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Facebook Online Support Groups for Hospice Family Caregivers of Advanced Cancer Patients: Protocol, Facilitation Skills, and Promising Outcomes

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Abstract

Research has demonstrated a lack of support for hospice caregivers and a higher than average level of self-reported anxiety and depression. While online support groups are gaining popularity, few protocols have been published, little research has demonstrated the skills required to facilitate, and virtually no data has explored the clinical outcomes affiliated with participation in such groups. This paper presents the preliminary experience and results of a clinical trial testing the use of online support groups designed to both educate and provide social support to caregivers of hospice cancer patients. A detailed protocol outlines educational strategies, discussion questions, and a blueprint outlining ways to engage participants. A review of field notes completed by the interventionist reveal specific facilitation skills and strategies used to engage participants. Finally, preliminary analysis of 78 participants shows the group is having a statistically significant impact on the caregiver depression.

Keywords

Facebook; Online group; Facilitation skills; hospice

In 2018 there were more than 1.5 million hospice patients cared for in the United States (National Hospice and Palliative Care Organization [NHPCO], 2020). Each of these patients had at least one family caregiver looking after them and attending to their needs. Research has shown that these caregivers need additional support and education (Parker Oliver, Demiris, Washington, Clark, & Thomas-Jones, 2017). A systematic review found that one-quarter to one-half of these hospice family caregivers (FCGs) are depressed (Parker Oliver, Albright, Washington, Gage, & Mooney, 2013; Parker Oliver, Washington, Smith, Uraizee, & Demiris, 2017). Caregiver depression can be compounded as social isolation increases during the time patients are enrolled in hospice (Albright et al., 2016). Research among FCGs in the general population has shown that online support groups can improve social support and self-efficacy (Parker Oliver, Patil, et al., 2017). Clinical trials testing interventions with hospice FCGs are rare, and no studies have assessed online support groups within a clinical trial for FCGs of hospice cancer patients (Kruse, Gage, Washington, & Parker Oliver, 2015).

Online support groups offer hospice agencies a chance for group interventions that are otherwise not possible given the distance and isolation of their homebound patients. Group interventions are rare in the hospice setting where individuals are often homebound and thus unable to participate in traditional support groups. Additionally, social work caseloads, while varied between agencies, have been found to often be inadequate to manage patient and family needs (Giordano, 2018). Therefore, group interventions that allow social workers contact with larger numbers of family members at one time may be one solution to the staffing problem facing many agencies (D Parker Oliver, Washington, Gage, Mooney, & Demiris, 2015; D. Parker Oliver, Washington, Gage, & Demiris, 2014)

Despite the controversy with the Facebook platform, it is a valuable tool to consider when offering these online groups. It is estimated that 32% of the global population use Facebook (Whitehead, 2020). Facebook has many advantages; it is a readily available, free, and generally acceptable online support group platform. The Facebook platform allows closed, private groups of approved individuals to come together online and share their common experiences. These hidden private groups protect privacy issues as group membership is controlled by the facilitator and the identities of participants is not revealed to anyone outside the group. Setting up these groups is simple and free. Individuals can access these groups with not only a computer or tablet, but also with apps on cell phones, providing seamless access between a variety of devices.

While helpful in connecting individuals, Facebook also has limitations. Privacy breaches and the loss of personal data highlighted by the Cambridge Analytica scandal have caused many concerns (Whitehead, 2020). People have reported not joining or leaving Facebook due to concerns with potential exploitation of personal data, feeling it is a waste of time and leads to procrastination, and believing there may be a negative psychological effect of social comparison (Whitehead, 2020).

After weighing the benefits of Facebook, and its limitations, the decision was made to use the platform for this study. In preliminary work we had found caregivers of hospice patients found the platform useable and beneficial. (D Parker Oliver et al., 2015; D. Parker Oliver et al., 2014)The ACCESS clinical trial (Access for Cancer Caregivers to Education and Support for Shared decision-making) provided the opportunity to create and test a detailed protocol for hospice family support.

ACCESS Clinical Trial

This study reports on the lessons learned and preliminary findings from a clinical trial using the Facebook platform for online support groups to improve the caregiving experience for FCGs of hospice cancer patients. The ongoing clinical trial named ACCESS (Access for Cancer Caregivers to Education and Support for Shared decision-making) is funded by the National Cancer Institute and registered on [ClinicalTrials.gov \(NCT02929108\)](https://clinicaltrials.gov/ct2/show/study/NCT02929108). ACCESS is a five-year, multi-site, cluster-crossover, pragmatic, randomized trial that 1) uses Facebook online support groups to provide education and emotional support to FCGs and 2) offers web-conferencing to involve FCGs in hospice care plan meetings, supporting shared decision making with the hospice team to reduce FCG anxiety and depression. Hospices are randomized into one of three arms: a control arm, a Facebook-only arm, and the ACCESS intervention arm which includes Facebook plus web conferencing with the hospice interdisciplinary team. Seven clusters (hospices) cross over every 12 months into a different study arm (Parker Oliver, Washington, Demiris, & White, 2020). The study design specifics are outlined elsewhere.(Oliver, Washington, Demiris, & White, 2020)

Facebook-specific protocols, skills required to facilitate the online groups, and potential outcomes of online support group interventions have not been thoroughly studied in published literature. This paper seeks to address this gap and accomplish three aims: 1) provide a protocol for an online support group for FCGs of hospice patients with advanced cancer, 2) share lessons learned regarding skills used in facilitating such a group, and 3) provide preliminary outcome data regarding hospice FCG anxiety, depression, burden, and quality of life following a Facebook intervention.

Protocol for ACCESS Online Support Groups

Given the short length of stay for hospice cancer patients (a mean of only 46 days; NHPCO, 2020), the study protocol is built around a four-week cycle. Each cycle is repeated, and individuals are able to remain in the group as long as they wish, until their care recipient dies. While the educational content repeats every four weeks, the support aspects change as group membership and engagement change continuously over time.

The goal of the Facebook group is to provide a safe online group for social support and vetted education for FCGs of hospice cancer patients. This private hidden group is managed and facilitated by a Masters-prepared social worker. We use a specific protocol designed to engage caregivers and provide a supportive forum for FCGs to share their experiences. The protocol is summarized in Table 1.

The educational content focuses on four topics, which were identified in preliminary research (Parker Oliver, Washington, Gage, Mooney, & Demiris, 2015; Parker Oliver, Washington, Gage, & Demiris, 2014). Topics include information on hospice, pain management, decision making, and the dying process. To support the education provided in the group, one author (DCO) wrote and filmed a four-chapter dramatic video story, a telenovela, to use as an educational tool. One video chapter is posted each Monday with discussion questions, followed by a Tuesday poll asking for a personal response to the video. Additional educational material is supplied through various online articles, websites, and a series of caregiving tips.

The four-week rotating themes for the online group, including the telenovela videos, are designed to allow members to come and go as their situation dictates. For example, someone can enter the group during week two of the rotation and not be confused or lost, as the weeks are independent and do not build upon one another. This was important again to accommodate the short length of stay for hospice patients. It is not practical to recruit independent groups of caregivers and have them start and stop at the same time. This wastes precious time for education and support and also prevents the building of a group large enough for meaningful interaction.

The social support component of the group involves the sharing of stories between caregivers and the use of validation techniques by the facilitator. These social support conversations have involved emotional, informational, and social support and are detailed elsewhere (Benson et al., 2020). Membership in the group has ranged from as few as ten to as many as 40 at any one time. Group guidelines ensure that the members understand the purpose of the group and feel they are protected from inappropriate and unsafe behavior. The facilitator is responsible to uphold the guidelines and discuss inappropriate or concerning posts with individual members as necessary. Individuals assessed to have serious emotional or mental health concerns are referred back to their hospice social worker for individual attention.

Facilitation Skills

The Council on Social Work Education's Educational Policy and Accreditation Standards (2015) identifies intervening with groups as a core social work competency; however, much of the education social workers traditionally receive empowers them with skills to manage face-to-face groups. Many of the skills required in online groups are similar, but there are some important differences.

Our pilot work outlined how the facilitation of online support groups compared with the National Association of Social Workers' (NASW) ethical guidelines for use of technology (Parker Oliver et al., 2015). ACCESS has built upon this experience and allowed us to examine effective skills over a 36-month period of the study. Table 2 outlines the skills our team has identified as critical to the successful facilitation of ACCESS support groups. This list was developed through review of field notes kept by the facilitator and a review of the Facebook postings made by both the facilitator and the participants.

While many of the traditional group work skills such as engaging all participants are valuable in an online environment, the techniques to use those skills can vary. For instance, rather than naming someone online, we have found “tagging” (linking a post to an individual’s profile), to be an important technique. Like in a face-to-face group, we see individuals engaging with group members or the group content in numerous ways. Some individuals are very active, posting and commenting frequently, while other members view the material but rarely respond. The facilitator’s role is to ensure that all participants feel comfortable, attended to, validated, and safe in the online environment.

Promising Outcomes of Facebook Support Groups

Based on our preliminary work and a meta-analysis of online interventions (Parker Oliver et al., 2013; Parker Oliver, Demiris, Washington, Kruse, & Petroski, 2017; Parker Oliver et al., 2015; Parker Oliver, Washington, et al., 2017), we chose to measure four outcomes to determine the efficacy of our online support groups. The Generalized Anxiety Disorder scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006) and the 9-item Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001) measure anxiety and depression, our primary outcomes, respectively. In both cases, scores of 10 or more likely indicate clinically significant levels of anxiety or depression. Additionally, we administer the Caregiver Quality of Life Index-Revised (CQLI-R; Courtney, Demiris, Oliver, & Porock, 2005; Parker Oliver, Kruse, Smith, Washington, & Demiris, 2019) and the Zarit Burden Interview (Higginson, Gao, Jackson, Murray, & Harding, 2010) throughout the 90-day intervention. For this preliminary study, paired t-tests were conducted to compare FCGs’ baseline and last outcome measures for those in the Facebook-only study arm. Potential confounding variables were not assessed.

Seventy-eight ($N = 78$) FCGs had completed their participation in the Facebook-only arm of the study at the time of the analysis (April 2020). The average age of FCGs was 55.6 years, the majority were Caucasian (88%), female (76%), caring for their parent (46%), and employed (60%). On average, FCG anxiety levels dropped 1.81 points from baseline to the last measure (8.35 vs. 6.54 respectively, $p = .0008$). Similar results were seen for caregiver depression (mean difference = 1.71, $p = .0003$), see Table 3. The range of anxiety and depression scores was broad, with standard deviations of 5.69 and 5.89, respectively. No statistically significant differences were noted in FCG quality of life or burden.

Discussion

We have successfully used the Facebook platform to support a private hidden online educational and support group for FCGs of advanced cancer patients in seven hospice agencies in the Midwest. We have established a four-week rotating protocol and identified important skills needed to facilitate the group. Lastly, in a small subsample of FCGs, we have found that participating in Facebook support groups was associated with decreased anxiety and depression. These preliminary findings align with prior research indicating that online support groups can lower anxiety and depression (Parker Oliver, Patil, et al., 2017). Additionally, the findings illustrate the sensitivity of the GAD-7 and PHQ-9 to detect

change in this sample size. The lessons we have learned during this preliminary period are summarized in Table 4.

This work has shown that these groups have the potential to improve participant anxiety and depression. While baseline mean scores of 8.35 and 7.86 indicate mild anxiety or depression (scores of 5-9), they are close to reflecting a moderate level of distress, which has been identified as being clinically significant. The range of scores was broad with a standard deviation of 5.69 and 5.89, respectively. While the sample is small, the levels of anxiety and depression found upon admission to hospice highlights a need for psychosocial interventions to reduce anxiety and depression in these FCGs. As social workers strive to provide evidence-based interventions, the need to understand and measure the potential outcomes of our practice (such as anxiety and depression) is critical. This preliminary analysis demonstrates the promise of a social media-based intervention to improve caregiving outcomes and thus the caregiving experience. If this intervention is found to be effective, this free, readily available intervention may improve the psychosocial care provided to hospice family members.

We have learned that a short duration intervention (4 weeks) is necessary in the hospice setting where patient lengths of stay, especially with cancer patients, are known to be short. While we are not entirely confident that 4 weeks is the most appropriate length for the intervention, we are finding it that timeline is feasible. According to the National Hospice and Palliative Care Organization Facts and Figures Report in 2020 the average length of stay in hospice was 89 days and the median length of stay was 18 days (NHPCO, 2020). The median reflects the number of days that half of hospice patients were in hospice. If an intervention focuses closer to this number rather than the 89 days a great portion of caregivers will be able to participate.

Another important lesson learned is that this intervention requires social workers to hone their skills on not only facilitation of online groups but also on using technology. While Facebook is an easy to use the platform it does require facilitators have an understanding beyond those required for basic group participation. Facilitators must understand the overall operations of the platform thoroughly so they may coach and help participants problem solve. For example, this includes understanding on how to set privacy settings, and communicating the differences between what is seen on an individual's newsfeed and what is seen by a participants social network.

Finally, we have found there is tremendous value in a written protocol such as the one we have provided. This protocol is helpful in assuring that objectives for the intervention are clear and that the postings and discussion are consistent with the objectives. It also allows new facilitators or multiple facilitators the opportunity to learn the intervention and consistently deliver it. While it allows protocol modifications, such as a change in one of the resources, those modification are also planned and designed to continue toward the specified objectives.

While promising, this preliminary work has limitations. The effectiveness of the educational content and the necessary skills for successfully engaging participants are still being

analyzed. The preliminary statistical analysis is limited by a small sample size in one geographic region, preventing the analysis of various demographic effects, such as age, race or gender. Statistical modeling was not conducted to assess the effect of any covariates. This is particularly important given the low numbers of minority accessing hospice care, thus the effect of the intervention on those population is still unknown. These findings reflect only the initial portion of our sample and do not reflect a comparison to any of the other study groups so as not to bias the results of the ongoing trial. It is important to note a large variation in scores, as noted by the standard deviation value. The lack of significant change in quality of life or burden may represent an underpowered sample at this preliminary stage. Despite the limitations of the Facebook platform and these limited data, it is clear that it is feasible to offer online groups with the Facebook platform. We have shown the groups are technically possible, privacy is secure, and participants will utilize and potentially benefit from the intervention.

Conclusion

While these results are preliminary and based upon simple analysis, they demonstrate an anxious and depressed population with needs, and suggest that online support group interventions may improve FCG anxiety and depression. This research has not yet been shown to be effective and thus utilization into practice is not yet evidence based. However, if shown effective there are several issues which must be considered before hospices should adopt the intervention. Once issue concerns the way these group interventions might be computed into productivity standards for social workers. Adding these additional responsibilities without adjusting caseloads and considering the time involved would not be helpful. It will be important for our research to estimate the time involved to deliver the intervention so social workers can make adjustments accordingly. Secondly, hospice agencies will need to carefully think through their technology settings and permissions as some institutions block access to social media platforms. Furthermore, given the isolation caused by the worldwide Covid 19 pandemic, these groups have the potential to be another strategy to overcome the increased isolation caused by such events

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Table 1

Summary of Protocol

	Week 1 Topic: Hospice	Week 2 Topic: Pain	Week 3 Topic: Shared Decision Making	Week 4 Topic: Dying Process
Monday				
Objective	Caregivers will understand the philosophy of hospice.	Caregivers will be able to recognize and assess patient pain.	Caregivers will understand the concept of shared decision making and will learn how to engage in shared decision making with their hospice team.	Caregivers will better understand the dying experience and will learn strategies to communicate with patients who are dying.
Text for Post	<i>We've made four short videos for this group. They are each about five minutes long. Our story focuses on Marinela, a woman caring for her husband, Tom, as he receives hospice services. In this week's episode, Marinela struggles to come to terms with Tom's diagnosis.</i>	<i>This week's episode addresses pain.</i>	<i>In this week's episode, Marinela makes an important decision to call hospice instead of 911 when Tom appears to be in pain.</i>	<i>This week's episode takes us through Tom's final journey: the dying process.</i>
Link	Video links here			
Discussion questions	<ul style="list-style-type: none"> > <i>Did you learn anything new from this video? If so, what?</i> > <i>How is Marinela and Tom's experience similar to or different from yours?</i> 	<ul style="list-style-type: none"> > <i>What was the most important thing you learned from the video this week?</i> > <i>How do you know if your loved one is in pain?</i> 	<ul style="list-style-type: none"> > <i>Do you feel like you are a part of the decision-making process with your hospice team?</i> > <i>If you feel comfortable, share information with the group about a time you had a similar experience to Marinela problem solving with your hospice team.</i> 	<ul style="list-style-type: none"> > <i>Did this video help you better understand what to expect as your loved one is nearing death?</i> > <i>How might you lean on your support network during your loved one's final days?</i>
Tuesday				
Objective	Caregivers will provide feedback on this week's video.			
Post text	<i>In yesterday's video, Marinela and Tom learned more about hospice from their nurse, Ricardo. Complete the poll below to answer the following question: On a scale of 1-5, with 1 being not at all and 5 being very much, how much did watching this video help your understanding of hospice care?</i>	<i>In yesterday's video, Marinela learned more about pain from her husband's hospice nurse. On a scale of 1-5, with 1 being not at all and 5 being very much, how much did watching this video help your understanding of assessing your loved one's pain?</i>	<i>In yesterday's video, Marinela worked with the hospice nurse, Ricardo, to decide how to treat her husband's pain. On a scale of 1-5, with 1 being not at all and 5 being very much, how much did watching this video help you understand how to make decisions with your hospice team?</i>	<i>In yesterday's video, Marinela cared for her husband, Tom, during his final days of life. On a scale of 1-5, with one being not at all and 5 being very much, how much did watching this video help you understand the dying process?</i>
Link	Facebook poll: Please reply to the post by answering: 1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much			
Discussion questions	Poll serves as discussion			
Wednesday				
Objective	Caregivers will provide personal updates and exchange support among group members.			
Post text	<i>How is everyone doing this week?</i>			
Link	No links today			
Discussion questions	No specific discussion questions are provided for today.			
Thursday- two posts				

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	Week 1 Topic: Hospice	Week 2 Topic: Pain	Week 3 Topic: Shared Decision Making	Week 4 Topic: Dying Process
Objective	Caregivers will learn practical tips to enhance their wellbeing and will become and remain aware of group rules.			
Post text	1. Caregiver Tip of the Day 2. <i>Each month, I'll be reposting our group rules so everyone can remain aware of them. While we haven't had any problems in the past, we think it's a good idea to share these with you periodically. Feel free to comment below if you have questions or concerns. You may also message me directly if you prefer to communicate privately. Thank you for making this group the safe and supportive environment it has become!</i>			
Link	1. Facilitator-selected Content 2. Attach the Group Rules of Conduct document, located under the Files tab in the Facebook group.			
Discussion question	No specific discussion questions are provided for today.			
Friday				
Objective	Caregivers will understand what hospice is and how to utilize it.	Caregivers will understand what hospice care is and how to appropriately utilize it for both the patient and oneself.	Caregivers will identify opportunities to engage in shared decision making with their hospice team.	Caregivers will be able to identify signs of imminent death and will be able to identify ways to assist the patient during this stage.
Post text	<i>Hospice care is a patient and family-centered approach that includes a team of doctors, nurses, home health aides, social workers, chaplains, counselors, and trained volunteers. Most of the time, family members or friends are patients' primary caregivers. As you develop a relationship with your hospice team, each hospice staff member will want to know how to best support you and your loved one. It's important that you let them know what your needs are. Learn more about the hospice team in the article below.</i>	<i>Have you heard of emotional or spiritual pain? It can be difficult to know if your loved one is in emotional or spiritual pain. Sometimes this appears to be physical pain, although it is not. The article below provides information on how to recognize emotional and spiritual pain</i>	<i>On Monday, we shared a video about shared decision making. In hospice, shared decision making requires family caregivers' active participation. When making decisions with your hospice team, listen to team members' suggestions for solutions and offer some of your own if you have them. Weigh the pros and cons of different options. Ask questions as needed. Think about how each possible solution relates to your personal values and preferences. Take time to make a final decision if you need it. Then work with your hospice team to decide what's best. This article discusses the importance of talking about your values and preferences with your hospice team.</i>	<i>The article below is from the American Cancer Society. It discusses what to expect when a person with cancer is nearing death. While the article was written for caregivers, patients may also be interested in this information. In addition to listing signs that death may be close, the article also provides caregivers with some ideas about how to help during the dying process.</i>
Link	Link to article about what patients and family need to know about hospice.	Link to article about pain management.	Link to article about communicating with healthcare provider.	Link to article about treatment at the end of life.
Discussion questions	<ul style="list-style-type: none"> > Did you learn anything new from this video? If so, what? > How is Marinela and Tom's experience similar to or different from yours? 	<ul style="list-style-type: none"> > If you or your loved one has experienced emotional or spiritual pain, how did this affect you as a caregiver? > What strategies have worked for you when trying to ease your loved one's emotional or spiritual pain? 	<ul style="list-style-type: none"> > What decisions have you made with your hospice team? > How do you let your hospice team know about your values and preferences regarding your loved one's care? 	<ul style="list-style-type: none"> > Are there special things you currently do or plan to do with your loved one or other family members when this time comes? > Was there anything in this article that surprised you, or was a new idea for you, about what caregivers can do to comfort a loved one in their final days?
Saturday				
Objective	Caregivers will be aware that humor can be an effective coping strategy.			
Post text	<i>Silly Saturday</i>			
Link	Facilitator-selected Content			
Discussion questions	No specific discussion questions are provided for today.			

	Week 1 Topic: Hospice	Week 2 Topic: Pain	Week 3 Topic: Shared Decision Making	Week 4 Topic: Dying Process
Sunday				
Objective	Caregivers will feel uplifted and inspired.			
Post text	<i>Supportive Sunday</i>			
Link	Facilitator-selected Content			
Discussion questions	No specific discussion questions are provided for today.			

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Table 2

Summary of Facilitator Skills

Revised	Explanation	Example
Provide leadership	The facilitator manages group membership. The facilitator monitors group rules. The facilitator establishes and maintains group norms.	<i>"I'll send you a link so you can join the group." "Please remember that our group rules prohibit political discussions." "We like to have everyone introduce themselves to the group, telling everyone as much or little about themselves as they would like."</i>
Create a welcoming and safe environment	The facilitator welcomes new members and encourages others to do the same. The facilitator fosters group safety.	<i>"Please join me in welcoming Mary to our group. Mary, we're glad to have you in our circle of support." "Thank you for sharing how you are feeling. Feelings are neither right nor wrong, and no one is here to judge you."</i>
Validate members' feelings	The facilitator engages in empathetic communication.	<i>"It sounds like your family members are criticizing the decisions you are making while being pretty unwilling to help out. It makes perfect sense that you are feeling frustrated."</i>
Communicate effectively	The facilitator thoughtfully considers the balance of positive and negative group content. The facilitator models appropriate use of humor. The facilitator seeks feedback on issues raised by group members.	<i>"We've had some heavy discussion this week. I want to make sure people also feel welcome to share positive experiences. For those who would like to share, what is bringing you joy this week?" Periodically post humorous content or memes, avoiding humor at the expense of particular groups of people. "I know last week was rough for many of you. How are you all feeling this week?"</i>
Educate group members to provide clarification and facilitate responses to questions and concerns with the support of the healthcare team	The facilitator ensures accurate and adequate information is available and shared among group members.	In response to a group member's post on using essential oils to address dyspnea: <i>"The physician on our team recommends this article, which provides many ideas on how to improve shortness of breath."</i>
Resolve conflicts and foster group cohesion	The facilitator assists group members in resolving disagreements and frames conflict as an opportunity for growth.	<i>"James, you seemed to have had a really strong response when Mary said she was looking into nursing home care for her husband. And, Mary, you indicated that James' response made you question whether you wanted to stay in the group. Can we discuss that a bit more?"</i>
Manage boundaries and orient members to facilitator and peer roles	The facilitator limits self-disclosure to instances when it is beneficial to the group. The facilitator clearly communicates boundaries regarding the frequency with which they are actively present in the group. The facilitator refers problems outside the purpose of the group to other providers.	<i>"I wonder if you're feeling nervous about your discussion with the hospice nurse tomorrow. Sometimes when I'm nervous, I feel sick to my stomach." "Please remember that I only check posts once per day. If you have an urgent need, please contact your hospice team." "It sounds like your hospice agency might be able to provide you with additional resources. I would suggest you speak to your hospice social worker about that."</i>
Encourage group member introspection regarding their group participation	The facilitator reminds group members to reflect on their reactions to group content and processes.	<i>"We've talked a lot lately about what happens during the dying process. Some people find talking about dying to be a relief. For others, it can be overwhelming. How are you feeling? For those of you who are feeling overwhelmed, how will you take care of yourself? Remember that your hospice team is available if you would like to individually discuss any of the information we share in this group."</i>
Encourage engagement	The facilitator monitors group members' interaction with group content such as videos or articles, and uses data to guide group work. The facilitator uses group features such as "tagging" to invite specific members to engage in group discussions. The facilitator poses direct questions to solicit group participation.	<i>"It looks like not many people have had a chance to watch this week's video on pain management. It's full of great information, so be sure to check it out." "It sounds like you're spending a lot of time and energy keeping all your family members informed about your husband's condition. @Kathy and @Roger, you were talking a while back about a program you used to keep everyone in the loop. Do you have any ideas to share?" "Let's take a quick poll. How many of you had thought much about spiritual pain before reading this week's article?"</i>

Table 3

Comparison of baseline and last outcome measures for ACCESS (Facebook-only group)

Instrument	Measure	N	Mean	SD	Mean difference (95% CI)	t	p-value
GAD-7	Baseline	78	8.35	5.69	1.81 (0.77 - 2.83)	3.50	.0008
	Last	78	6.54	4.93			
PHQ-9	Baseline	78	7.86	5.89	1.71 (0.80 - 2.61)	3.76	.0003
	Last	78	6.15	4.97			

SD=standard deviation, CI=Confidence Interval, PHQ=Patient Health Questionnaire, GAD=Generalized Anxiety Disorder

Table 4:

Summary of Lessons Learned

- Use of Facebook for online support groups with caregivers of hospice cancer patients is feasible
- Participation in Facebook online support groups may impact caregiver depression and anxiety
- An online intervention of 4 weeks is a feasible length for the intervention. Given the short length of stay in hospice for cancer patients, interventions targeting those caregivers must also be short.
- While facilitation of online groups requires similar group work skills as face to face facilitation, there are also unique skills required for this media.
- A written protocol for group facilitation with hospice caregivers focusing on education and social support is helpful.

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