Online Social Support Groups for Informal Caregivers of Hospice Patients with Cancer

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Abstract

Purpose: Social support is an important factor in reducing caregiver burden, however, accessing social support via traditional means is often challenging for family caregivers of hospice patients. Online support groups may offer an effective solution. The present study sought to understand dynamics of online social support among family and other informal (e.g., friends) caregivers of hospice cancer patients in an online social support group. The primary aim of the study was to identify types of online social support and support-seeking behaviors, with a secondary aim to understand informal hospice caregivers' preferences for social support.

Method: Data used in this study were collected as part of a federally funded randomized clinical trial of an informal hospice cancer caregiver support intervention. Findings are based on directed and conventional content analysis of support group members' posts and comments—including text and images—and a sample of caregivers' exit interviews.

Results: Analyses demonstrated that the majority of online support provided by group members was emotional support, followed by companionship support, appraisal support, and informational support. Instrumental support was rarely provided. Support was primarily elicited in an indirect manner through self-disclosure and patient updates, with few overt requests for support.

Conclusions: Findings suggest online social support groups can be a valuable resource for informal caregivers who are in need of emotional support and lack the ability to access face-to-face support groups. Clinical implications of this research to healthcare systems regarding the importance of incorporating nurses and other medical professionals as co-facilitators of online support groups are discussed.

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Declarations of Interest: None

Keywords

cancer; oncology; family caregivers; informal caregivers; hospice; Internet; support groups; social support

Background

In 2016, approximately 1.43 million Americans were enrolled in hospice care (NHPCO, 2017). Of those, 27.2% had a principal diagnosis of cancer. Family and friends who care for individuals with advanced cancer experience very high levels of stress due to intense physical, psychological, and economic strain. The demands associated with such intense caregiving place informal caregivers (i.e., family and friends) at risk for worse physical health, clinical depression and anxiety, sleep disturbances, financial problems, and overall poor quality of life (Butow et al., 2014; Cameron et al., 2002; Given et al., 2004; Hsu et al., 2014; Northouse et al., 2012; Ostlund et al., 2010; Vanderwerker et al., 2005). They are also at risk of unmet social support and social isolation (Bee et al., 2009; Funk et al., 2010; Kutner et al., 2009; Newton et al., 2002; Reblin et al., 2015). These problems often increase in frequency and intensity as patients draw closer to death (Grunfeld, et al., 2004; Kershaw et al., 2015) even in the context of hospice (Haley et al, 2001).

Social Support Theory and Caregiving

Social support is an important factor in reducing caregiver burden (del-Pino-Casado, et al., 2018; Rodakowski et al, 2012) and improving caregiver health (Baron et al., 1990). Sarason et al. (1983) broadly defined social support as "the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us" (pp 127). From a functional perspective, social support has been classified into the following types: emotional, appraisal, companionship, informational, and instrumental (Cutrona & Suhr, 1992). Emotional support consists of expressions imbued with caring, concern, empathy, and sympathy. Appraisal support, also called esteem support, includes statements intended to promote another's intrinsic value or skills. These statements often take the form of compliments or validation.

Companionship support, also called social network support, includes messages conveying a sense of friendship, inclusion, togetherness, and solidarity. Informational support refers to sharing information, knowledge, or facts. This type of support also takes the form of advice, tips, and suggestions based on personal experience. Finally, instrumental, or tangible, support includes the physical provision of goods and services.

Support elicitation.

Most research on social support has focused on understanding its impact on psychological and physical wellbeing. Less is known, however, about support seeking behaviors. In the Social Support Activation Model proposed by Barbee et al. (1993) support elicitation is described as either verbal or nonverbal, and either direct or indirect. Direct elicitation includes asking a question or making a request, whereas indirect elicitation typically takes

the form of self-disclosure of information revealing a need. Although Barbee et al.'s model was proposed to explain support-seeking behaviors in face-to-face environments, recent research suggests this model is germane to online support-seeking behaviors as well (Chang, 2009; Wang et al., 2015; Youngvorst & High, 2018).

Social Support in Online Support Groups

A variety of social support interventions for informal caregivers have been tested using multiple modes of technology, including both the telephone (Bank et al, 2006; Carr et al, 2008) and more recently, the internet (Bateman et al., 2017; Vlahovic et al, 2014) In online settings, the majority of social support interventions are group based, targeting patients with specific medical conditions. Fewer opportunities exist for family and other informal caregivers to participate in online social support communities, especially individuals who are actively caring for a hospice patient with cancer (Golant & Haskins, 2010). However, findings of recent research examining secret Facebook groups as interventions to reduce anxiety and depression among bereaved hospice caregivers suggest social support delivered via similar means may likewise be appropriate for active caregivers (Parker Oliver et al., 2015; Wittenberg-Lyles, et al., 2015).

Study Purpose and Research Questions

The primary aim of the current study was to examine the provision and elicitation of social support through a combination of directed and conventional content analysis (Hsieh & Shannon, 2005) of messages posted to an online support group for informal caregivers of hospice cancer patients. Informed by Cutrona and Suhr's (1992) conceptual framework of social support and Barbee et al.'s (1993) Social Support Activation Model (SSAM) direct vs. indirect dichotomy, we sought to answer the following research questions: (1) What types of social support do informal caregivers offer one another in an online support group? (2) How do informal caregivers elicit social support in an online support group? A secondary, exploratory aim of this study was to conduct an inductive analysis of a subsample of caregiver exit interviews to identify informal caregivers' social support preferences. Thus, our third research question was: (3) What are the social support preferences of informal caregivers who participated in an online support group?

Methods

We conducted a mixed methods study with a concurrent nested design.[34] Data were collected as part of an ongoing cluster crossover randomized pragmatic trial sponsored by the National Cancer Institute (R01CA203999) and approved by the University of Missouri Institutional Review Board (#2006270). The full trial protocol is registered at clinicaltrials.gov (). While data were generated during a randomized trial, the present study was not focused on determining the group's effect. Rather, consistent with our previously described research questions, we sought to understand dynamics of online social support among study participants.

After providing informed consent, informal caregivers were enrolled into a professionally facilitated "secret" Facebook (a non-searchable platform) support group created specifically for the study. Only informal caregivers who were consented into the study were allowed access by the facilitator to the Facebook group. A masters-prepared social worker who was also caring for a cancer-diagnosed family member on hospice facilitated the group. Her dual role as group facilitator and active caregiver meant that she would interact with other group members as a peer undergoing a common experience, but would also serve as a group leader by assuming the responsibility of posting educational content at least twice per week. In addition to the educational content, the facilitator fostered discussion among group members by posting a midweek "check-in," inviting members to provide personal updates that were used as a springboard to encourage support exchange among members. Finally, the facilitator also led introductions between group members by submitting a "welcome" post when new members were added to the group. In the dialogue (i.e., comments) that unfolded following these initial welcome, check-in, and educational posts, the facilitator participated as a peer by sharing her own personal experiences, feelings, and concerns about caregiving for her father who was dying of cancer. She provided support, as well as actively solicited support from other group members. Without prior approval before publication, all group members were able to create posts, comment on existing posts, or use Facebook's reaction buttons (i.e., like, love, haha, wow, sad, angry) to interact with other members. The facilitator read and reviewed all published posts to evaluate appropriateness. No removal of posts or comments was required.

Data Collection

To address the first two research questions, data were drawn from all posts ($n = 336$; posts are content published to originate discussion/elicit comments) and comments ($n = 2349$; comments consist of replies to posts or other comments made within a post) made in the Facebook group. For the third research question, data were collected from a subsample ($n = 58$, 64%) of group members' exit interviews that were conducted during the first year of the project (September 1, 2017 – August 31, 2018). During this period, 90 family caregivers were enrolled in the Facebook support group (see Table 1 for sample description). As part of the inclusion criteria, all were caring for cancer patients receiving hospice services from one of six agencies in the Midwestern United States. The hospices were randomized to a treatment condition schedule for twelve months, a 90-day washout period, a second treatment condition and washout, and a final treatment condition. Data included in this study reflect caregivers in hospices receiving one of two treatment conditions. While all received usual hospice care in addition to participating in the Facebook group, some also participated in biweekly care planning meetings via telehealth technologies.

The exit interviews were designed to obtain general feedback from group members, including likes and dislikes about the group and suggestions for improving the experience. Only group members who completed the intervention were invited to participate in an exit interview. All interviews were conducted by telephone, digitally audio-recorded, and transcribed by a contracted third-party service. The average duration was 23 minutes. Approximately 34% ($n = 31$) of group members did not participate in an interview during the first year of the project. Some participants could not be reached ($n = 15$), others refused

due to bereavement stressors ($n = 5$). Finally, some were not eligible to be exit interviewed because they were still active participants in the group ($n = 11$). In one instance, an interview was conducted but the recording failed. As a result, 58 interviews were analyzed for this study. A summary of interviewee characteristics is provided in Table 1

Data Analysis

Five members of the research team conducted the analyses for this study. All data coding was performed in Microsoft Excel. The first author developed an initial coding frame based on a review of the literature and the theoretical frameworks informing this study. To address the first research question about types of social support, deductive coding was employed— five codes based on Cutrona and Suhr's (1992) conceptual model of social support were included in the coding framework: *emotional support, appraisal support, companionship support*, and *informational support, instrumental support*. To address the second research question about support elicitation/seeking strategies, a combination of inductive and deductive coding methods were utilized (Ligurgo, Philippette, Fastrez, Collard, & Jacques, 2018). Two deductive codes (*direct request for support* and *request via self-disclosure*)— inspired by Barbee et al's (1993) SSAM direct vs. indirect dichotomy—were included in the coding framework. In addition to applying these directed codes to the data, coders also engaged in inductive coding to allow additional insights and category development (Hsieh & Shannon, 2005; Kondracki & Wellman, 2002, Mayring, 2000) regarding support seeking/ elicitation to emerge from the data. Finally, a general code "other" was added to the initial coding frame for coders to use to capture data excerpts deemed relevant to the research questions but which specific coding certainty was otherwise unclear.

To test the initial coding framework and finalize the codes, two members of the research team utilized the eight-item coding frame to separately code a single 6-week subset of posts and comments. This resulted in intercoder agreement of 63% for the eight initial deductive codes (*emotional support, appraisal support, companionship support, informational support, instrumental support, direct request for support, request via self-disclosure*, and *other*). The first author met with the coders to discuss conflicting codes, review and categorize the "other" codes and any new codes that were generated inductively, and refine all code names and corresponding definitions until 100% agreement was collectively reached for all coding decisions (Campbell et al., 2013). Coders produced three additional codes for support elicitation based on inductive coding: *patient information, patient updates*, and *obituary*. Based on further discussion, two codes—*patient information* and *patient updates*—and corresponding excerpts were collapsed into a single category: *patient information/updates*. Moreover, after reviewing and discussing excerpts that were coded as "other" and comparing those excerpts among other directed codes, a new coding category—*non-verbal strategies*— was created and applied to all excerpts that included images, Gifs, and Emoji. Finally, because such a large proportion of excerpts for support elicitation (75.64%) were coded as "request via self-disclosure," this code was reoperationalized into two codes for self-disclosure: *emotional self-disclosure* and *informational self-disclosure*. The final coding frame included the following codes: *emotional support, appraisal support, companionship support, informational support, instrumental support, emotional self-disclosure, informational self-disclosure, patient information/updates, obituary, direct requests*, and

non-verbal strategies. Several examples for each of these codes are delineated in the results section.

To address the third research question, two members of our research team conducted an inductive analysis of the exit interviews by collaboratively identifying data segments pertaining to the Facebook group. Next, they grouped conceptually similar data segments into initial themes related to positive and negative dimensions of social support engagement. The first author then inductively coded these data, identifying three emergent themes about social support preferences: *face-to-face meetings to augment online interactions, explicit request for more informational support, implicit request for more appraisal and/or companionship support*.

In summary, coding reliability in posts and comments, consensus coding in interviews, member checking by staff with prolonged engagement in the study and peer debriefing with remaining authors assured trustworthiness in the analysis for all research questions.

Results

The research team applied a total of 5133 codes to the posts and comments analyzed for this study. Of those, 2378 codes addressed our first research question regarding the types of support that group members provided (Table 2.). The remaining 2169 codes addressed our second research question regarding the ways group members elicited support for themselves (Table 3.). By means of inductive coding, n*on-verbal strategies* (Gifs, Emoji, and images) emerged as an important sub-theme relevant to the first and second research questions. Three emergent themes of social support preference were identified from the inductive analysis of exit interviews that was conducted to address our final research question. To maintain confidentiality, pseudonyms were assigned to all group members.

Types of Support

Emotional support.—The most common type of support provided was emotional support. Comments or posts coded as emotional support included statements conveying empathy, sympathy, affection, and concern. Examples included: "hang in there," "I wish you all the peace right now," and "I'm so sorry. How are you coping with all this?" Compared to other support codes (instrumental, appraisal, companionship), it was more common for emotional support to be singularly applied to a post or statement. However, when other support codes were applied to a post or comment, the code for emotional support often accompanied them. For example, if a group member offered informational support (i.e., advice) about how to solve a caregiving problem, he or she rarely did so without also including an emotionally supportive statement (e.g., "Maybe getting some respite care for a few days might help you…sending you prayers, hugs and a lot of love!"). When the code for emotional support was singularly applied to a post or comment, the emotionally supportive statement made was often a simple sympathetic response (e.g., "I'm so sorry") to a group member reporting on the recent death of a hospice patient:

Gwyneth My mom passed away Saturday evening. I am thankful that her pain is gone. She is in a much better place, but will be sorely missed.

Louis Gwyneth, I have no words. I cannot say anything but I am so sorry.

Companionship support.—We applied companionship support codes to statements fostering a sense of belonging, welcoming, comradery, friendship, and solidarity (e.g., "we are all in this together"). Although these codes were the second most frequently applied, statements associated with this code were fairly homogenous in terms of content due to the practice of welcoming new group members. When the group facilitator submitted a post introducing a new member to the group, it was common practice for existing group members to reply with a brief comment welcoming the new member (e.g., "Welcome to the group, Lily!"). A much smaller number of comments coded as companionship support included group members making invitations to others to spend time together in social activities outside of the group. Statements demonstrating shared preferences, interests, and hobbies were also examples of this code, and occurred in greater frequency than requests to socialize. The following exchange is representative of this type of support:

Louis I use a lot of music to help me relax. Anybody else? What do you do?

Sandy I have been [playing music] all day. I listen to music and play multiple instruments.

Marion I also use music to relax! What instruments do you play, Sandy?

Sandy Viola, drums, and I sing… I have music on all the time…from Beethoven to Black Sabbath and the Beastie Boys, to Johnny Cash. I love it all!

Marion Sandy, you are very eclectic in your taste! I am the exact same way! Notably, conversations similar to the one just described received multiple codes, as it was common for appraisal support codes to occur in tandem with companionship support codes.

Appraisal support.—Appraisal support codes were applied to posts and comments that included statements of affirmation or emotional validation. For example, a particularly active member, Louis, posted the following comment to the group after several members shared their caregiving distresses: "I know it's hard, I know it's sad, but you matter to the person you are taking care of. Their world would collapse if you weren't there. You mean something." As Louis's statement exemplifies, the appraisal support code was often applied to statements made by group members attempting to praise others for doing a good job, for their skills, or to encourage group members about the decisions they were making or had made. In another example, Marion offered appraisal support to Elyse by praising her for being able to effectively and eloquently communicate her emotions about her mother's impending death:

Elyse …I wake up each day wondering if the end of [my mother's] suffering is today. I'm not afraid of death for her. In that moment she will be free of cancer and all the hell it has taken on her body. Until then, we live each moment we have, and we embrace the miracle of those moments. I am her rock right now and she can lean on me until the end. All I ask for is your prayers and positive thoughts for peace and comfort to my mom and her body….

Marion Elyse, this is so beautiful and so well stated! You write so well and I can feel all of your emotions behind every word! Thank you so much for sharing this with us!

Informational support.—The support code applied least often was informational support. This code included all statements offering information, advice, tips, and suggestions for problem solving. All posts made by the group facilitator that included educational content had this code applied. For example, to provide educational information on the topic of "assessing your loved one's pain," the facilitator posted the following:

> We have created a video that can help you assess if your loved one is having pain. The video below provides five simple tips to help you know if your loved one is hurting…

When group members offered informational support to help another solve a problem, their statements commonly included tips for self-care (e.g., "make sure she's in a safe place and then just step out the door for 5 minutes to get a break") or questions to provoke ideas and/or probe for possible solutions to a problem (e.g., "maybe a visit from the chaplain would be helpful?").

Eliciting Support

Emotional self-disclosure.—The most frequent support elicitation code applied to the data was emotional self-disclosure. These codes included subjective statements such as, "It makes my heart sad…," or "today was a good day." Similar to emotional support, these codes were often associated with other codes. For example, when group members made statements that we coded as informational self-disclosure or patient information/updates, they rarely did so without also including a statement about their emotional status or how they were feeling. Marla said, "I'm tired but feeling hopeful. He was awake longer yesterday; maybe he was catching up after our big weekend." In what appeared to be demonstrations of solidarity, sometimes group members would emotionally self-disclose when offering support to others. One member, Denise, submitted the following comment in reply to another member who was lamenting her frustrations about her mother's (the hospice patient) tendency to "lash out":

> Remember that your mom isn't the same sweet mom you remember. She's sick and in pain and probably hates it that her children have to do the things for her that they do. I know it's tough. I'm in the same situation … I lose my patience, too…

Informational self-disclosure.—Informational self-disclosures included objective statements made by group members about their life history and daily activities as a caregiver. When members were added to the group, they often provided background information about themselves (e.g., age; marital status; parental status) and a brief description of their caregiving situation (e.g., "I am caring for my 73 year old mother, who was diagnosed with pancreatic cancer."). Informational self-disclosures also included posts and comments from group members reporting on their own self-care activities. These types of informational disclosures often occurred in response to the facilitator's "weekly check-in" posts, and elicited support in the form of emotional and/or appraisal support. For example,

when the group facilitator asked group members to share what they were doing for self-care, the following exchange occurred:

Martin I reintroduced exercise. I walked twice and then went for a 10 minute run. Today I am going to run 20 minutes. I allowed myself to use eating as a coping mechanism when I thought this [caregiving] experience was going to be hard and short. I'm feeling better and better about myself.

Group Facilitator That's wonderful, Martin! Exercise is such a great self-care! How are you feeling after running 20 minutes today?

Patient information/updates.—Statements coded as patient information/updates focused on the patient's health status, activity, or behavior. These codes differed from informational self-disclosures because the primary focus was the patient, rather than the caregiver. Posts and comments including patient information/updates were sometimes brief (e.g., "I don't think my mom is going to last too much longer. She can barely move."), however, it was common for informational self-disclosure and emotional self-disclosure statements to be made in the same post or comment that patient information/updates were shared. For example, when Marla posted about her husband's health status, she also talked about the emotional toll she was experiencing as a result of witnessing his decline. "My husband had a spell today," she said. "Hospice says he is deteriorating. He has to stay out of the heat we are no longer at months, we are at weeks. My heart is breaking again."

Obituary.—Posts and comments were coded as "obituary" whenever a group member initially posted about their hospice patient's death. Although arguably a "patient update," obituary posts/comments differed from patient updates due to the nature of the support that was elicited. Patient information and updates elicited varied types of support depending on the content, whereas obituary posts and comments mostly elicited simple statements of emotional support.

Direct requests.—Direct requests for social support were uncommon (n = 44) and nearly equal numbers of requests were made in an original post to the group as were made in subsequent comments. Most requests for support were requests for informational support in the form of advice/informational support (e.g., "How do I comfort him and help him through his anger?" "Should I contact hospice, or just wait?"), emotional support (e.g., "Please pray for my mother" "I need strength"), or companionship support whereby group members were seeking solidarity (e.g., "Is any of this familiar to others?" "Is it normal to daydream about running away from home?"). In a few cases the facilitator requested support from another group member by asking them to share his or her experience. For example, when one group member disclosed that she was struggling with how to address one of her father's symptoms, the facilitator tagged another group member asking her to share, "Renae, didn't you have a similar situation with your Dad?" In two cases group members asked for assistance finding instrumental support. One request was a referral for an attorney or social worker, and another was a request for a formal caregiver.

Non-verbal Strategies of Support Provision and Elicitation: Gifs, Emoji, and Images

In addition to textual messages, group members would also post Gifs, Emoji, or images as either gestures of support, or to emotionally self-disclose. Gifs and Emoji were typically accompanied by written text. For example, one group member posted a heart emoji at the end of her statement, "please also know that we are here for you in your pain [heart Emoji]." Another member wrote: "Sending positive thoughts your way! [flower Emoji]." Emoji faces with sad expressions or tears were sometimes used in comments to non-verbally disclose feelings of sadness or sympathy. Still images or photos were usually shared as a main post, with little to no written text involved. The lack of written text was likely because the images posted by most group members were sentimental memes, or pictures of inspirational quotes, with text already embedded.

Emergent Themes about Social Support Preferences

Three emerging themes regarding group members' preferences for support were identified in the qualitative data that were analyzed for this study. First, several members talked about *wanting face-to-face meetings to supplement the online support group*. For example, one group member stated, "I think the support group through Facebook is a good venue, and it's certainly a start, but I think connecting people to other support groups that are more face-to-face would be beneficial." The primary reason for desiring face-to-face interaction appeared to be due to a desire for live chat versus a desire to share the same physical space as other members. In this instance, the member suggested hosting a "set time" in the Facebook group for "anyone who wanted to talk" with other members in real time.

Secondly, although it was not clear from the abovementioned statements what type of support was desired from the proposed face-to-face interactions, as a general recommendation other *group members explicitly requested more informational support*, or what they deemed "educational support." One group member stated, "I wish there was more educational material in there. And I'm sure there's a ton. I was so busy and I didn't take the time to go back and search for it. But I wish I had seen some of those articles before Dad had passed because it would have been very helpful." Another suggested the need for "lots of education about how to handle the stress in a healthy way." Others alluded to a desire for more informational support by mentioning how it would be helpful to have hospice staff participate in the online group so that they could report on the status of the hospice patient. This was a suggestion made by a group member who was caregiving at a distance and was thus dependent on hospice staff to communicate updates about the patient. Hosting an informational "question and answer" session was also recommended, as one group member stated, "having a moderator type [event] going on would be something to do, if people had questions that they wanted to ask."

Finally, although not stated explicitly, there were several comments that together suggested *a desire/appreciation for more companionship and/or appraisal support*. "Staying positive," and avoiding "doom and gloom" and "depressing" conversations was a consistent theme regarding the desired tone of the support group. Several group members talked about the strain they experienced by being exposed to others' grief. For example, one member talked

about her hesitancy to share her own feelings of distress because she preferred fostering positive dialogue in the group:

> I don't like to put stuff on there that makes people sad. I like to put a smile on peoples' face. I'm a people person. Then I read some of the [group members'] stories, I kind of felt it and I was like, "I can't do this." I could really feel what they were feeling.

Another mentioned how reading about the deaths of other members' hospice patients was her "least favorite part of the [group]." She continued, "…having to deal with [other group members'] grief almost on a daily basis I found to be more depressing than the value of the Facebook group." This strong dislike toward repeated exposure to death was echoed in the interviews of several others. One lamented the frequency of "obituary" posts. "They repeated throughout the study, and it was really depressing." Because death was such a common topic in the group, another member pondered whether or not her participation in the group was a net benefit to her mental wellbeing:

> Maybe some people feel alone in it and draw a benefit from [talking about death], but it just seemed like I'm already in a depressing situation and the Facebook group is a lot of sadness and frustration and people dying. I don't know. I felt like I gave more than I got out of it. It probably would have been better for my mental wellbeing if I hadn't engaged with it.

However, in addition to these concerns were incidences where others talked about their disappointment regarding how "impersonal" the group felt. Some members critiqued the group's conversation for being too superficial or "light;" or that interaction was limited, making it a challenge to feel a sense of connection. "I felt like other caregivers weren't being open enough," said one group member. Another said, "you don't have time to get to know anybody in the group." In sum, these seemingly paradoxical viewpoints of wanting to avoid grief-inducing conversations, yet also wanting a stronger connection with others, suggests garnering more support focused on fostering friendship and esteem may be an implicit preference among those who participated in the online support group.

Discussion

The aim of this study was to examine types of support provision and identify support elicitation strategies in an online support group of informal caregivers of hospice patients with cancer. Our analysis demonstrated that group members exchanged several types of support, including emotional, appraisal, companionship, and informational. Unsurprisingly, there was no evidence of instrumental (i.e., tangible) support provision among members, however, consistent with the findings of others (Evans et al., 2012), several posts or comments coded as informational support included suggestions for ways group members could obtain instrumental support offline from local friends, family, hospice staff, and/or formal service providers.

It was perhaps unsurprising that emotional support was the most common type of support provided by group members, but some members' requests for more informational support suggest exploring strategies to increase this exchange among members may be worthwhile.

For example, the facilitator could submit a post inviting members to share the best caregiving advice or tips they had received. However, there is a risk that group members may share inaccurate information. Therefore, the monitoring feature on Facebook would need to be activated so that the facilitator could approve all comments for accuracy and appropriateness before publication. Group members also suggested in their exit interviews a desire for more companionship support, yet, companionship support ranked second to emotional support in terms of coding frequency (see Table 2.). As noted in the results section, the majority of companionship support took the form of pro-forma interactions (i.e., welcoming posts/comments). Although these types of comments are intended to make other group members feel welcomed, it may be that the participants who described in their exit interviews a greater desire for companionship support were explicitly interested in companionship support that included making/receiving invitations to others to spend time together in social activities outside of the group, or dialogue revealing shared preferences, interests, and hobbies.

There was a notable difference between the group facilitator and group members in terms of posting/commenting frequency and style. The group facilitator authored the largest proportion of both posts (65%) and comments (37%). As well, the group facilitator typically authored the longest and most densely coded posts and comments (i.e., posts and comments with three or more codes applied). This, combined with findings from the exit interviews regarding several members' desire for less superficial interactions, underscores the need for additional strategies to strengthen relationships and increase interactions among group members. However, certain characteristics about this particular group made this challenging: the group interacted online only, members were unfamiliar/had never met with one another before joining the group, group membership was short-term due to patients' end-of-life status, group membership was fluid—members did not enter or exit the group at the same time, and interactions were asynchronous. Additional research and exchange of practice wisdom and experiences are needed to understand how to do this well in online settings. Indeed, current research suggests that commenting on Facebook, particularly self-disclosures, may be high in quantity compared to face-to-face disclosures, but are lacking in quality (Attrill & Jalil, 2011). Related to the aforementioned concerns, examining the impact of the facilitator's dual role as professional and active caregiver on other group members' participation style and posting/commenting frequency is worthy of investigation. Some research suggests that peer-led support groups are as equally effective at improving caregiver health outcomes as professionally-led groups (Klemm, Hayes, Diefenbeck, & Milcarek, 2014). However, it is not well understood how facilitators impact support group dynamics when they vacillate between roles—interacting as a peer during certain interactions (including engaging in their own support elicitation behaviors) and as a professional facilitator or subject matter expert in other interactions. The overall satisfaction with group engagement experienced by current study participants suggests dual-role facilitators may be effective, but additional research is needed.

Moreover, based on other work (Parker Oliver et al., 2015) we were surprised that none of the group members surmised in their exit interviews that group members' relationships to patients (adult child, spouse, etc.) impacted the nature and type of support that was exchanged in the group. However, group members may have agreed that this was a salient

issue if we had directed our interview questions toward this specific topic. Additional research is needed to justify whether or not relationship-specific support groups serve as a strategy for strengthening relationships among group members, and subsequently increasing the quantity and quality of support exchange.

Finally, the posts and comments eliciting the most support in our study were those coded as emotional self-disclosure. This code included posts and comments containing text and/or non-verbal content (e.g., Emoji). Although self-disclosure in online support group settings has been highlighted as an important behavior for receiving social support (Tixier & Lewkowicz, 2011; Wang et al., 2016), some research suggests that direct requests for support and informational self-disclosure are better strategies for eliciting support than emotional self-disclosures (Chang, 2009). However, this research also revealed that posts including both text and non-verbal content elicited more support than posts without non-verbal content. These findings and ours suggests that the ideal posts for eliciting support in an online group may be those combining informational self-disclosures with non-verbal, emotional self-disclosures. However, additional research is needed to confirm this hypothesis.

Some limitations of the present study are worth consideration. Foremost, the sample was fairly homogenous and therefore may not represent the experiences of informal caregivers with different ethnicities or gender status. Secondly, this study was a descriptive study about the types of support provided, and the support elicitation strategies used, among participants. Thus, an investigation about the reciprocal nature of support exchanges was not conducted. Future research questions regarding reciprocal exchanges that are worthy of empirical study include: Are certain types of support elicitation linked to certain types of support provision? Or, do certain types of support elicitation yield non-responses in terms of support provision? Answers to these questions would inform members of support groups about which support seeking strategies might be most effective at producing desired responses. Finally, we were not able to ascertain whether presumably supportive posts and comments were interpreted as such by the recipients of those messages. According to optimal matching theory (Cutrona & Russell, 1990), any benefit derived from support depends on how well the support provided matches need. Asking participants in exit interviews to subjectively report their perspective regarding which types of social support were most helpful to them, and which ones were not, would be illuminating. Thus, future research using a variety of data collection techniques (i.e., qualitative and quantitative) is needed for a definitive understanding about what types of support in online groups provides the most benefit, and to whom.

Implications for Oncology Nursing Practice

The online support group provided a mechanism for exchange of social support, aligned with oncology nursing's commitment to supporting the biopsychosocial needs of patients and their caregivers. Nurses have key roles as providers of patient and family education (Rieger & Yarbro, 2003), but their time to provide meaningful/important education is often limited in hospice, given the short length of service, which is particularly short for cancer (NHPCO, 2017). Online groups could provide a mechanism for the dissemination of information to informal caregivers in an efficient (and potentially low-cost) manner. Plus,

caregivers can access the information when needed versus being inundated with information at once by nursing staff. Finally, although we had a social worker facilitate the group, many nurses have the skills and expertise needed to be successful facilitators of online support groups as well. Ideally, nurses would partner with social workers to co-facilitate the groups so that nurses can provide expertise from a medical/nursing perspective and social workers can offer a therapeutic perspective.

Conclusion

Social support groups delivered via online social networking sites can provide a valuable resource to family and other informal caregivers of hospice patients due to their limited ability to access face-to-face support groups. This study suggests secret Facebook groups are an effective platform for delivering and receiving various types of social support via text and other non-verbal communication strategies.

Acknowledgement of Funding:

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Highlights

- Informal hospice caregivers of cancer patients utilized online support groups primarily for the exchange of emotional support.

- Informal hospice caregivers of cancer patients mainly elicited support online by self-disclosing their emotional state, sharing details about their daily caregiving activities, or describing their patient's current health status.

- Informal hospice caregivers of cancer patients requested additional informational, companionship, and appraisal support.

- Including nurses as facilitators of online support groups may bolster the provision of informational support and ensure accuracy of information provided.

Table 1.

Participant Characteristics

	OSG Members (n = 90)	Interviewees (n = 58)
Gender, *n* (%)		
Male	16 (18%)	11 (19%)
Female	74 (82%)	47 (81%)
Age, mean (*SD*)	55.44 (12.18)	56.54 (12.18)
Race/Ethnicity, *n* (%)		
Black/African American	9 (10%)	7 (12%)
White/Caucasian	79 (88%)	49 (84%)
Other	2 (2%)	2 (4%)
Relationship to Patient, *n* (%)		
Spouse or partner	21 (23%)	13 (22%)
Parent	12 (13%)	7 (12%)
Adult Child	39 (43%)	29 (50%)
Sibling	6 (7%)	1 (2%)
In-law	2 (2%)	1 (2%)
Ex-spouse or ex-partner	1 (1%)	1 (2%)
Non-relative	3 (3%)	2 (3%)
Other	6 (7%)	4 (7%)
Distance lived from patient, *n* (%)		
In the same residence	41 (46%)	24 (41%)
Up to 1 hour away	37 (41%)	27 (47%)
More than 1 hour away	8 (9%)	5 (9%)
Prefer not to answer	4 (4%)	2 (3%)
Highest level of education, *n* (%)		
Less than high school	3 (3%)	2 (3%)
High School/GED	16 (18%)	9 (16%)
Some college/trade school	34 (38%)	23 (40%)
Bachelors/undergraduate degree	20 (22%)	11 (19%)
Graduate/professional degree	16 (18%)	12 (21%)
Other	1 (1%)	1 (2%)
Household Income, *n* (%)		
Under $20,000 per year	15 (17%)	10 (17%)
$20,000–$39,999	15 (17%)	9 (16%)
$40,000–$69,999	18 (20%)	13 (22%)
Over $70,000	33 (37%)	21 (36%)
Prefer not to answer	9 (10%)	5 (9%)

Table 2.

Frequency of Support

Types of support	No. of appearances	% of total
informational support	326	13.71
emotional support	1107	46.55
appraisal support	402	16.90
companionship support	541	22.75
instrumental support	2	.08
TOTAL	2378	

Table 3.

Frequency of Support Elicitation

Types of support elicitation	No. of appearances	% of total
Indirect		
emotional self-disclosure	756	42.23
informational self-disclosure	598	33.41
patient information/updates	359	20.06
obituary	33	1.84
Direct		
requests support	44	2.46
TOTAL	1790	