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Talking with text: Communication in therapist-led, live chat cancer support groups



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ABSTRACT

CancerChatCanada is a pan-Canadian initiative with a mandate to make professionally led cancer support groups available to more people in Canada. Although online support groups are becoming increasingly popular, little is known about therapist-led, synchronous groups using live chat. The purpose of this study was to generate a rich descriptive account of communication experiences in CancerChatCanada groups and to gain an understanding of processes associated with previously-reported benefits. We used interpretive description to analyze interview segments from 102 patients, survivors and family caregivers who participated in CancerChatCanada groups between 2007 and 2011. The analysis yielded four inter-related process themes (*Reaching Out From Home, Feeling Safe, Emotional Release,* and *Talking With Text*) and one outcome theme (*Resonance and Kinship*). The findings extend previous research about text-only online support groups and provide novel insights into features of facilitated, live chat communication that are valued by group members.

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Introduction

The value of structured, professionally led support groups for people living with cancer has been demonstrated in controlled studies that have shown significant reductions in pain and psychological distress, significant improvements in quality of life (Baider, Peretz, Hadani, & Koch, 2001; Classen et al., 2001; Fobair

et al., 2002; Gottlieb & Wachala, 2007; Sheard & Maguire, 1999; Targ & Levine, 2002; Taylor, Lamdan, & Siegel, 2003), and some improvements in immune function and survival time (Andersen et al., 2008; Fawzy, Canada, & Fawzy, 2003; Goodwin et al., 2001). Benefits have been demonstrated in evaluations of communitybased cancer support programs and uncontrolled studies (Helgeson, Cohen, Schulz, & Yasko, 2000; McLean, 1995) also. Despite the known benefits and the high levels of reported interest in psychosocial oncology services in general and support groups in particular (Liang, Dunn, Gorman, & Stuart-Harris, 1990), many people with cancer who are interested in receiving such services are unable to do so. Some cannot get to cancer centres where professionally led support groups are held; many people with cancer experience high levels of fatigue that make it hard leave home (Howell et al., 2011); while others are constrained by caregiving responsibilities. Some cancer centres do not have support groups or only offer them during regular working hours. Stigma is a further impediment (Bettencourt, Schlegel, Talley, & Molix, 2007; Crosato & Leipert, 2006; Kelley, Sellick, & Linkewich, 2003). Sometimes people caring for people with cancer do not access support because of not wanting to leave the person they are caring

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for, which can have a negative impact on their own health (Canadian Institute for Health Information, 2010).

Professionally led online support groups are a way to overcome these and other barriers and to extend the benefits of structured psychosocial support to more people (Lieberman et al., 2003; Owen, Klapow, Roth, Nabell, & Tucker, 2004) while offsetting isolation imposed by illness (Hara, 2010; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Seçkin, 2011). Internet-based psychological interventions have been shown to be as effective or more effective as in-person interventions (Barak, Klein, & Proudfoot, 2009). Contrary to what stereotypes might suggest, computer-based support appears to be especially appealing to older people with cancer and people from marginalized groups (Gustafson, Taylor, Thompson, & Chesney, 1993). Pilot studies of internet support groups for people with cancer have shown high levels of participation and satisfaction (Lieberman et al., 2003; Winzelberg et al., 2003).

Internet support groups can be offered using asynchronous modalities such as email, listservs, and electronic bulletin boards or with synchronous modalities such as Skype, telephones, live chat (Hara, 2010), and videoconferencing (Collie et al., 2007). Most use asynchronous communication, which allows for large group sizes and lets members access their group at any time (Tate & Zabinski, 2004; Walther, Boyd, Lin, & Atkin, 2002, pp. 153-188). Less is known about synchronous support groups, which have the advantage of allowing for direct and immediate communication, but can have challenges related to their immediacy and dynamic nature. Live chat support groups require group members to be available at the same time, which can present scheduling problems (Walther et al., 2002, pp. 153–188) and can result in one person's technical problems affecting the entire group (Tate & Zabinski, 2004). Professional facilitators have described challenges related to discussion focus and pace (Owen, Bantum, & Golant, 2009; Stephen et al., 2010).

Despite the potential challenges of communicating in what can be a free-flowing and fast-paced chat environment, early evidence suggests groups conducted with live chat can yield positive results. For example, in an uncontrolled trial of a 16-week professionally led online support group using live chat, Lieberman et al. (2003) found that the cancer patients in the study exhibited reduced depression and increased emotional control after participating in the group. Approximately two thirds of the participants said they found the experience beneficial.

We previously reported the results of a qualitative content analysis of interviews with 102 cancer patients and family caregivers who participated in 10-week therapist-led live chat groups through CancerChatCanada (Stephen et al., 2013). This analysis showed high levels of satisfaction with the communication modality and the facilitation. We found that despite experiencing challenges with the modality during the first week or two, the large majority of interviewed participants (89%) adapted, and reported that their communication experience was better than expected. The findings of this study highlighted the important role of the facilitator and suggested that the participants' satisfaction was due in part to quality of the facilitation. Participants described how facilitators provided direction and depth to the chat, guided topic choice, maintained focus, and summarized discussions. The facilitators were perceived to have anticipated important issues and to have acted as a "safety net", which helped members to open up emotionally and understand each other better.

The present study builds upon our earlier work about Cancer-ChatCanada, a large, multi-site program of online support groups for Canadians affected by cancer that the authors have been instrumental in developing, implementing, and evaluating. The low population density in Canada makes it particularly difficult for

people affected by cancer to access appropriate support services. However, a recent study showed that 72% of Canadians living in rural and smaller towns use the internet (Statistics Canada, 2010). A primary motivation for our program was to overcome this well documented health care barrier (Bettencourt et al., 2007; Crosato & Leipert, 2006; Maddison, Asada, & Urquhart, 2011) by providing online access to professionally facilitated support groups to people across Canada (see (Stephen et al., 2013) for a full description of the multi-site initiative). We chose to use synchronous text communication in password protected chat rooms (live chat) for Cancer-ChatCanada because of the relative lack of research about synchronous support groups and because of the promising early findings from studies about cancer support groups using this modality.

The results of our previous study suggested relatively high satisfaction with the live chat modality on the part of participants. A panel of independent raters judged 44% to have been 'very satisfied' based on their responses to interview questions; 45% 'moderately satisfied' and only 11% unsatisfied. The objective of the present study was to derive an in-depth, contextual understanding of participant communication experiences and to create an interpretive descriptive account of processes in therapist-led, live chat cancer support groups.

Method

The present study was a secondary analysis of interview data collected in the context of a comprehensive evaluation of Cancer-ChatCanada online support groups (Stephen et al., 2013). During the interviews, we asked people who had participated in Cancer-ChatCanada groups about their experiences communicating with live chat.

Recruitment

We recruited cancer patients, survivors, and family caregivers within the context of a pilot of the groups and 2 randomized studies. We used multiple channels to promote the online support groups, including professional presentations, posters and brochures in participating cancer centres, email newsletter notifications to community palliative organizations, and direct referrals from psychosocial professionals at partnering cancer centres. For the randomized study groups, we also sent letters of invitation through provincial cancer registries. When potential members enquired about the groups, we used telephone interviews to inform them about the objectives and requirements of group participation to determine suitability. Socio-demographic information and medical status were obtained. Research ethics boards at 6 cancer centres, British Columbia Cancer Agency, Tom Baker Cancer Centre, Cross Cancer Institute, CancerCareManitoba, Sunnybrook Health Science Centre, Queen Elizabeth II Health Science Centre approved the studies.

Participants

The participants whose interviews we analyzed were 102 cancer patients, survivors and family caregivers who were a subset of a larger sample (n=351) from the previous study. They enrolled in CancerChatCanada online support groups between January 2008 and December 2011 and had provided consent to be interviewed. We interviewed from four population sub-groups: young (n=36) and rural dwelling (n=26) breast cancer survivors (recruited in two separate trials, early in the initiative); family caregivers (n=20); and cancer patients (n=20) with a variety of diagnoses and stages of treatment, including palliative.

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