring activities.

Group assembling: Group-assembling text (regarding group activities, events, welcome messages) were present in 800 messages (18.5%).

Tangible support: Comments related to instrumental support (offering and asking for something, for example, "money donation") accounted for less than 10% of all messages.

Themes

Obtaining action – facilitating and nurturant support: One of the themes derived from data analy-sis was experiencing two types of social support – including action-facilitating support (obtained in-formational support) and nurturant support (obtained emotional support). Action-facilitating support is assistance that helps stressed individuals to solve or eliminate the problem causing the distress, while nurturant support encompasses comfort or consolation without direct efforts to solve the distressing problem.

Empowerment: The second emerged theme sowed the use of the Ovarian Cancer Facebook groups and obtained action-facilitating support was associated with empowerment. Finding revealed cancer carers could experience being assisted and receive information and make sense of information (through receiving action facilitating) which enabled them to take control of the stressful situations and make better deci-sion and, be empowered, and experience better quality of life.

Better stress coping: The third theme was that cancer carers felt they were cared for (through receiv-ing nurturant support) and therefore able to cope better with stressful situations. There was acknowl-edgment that the perceived empathy helped them to emerge from stressful situations stronger and less vulnerable and improved their quality of life

A theoretical model

Findings in this study are in line with the concepts of the health-generating theory (Antonovsky, 1979), which explains that a strong sense of meaningfulness in a difficult situation enables the individual to see the experience as one "that can be coped with, and challenges that can be met" (p.17). In addition, findings are consistent with social support theory and studies that hold that informational and emotional support plays an important role in improving individual's health outcomes and empowerment (Shumaker and Brownell, 1984; Erfani et al.,2017a). In addition, results are consistent with the concepts of Sociocultural theory (SCT) states learning as a social process that occurs through conducting interactions or observing interactions (Lantolf, 1994). The results support finding form previous studies that showed carers learning through participating in online support groups is a predic-tor of health outcome (Hong et al., 2012). Based on finding in this study, a theoretical model was pro- posed that depicts how using a Facebook cancer support group can influence cancer carers that in-forms our understanding of the relationship between Ovarian Cancer Facebook groups use and cancer carer's health out-come.

Figure 1. Ovarian Cancer Facebook groups use and heath outcome

Conclusions and future research

This study contributes to a better understanding of cancer carers' use of Facebook cancer support groups and the impact of this use on their quality of life. By clarifying this relationship, this study demonstrates

that using Facebook cancer support groups does indeed have possibilities for improving cancer carers' health outcomes. It also shows the advantages of Facebook support groups in the con-text of healthcare, particularly with respect to cancer carers. This study focused on Ovarian Cancer Facebook groups, but our findings are generalizable to other social network sites with similar characteristics.

Our findings expand on previous research that showed that the use of Facebook cancer support groups was associated with better health outcomes in cancer patients (Erfani et al., 2017). Our findings show a positive relationship between use of a Facebook cancer support group and cancer carers' empower-ment and coping, mediated through action-facilitating support and nurturant support. Our results will prompt health organizations to generate policies for using Facebook support groups to improve carers' empowerment and coping. Relevant organizations should consider introducing Facebook support groups as online resources for cancer carers.

In the next phase of the study we will confirm the codes and themes with experts through conducting expert interviews and will quantitatively and longitudinally examine the relationship between Face-book cancer support group use, its mediating factors, and cancer carers' empowerment, coping and quality of life.

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