

LOGGING IN STRAINED, LOGGING OUT SUSTAINED: THE UTILITY OF
ONLINE SUPPORT GROUPS FOR CAREGIVERS OF INDIVIDUALS WITH
ADVANCED-STAGE CANCER

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Abstract

The current investigation explored both the process and content of four separate online support groups run through CancerChatCanada, with a national sample of caregivers of individuals with advanced-stage cancers. A grounded theory analysis of the chat transcripts led to the generation of the core category, "Logging In Strained, Logging Out Sustained", which captures the essence of the group experience, and is characterized by the following main categories: (1) The Life of a Caregiver; (2) Group as Something to Look Forward to; and (3) Facilitator as Guarantor of Maximal Group Utility. Altogether, the findings that emerged from this study provide insight into the range and depth of the cancer caregiver experience, the meaning of online caregiver support groups to those who utilize them, and the various ways in which facilitators skillfully manage group sessions so to enhance their value.

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Logging In Strained, Logging Out Sustained: The Utility of Online Support Groups for Caregivers of Individuals with Advanced-Stage Cancer

The Canadian Cancer Society estimates that there will have been 187,600 new cases of cancer in Canada in 2013, 1,200 more new cases than there were in 2012 (Canadian Cancer Society, 2013). As the incidence of cancer continues to rise, there will be a concomitant increase in the strain placed on the Canadian health care system. When the availability of quality health care decreases, it is often the case that spouses, family members, or friends must compensate for the reduction in available care.

Psychosocial and Health Impacts of Informal Caregiving

Caring for an individual with advanced-stage cancer is mentally and physically burdensome. As a result of the disease and/or associated treatments, patients are often rendered more dependent on their caregivers. Assisting with basic physical care, providing transportation to and from doctor appointments, providing psychological support, and in the case of more advanced disease, end of life planning, are among some of the onerous responsibilities associated with caregiving. In addition to supporting their loved one, many caregivers assume greater responsibility in terms of managing the household and caring for dependents - all the while struggling to cope with their own feelings of personal grief and despair. It is not surprising, then, that caregivers of cancer patients often report levels of distress comparable to those of patients themselves (Baider, Koch, Esacson, & Kaplan De-Nour, 1998; Northouse et al., 2007; Omne-Ponten, Holmberg, Bergstrom, Sjoden, & Burns, 1993; Segrin et al., 2005; Zacharias, Gilg, & Foxall, 1994), if not higher (Baider, Walach, Perry, & Kaplan De-Nour, 1998; Braun,

Mikulincer, Rydall, Walsh, & Rodin, 2007; Gilbar, Steiner, & Atad, 1995; Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Northouse, Mood, Templin, Mellon, & George, 2000).

Caregivers often become isolated as a result of physical and social barriers (Brennan, Moore, & Smyth, 1991) and often struggle with relationship, psychological, and somatic problems (Ferrell, Grant, Borneman, Juarez, & Ter Veer, 1999; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Pitceathly, & Maguire, 2003; Stenberg, Ruland, & Miaskowski, 2009) such as, depression (Chentsova-Dutton et al., 2002; Sansoni, Vellone, & Piras, 2004), suppressed immune function (Kiecolt-Glaser et al., 2003; Kiecolt-Glaser, Dura, Speicher, & Trask, 1991; Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996), cardiovascular morbidity (Lee, Colditz, Berkman, & Kawachi, 2003; Shaw et al., 1997) and chronic sleep disturbance (Carter, 2002; Smith, Ellgring, Oertel, 1997; Wilcox & King, 1999).

Financial strain represents another common source of distress for caregivers. In a large American study of over 2,000 families caring for a loved one with a serious illness, approximately 20% of caregivers quit their jobs or made other major life adjustments to be able to provide care, 31% lost most or all of their life savings, and 29% reported losing their main source of income (Covinsky et al., 1994).

It appears that while the caregiver is supporting the cancer patient, he or she can be faced with grave economic, physical and/or emotional consequences as a result of the illness. What is particularly concerning is that caregivers often cope in solitude, without adequate support resources (Farkas, 1980; Fengler & Goodrich, 1979). Studies have

consistently reported that these individuals have fewer support resources available to them than do patients (Davis-Ali, Chesler, & Chesney, 1993; Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Northouse et al., 2000; Northouse et al., 2007) and are more likely than non-caregivers to neglect their own health care needs (Stein et al., 2000). Evidently, caregivers represent a highly vulnerable population for whom it is of particular importance to develop accessible support resources.

The Benefits of Social Support for Caregivers

Research has indicated that social support promotes the psychological well-being of caregivers of individuals with cancer. A longitudinal study by Nijboer, Tempelaar, Triemstra, van den Bos and Sanderman (2001) found that the relationship between caregiver experiences and depression was moderated by perceptions of daily support. Caregivers who perceived their caregiving duties as more disruptive to their schedules were more likely to display increased levels of depression over time if they reported lower levels of daily emotional support. Relatedly, Ownsworth, Henderson and Chambers (2010) found that satisfaction with social support was significantly correlated with caregiver psychological well-being, as indicated by ratings on self-esteem, positive and negative feelings, and spirituality. Satisfaction with social support also significantly moderated the relationship between patient functional impairment and caregiver well-being in the context of cancer, suggesting that when the individual with cancer experiences greater physical limitations, the caregiver's satisfaction with the level of social support they received played a particularly important role in buffering against stress and enhancing or preserving their psychological well-being. These findings

demonstrate that it is not only the amount of social support, but also one's satisfaction with it, that is instrumental to caregiver coping and adjustment.

Support groups represent a specific form of social support that have been shown to be effective in promoting more positive coping and adjustment amongst caregivers of individuals with various medical and psychological conditions (e.g., frail elderly, schizophrenia, Alzheimer's disease, etc.) (Chou, Liu, & Chu, 2002; Chu et al., 2011; Greene & Monahan, 1989; Toseland, Labrecque, Goebel, & Whitney, 1992; Wei et al., 2012). There remains, however, a shortage of academic literature evaluating the benefits of support group participation amongst caregivers of individuals with cancer, specifically. The few available studies that do exist suggest that involvement in support groups promotes more active and positive coping responses amongst caregivers. For example, Chesney and Chesler (1993) found that individuals caring for a loved one with cancer who participated in support groups were more likely to engage in active coping, help-seeking behaviour, and social activism. In an exploratory, qualitative study of support groups for caregiver relatives of terminally ill cancer patients, participants reported that mutual support and exchanges with other group members were fundamental to decreasing feelings of sorrow and loneliness, and to helping them cope (Witkowski & Carlsson, 2004). Caregivers also felt that their group participation had an indirect positive effect on their ill loved one. This gain was observed when useful information and advice on the disease and on pain relief received in-group could be applied outside of the group when interacting with the patient. Furthermore, caregivers expressed that by participating in the group, their friends and family were less burdened with the responsibility of being the

caregiver's main source of support. Participants also felt that the support group had health-promoting effects for them, reporting that their depressive feelings had decreased after joining. However limited in quantity, the available findings that have emerged from research on support groups for caregivers of individuals with cancer indicate a number of benefits, whether assessed with objective measures or by means of qualitative data. Further investigation is warranted, of the effectiveness of support groups for this population, and the mechanisms by which such positive outcomes are achieved.

Online Support Groups as a Budding Resource for Cancer Caregivers

Research studies of *online* support groups (OSGs) are currently of particular scientific relevance considering the recent marked increase in availability and use of these web-based services (Bender, Jimenez-Marroquin, Ferris, Katz, & Jadad, 2013; Cook & Doyle, 2002; Owen, Bantum, & Golant, 2009). Monnier and colleagues (2002) surveyed cancer patients and caregivers and found that 65% were interested in participating in online support groups. As the demand for these services continues to grow (Stephen et al., 2010; Tate & Zabinski, 2004), so too does the need for related investigation that can inform program development and effectiveness. Although research suggests that caregivers benefit from participation in face-to-face (F2F) support groups, it remains to be seen whether involvement in OSGs would similarly produce positive effects.

OSGs exhibit many of the same factors and processes of traditional F2F support groups. Among these processes are: universality of experience, instillation of hope, group cohesion, interpersonal learning, and expression of feelings (Cook & Doyle, 2002; Lewis,

Coursol, & Herting Wahl, 2004; Rains & Young, 2009; Rochlen, Land, & Wong, 2004; Shaw et al., 2006; Toseland & Rossiter, 1989; Weinberg, Uken, Schmale, & Adamek, 1995). Group facilitators also report serving similar roles in OSGs as in F2F support groups, including setting the pace of interaction, encouraging deeper discussion, checking in with quiet group members, maintaining group focus, providing feedback, and summarizing discussion (Stephen et al., 2010).

There are a number of characteristics unique to OSGs (as compared to traditional F2F support groups) that distinguish them as a particularly promising resource for a caregiving population. For these individuals, who are heavily constrained by the demands and daily restrictions imposed by their loved one's illness, participating in a F2F support group is less practical because of having to travel and leave the patient unattended for the duration of the meeting. Moreover, because of the risks to the patient's safety and the potential for caregivers to feel guilty about being inaccessible to the patient while attending F2F support groups, it is likely that many caregivers choose to forego these self-help opportunities. By introducing support services online, the disadvantage of temporarily separating from the patient is eliminated, thus enhancing the likelihood of caregivers utilizing such resources.

The implications of physical separation from the cancer patient aside, many caregivers do not have convenient access to F2F support groups, should they choose to attend. A recent review identified geographic location of residence as one of the most significant determinants of inequity of access to cancer services in Canada (Maddison, Asada, & Urquhart, 2011). Rural-residing cancer patients and caregivers have been found

to suffer poorer quality of life than those in urban areas (Albert, Koller, Wagner, Schulz, 2004; Girgis, Boyes, Sanson-Fisher, & Burrows, 2000; Heishman, 1999; Palesh, Shaffer, & Larson, 2006) and to have less specialized psycho-social services available to them (Bettencourt, Schlegel, Talley, & Molix, 2007; Crosato & Leipert, 2006). With 30% of Canadians being rural dwellers, there is, presumably, a large proportion of Canadian caregivers and patients in need who are currently being under-served. Thus the Internet presents a promising vehicle for reaching those Canadians who do not have physical access to support groups but who wish to utilize such services. What is further encouraging is that research shows that counseling interventions can be effectively delivered online (Lieberman et al, 2003; Rains & Young, 2009; Winzelberg et al., 2003).

In addition to catering to the practical constraints posed by caregiving commitments, the text-based means of communication of OSGs allow group members to delay a response and reflect in order to make a more meaningful contribution to group discussion, or to passively observe and relate to other group members when they lack the mental capacity or energy to actively engage in discussion (Walther, Pingree, Hawkins, & Buller, 2005). The anonymity and lack of physical attendance of online groups also minimizes social cues that may lead to interpersonal biases such as racial or sexual discrimination and may reduce anxiety amongst those who are uncomfortable sharing sensitive or personal information, or meeting face-to-face (e.g., social anxiety, disfigurement) (Cook & Doyle, 2002; Namkoong et al., 2012; Owen et al., 2009). Privacy is further preserved by the use of email addresses and pseudo screen names rather than personal home addresses or real names, which some individuals may not wish to

share publicly (Walther et al., 2005). Finally, OSGs present a cost-effective method of intervention as compared to paying for individual psychological services, which makes them an attractive option for individuals who are already under financial strain as a result of treatment-related costs and employment leave (Leykin et al., 2012).

Despite the benefits of online intervention, there are also a number of potential limitations. Firstly, online services require access to the Internet and basic computer competency, and thus, OSGs may be at risk of excluding individuals from lower socioeconomic brackets (Leykin et al., 2012). The inherent text-based means of communication may also present a barrier to participation for individuals with low literacy skills, those who are visually impaired, or the elderly (Klemm et al., 2003). Furthermore, the anonymous nature of Internet interventions makes it easier for group members to drop out, show up late or miss meetings (Eysenbach, 2005; Owen et al., 2009). The online format also allows group members to be more easily distracted during a session by events in their immediate physical surroundings (Owen et al., 2009). The utility of OSGs is further called into question by research that indicates a positive relationship between the amount of time spent on the Internet and depression and loneliness (e.g., Kraut et al., 1998; Nie & Lutz, 2000). It is possible that if OSG participants spend a substantial amount of time on the Internet, including, and in addition to their time in-session, they may paradoxically limit their social interactions, at least in everyday life, which may contribute to low mood and feelings of social isolation.

It is important to note that while the aforementioned disadvantages pertain to all OSGs, those that are peer-led, as opposed to professionally facilitated, are especially at

risk of being compromised. Without a facilitator, there is greater potential for the course of group discussion to be overrun by select group members who are relatively expressive and for more passive members to feel ignored or uninvolved. The participants of these groups are also more susceptible to sharing and receiving inaccurate medical information, as well as being verbally insulted or attacked by fellow group members (Oravec, 2000). Finally, when groups lack a professional facilitator, there is the danger that group members will not be appropriately responded to or referred to available resources in the case of a crisis (Leykin et al., 2012).

Like most interventions, there are both risks as well as advantages to participation in OSGs. This is precisely why prospective research evaluating the utility of these online services is so important; it must be determined whether the benefits of involvement are worth the potential risks. Furthermore, it is critical that researchers explore how professional facilitators can effectively monitor and intervene when problematic group dynamics arise.

The Need for Greater Understanding of Therapeutic Processes and Effectiveness of Online Support Groups

Considering the available literature suggestive that OSGs improve *patients'* psychological adjustment to cancer (Lieberman et al, 2003; Owen et al., 2009; Stephen et al., 2010), it is quite possible that involvement in OSGs should produce positive effects for caregivers of cancer patients. Participation in such interventions has been shown to reduce the prevalence of cancer patients' depression, loneliness, cancer-related trauma, perceived stress, self-perceived pain and self-perceived health status (Hopps, Pépin,

Boisvert, 2003; Lange et al., 2003; Owen et al., 2005; Shaw et al., 2006; Winzelberg et al., 2003). OSG involvement has also been found to enhance patient well-being, quality of life, social support, information-seeking skills and health care participation (Gustafson et al., 1999; Gustafson et al., 2001). Evidently, online support services constitute an effective resource for individuals who have been diagnosed with cancer.

In spite of growing evidence for the benefits of OSG interventions for cancer patients, there remains a paucity of research surrounding OSGs for caregivers. One study, conducted by Namkoong and colleagues (2012), explored the effects of participation in an Interactive Cancer Communication System (ICCS) for caregivers. This platform offered a variety of online information and support services to members, of which, the most frequently used was a professionally facilitated OSG. Results demonstrated that the participants assigned to the ICCS condition perceived higher bonding with other caregivers (as measured using a validated scale of universality, group cohesiveness and information and emotional support exchange) than those who were assigned to an Internet group control condition (i.e., they had Internet access with links to high-quality cancer websites but no explicit programming). The authors also found that participation in the ICCS, as compared to the control condition, produced a significant and positive effect on caregiving coping strategies at 6 months follow-up, including active behaviour, positive reframing and instrumental support strategies. Interestingly, structural equation modeling revealed that the ICCS participation alone did not have a direct significant effect on coping; rather, perceived bonding fully mediated the effect of treatment on caregivers' coping strategies. Another study exploring ICCS involvement found that

caregivers who used the system felt less burden and fewer negative emotions than those who just used the Internet (DuBenske et al., 2010). Because these two studies explored the effects of participation in a program that included a variety of services in addition to OSGs, we cannot conclude that the results are strictly attributable to OSG involvement. Nevertheless, the findings point to the possible benefits of bonding with similar others, specifically through computer-mediated communication.

There is evidently a pressing need for the development of valuable support resources for caregivers of individuals with cancer. Online support groups offer a relatively novel means for caregivers to tend to their own needs, which are often neglected at the cost of attending to those of their ill loved one. In light of the demonstrated benefits of OSG involvement for patients, and the preliminary findings that have emerged from studies on ICCSs for caregivers, this form of online social support represents a promising resource for the caregiving population, one worthy of further development and evaluation.

Present Study

Although the benefits associated with online support services, such as anonymity, convenience and enhanced self-reflection, are gaining recognition (Cook & Doyle, 2002; Owen et al., 2005; Stephen et al., 2010; Winzelberg, 1997), the majority of the literature represents investigations of patient, rather than caregiver, experiences with these online services. As such, research concerning the properties of effective OSGs for caregivers is scant. The intent of the current study was to investigate therapeutic factors associated with OSGs and group member experiences, using a national sample of caregivers of

individuals with advanced-stage cancers, including spouses and other family members. Potential facilitator effects were also explored by analyzing qualities of group leaders and techniques they employ that influence group progress and outcome. A secondary objective of this research was to examine the experiences constitutive of the caregiver role in terms of, for example, anticipatory grief and loss, caregiver burden, and coping strategies. With these goals in mind, transcripts from professionally facilitated text-based OSGs were analyzed. The groups were run through the CancerChatCanada web-based platform, a free online support resource for all Canadians affected by cancer (further description below). The OSG discussions took place in the form of real-time group chats, as opposed to asynchronous discussion board correspondences.

Method

Participants

Participants were members of online support groups run via the CancerChatCanada platform. This was a self-selected group of individuals living in Canada who were caring for a family member who had been diagnosed with cancer and who had learned about the program through advertisements posted on cancer-related websites, e-mail notifications, health care providers, fliers in hospitals or community agencies, and/or letters of invitation mailed directly through the use of patient registries. Through use of these media, efforts were made to reach members of the community known to be underserved and to be experiencing high levels of burden or distress, such as rural caregivers.

Each prospective group member was screened by telephone interview for his/her suitability to receive online support based on support needs and psychiatric history. Individuals deemed unsuitable (e.g., presence of untreated or severe mental health condition) were referred to alternate services within their communities. Where possible, identity and status as a family member of a cancer patient was confirmed by patient registry or by verification with a health care professional identified by the participant. Emergency contact information was also collected along with the name and telephone number of the participant's primary physician.

The original sample registered to partake in the online groups consisted of 32 caregivers. After accounting for dropout members who never began the group, the total sample was comprised of 25 group member participants who took part in four different groups. Eighteen of the participants resided in British Columbia, six in Ontario, and one in Manitoba. The average age of this caregiving sample was 51 years, ranging from 27-75 years. The majority of participants were female ($n = 19$) and most were caring for a spouse/partner with cancer ($n = 19$), followed by an ill parent ($n = 5$) or young adult child ($n = 1$). Most of the caregivers were not currently working, either because they were retired or on personal leave. For a more detailed breakdown of participant demographics, including patient diagnoses, see Table 1.

Table 1

Participant Demographics (n = 25)

	<i>n</i>	<i>%</i>
Gender		

	Female	19	76
	Male	6	24
Relationship with Cancer Patient			
	Husband	11	44
	Wife	5	20
	Mother	4	16
	Partner	3	12
	Son	1	4
	Father	1	4
Work Status			
	Not working (retired or on leave)	13	52
	Full-time	9	36
	Part-time	3	12
Area of Residence			
	Urban	17	68
	Rural	8	32

Facilitators

Group facilitators were affiliated with the Sunnybrook Odette Cancer Centre in Toronto, Queen Elizabeth II Health Sciences Centre in Halifax, and the British Columbia Cancer Agency, all of which are partnering cancer centres with the CancerChatCanada program. The facilitators were accredited professionals in the fields of psychology, nursing, or social work with extensive experience in psychosocial oncology. All group leaders received 10 weeks of training in which they learned facilitation techniques for

text-only groups as developed by The Cancer Support Community (Lieberman, Golant, & Altman, 2004; Stephen et al., 2010). Cognitive behavioural and supportive expressive group approaches (Classen, Diamond, & Spiegel, 1999; Spiegel et al., 2007) were also integrated into their techniques. To ensure their competency, facilitators were required to attend peer supervision upon completion of training and while running groups. While in the process of facilitating the OSGs, facilitators were also required to complete weekly clinical notes to report on participation and engagement among members, as well as challenges or problems encountered. The enrolment coordinator and the primary investigator at the BC Cancer Agency reviewed these notes regularly to afford early intervention and troubleshooting for safety or technological issues.

Methodology

Unlike traditional approaches in psychology that seek to verify existing theory by means of deduction, grounded theory is an inductive approach that results in the generation of new theory. This is achieved through the categorization of qualitative data and the eventual patterns that emerge through this process (Rennie, Phillips, & Quartaro, 1988). More specifically, the grounded theory method involves: the collection of qualitative data, usually through interviews and other means of communication; the open categorization of the data based on their meaning; memoing, or systematically recording ideas that occur during analysis in order to track assumptions that may be guiding the analysis and to preserve ideas that have the potential to later enhance theory development; the eventual identification of a core category that best represents all subcategories and properties; and formulating a theory based on the resulting framework.

Qualitative analysis involves a certain degree of inference and bias. The data are the product of socially constructed experiences, memories and accounts of the participants, each of whom has their own unique perspective. In addition, the researcher introduces his or her own biases and perceptions when interpreting the meaning of the data, based on previous experiences, self-knowledge, cultural values, and analytic and empathic abilities (Rennie, 2000). In light of the various sources of subjectivity inherent in qualitative analysis, researchers who adopt such approaches should acknowledge and record their personal perspectives and beliefs about the data throughout the process (often by means of memoing) in order to ensure the validity and reliability of their results. This strategy of transparency reflects not a goal of capturing an objective and positivistic truth; rather, the intent is to understand and explain the context-specific phenomenon of study as representatively as possible of the lived-experiences of participants while also acknowledging that the emergent interpretations are inherently tentative.

I acknowledge that I held certain a priori assumptions about the findings to emerge. As a graduate student training to be a clinical psychologist, I admit that I deeply value the exchange of social support and intimate sharing of one's experiences with others in a safe and empathic environment. Holding these biases, I predicted that the caregivers who participated in the OSGs would find their involvement to be personally beneficial. I also expected to find that the facilitators would make important contributions to the group experience, as I believe that having a therapist guide the online discussions is more effective than having a peer-led OSG. I further suspected that as the online sessions

progressed, a sense of community and intimacy amongst the group members would develop.

While these assumptions inevitably coloured my lens, the categories, and eventual theories, that emerged through analysis were grounded in the data. In fact, in accordance with Glaser and Strauss's original protocol (1967), I refrained from conducting an initial review of the relevant scientific literature, and only did so to inform the discussion section after having completed the data analysis and reporting of the results. A category did not stand without sufficient evidence for its existence in the transcripts. Furthermore, consensus was incorporated into the study by having a second senior investigator (my academic supervisor) analyze the data independently, resulting in the retention of only categories that were endorsed by us both. Throughout the entire research process, we made constant efforts to be mindful of our own subjectivity and to record or 'memo' all of our reflections and/or predictions.

Procedures

CancerChatCanada is an online platform, funded by the Canadian Partnership Against Cancer, that offers real-time, professionally facilitated OSGs for individuals diagnosed with cancer and separate OSGs for their caregivers. The project is run in partnership by an inter-professional group from seven cancer centers in five provinces across Canada, including: the British Columbia Cancer Agency; the Tom Baker Cancer Centre in Calgary, Alberta; Cancer Care Manitoba; Sunnybrook Odette Cancer Centre in Toronto, Ontario; Queen Elizabeth II Health Sciences Centre in Halifax, Nova Scotia; the Cross Cancer Institute, in Edmonton, Alberta; and Thunder Bay Regional Health

Sciences Centre. Registered group members (between 6-10) log in to a live text-based “chat room” once per week for 90 minutes for approximately 10 weeks, to discuss challenges associated with caring for someone with cancer and to support one another. The small groups provide a safe and private venue for members to bond over shared experiences and to exchange informational and emotional support. A professional facilitator guides, but does not determine, the discussion and keeps the conversation focused, while encouraging participation from all group members.

Data was sampled across four separate caregiver groups, each led by a different facilitator. For each online session, a record, or a transcript, of the interactive discussion between all members and the facilitator was produced for each group. All groups were time-limited ranging from 8 to 11 sessions; transcripts were analyzed from all eight sessions of a provincial Ontario group, all 10 sessions of a national group, all 11 sessions of another national group, and all nine sessions of a provincial British Columbia group.

In accordance with published guidelines and existing professional standards for online counseling (Maheu, 2003; Mallen, Vogel, & Rochlen, 2005; Shaw & Shaw, 2006), a detailed set of protocols, procedures and practices of professional conduct were developed for the OSGs. Informed consent was obtained from all participants, with the assurance that any and all identifying information would remain confidential. Ethics approval was received from the Research Ethics Boards of all participating Cancer Centres, including the British Columbia Cancer Agency, QEII Cancer Program in Halifax, Nova Scotia, the Sunnybrook Health Sciences Centre and York University.

Analysis

Using the grounded theory method (Glaser & Strauss, 1967), the real-time online text chat transcripts were analyzed in order to identify recurrent themes pertaining to areas identified a priori as areas of interest that would help to guide the analysis. Such “sensitizing concepts” (Blumer, 1954) included: (1) the experience of caring for a loved one with advanced cancer; (2) the ways in which group members support one another; (3) online group member interactions that are conducive to positive outcomes; and (4) facilitator techniques that promote successful group progress. A qualitative approach was appropriate given the aim of this study, which was to describe and understand the potentially beneficial elements of OSGs for this particular caregiver population, which have yet to be defined and established.

All 38 transcripts were analyzed, from first to last session, one group at a time. In reviewing the transcripts, discrete units of text, referred to as “meaning units” were identified (Giorgi, 1970; Rennie, 1998). Unlike the original grounded theory practice of analyzing data line-by-line, this contemporary approach to organizing the data based on distinct ideas allowed for a “thought-by-thought” analysis (see Rennie et al., 1988). Based on the essential meaning of each thought, representative categories were constructed and the meaning units were assigned to as many of the categories as possible, allowing for perseveration of as much variation in the data as possible. For example, descriptive categories, more closely tied to participants’ language, were developed to represent the full range of explicit ideas communicated in any one meaning unit, while more abstract categories, often informed by the researcher’s empathic attunement, were created to capture the implied meaning(s) and impact(s) of the meaning unit or of a

particular group process or interaction. For each new thought conveyed in the data, a new category was generated, until no new themes emerged and saturation had been achieved. In particular, information pertaining to process and content of the OSGs was identified and categorized. N-Vivo, a qualitative research software program, was used to manage and analyze the group transcripts more efficiently.

Intermittently, throughout the analysis, I met with my research team, including my academic supervisor, who is a senior qualitative researcher, and Dr. Joanne Stephen who chairs the CancerChatCanada initiative. Meetings were also held with several members of the Psychosocial Oncology Lab at York University, in order to discuss and review select emerging categories in the data. In this way, preliminary interpretations were further developed through a process of consensus, elaboration and disagreement. Subsequently, the data were subjected to a second independent audit by my supervisor to ensure validity and reliability of the findings. During the final stage of analysis, I worked closely with my supervisor to group and organize the data into a hierarchy of lower- and higher-ordered categories, according to their respective meanings and levels of abstraction.

Results

Analysis of the online chat transcripts revealed three main categories underlying the core category of “Logging In Strained, Logging Out Sustained”. These main categories include: (1) The Life of a Caregiver; (2) Group as Something to Look Forward to; and (3) Facilitator as Guarantor of Maximal Group Utility. Each of these main categories is comprised of first-order and second-order sub-categories (or defining

properties) of their own. Table 2 represents a complete hierarchical organization of all categories, from the most inclusive categories to the most exclusive defining properties. Main categories are represented in the body of text as flush left, uppercase and lowercase headings, sub-categories are signified by indented, lowercase paragraph headings ending with a period, and defining properties are identified by indented, italicized, lowercase paragraph heading ending with a period. Pseudonyms are used to identify all text-based quotations, which are represented as verbatim text. Typos and lack of punctuation have been retained in order to preserve the tone and context of the original expression.

Table 2

Logging In Strained, Logging Out Sustained: Main categories, sub-categories and defining properties

Main categories	Sub-categories	Defining properties
The life of a caregiver	Unrelenting assault	Emotional limbo
		Struggling to tolerate the intolerable
		Dreading what's to come
		Resenting cancer
	A new us	Change in context
		Changes in the person of the patient
		Navigating disequilibrium
	The dark side of caregiving	Burden of responsibility
		Costs and constraints of caregiving
		Taking it on
	Lightening the load	Just me, myself and I
		Imperative to self care
		Feeling cared for

	Living more intentionally	Maintaining and restoring emotional ties Tapping into strengths Lessons learned
Group as something to look forward to	A mosaic of resources	Group validation and emotional support Group as knowledge Group as a source of perspective Group as safe outlet
	Approximating F2F reality	Compensating for technological obstacles Social norms and group etiquette Getting 'real'
	An indispensable resource	Part of something special Thread of connection
Facilitator as guarantor of maximal group utility	Structuring and guiding	Instilling group structure Creating a comfortable environment Engendering confidence (in facilitator, in group, and in selves)
	Actively scanning	Safeguarding against overlooked experiences Continually considering and including members
	Modulating experiencing	Deepening experiencing De-escalating emotional intensity

The first main category, The Life of a Caregiver, provides a context for understanding the participants' experiences since informally assuming responsibility for caring for their ill loved one. This category captures the major ups and downs that characterized the caregivers' lives, and illustrates how they were constantly challenged and stimulated to adapt. The second main category, Group as something to Look Forward to, depicts how the OSGs were experienced by the participants in light of their caregiving

challenges. Overall, the group presented an opportunity to process their vast range of emotional reactions, in a supportive and empathic environment. The final main category, Facilitator as Guarantor of Maximal Group Utility, portrays the various ways in which these professionals skillfully and efficiently managed the sessions so that they were as beneficial as possible to the group members. Altogether, these data portray how OSGs, via the genuine exchange of support amongst group members as structured by means of the professional facilitation, afford caregivers strength, clarity, and calmness amidst an otherwise all-encompassing dark and turbulent period.

The Life of a Caregiver

Week to week, the content of group discourse largely pertained to what is involved in being a caregiver to someone with advanced-stage cancer. In their exchanges, group members conveyed the following shared perceptions and experiences surrounding the caregiving journey:

Unrelenting assault. A common experience reported by group members was that of cancer presenting an unrelenting assault upon their lives since the time of their loved ones' diagnosis.

Emotional limbo. Upon receiving new information about the patient's condition, or when feeling simply overwhelmed, caregivers described experiencing a variety of mixed emotions. At times, they referred to having an "outer body experience", characterized by feelings of numbness and difficulty concentrating; other times, they reported wavering between intense, polarized emotions. Furthermore, caregivers often believed that their judgment and rationality were clouded by their affective state and they

expressed feeling “stuck”, unable to mobilize ideas and plans into action. To this point, one caregiver admitted, “I find it the most difficult time to connect to your resources or tools is when you need them the most! When I am calm, I can use them...when I am emotionally upset...I forget to use them” (Sheila). Another stated, “I believe it’s partly grief...that consumes a lot of energy, leaving less for brain function” (Jane).

Struggling to tolerate the intolerable. Group members unanimously described the imposition of cancer as being painfully unbearable. Many struggled to cope, or come to terms with such a grim reality that continually tested their capacities and left them feeling drained, defeated and hopeless. The caregivers frequently portrayed their lives like a bad nightmare that they could neither escape from nor become accustomed to. One caregiver explained it as such: “I feel more like I am sliding off a cliff and my nails are trying to dig into the side of the rock and hands are grasping for whatever rock/vine/branch might be there to pull us out...” (Cynthia).

Dreading what’s to come. Even in moments of calm between the habitual storms, the caregivers were often consumed with apprehension of what their futures held. They constantly feared the moment when things would get worse and they would, ultimately, have to say goodbye to their loved one. In this way, the battle against cancer was often perceived as one without a fighting chance, with the threat of their loved ones’ death continually looming over them. Living in constant anticipation of loss, many of these individuals viewed the time that they did have with their ill loved one as precious and felt grateful for his or her presence; some even felt pressure to live more fully with what time remained so as not to miss out on any opportunities.

Resenting cancer. Caregivers indicated feeling strong resentment toward the disease for all the drastic ways that it had changed their lives. Hopes and expectations for their future and their relationship with the patient had been shattered by the constraints of late-stage cancer, and for many caregivers, these losses were experienced as a violation or a robbery. One caregiver confessed her “hidden resentment that this disease has stolen precious life things” (Carla) from her and her husband. Cancer’s impacts often seemed inescapable and uncontrollable, and left many caregivers feeling like a prisoner of the disease, wishing they could go back to a time when things were simpler and happier.

Participants conveyed how the demands and duties of caregiving, including time spent between travel and appointments, were so extensive and incessant that little time was left for other concerns. They experienced bitterness over the entire caregiving process, the responsibilities that it forced them to assume and the unwelcomed stress it placed them under. These feelings of anger toward the illness were often complicated by conflicted feelings of both love and resentment toward their loved one. As put by one participant, Anne, “I just wish I could enjoy my mom for what we had. I hate all the [appointments], emotions and her feelings get me down...Wish it wasn’t that way”.

And as another caregiver explained:

Kara: I don’t think we can just say anger at the loved one. I tend to feel all the emotions so close together and thnk they often get mixed up. One minute I am mad because I am being used like a servant then the next I am happy to be relied on them the sorrow and guilt and everything I don’t know if I can ever single out one emotion.

Thus caregivers often expressed how resentful thoughts toward the patient were soon followed by intense feelings of shame and guilt, leading ultimately to a state of disheartenment; these caregivers felt they had no choice or control over their circumstances, but neither did they feel entitled to a natural, selfish reaction to such confinement. For example, one caregiver acknowledged, “Anger is honest but where do we go with our own anger – can’t burden someone who is in treatment with our feelings most of the time” (Carla). The online group, however, acted as a “safe place to be open with those dreaded feelings [they] do not want to have” (Carla). Sharing these sentiments with one another in-group led to the realization for some caregivers that they were not alone or “crazy for getting angry.” For example, one participant wrote, “Well I feel more ‘normal’ hearing you all say that you have some anger and fights. That has been the hardest part for me...” (Sheila).

A new us. One of the most significant ways in which cancer altered participants’ lives was in regards to the relationship between caregiver and patient. Caregivers commonly experienced cancer’s ongoing presence as an intrusion on the relationship. As one group member put it, she and her partner “had to rethink [their] relationship with this unwanted third party tagging along all the time” (Carla).

Change in context. From the point of diagnosis onward, the relationship witnessed, among other changes, a change in context. In the case of caregivers of parents, there was an unnatural role reversal whereby the parent who once cared for them assumed a more dependent role, while they took on a more nurturing, parent-like role. Similarly, when caring for a romantic partner, there was often role confusion,

characterized by reassignment of duties from one person to the other, and/or the adoption of new responsibilities. Cancer not only affected the dyadic relationship between primary caregiver and patient, but also, according to participants, caused ruptures in the broader family system. For example, young children sometimes acted out in their struggle to adjust to a parent's illness, or family members disagreed on certain decisions to be made regarding the patient's care. Limitations in the patient's physical abilities and energy levels also meant that previously enjoyed shared activities, such as hiking, bicycling, dining out or, in the case of couples, sexual intimacy, became restricted. Some caregivers learned to live more autonomously, by either engaging in these formerly shared activities on their own, or by taking up new ones. In general, cancer introduced new challenges to the relationships between patient and significant others, as the patient was no longer capable of fulfilling the same roles he or she once did.

Changes in the person of the patient. Oftentimes, in addition to alterations in relational dynamics, the patients' positive attitude and perspective deteriorated as a result of coping with cancer for many months or years. Some caregivers complained that their ill loved one had become pessimistic, angry and negative, or sad and dejected. When the caregivers witnessed such transformations in the patient's personality, they often could not help but experience a deep sense of sadness and longing for the person that he or she used to be. In the words of one caregiver, "Tom has always been a very upbeat, personable person, with a great sense of humour...he rarely smiles now, and isn't into conversation as much...it makes me feel so lonely" (Nadine). Moreover, caregivers were often pained by having to witness dramatic changes in the mood and physical abilities of

their loved ones; however, they often felt obligated to mask their own anguish.

Navigating disequilibrium. Despite the patients' more limited capacities, many caregivers felt that it was important to override their own impulses to act on behalf of the patient. For example, instead of expressing concern and desire to help whenever the patient struggled to accomplish a task, caregivers commented on the value of allowing their loved one enough space to try on their own, as this was thought to preserve his or her sense of independence and self-efficacy.

Navigating through difficult feelings and experiences within a relationship required varying degrees of communication, ranging from more to less restricted. According to the caregivers' accounts, overreliance on any one style of communication was likely to result in some form of barrier that could undermine the connection between caregiver and patient. For example, the following caregiver spoke of how her ill husband's limited communication negatively impacted them as a couple: "Sometimes I am so mad at my spouse. My husband does not like being sick and doesn't want to talk about how he is feeling. I feel alone in my relationship" (Sheila). Sheila elaborated further on this emotional disconnect between she and her husband in a later session:

Sheila: Communication was the difficult part of the cancer diagnosis for me. My husband shut down...did not want to talk about his feelings and didn't ask how I was. I was very alone and angry...I felt I had lost my partner.

Participants also claimed that their relationships suffered from times when they "snapped" at their loved one or engaged in other "negative reactions" that they were "not proud of".

Caregivers and patients who were overly restricted in their expression of feelings to one another seemed to have done so for several reasons. In some cases, caregivers were reluctant to express their true emotions to the patient for fear of stressing them out, hurting them, overwhelming them, or bruising their egos. They feared that talking about difficult issues with their loved ones would unduly burden them, and so they resolved to suffer in solitude. Similarly, patients may have, perhaps unintentionally, distanced themselves emotionally from their loving caregiver because they too wanted to spare them as much pain, or time as possible. Group members even speculated that patients might have been distancing themselves emotionally as a way of coping with the fact that they were dying. Likewise, some caregivers admitted to retreating emotionally, themselves, in anticipation of their loved ones' death. Another type of communication barrier pertained to caregivers turning inward and focusing on simply surviving through difficult times. When things got particularly tough, some caregivers indicated that they could not manage to find the time or energy to stop and think, or talk about it with their loved one.

On the other hand, when caregivers and patients were unrestricted in their communication with one another, the relationship also appeared to suffer. These interactions were characterized by one party unfairly directing his or her anger or frustration toward the other and, in essence, treating the other like a punching bag. This displacement of emotions seemed to occur rather automatically because, usually, these individuals were one another's' closest companions, proximally and emotionally. These encounters usually bred feelings of guilt and regret for the transgressor, as demonstrated

by the following excerpt:

Hannah: ...this past Christmas, my boyfriend's mother wanted my mother to come over for christmas dinner so badly... and she was still feeling quite ill from chemo (still tired, etc., and this is the most important point). i wanted her to go (for my own selfish reasons) and when she didn't want to, i (very shamefully) got very upset with her and a fight ensued (by fight, i mean really just me freaking out and my sister, mother, boyfriend and brother-in-law trying to calm me down). i kept saying to my sister that we don't know how long she will be around for, maybe this is the last Christmas? That's when i realized how much death was hanging in the air for me. My mother was very surprised by it...i apologized to her for about a week after that...that's a really hard thing to forgive myself for. It was really unexcusable and i know it.

Understandably, those on the receiving end of such behaviour often felt betrayed and violated:

Penny: I totally get it that it is [my ill son's] fear of the prognosis that [his behaviour] came from but it is one thing to deal with the anger but totally another to deal with being verbally abused, it got to a point that I tried to avoid him in the house, there was absolutely nothing I could say or do without repercussions, even saying hi...I know I am the one he feels free to explode with but this was more than I could cope with. I am glad he can feel free to turn on me but there has to be limits also.

Navigating the challenges of the new relationship was a trying task for caregivers

and patients, one that was often addressed too forcefully or avoided altogether. If either party closes off and fails to share his or her thoughts and feelings, the ‘unspoken’ inevitably occupies an emotional space in the relationship. In contrast, when one party is unconstrained in his or her communication and overwhelms the other, the other’s reaction is to withdraw, again resulting in an emotional gulf between the two.

The dark side of caregiving. Not surprisingly, caregiving is experienced as a formidable and often overwhelming calling. The disease seems to impact caregivers as severely as one would expect the patient him or herself to be, and imposes comparably on the caregiver’s autonomy. Sadly, though, unlike patients who, by virtue of their illness, are naturally positioned to be cared for, caregivers themselves often cope without adequate support from others.

Burden of responsibility. Many of the participants seemed to hold an attitude that caring for the patient was an inherent duty that came with their mutual love and commitment for one another; a duty that the patient would have readily assumed had the roles been reversed. Inasmuch as these caregivers took pride in their dedication to their loved one, their profound concern bore with it a tremendous onus of responsibility. These individuals knew that as primary caregivers, their loved ones’ wellbeing depended greatly on their own efforts, and as such, they constantly went out of their way to serve, support, and protect him or her. One of the many ways in which these caregivers served their ill loved one was by taking on difficult but necessary tasks, such as having to inform friends and family when there was bad news. While caregivers appreciated their friends’ and family’s concern, many reported that having to repeat difficult and sensitive information

was physically and emotionally exhausting. Some even preferred to mass-update people via email “because it is too emotionally draining to repeat everything over and over especially when it is bad news” (Penny). Furthermore, in the case of spousal caregiving, these individuals often engaged in heart-breaking conversations with their child(ren), including having to explain that their parent was dying.

Despite being in a state of personal grief, caregivers felt that they must stay strong for their loved one and the broader family. Whether it meant just being there for the patient as a safe place to release when they struggled to cope, or being courageous, optimistic, and resourceful when the patient was scared or lost stamina and hope, one of the most important roles of the caregiver was to act as an unwavering support system. Mustering resilience was often a lonely and tiring endeavour, as one group member stated, “I find as a caregiver I am always trying to make things positive for my mom but it is difficult when they seem to give up on themselves” (Anne).

Another commitment that these primary caregivers made to their loved one was that of protecting them and ensuring that they received quality care. Obstacles were frequently encountered within the health care system, and in such instances, the caregiver often acted as the patient’s personal advocate or ombudsman, voicing concerns or complaints and demanding proper professional service and consideration. These arrangements were often made without the patient’s knowledge, in hopes of sparing them unneeded stress. Oftentimes, the caregivers would independently research the disease, their rights within the health care system, and other information in order to be effective in their role of mediating between their loved one and the health care team and system. This

active pursuit of self-education better positioned caregivers to cope and to care for their loved one's health needs.

Despite rising to exceptional challenges and relieving the patient of numerous pressures, it was not uncommon for caregivers to feel that they were not doing enough for their loved one or to wish that they could do more. One caregiver admitted, for example, "I am just sad for her—mixed emotions...all over the place...wishing I could cure her and then wishing it would just be over for her...Wishing I could have done more for her...holidays, trips, visits, shopping, etc." (Cynthia). Relatedly, there were those caregivers who expressed regret or disappointment for having done, or failing to have done, something in the past.

Hannah: The doctor had been mentioning to us since last year about a possible trial my mom could go on but nothing concrete was ever set. She mentioned this trial again this Monday and asked if my mom would like to be on it. It's a new drug for lung cancer that is still in trial stages so 2:1 chance my mom will actually get the drug...she could possible get only a placebo. Anyways, the doctor asked if we wanted in and I said maybe so she was going to send the nurse in to talk to us but apparently it closed on jan. 4. Just feeling a bit disappointed about that. I should have asked her about it sooner...regret that maybe I screwed up a chance for my mom...it's one of those things, I keep thinking what if she was the 2 out of 3 people who got the drug? Apparently people are doing very well on it. It might have saved her.

There were also those caregivers who recognized that they could only do their best. These caregivers spoke of being self-compassionate and recognizing the point when

it is no longer healthy to strive to meet the needs of others, but rather to care for oneself. These individuals represented an asset to the group, offering support and mercy to those feeling blame or guilt. Words of wisdom, such as, “Don’t get down on yourself. We do our best and even if it doesn’t seem like enough know it is appreciated...” (Kara), modeled adaptive coping and presumably helped foster self-forgiveness.

Costs and constraints of caregiving. The reality is that these caregivers, for the most part, struggled to keep up with all that was expected of them. They often felt as though they were spread too thin, unable to successfully fulfill any one role (e.g., partner, wife, husband, employee, etc.) because of their limited time and energy. A common caregiver experience was to feel (and know) that their needs were secondary to those of the patient, of which they felt constant pressure to accommodate, even if it interfered with fulfilling their own needs. In the words of one caregiver:

Anne: I feel pulled in different directions...wanting to spend time with my grandkids, help my expectant daughter...be here for my husband and also be there for my mom [the patient]. This morning I babysat for my daughter, then into the car and shopped for mom, spent the afternoon and then cooked her dinner. My dinner was a drivethrough Swiss Chalet on the way home.

These caregivers had to be on call, readily available for assistance at any moment, regardless of the convenience, or their desire, or ability to do so. Even in times of respite with the patient, caregivers did not benefit from feelings of rejuvenation; they often went to such great lengths and extended so much energy coordinating enjoyable activities and ensuring the patient was comfortable, that when the time came to relax, they were unable

to fully enjoy the experience.

Taking it on. Caregivers disclosed that they often felt little control over their own emotional experiences. They described being highly sensitive to their loved one's verbal and non-verbal cues, which, in turn, permitted the patient's mood or feelings to influence the caregiver's affect. Quite frequently, overwhelming and unfamiliar feelings of pain, irritability, sadness, anger, frustration or defeat left both parties feeling not like themselves. Often, these emotions were experienced so intensely that they manifested physically (e.g., weight loss or gain, bodily tension), signaling the extent of the caregiver's distress to the patient. When this occurred, caregivers described various ways in which the patient tried to compensate for the burden they felt they presented to the caregiver. One commonly referenced way that caregivers reported that patients did this was by resisting assistance from the caregiver and insisting that they could take care of themselves. If the caregiver was fortunate, however, the patient coped with this feeling of burdening the other by offering support, such as allowing and sometimes encouraging the caregiver the space and time to do the things he or she wanted and needed outside of the caregiver role.

Just me, myself and I. Sadly, for some caregivers, support from their loved one, if they were fortunate enough to receive it, represented their sole source of satisfying social support. Too often, caregivers expressed feeling alone and unsupported by those around them. Friends could rarely be counted on to lift their spirits, either because they could not relate, did not know the right words to say, or because their gestures were perceived as being superficial and insincere. Even when well-intentioned friends and

family genuinely wanted to help, some caregivers preferred to hide their heavy burden from them, for fear of the “emotional repercussions of ‘dumping’” (Carla) on them and how it might alter their relationships. Others refused to ask for help or accept it because they believed that it would come with too many strings and that essentially, taking help from these people would create more problems than it would alleviate. For example, one caregiving husband shared, “[my wife’s] friends didn’t do very much at all (including call) and her Dad just made things worse. In fact at one time she said the hardest thing about her disease was dealing with her Dad” (Phil).

Caregivers commonly expressed disappointment, anger, and resentment toward friends and family who were expected to be supportive and involved, but who were not. Failure to ask how things were going, to offer help, or to acknowledge and discuss difficult issues left caregivers feeling uncared for by key figures. When people backed off, caregivers often felt disconnected from the outside world, as though they were no longer “in the loop” of their former social circles. Sometimes, feelings of isolation resulted because the caregivers’ priorities had changed, such as when they lost touch with former co-workers after having to stop working to stay home and care for the patient. Other times, caregivers felt alone because they perceived their social community, at large, as being unsupportive. For example, some individuals complained of doctors insensitively discussing cancer in general or statistical terms, failing to consider the individual behind the disease. A desire to break through this sense of social isolation and reestablish connection and unity with others was a major motivating force behind the caregivers’ enrolment in the online group. The group promised an opportunity to express

oneself freely, in the presence of others who shared a similar situation, and to be heard and accepted.

Lightening the load. As portrayed above, caring for someone with advanced-stage cancer is both isolating and extraordinarily burdensome. Unless self- and/or other-proffered support is accessed, the process can become unbearable. The caregivers in this study spoke of several active measures that they took to ensure the preservation of their own wellbeing, and of the importance of social support for their own optimal coping and adjustment.

Imperative to self care. A common theme of discussion across all four groups pertained to the importance of self-care. At some point or another, all caregivers acknowledged that caring for oneself should be a priority while caring for someone else; however, some seemed to struggle more than others at achieving this objective. Group members were unanimous in their belief that the quality of their own physical and mental health influences the level of care they are able to provide to their loved one, but for some, the idea of ministering to themselves brought about feelings of guilt. These caregivers felt so indebted to their loved ones that they experienced any self-caring act as “selfish” and thus an injustice to the less fortunate patient. As one caregiver expressed:

Cynthia: I was feeling very guilty some time ago when Mom was bedridden - I felt guilty that I could move around, work, not have pain, eat normal foods, etc. and she just laid there suffering. But then someone told me that she would be happier knowing that I was living a normal life and not 'being sad' and 'denying myself a laugh or two'. They were right.

Three caregivers conveyed a similar sentiment, in the following discussion thread:

Hannah: Sometimes I feel guilty about doing normal things...because my mom's life sure isn't normal.

Jennifer: Yes, feeling guilty about doing normal things is a hard one to deal with.

Penny: Trying to be normal is hard and takes more work because your life is everything but normal. Guilt does show its head sometimes.

Both excerpts demonstrate the ambivalence with which caregivers often live their lives. Ultimately, they managed to grant themselves occasional personal pleasures, including participation in the present online group, but it was not uncommon for them to feel conflicted about taking this time for themselves.

Caregivers often needed a break from their caregiving duties and, when they managed to come to terms with the fact that they, too, had needs that deserved to be met, many actively carved out time and created opportunities for respite that would not have been possible, otherwise. For one caregiver, this meant, "I can now say that I feel and can say I need to do something for myself. That doesn't mean I... care any less but realize I need to keep well in order to be the caregiver I want to be" (Anne).

An important way that the caregivers in the current study supported themselves was by taking charge and making pragmatic decisions about the future, such as planning in advance for hospitalization, surgery, or even end-of-life care. By making these arrangements in advance, they proactively lightened their load down the line, eliminating the need to perform such daunting tasks later, when it would become more difficult to

cope. Furthermore, these self-initiated efforts empowered the caregivers by allowing them to reclaim a sense of ownership and control over certain aspects of their lives.

Skillful and adaptive caregiving involved astute discernment of how and when to transition between giving and taking support. Sometimes the most self-supportive gesture caregivers made for themselves was to reach out and accept help from others. The caregivers in this study emphasized the importance of utilizing resources available to them in their community that could alleviate some of their responsibilities, such as advanced health care services, educational and support programs and groups, or simply, friends. They understood that many resources readily offered support and, as such, should not be taken for granted. They also acknowledged that there are times when the only way to get the support they need is by asking for it directly and informing others of what exactly they would like from them. For example, one woman described how she had to help her husband help her in the following quote:

Carla: Someone once said that you teach people how to treat you. I thought this was simplistic and not really supportive but then I realized that [my husband's] role of providing something for me had eroded too. I had to retrain myself to be a partner again.

In other words, this woman realized that she had become so absorbed in the caregiving role that she had lost sight of her own needs as a wife, and of her right to be mutually supported. She recognized that the former reciprocities that had existed in her marriage had dissolved and it was important for her to relearn how to communicate her needs to her husband so that a bidirectional flow of assistance and affection could be restored.

Feeling cared for. Notwithstanding the readiness of some caregivers to solicit assistance from others, when unexpected support was offered, it was received with profound gratitude. Emotional and instrumental support, offered by family members who were characteristically helpful and unassuming, was perceived as being unconditional and lasting, and as such, could be accepted without reservations or without feeling obligated to exchange something in return. Some caregivers expressed feeling cared for in ways that went above and beyond what was expected from their family, especially when it involved others going out of their way for them at a cost to their own freedom. These gestures of love were accepted with deep appreciation.

Beyond family, caregivers considered the support of close friends to be invaluable. While many caregivers expressed disappointment, at times, with the amount and quality of care and assistance offered by friends in general, they also spoke highly of those rare confidants who could be reliably depended upon. These individuals offered distraction or escape from caregiving duties, and could be confided in when needing to vent honestly about feelings that the caregiver preferred not to disclose to the patient. Spending quality time with these special people often lightened the caregivers' spirits and afforded them a sense of relief. An additional source of support that caregivers cherished was that extended by health care providers in their circle of care. As captured in the following confession, these acts of kindness and sensitivity were deeply appreciated and significantly impacted the cancer journey: "In all of the misfortune of her cancer, I am thankful for the oncologist we have because he's been GREAT! He's even taken an interest in us as humans, and has talked to my wife about non-cancer things" (Phil).

Living more intentionally. Cancer dictates so many aspects of the patient and caregiver's lives; it continually challenges their relational bond and tests each other's fighting spirit. The disease not only compromises both patient and caregiver's quality of life, but it threatens the existence of a life together. Inability to escape the awareness that their loved one will die prematurely forces many caregivers to live life in the face of death, where each day is seen in relation to a future without their loved one. It was common for these caregivers to experience anticipatory grief whereby they reflected on what it would be like for them and their family when the patient died, and how they would cope. Regardless of the specific ways caregivers planned to cope with this grim reality, many of them spoke of searching for meaning in the cancer journey and in life. Under such dire circumstances, they indicated their resolve to grow from the experience, and to live more intentionally and fully.

Maintaining and restoring emotional ties. One way that caregivers sought to give their present lives more meaning was by cherishing and nurturing what intimacy remained within their relationship with the patient, or by repairing relational ties that had been severed. Caregivers placed great importance on this bond and thus, when well cultivated, it represented a significant source of strength. By nurturing the relationship with their terminal loved one, caregivers derived a sense of security and strength that could be drawn upon later, when facing the loss that lay ahead. When relationships thrived, caregivers and patients seemed to adapt to the changes of their new life together and explored new things to look forward to or enjoy. One caregiver described it as such: "I refuse to sit around accepting a 'ripped off' existence... and scramble to find ways to

build on what we actually have” (Carla). These individuals tried to enjoy life and one another by carrying on as ‘normally’ as possible and refused to let cancer dictate all aspects of their lives. They found moments to bond in happiness, rest and love amidst the journey. The following quotes illustrate how two of the caregivers managed to step outside the illness for a short while and do something enjoyable or relaxing to escape their roles as patient and caregiver:

Phil: The one good thing about the day before treatment for me was going out for dinner...the travel was tiring, but because she was capable of eating anything we always went out for dinner. We always thought of it as a bit of a treat...

Carla: I actually crawled into bed beside my partner and we shared the hospital headphones to watch a movie together on one of his admissions. It has become a wonderful memory to share and we didn't scandalize the nurses as much as I worried we might.

Another important part of fostering intimacy involved leaning on one another in hard times. Many caregivers reported feeling relief, inspiration, renewed energy, and a sense of bonding when they were able to unload together with their loved one. They considered themselves fortunate if they were able to communicate together, openly and honestly, about their feelings and concerns.

Tapping into strengths. In many ways, caregivers responded to the trials of the cancer journey by tapping into their own personal strengths and sources of inspiration. Those who seem to have coped adaptively, for the most part, held a positive and hopeful perspective and approached life one day at a time. As stated by one caregiver, “I worry about [cancer], but I certainly don't want it to consume things because I focus on the here

and now—she’s alive and I try to enjoy what we have now without worries of what will happen tomorrow...I try to be as positive as possible about the what’s next” (Phil).

These caregivers appreciated life and honoured it by living in the moment, being thankful for small pleasures and by not taking these for granted. They also drew inspiration from precious past memories and hopes for a brighter future. Reminiscing and reflecting on cherished experiences from their past or that took place amidst the sadness and loss gave some caregivers great strength. One participant eagerly shared one such experience with her fellow group members:

Fiona: I must share some fun with all of you. On Monday night my husband finally cut his hair. He had my eldest grandson shave it to withing 1/2" and the youngest one helped make a Mohawk and put blue gel in it. Fun was had by all and my husband laughed too.

In contrast, some caregivers struggled to see beauty in the current state of their lives, and instead, found strength and determination by looking to the future and envisioning happier times:

Kara: I am not sure if it is ok or not! But I want to pick up the peices and do things that we haven’t been able to do for the last 2 years. I do feel guilty because I want it over to begin again...I want ot enjoy the kids. I want to go boating and camping and waterskiing, hop in the car and take a trip to who knows where. In the last 2 years we haven’t seen people or done much and I feel like I am dying inside and I want to be me again.

Lessons learned. Through all the ups and downs of caring for someone with cancer, there does seem to be a process of habituation involved. Caregivers demonstrated

that they became more practiced in their roles and, as time went on, they seem to have gradually learned to deal more effectively with the stressors associated with their new lives. In addition to becoming accustomed to the challenges of caregiving, there were lessons to be learned about life and oneself that gave meaning to an otherwise very painful process. Valuable lessons or opportunities that resulted from having gone through the experience of coping with cancer were often viewed as beautiful “gifts” wrapped in ugly packaging. As described by one caregiver, “the wonderful times can’t be appreciated nearly as much if we don’t experience sad ones” (Cynthia). Some families grew closer through the hardships, as was the experience of the following caregiver:

Leanne: All my kids have helped out when we went to chemo. I took my husband but one of our kids joined us to spell me off when I needed a break and they wanted to be there with their dad. They have all felt part of this process and we have all pulled closer than ever.

Group as Something to Look Forward to

Living as a primary caregiver, who often feels inadequately supported amidst the incessant demands, daily restrictions and struggles imposed by cancer, the online support group represented an invaluable resource that caregivers looked forward to attending each week.

A mosaic of resources. The online group served a variety of important functions for each caregiver.

Group validation and emotional support. First and foremost, the group offered tremendous acceptance and emotional support to those caregivers who partook. It was a

'place' that the caregivers could relate to others who shared an understanding of what was involved in being a caregiver, regardless of whether they were at different stages of the journey. The group was a safe environment that welcomed diversity, as members appreciated and respected one another's varying beliefs and views. They were united in their common experiences, feelings and concerns and expressed support, understanding, agreement, and approval to one another. For example, after one of the group members, Kara, admitted that she felt resentment toward her husband's family for not being more supportive, a fellow caregiver was able to validate her experience and communicate that she was not alone:

Nadine: ...no need to apologize, I feel the same way about my husband's family (not his mother) but the rest. I don't even talk to my sister...she is one of the most self centred, and least compassionate person I have ever met.

Kara: Good, it isn't just me. I often wonder if it is just me. That is why this group is great.

The caregivers expressed an interest in what one another was going through and demonstrated a sincere desire to help by responding empathically and by offering encouraging words or well wishes. These mutual words of encouragement, and overall benevolence, fostered a sense of belongingness amongst the group members and brought them together as a special community.

Group as knowledge. The group also functioned as a source of knowledge, where members could exchange information and refer one another to available resources. They were constantly seeking and receiving new ideas about ways to cope, care, and live more

successfully. It was clear that the group was a place group members felt comfortable asking for help in a forthright manner, without feeling as though they were inconveniencing one another— as was demonstrated in the following chat excerpts:

Hannah: I'm just wondering what each you do to feel happy. What makes you feel better when it's been a rough day (and many of them are rough)

Jennifer: I change my thinking, think of something that I can feel good about, like dreaming of what we will be doing when my husband gets better

Carla: Has anyone accessed the peer counseling at the Cancer Society? Or have your partners found supportive groups to speak with?

Phil: My wife has become very active with programs at Hearth Place in Oshawa. They're very important to her now, and have done a lot for her 'mental' health

Ivan: Carla, [my wife] has used Wellspring but only recently and only for yoga but she does get support from a psychologist at Sunnybrook

Group as a source of perspective. A benefit to conversing with fellow caregivers was that the group members often received advice and outside suggestions about how they may approach their issues. Additionally, many of the group members contributed unique opinions, thoughts and ideas to the discussion that helped shed light on one another's situations and stimulated them to think about things differently. Furthermore, group members gained new perspective into their own issues by vicariously experiencing the emotions of their peers when they recounted difficult events. Hearing one another's

stories put things into perspective, either because it incited appreciation for their own circumstances, or because they realized that they themselves were indeed worse off than others in the group. As such, the group served as an important reference point from which the caregivers gauged how well they were coping, and from which they borrowed new ideas regarding how to cope more adaptively.

Group as safe outlet. Finally, the group provided an outlet where members could express their thoughts and emotions. The caregivers often used their time in-group to share news about their loved one's physical and emotional health status or about how they, themselves, were coping. Other times, the group allowed them the opportunity to unload and divulge concerns that were weighing heavily upon them. This often took the form of candidly confessing their thoughts surrounding a sensitive issue that may have been judged more harshly by a different audience. For example, one caregiver revealed, "I could never share certain things with a friend that I could share with you all. For example – that I just wish Mom would go to sleep and never wake up (would feel judged)" (Cynthia). Likewise, another caregiver divulged, "well, I wont tell [my husband] that I want him to die so I can have the summer to be with our kids and try to bring them back to real life..." (Kara).

The group meetings were a time that members could allow themselves to finally acknowledge, and confront thoughts and sentiments that they had either chosen or needed to repress. By 'talking' things out or simply exploring them more deeply in session, caregivers often gained awareness into their issues. For example, when invited to self-reflect, one caregiver was surprised to discover just how distressed she was: "I guess I am

ok...nah, that is a lie, I am a mess as always. Thought I was better than this, but the tears are flowing and we haven't even started. :(" (Kara).

Emotional expression in the form of crying was not uncommon during group meetings, as many difficult topics were broached. Fortunately, group members also bonded through use of humour and benefited from the emotional release of laughter, as demonstrated by the same group member on a separate occasion: "Well ladies, I needed this today. The lightheartedness of it all feels great!" (Kara). In many ways, the purging of intense emotions in-group was restorative, as it helped the caregivers clear their minds and renewed their energy.

Approximating F2F reality. The capacity for group interaction to evoke authentic affect (e.g., actively crying and processing) is an indication of how 'real' these group dynamics were despite taking place in an online environment.

Compensating for technological obstacles. A genuine group ambiance was achieved, in part, by the members' ability to overcome the constraints of an online space that would have otherwise impeded effective communication. For example, longer-than-expected periods of silence or typographical errors can, and did at times, cause confusion within the group. For this reason, many group members chose to warn others of potential personal and technical hindrances, such as slow typing skills, poor spelling abilities, or weak Internet connection. This disclosure minimized uncertainty and impatience from others, and reduced anxiety as group members learned to orient themselves to new, cyber territory. Group members also found ways to 'workaround' the challenges of online chat, particularly those that posed a threat to timely communication. For example, they

explicitly decided to refer to one another by first initial only, rather than type out first names in full, which demonstrated a desire to make the most of their precious meeting time.

Given the lack of face-to-face interaction, the group members took advantage of the technological tools available through the chat interface to create a more personalized identity, such as customizable avatars, text font and colour, and distress ratings. They also made frequent use of emoticons and descriptive imagery to emote themselves more effectively. Creative language was also used to bring the online meeting space to life, either by referring to it as a tangible location (e.g., “who’s bringing the potato salad next week?...I’m bringing kabobs” (Tim).) or by describing imaginary interactions taking place in the ‘room’, such as sending one another group hugs or other virtual gifts.

Social norms and group etiquette. Like group interaction in general, the online groups were characterized by distinct customs and norms. As the weeks went by, the formation of a unique group culture was observable within and between each group. Discernible rituals seemed to evolve naturally, many of which were common across facilitators and the four groups. For example, all group members and facilitators would engage in relatively casual conversation, or ‘small talk’ to pass the time cordially while waiting for others to join the session before commencing. Likewise, everyone would declare their attendance upon logging into the group and would announce if, and why, they had to step away momentarily from their computers. Publicly sharing this information demonstrated consideration and respect for one another. Group members further exhibited their consideration for one another by taking turns hanging back and

allowing others the spotlight when it was clear that one group member was hoping to discuss a personal issue. This prioritizing of others' needs was a common group norm that spoke to the group's awareness and appreciation for one another's wellbeing.

Normative group behaviour appeared to be acquired through a process of imitation, as group members would often adopt the same behaviours that were modeled by their facilitator week after week. For example, there were clear instances when group members would take on the facilitator role and guide discussion, or take it upon themselves to check in with peers who seemed to be less engaged. It was common practice to communicate concern and empathy to one another, and in the rare cases when the facilitator self-disclosed, group members would reciprocate to her the same empathic, caring and supportive responses that she had continually modeled herself. It was evident that a set of predictable social patterns had been established within all four groups.

Getting 'real'. Perhaps the groups most closely resembled those that occur in the 'real' world to the extent that its members were personal with one another; the social dynamics largely paralleled those that are typical of friendship. For instance, the group members initially established open communication and sharing by introducing themselves and developing their identities beyond their usernames. They disclosed personal information about themselves including age, gender, geographic location, physical features, and other personal characteristics such as the relational or professional roles they assumed. Also very important to presenting oneself as a group member was introducing one's loved one, the patient, to the group. By opening up about their loved one and his or her medical condition, for the first time, and thereafter, the group members

revealed an intimate side of themselves. Furthermore, they created a context for understanding one another's situations. This context was continually elaborated and expanded upon with each successive group meeting, as the caregivers checked in with one another about how their week had been or about upcoming plans. By updating one another about their lives, these caregivers communicated a desire to be included and to connect in a way akin to close friendships.

The quality of conversation that took place in these groups represents another facet of their authenticity. The group members broached many intense and disturbing issues during a relatively short period of time each week, but benefited greatly from doing so: "Last week was heavy...but in a good way. We covered a lot and I felt I came out feeling a connection with everyone" (Sheila). Group members felt comfortable enough to self-disclose in ways that demonstrated humility and a willingness to confide in one another. This personal sharing seems to have been fostered by a communal vulnerability with which group members honoured and practiced being open and honest because they trusted that there was a safety and shared appreciation in doing so together. This was conveyed by one participant, who stated, "I want to thank everyone for being so open – it made me feel more comfortable to be open too" (Cynthia).

An indispensable resource. The interactions that took place in the online groups week after week forged a secure sense of association that had been formerly missing in the lives of its members. Once formed, the bonds established were so strong and so highly valued by the caregivers that, as group members often conveyed, they would be forever cherished.

Part of something special. Caregivers considered their group to be very special and greatly valued being a part of something that inspired feelings of strength and hope. They expressed deep appreciation for having had the support of one another and eagerly conveyed what they felt they had gained by being a part of the group, including feeling “lightened” and “invigorated” after their meetings. In his last session, the following male caregiver reflected on what the group had meant, and would continue to mean, to him:

Jerry: I will take from the group a sense of belonging, and a sense that there are others out there on the caregiver journey, at different places on that journey. Thinking of the group gives me strength, the knowledge that this journey will continue, and even brings me a twinkle of joy.

Thread of connection. The caregivers regularly stated how much they looked forward to their next meeting and, at times, even sought to keep in touch between weekly scheduled meetings via the asynchronous ‘CancerChatCanada’ discussion board or through e-mail exchange. Relating to one another reminded the group members that they were not alone in the challenges they endured, and when it came time to exchange final words during the last session, they expressed that they would miss each other and the support they had received.

Tim: Our time together has been way too short for me. I feel that there are too many questions I have for all of you. I want to glean what the future might hold in store for me and what I might expect and how you have dealt with issues. I want to know even more than the wonderful & helpful things you have shared with me. Thank you, everyone.

Some were so disappointed with the group's termination that they requested to prolong their interaction. Several of the caregivers spoke of rejoining a future group together, of keeping in touch via e-mail, or of reconnecting as a group again some time in the future to catch up. Some caregivers in the provincial groups even discussed the possibility of transcending their virtual boundaries and meeting in person. It is clear that the relationships forged in these online groups were no less real than those they held with face-to-face friends. Indeed, by all accounts, these bonds were among the deepest many of these individuals had experienced, and it seems as though their connections would extend well beyond the course of the present group.

Facilitator as Guarantor of Maximal Group Utility

The OSG represented one of the very few opportunities caregivers had to dedicate to themselves, and with only ninety minutes to do so, it was of critical importance that the sessions run efficiently. The group facilitators were central to the success of the groups as it was their role to ensure that the time allotted each week was maximized and utilized in a way that benefited each and every group member.

Structuring and guiding. One of the fundamental ways in which the facilitators ensured smooth group proceedings was by introducing order and direction.

Instilling group structure. In early sessions, the facilitators oriented group members to the chat room by instructing them on how to navigate the online space, by explaining, for example, what a particular acronym stands for, where they could locate font changes or emoticons, or where they could find the discussion board should they wish to connect outside the live chat sessions. The facilitators also set the stage for the

group by providing contextual information such as the background, origins, and history of the online platform, the number of members registered in their group, and the duration of their meetings. The facilitators outlined the boundaries within the online space by laying ground rules regarding what would be acceptable and unacceptable within the group. For example, they established early on that information that would be shared in-group was to remain confidential, which was crucial not only for ethical reasons, but also in order to promote open and honest communication.

Beyond the initial meetings, facilitators continued to structure the group by leading the commencement, the winding down, and the conclusion, of each session. They established when and how the groups began by creating a comfortable, non-rushed environment where members could take a few moments, if need be, to settle in, before officially commencing. For instance, as group members logged in for their first meeting, Facilitator#3 welcomed them by stating, “Hi all. We’ll just give it a couple more minutes. Glad to see you found the place.” A few moments later, the facilitator informed the group that, “We’re just waiting for one more person so I’ll give it a couple minutes before we start the group officially.” Finally, after allowing the group members a few more minutes to ease into the chat room, she remarked, “Why don’t we start with introductions... Generally your situation, what brings you here, what you’re hoping to get from the group. Anyone care to start? Or I can start...” Later, when one group member joined the session late, the facilitator greeted her by name and exclaimed, “Glad you could join! Feel free to take some time to read backward a bit, and when ready maybe introduce yourself to the group?”

In terms of winding down, the facilitators slowed the pace of discussion and announced how much time remained before they would have to end their meeting. These notifications encouraged members to share any last words that they felt were important and, when approaching the end of a session, safeguarded against the introduction of new topics that may not be adequately addressed in the time remaining. This strategy ensured that nothing new was introduced that could have, potentially, been overlooked. Finally, the facilitators declared when the group session was ending and, ultimately, guided the members in their exchange of final goodbyes. Overall, the facilitators kept the group on track by maintaining a favourable pace and managing time well. Implementing these practical parameters may seem like a relatively basic task, but it was integral to the effective operation of the groups. By clearly outlining the group format and structure, facilitators minimized the amount of time spent addressing questions and concerns and clarifying any confusion. By doing so, facilitators, in effect, maximized the time spent discussing important issues.

Creating a comfortable environment. Not only does group efficiency rely on proper organization, but it also depends upon a favourable social climate. As such, it was crucial that the facilitators foster a welcoming and secure group setting. They achieved this by relating to each group member in a warm and friendly manner. For example, the following facilitator responded amicably to a group member who warned the group of her poor typing skills: “Hey Cynthia...typos are welcome here...I will probably make the most!! So go for it. Welcome to the group!” (Facilitator#1). The facilitators did not pressure group members to initiate or engage in conversation, but always invited them to,

tentatively. In general, the facilitators treaded lightly in their process direction so as not to offend or appear to reject anyone. This gently directive, yet respectful, approach afforded the group members choice and freedom to share openly within the group context.

Engendering confidence (in facilitator, in group, and in selves). In order for group discussion to be meaningful, it was also important for the facilitators to engender the group members' confidence in the facilitators' abilities, in the group as a whole, and in they, themselves. The facilitators first elicited the group's trust by introducing themselves and listing their professional qualifications, training background, and relevant experience in the field. They continued to do so by offering psycho-education or imparting other knowledge to the group members, such as new concepts, ideas, or interventions that group members might not have known about. The facilitators further demonstrated their commitment to serve the caregivers by following up on their requests, sharing information that the caregivers sought, and generally behaving in a manner that demonstrated that they had the group's interests at heart. These gestures successfully established the group members' confidence in their facilitators as credible and knowledgeable, as evidenced by their tendency to look to them for advice, wisdom, or other information. For example, one group member asked her facilitator, "What does it mean that we covered so many different things, [Facilitator#4]?" (Fiona). In another instance, this member elicited the facilitator's expert opinion when unsure of the appropriateness of a suggestion she offered to a fellow caregiver: "I don't know if this is a good suggestion or not. [Facilitator#4] please help here. (Directing to a fellow group member) Has your son been to the oncologist with you?...Don't know, maybe that would

be too much for his age???”

Facilitators also fostered faith in the shared wisdom of the group by inviting members to brainstorm together for an answer to a question that was initially posed to the facilitator. Implicitly, such an approach communicated to the group that they played a significant role in shaping the group and its worth. Facilitators made sure that each member felt entitled to use the time in-group to obtain the support they needed, and in turn, to contribute by way of making suggestions or sharing feedback. For example, one facilitator posed to the group, “just curious...how you were feeling coming here today? Were there particular things you wanted or hoped for today? Anyone feeling especially sad or needing something?” (Facilitator#3). Likewise, the facilitators instilled hope in the group by sharing their own impressions regarding how well the group was doing or how well they were interacting with one another. One facilitator shared, “there is incredible wisdom in the group I think – I am amazed by how you manage what you do and what you have to offer each other” (Facilitator#3). Overall, the facilitators expressed a genuine interest and valuing of the group members’ perspectives and demonstrated that their aim was to support them the best they could, by guiding, not leading, the group to success.

Actively scanning. Facilitating meaningful interaction of 5 to 9 people online at any given time, in the absence of physical or auditory expression, is a highly involved task. Group members read, think, and type at different speeds, which interferes with everyone staying on the same track at the same time. A common challenge in these groups was for the thread of conversation to be out of order or for several different ideas to be expressed simultaneously. Additionally, group members differed in the extent to

which they appeared engaged at any given moment, and at times, had technical trouble logging in, or staying logged in, to the chat room. If these issues were not well managed, there would have been potential for great confusion and for some important contributions by group members to be inadvertently overlooked.

Safeguarding against overlooked experiences. It was extremely important that the facilitators ensured no expression of thought go unnoticed in session. One way that facilitators did so was by directing the course of conversation. When multiple topics were being discussed, they skillfully acknowledged the importance of each comment and ensured that they would talk about each eventually, but narrowed the focus to one area so that group members could follow the discussion more easily. In one such instance, the facilitator suggested, “I feel as though we have three different strands here...can we take each one in turn? Would that be okay? This is all really important and I don’t want us to miss anyone” (Facilitator#4). In cases such as this one, the facilitators skillfully managed and directed several strands of discussion preventing them from becoming entangled and thus interfering with meaningful interaction.

In addition to acknowledging the group members’ thoughts and ideas, it was equally important not to overlook their affective states. The facilitators demonstrated keen emotional attunement and intuitive ability to ‘read between the lines’ of text and perceive subtle emotional cues, such as silence (i.e., inactivity), that may have indicated something was wrong with a group member. They often checked in with individual caregivers to determine how they were feeling about a discussion that was taking place, especially if the group member had fallen quiet, or if there was concern that the topic

discussed may have been particularly upsetting.

Continually considering and including members. Given the lack of physical presence in an online group, there is also a risk of the group members and facilitator being preoccupied with fast-paced discussion and unintentionally disregarding their peers who type less actively. It was, thus, imperative that the facilitators were continually aware of, and included, all group members, and that they ensured that everyone was equally involved and received what they needed out of the group. One way that facilitators communicated an ongoing awareness of group members was by acknowledging those who had not made it into the group and by welcoming them to the session if, or when, they arrived. For example, when two group members did not log in to a session one day, the facilitator remarked, “I just regret that Penny and Sheila have missed our discussion today...hope they are both back next week” (Facilitator#4). Similarly, the facilitators alerted members to the absence of their peers and noted if a member was bumped out of the chat because of a technical glitch: “Hoping Carla’s disappearance is just a computer glitch...will follow up after group if she does not come back, and will notify [tech support] if it’s tech problems!” (Facilitator#2). When the facilitators acknowledged someone’s absence, it communicated to group members that their presence was valued and that others would be concerned if they, themselves, were missing. Upon returning to a subsequent group meeting after having been absent, group members were brought back up to speed by the facilitators’ summarizing themes from the previous meeting.

Facilitators also made a point of apprising caregivers of new information

regarding the group that they were privy to as facilitators but that group members were not, such as upcoming changes to the discussion board or the possibility of extending a particular group's interaction in a future group. Furthermore, in an effort to offset potential anxiety or confusion that may have arisen from not being able to physically see them, facilitators often explicitly stated their thoughts and actions to the group. One facilitator, for instance, accounted for her silence by assuring her group that she was "still here, still listening intently, just hanging back to allow [them] all to chat with each other directly" (Facilitator#2). Similarly, facilitators declared when and why they were changing font colours (e.g., for clarity sake if the colour resembled too closely another group member's font), or when they needed a moment to read a lengthy chat segment.

Another way that facilitators ensured that group members felt included was by calling on those who were less active in the conversation. Encouraging involvement from quieter members drew them in and communicated that their input mattered. Similarly, the facilitators often checked in with group members to follow up for updates about issues that were formerly raised in-group, such as the health status of an ill loved one, or the outcome of an appointment. These thoughtful gestures conveyed the facilitator's sincere consideration and awareness of each member's particular situation.

Modulating experiencing. The weekly online meetings were intended to be a time for mutual reflection and adjustment or growth, and in order for this to occur, group members had to be able to tolerate the experience of deep emotions, without becoming overwhelmed. With this aim in mind, the facilitators continually helped to regulate the level of affect within the group, sensitively alternating between deepening of

experiencing and de-escalation of emotional intensity.

Deepening experiencing. In order for real change to have taken place in the group, the caregivers had to be emotionally involved in the discussion, and toward this end, the facilitators helped engage them in several ways. One of the most fundamental ways was by guiding the group toward meaningful discussion. They actively gauged the usefulness of the conversations taking place, and discriminately chose to introduce new topics that may have been more helpful. They also highlighted key points raised by group members, and encouraged the group to explore them further, or from different perspectives. For example, they typically responded to group members with sincere interest in what they said and asked them to elaborate, or probed deeper in a specific direction by delicately asking them questions. In such instances the facilitator would ask something like, “What are the feelings under that statement Kara? Have you thought about that?” (Facilitator#1).

Another way that facilitators enhanced in-group experiencing was by recalling, repeating or paraphrasing something a group member had said so that they would further contemplate their own words. The facilitators would often listen intently to the caregivers’ words in hopes of detecting implicit emotions or messages. They would then playback the thought, now containing some added insight, or angle, that took the conversation one step further. By picking up on the edge of the caregivers’ meanings and communicating what they, themselves, were not explicitly stating, the facilitators invited the group members to experience their thoughts and emotions more profoundly. The following chat excerpt, featuring a group member and his facilitator, captured this

interchange of thought:

Phil: I think that's normal [feeling like life is a roller coaster ride] when your going throug the treatments - I know I felt like that for a good part of last year. At times I thought it was an endless-loop.

Facilitator#2: Phil-it strikes me you're talking in past tense. It's not quite the same roller coaster now? Not as many really high peaks and valleys?

Phil: Yeah-I find things are smoother, and we're more in control.

The facilitators' empathic attunement also allowed them to more fully understand and appreciate the caregivers' struggles, and in turn, they often shared their own emotional reactions with the group. As one facilitator confessed, "I find I'm tearing up as I read what all of you are writing. Sense so much sadness and loss for you under the anger and resentment" (Facilitator#2). By empathically disclosing, the facilitators were able to capture the 'here and now', prolong such intimate moments, and honour the group members' experiences with the intention of deepening their level of processing.

De-escalating emotional intensity. While affective processing requires sufficient emotional activation, it is just as important to modulate emotions when they become too intense. Failure to achieve a stable balance between being detached and being completely overwhelmed by one's emotions can interfere with adaptive coping in-session. One strategy the facilitators used when group discussion got too heavy was to shift attention away from the gravity of the caregivers' hardships, and instead, toward discussing ways in which they typically deal with stressful situations. For example, the facilitator would say to the group, "We've talked about a lot tonight...feeling overwhelmed, torn, guilty,

frustrated...wondering what helps. What ARE the small things you enjoy? Or that ease the way a bit?" (Facilitator#2). Alternatively, when discussion became too somber, the facilitators engaged group members in imagining a fantasy that would help relieve some of their stress. This sort of hypothetical thinking, or dreaming, was welcomed by one facilitator, Facilitator#1, who posed, "If I gave you the virtual gift of an hour to yourself what would you do with it? What would I see you doing?" and "I wonder if we could give you the gift of a virtual holiday...where would you want to go with [your husband]? In your imagination?"

Occasionally, the facilitators tried to regulate their group members' affect more concretely by leading relaxation or breathing exercises. As the following quote illustrates, the facilitators guided their groups in taking a moment to calm down and reconnect with the physical world and their bodily sensations: "So let's just take a moment and regroup...I think we all need to take a big deep cleansing breath...and then we will jump back in...sound okay? ...I am breathing in...I am breathing out" (Facilitator#1). In order to have brought these imaginative exercises to life, and for them to have been effective, the facilitators had to compensate for the lack of visual and physical cues and be especially creative and descriptive. When successfully implemented, these various forms of in-the-moment-coping were critical facilitator interventions that soothed group members and allowed them to resume talking about difficult, but worthy, issues.

Logging In Strained, Logging Out Sustained

Altogether, findings of this analysis depict an emotionally complex journey originating in the depths of caring for a loved one with advanced-stage cancer, and

traversing, temporarily, through a refreshing and invigorating online space. By virtue of the quality and range of support exchanged between the caregivers who visit this ‘place’, and the reliable and meaningful interaction warranted by professional orchestration, the OSGs constitute a sanctuary of virtual sustenance. By taking pause through the online space each week, caregivers are able to sort through some of the heavy load they carry with them, replenish their inner reserves, and create lasting connections with others from which they may derive strength when they return to their caregiving duties.

Discussion

The findings from this analysis elucidate the specific struggles and concerns that caregivers of individuals with advanced-stage cancer face. Additionally, the results expand upon our understanding of the various social exchanges that take place in OSGs that cater to caregivers and the high degree to which members value the groups. Furthermore, the results from this study yield a comprehensive overview of the online facilitator’s role — one that appears integral to efficient and meaningful group interaction. It is important to note that, given that this data emerged via therapeutic group interaction, that is, a highly specific social process entailing mutual-expression and support (as compared to an individual interview inquiry), the resultant knowledge represents a *co-construction* of caregiver experiences, which are not necessarily representative of any one caregiver.

Similar to other studies, these findings depict informal caregiving for cancer patients as a highly stressful process, commonly endured with a sense of isolation and protracted loss (Farkas, 1980; Fengler & Goodrich, 1979; Hasson-Ohayon et al., 2010;

Northouse et al., 2002; Pearlin, Mullan, Semple, & Skaff, 1990). Sadly, many of the participants in the current study expressed disappointment with the quality of help offered by friends and family and reported being unable to discuss effectively their concerns and emotions with their ill loved one (who, in most cases, was an intimate partner). It seems that the OSGs filled a significant gap in the social networks of these caregivers, as they confided in one another and reported receiving tremendous support from their peers in the group. Even those caregivers who felt that they could rely on their ill loved one for support, expressed benefiting greatly from that which they received in-group. This finding is consistent with research that suggests that support extended by 'friends' may serve a unique, and more protective role than that offered by ill spouses (Hasson-Ohayon et al., 2010), possibly because the dyadic distress associated with role changes makes the support provided by an ill spouse more complicated. Moreover, in light of what these caregivers revealed about friends sometimes failing to provide adequate support, the OSG represents a potentially significant alternative form of support for caregivers.

Online support groups for caregivers present a source of social support that is distinct from that offered by family and friends. Group members are well prepared to support one another because of the common concerns that they share and because the support that they offer one another is informed by their own personal needs and preferences as caregivers. The group members consistently comforted one another, validated each other's thoughts and feelings, 'listened' attentively, allowed one another to vent, extended informational support, and offered one another suggestions, fresh perspectives and insight. The analyses from this study suggest that there is therapeutic

gain in both receiving and providing these forms of support within group, a finding that has been described elsewhere (Han et al., 2011; Roberts et al., 1999; Rodgers, & Chen, 2005). For example, a recent study investigating emotional social support in OSGs for cancer patients found that group members who received higher levels of support from others had fewer cancer-related concerns, while those who offered higher levels of support to their peers reframed their issues in a positive light or adopted positive coping strategies (Kim et al., 2012).

It is also possible that caregivers may experience enhanced self-worth by helping others who are faring less well than they are, via downward social comparison (Sherman et al. 2004; Stanton, Danoff-Burg, Cameron, Snider, & Kirk, 1999; Taylor & Lobel, 1989; Wood, Taylor, & Lichtman, 1985). Despite facing constant and taxing demands, some caregivers manage to learn and grow from the experience, and consequently, approach their day-to-day lives with more purpose (Cassidy, 2013; Hudson, 2004; Kim, Schulz, & Carver, 2007; Manne et al., 2004; Weiss, 2002; Weiss, 2004; Wong, Ussher, & Perz, 2009). There was evidence of this in the current investigation where caregivers seemed to possess a contagious resilience; by willingly imparting their wisdom, these caregivers seemed to promote personal discovery and more adaptive coping in their fellow group members. It seems that OSGs are a habitat for reciprocal support, whereby all parties benefit. Supportive group exchanges appear to propel a “beneficent cycle of mutual reinforcement” (Gouldner, 1960, p. 173) in which the positive effects of supportive interaction alternate from provider to recipient and vice versa.

In addition to enacted exchanges of social support, another group factor that is thought to have been of significant therapeutic importance is that of bonding. The group members appeared to have shared a special connection rooted in shared experiences, challenges, and understandings. This bonding aspect of group intervention has been stressed by Yalom (1985) who spoke of group cohesiveness, which he defined as “the attractiveness of a group for its members” (p. 49). This concept includes the relationship between fellow group members, group members and therapist (i.e., facilitator), and the relationship of the group as a whole. Members who belong to groups with greater cohesiveness place greater value on the group, are more committed to it, and are more likely to participate and exchange mutual assistance (Yalom, 1985). Yalom asserted that group cohesiveness is not a therapeutic factor in itself, but rather, is a prerequisite for successful group intervention, as it fosters the conditions conducive to self-disclosure and psychological and social exploration. Similarly, researchers Wasserman and Danforth (1988) argued that many group factors depend upon the element of human bonding. In this study, cohesiveness was witnessed across all four OSGs and seems to have promoted discussion of issues that the caregivers felt unable to express with others leading to validation of, perhaps otherwise, controversial thoughts and emotions. This intimate sharing of one’s inner world and the ensuing acceptance by similar others is thought to be a central component of the group change process (Yalom, 1985).

Originally, cohesiveness or bonding was understood to be important in F2F groups. However, this concept has since been demonstrated to be beneficial in online forms of group discussion (i.e., asynchronous bulletin boards) as well, where

communication with fellow group members leads to a sense of belonging, and this perception of bonding has positive effects on their coping strategies, including active behavioural coping and instrumental support seeking (Namkoong et al., 2012; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; Wright & Frey, 2007).

Human bonding has been alternately conceptualized by Barrera (1986) as one form of social support referred to as 'social embeddedness'. Social embeddedness is considered to represent the connections that individuals have to significant others in their social environments. The importance of this experience is grounded in the notion that social connection is central to one's "psychological sense of community" (Sarason, 1974, p. 4) and stands in contrast to social isolation and alienation (Gottlieb, 1983). It is hypothesized that the connections that occur in groups supplement social support from family and friends or even compensate for inadequate or ineffective natural supports (Goodman & Pynoos, 1990). In fact, many of the participants in this study expressed joining their group because they were hoping to connect with others. The bonding that took place in these OSGs is thought to have been a therapeutic factor of group participation, or an antidote to the common sense of social isolation amongst these caregivers.

Barrera further contends that another major type of social support is that of perceived support, which is "the cognitive appraisal of being reliably connected to others" (Barrera, 1986, p. 416). This concept fits cognitive models of stress and coping (Folkman, Schaefer, & Lazarus, 1979; Lazarus & Launier, 1978) that emphasize the human tendency to appraise potentially threatening stimuli and available resources that

can be accessed when attempting to cope. Perceived social support is thought to encompass two dimensions, perceived *availability* and *adequacy* of supportive ties (Cohen & Hoberman, 1983; Holahan & Moos, 1981; Procidano & Heller, 1983; Turner, Frankl, & Levin, 1983). This type of support refers to an “individual’s confidence that adequate support would be available if it was needed or to characterize an environment as helpful or cohesive” (Barrera, 1986, p. 417). This concept best captures the sense of isolation and dissatisfaction with perceived social supports that so many of the caregivers in this study reported. Although the participants’ levels of perceived support were not measured quantitatively pre- and post- intervention, it is plausible that their satisfaction with support may have increased as a result of the new social connections formed in-group.

When support groups take place in cyber-space, a place where intimacy and connection cannot be communicated through body language or other subtle physical cues, the establishment of these and other group processes represents a significant challenge. It is the role of the facilitator to orchestrate constructive social interactions and it is crucial that they be equipped or trained in the skills required to do so. In contrast to F2F support groups, which typically involve two co-facilitators, when online groups are led by a sole facilitator, as was the case for the four groups analyzed in this study, it is especially important that the leader be prepared to successfully carry out these responsibilities on her or his own so that the sessions run efficiently and effectively.

Unlike F2F, groups where a facilitator physically occupies a place in the meeting room, in an OSG the boundaries between facilitator and caregiver group members are

less defined and thus facilitators must express themselves more deliberately and explicitly. Without the benefit of physical or auditory markers, it is more difficult for online facilitators to differentiate themselves from the other group attendees – that is, from being perceived as ‘just another group member.’ The facilitators in the present investigation endeavoured to make this distinction through text-based communication. For example, they stated their professional credentials and occasionally recounted past experiences of working with clients when offering an idea or response. Furthermore, one facilitator demarcated her professional boundaries by politely declining a request to meet in person with some of the group members. These discretions, along with the various skills and techniques discussed herein (i.e., structuring and guiding, actively scanning, and modulating experiencing) represent fundamental ways for online facilitators to exercise and establish their role in the group.

The quality of the facilitation of unstructured online groups has been shown to be a key factor influential of outcome (Kissane et al., 2003; Sheard & Maguire, 1999; Sherman et al., 2004). While no conclusive statements can be made about the effectiveness of the facilitation in the current study, the qualitative analyses and participants’ comments in session suggest that the success of the OSGs was largely attributable to the facilitators’ contributions. In order to be effective in their role, the facilitators remained highly attuned to the group activity and slightly ahead of the other members so that they could effectively impose structure on the group, ensure that group members felt continually included and acknowledged, and deepen in-group experiencing. It seems that when these group processes are successfully implemented, and a sense of

bonding or cohesion is established, the experience of participating in an OSG is one of great therapeutic value. These conditions allow for adaptive experiential processing, adjustment, coping, and growth for caregiver members, positive outcomes that may not have occurred in the absence of similar others or a professional facilitator.

Limitations

This grounded theory analysis yielded valuable new information that advances our current understanding about the experiences of providing informal care for a loved one with advanced stage cancer, and about the processes and factors that take place in OSGs for these caregivers. Nevertheless, it is important to acknowledge some of the inherent limits of the present study, the first of which pertains to the online modality of the support group program. In order to enroll, participants had to have access to a computer and secure Internet connection and have been capable of typing and communicating in writing, conditions that presume a certain level of socioeconomic status (SES), education level, literacy, and/or age. It is likely that other Canadian caregivers, who fail to meet these personal prerequisites, were unintentionally prevented from utilizing such services and from being included in related research. Future investigations concerning computer-mediated social support should aim to be more inclusive of all caregivers of all, perhaps by being prepared to equip them with the technology, training, or accommodations necessary to participate. Not only would a broader range of caregivers benefit from such efforts, but also, researchers might mutually profit from having access to the study of an even larger scope of caregiving challenges and concerns.

This sample also consisted disproportionately of females (76%) and of spousal caregivers (64%, or 76% when inclusive of “partners”). Although these numbers might seem remarkably high, they are consistent with relevant literature, which indicates that women, specifically wives, represent the majority of informal caregivers (Coyne, Ellard, & Smith, 1990; Nijboer et al., 1998; Peplau & Gordon, 1985; Smith, Redman, Bums, & Sagert, 1985; Snyder, 2005; Toseland & Rossiter, 1989). Notwithstanding this point, it is important to keep in mind that the themes that emerged from this analysis represent, primarily, the views of women and those caring for an intimate partner with cancer. Prospective studies on cancer caregiver experiences or OSGs geared toward this population may do well to group, and study, participants according to gender and relationship to patient (Bourgeois, Schulz, & Burgio, 1996; Nijboer et al., 2000; Toseland & Rossiter, 1989). This sort of design may afford a more nuanced understanding of the different caregiver-patient dynamics and of how to best support different kinds of caregivers.

Finally, it is important to note that the current sample may be biased by self-selection, as those who volunteered for participation and remained committed to the intervention are likely those who enjoyed and benefited from the group. It may be that OSGs are best suited for specific caregivers who possess certain qualities. For example, the caregivers in this study may have been more social, agreeable, self-disclosing, psychologically-minded or growth-oriented than those who elected not to participate. A caveat of this project then, given its voluntary nature, is that the results pertain to caregivers who are open to this form of support.

Implications

Research consistently indicates that caregivers experience comparable levels of distress to patients, if not higher, yet patients receive significantly more social support (Davis-Ali et al., 1993; Hasson-Ohayon, et al., 2010; Kornblith, Herr, Ofman, Sher, & Holland 1994; Northouse, 1988; Northouse et al., 2000; Northouse, Dorris, & Charron-Moore, 1995; Oberst & James, 1985). This finding mistakenly implies that patients are more vulnerable and needful of support than are their caregivers when, in fact, caregivers are often equally needful recipients. It has been suggested that one of the possible barriers to adequate provision of social support may be a lack of knowledge concerning the specific types of support these individuals would benefit from (Davis-Ali et al., 1993). The current study sheds light on the needs and concerns of those caring for a loved one with cancer, and therefore, may be of value to individuals supporting caregivers such as friends and family or health care providers. Efforts to improve and delineate conditions of quality care for caregivers is especially worthwhile considering that caregivers who participate in support groups are less likely to institutionalize their ill relatives than are caregivers who do not participate in such groups (Goodman & Pynoos, 1990; Greene & Monahan, 1987). This finding has important implications for a health care system that is overly burdened and limited in available resources.

This study was exploratory in nature, and intended to generate an in-depth understanding of the experiences of caregivers and the processes that occur in OSGs for these individuals. The preliminary findings that emerged from this investigation warrant future experimental evaluations of the effectiveness of OSGs for caregivers. Beyond the

assessment of whether or not OSGs yield significant outcome effects, it will be important to determine what specific factors of group participation are responsible for producing change. The identification of various group interactions and facilitator techniques in the present study may inform future research of this kind and, particularly, the development of scientific measures that may be utilized to reliably demonstrate what variables are conducive to successful OSG intervention.

The constructs upon which objective measures are based should be selected very thoughtfully, as standard indices of support group outcome (e.g. improvements in depression, anxiety, quality of life, etc.) have failed to consistently detect significant positive effects (Griffiths, Calear, & Banfield, 2009; Haley, Brown, & Levine, 1987; Zarit, Anthony, & Boutselis, 1987). Some studies have even found that support group participation leads to decreased functioning, despite high levels of satisfaction reported by participants (Høybye et al., 2010; Salzer et al., 2010). However, it is important to bear in mind that poorer outcomes on common measures of mood or quality of life may be better accounted for by the progressive decline of patients' health and stamina than by the effects of the intervention. For example, many researchers employ the Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980), which is thought to be a two-factor measure of role strain and personal strain (Whitlatch, Zarit, & von Eye, 1991). Arguably, role strain is a phenomenon that is resistant to manipulation of psychological interventions, and thus, researchers that make use of this scale are likely to underestimate treatment effects. Given the general permanence and progressive nature of a terminal cancer diagnosis, it is illogical to gauge the outcome of support groups according to

constructs that may be confounded by the effects of the illness, or that are insensitive to change. In order to accurately determine the effectiveness of online, let alone face-to-face-, support groups for caregivers, future research should seek to use measures that are informed by empirically derived understanding of constructs that are likely to demonstrate improvement for caregivers. In the present study these included feeling less alone in their experience, more validated, self-compassionate, mentally discharged and flexible, and more informed about the disease and available external resources. Evaluative research resulting from the use of instruments that assess states such as these would likely detect significant change more reliably, and be more consistent with the gains reported by participants.

It is worth emphasizing that despite the presence of various technological limitations to intimate social interaction, the group members in these OSGs reported experiencing a deep sense of connection with one another. This finding is rather promising, given the recent increased interest in online support services. Analyses from the current study revealed numerous ways that group members and facilitators interact in an online space to overcome barriers to communication and intimacy, and to enhance authenticity. While an online modality conceivably presents real challenges to successful execution of interactions typical of F2F groups, this research adds to the preliminary evidence suggesting that these processes can be achieved online (e.g., Kim et al., 2012; Namkoong et al., 2012; Shaw et al., 2000; Tate & Zabinski, 2004). Furthermore, it is even possible that an online format introduces unique advantages to group members. For example, the necessity of translating experiences into text may actually stimulate more

deliberate contemplation, help caregivers gain insight and cope more effectively (Kim et al., 2012).

As the prevalence of cancer continues to rise, as more Canadians enter old age, and as the Internet continues to gain popularity, the development of accessible and effective support resources for caregivers is of paramount importance. As such, this study was intended to develop an in-depth understanding of what it is to be a caregiver for a loved one with cancer, the potential therapeutic processes and factors of OSGs for these individuals, and how facilitators contribute to the success of these groups. Indirectly, this knowledge may be informative to health care providers who wish to develop and offer OSG resources to individuals affected by cancer and may inform the quality training of future facilitators. Furthermore, by elucidating the sorts of struggles caregivers of individuals with cancer face, individuals in their direct social circles may better understand their concerns and be better prepared to support them in helpful ways; in turn, the care that they provide to their ill loved ones may also be enhanced.

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