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It is the “starting over” part that is so hard

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Abstract

Although hospices are required to provide caregivers with formal bereavement support when their loved one passes, most bereavement interventions lack standardization and remain untested. The Dual Processing Model of Bereavement was used as a theoretical framework for assessing the potential of a Secret Facebook Group for bereaved hospice caregivers. Online communication was analyzed and reported outcome measures were compared pre and post intervention. Bereaved caregivers shared abrupt and anticipated triggers resulting in loss-orientation and shared restoration through storytelling, advising, and encouragement. Caregiver anxiety and depression were lower post intervention. This study highlights the promise of Facebook for hospice bereavement support.

As a requirement for participation in the Medicare Hospice Benefit program (Centers for Medicare and Medicaid Services, 2008), which accounts for 84% of all hospice care in the United States (National Hospice and Palliative Care Organization, 2012), hospice agencies must provide caregiver bereavement support following a patient's death. Such services can include mailed educational materials, personalized letters of support, staff/volunteer home visits and funeral attendance, annual memorial services, and support groups and workshops; a small number of agencies provide individual or group therapy. Although required by Medicare, hospice programs receive no reimbursement for providing bereavement services, creating variation in the nature and scope of services offered across the nation and leaving few caregivers actually receiving any formal bereavement support or information (Barry et al., 2012). Medicare budget sequestration further complicates the provision of hospice bereavement support, and tested interventions related to these services are already limited (Schut & Stroebe, 2005).

Online health communities such as blogs, chat rooms, forums, collective libraries, and wikis offer one potential solution for providing low-cost hospice bereavement support. Early research on these social media platforms shows that online health communities facilitate support for disease self-management (van der Eijk et al., 2013). Facebook, for example, has been found to be a platform where individuals share health-related information, share advice and give opinions, and find value in peers' personal experiences (Bender, Jimenez-Marroquin, & Jadad, 2011; De la Torre-Diez, Diaz-Pernas, & Anton-Rodriguez, 2012; Zhang & Lane, 2013). This paper focuses on evaluating the bereavement experiences of hospice caregivers who participated in a pilot study using a Secret Facebook Group for online bereavement support (Parker Oliver et al., In review).

Theoretical Model

The Secret Facebook Group intervention was based on the Dual Process Model (DPM) of coping with bereavement (Stroebe & Schut, 1999). This online asynchronous intervention had the goal of helping participants with coping processes related to bereavement, thereby aiming to improve the consequences of the bereavement experience. Coping is defined in this model as the process of developing strategies, or ways of managing bereavement-related stressors. The consequences or outcomes of coping processes include such things as anxiety and depression (or lack thereof) resulting from the degree of success with the coping process (Stroebe & Schut, 1999). DPM holds that there are two categories of stressors associated with bereavement that drive the coping process: loss-oriented stressors and restoration-oriented stressors. Coping with loss-oriented stressors occurs when the bereaved individual processes the loss experience itself. Loss-oriented coping involves such things as painful dwelling on the deceased person, looking at old photographs, and ruminating about the circumstances surrounding the death. Conversely, individuals coping with restoration-oriented stressors are managing the challenges associated with rebuilding life without the deceased person. Restoration-oriented coping may include attention to practical matters such as learning to manage finances or prepare meals if these tasks were previously managed by a now-deceased spouse or partner; however, it may also involve rebuilding on a deeper level, such as developing an identity as a "widow" rather than a "wife" and discovering ways to be socially active without a deceased significant other. The DPM suggests that a dynamic

process of oscillation in which an individual alternately confronts and avoids these different stressors is key to adapting to loss in a healthy manner, increasing positive bereavement outcomes, and reducing negative outcomes.

Recommended guidelines for testing the DPM urge researchers to undertake longitudinal investigations and to carefully differentiate among stressors, coping processing, and outcomes of coping efforts (Stroebe & Schut, 2010). This study explored bereavement over time among hospice caregivers using a Secret Facebook Group developed to provide bereavement information and support. Our goal was to show how bereaved individuals experience loss- and restoration-oriented stressors, how they cope with these distinct types of stressors, and to explore the outcomes of participation in a Secret Facebook Group for bereavement. As background for this intervention, this study seeks to answer the following research questions within the DPM framework: (1) What are loss-oriented stressors experienced by bereaved hospice caregivers? (2) How does a Secret Facebook Group for bereaved hospice caregivers facilitate restoration? (3) What are the reported outcomes of bereaved hospice caregivers participating in a Secret Facebook Group?

Methods

This mixed methods study relies on the self-reported measures and online communication (comments and postings) of a Secret Facebook Group of bereaved hospice caregivers during a pilot study of this intervention. Specifics on the intervention are published elsewhere (Parker Oliver et al., In review) but, in summary, a Secret Facebook Group was created and caregivers from three hospices were invited to participate in the online support group following their hospice experience. Participants were given a list of guidelines for appropriate participation and supplied with educational information and discussion questions as a means to facilitate discussion. At the conclusion of the nine-month pilot study, the postings were transferred into word documents for qualitative analysis. In addition participants were asked to complete instruments screening for anxiety and depression, two potential negative outcomes of coping processes. We used two screening tools, the 9-item Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer, & Williams, 2001) and the Generalized Anxiety Disorder 7-item screening tool (GAD-7) (Lowe et al., 2008).

Data Analysis

Two members of the research team coded the Secret Facebook Group online communication using content analysis methods. A caregiver's post or comment was the unit of analysis for the study. "Comments" were defined as remarks made in response to material posted by the group facilitator (a member of the research team) or another bereaved caregiver, whereas bereaved caregivers' original statements that were typically self-prompted and consisted of new topics were referred to as "postings" or "posts." Comments and posts were first coded as either loss-oriented or restoration-oriented, as described in the DPM (Stroebe & Schut, 2010). Initially, a one-hour coder training session was held to jointly review a sample from the data and discuss specific coding definitions. Several discussion sessions were held between coders to review differences in coding and resolve discrepancies. Once coding was refined, with 92% inter-coder reliability, the data were split between coders who

independently coded the remaining sample. Within loss- and restoration- orientation categories, we explored patterns and themes using constant comparative processes (Creswell, 1998). The final coded comments and posts were reviewed by a third research team member and a peer debriefing was done with all investigators to ensure consensus on the assignment of codes. To assess reported outcomes among bereaved caregivers in this study, self-reported measures on anxiety (GAD-7) and depression (PHQ-9) were entered into SPSS and average mean scores were calculated at baseline (Time 1) and completion of the study (Time 2).

Results

A total of 16 bereaved hospice caregivers participated in the group. Group members were predominantly female ($n = 11$) and Caucasian ($n = 15$). Half were employed outside the home on a full-time basis. Nearly equal numbers of bereaved spouses/partners ($n = 7$) and adult children ($n = 6$) were included. Other participants had experienced the loss of a mother-in-law ($n = 1$), a father-in-law ($n = 1$), and a grandmother ($n = 1$). The group was relatively diverse with regard to the highest level of education achieved by participants and annual household income. While all participants were able to access the group using their personal computers, some also participated via Internet-enabled Smartphones ($n = 7$) and/or Tablets ($n = 4$). A summary of participant characteristics is provided in Table 1.

Online Communication

There were 71 posts and 268 comments made by bereaved caregivers in the Secret Facebook Group. The research coordinator made 45 posts and 191 comments. Bereaved caregivers made 315 “likes” to a post or comment. Posts from bereaved caregivers ranged from 0–24 and their comments ranged from 0–64, with no comments or posts from three of the caregivers in the study. To help facilitate community, nearly all posts or comments by caregivers were liked by the research team member who facilitated the Facebook Group. Coding of the online communication revealed that the majority of caregiver comments and posts were restoration-oriented ($n=172$), followed by loss-orientation ($n=84$) and remaining talk was categorized as social small talk ($n=83$). Social small talk among bereaved caregivers included shared appreciation for hospice services and staff and small talk about current events, anniversary of deaths, and brief posts welcoming others to the group.

Triggers of Loss-Oriented Stressors

In online communication, bereaved caregivers shared loss-orientation experiences by describing two different types of emotional triggers that reminded them of their loss. Abrupt triggers were experienced when remnants of the past intruded into the present, evoking emotional distress (“Certain things trigger the sadness”). Belongings and other “little things” such as perfume, music, commercials, handwriting, and the weather, were frequently described as abrupt triggers that stirred up painful memories causing both an emotional and physiological response. Although aware that such emotional triggers existed within their everyday life, they were unaware of the impact it would have on them (“I literally gasped and could feel my breathing get rapid”). Bereaved caregivers described feeling unprepared and unguarded to protect themselves from the random remnants of their loved one. In one

woman's post she explained: "It is the little things that I have a problem with, they tend to sneak up on me."

The reactions and comments of other individuals were shared during online communication and articulated by bereaved caregivers as abrupt triggers that precipitated emotional distress. Caregivers commiserated that "'well intentioned' but regurgitated quips often have the opposite affect [sic]" on the bereavement process, noting that such sayings are often not heart-felt. One bereaved caregiver described how a lack of acknowledgement of her loss was considered hurtful and disrespectful:

I find it very unsettling when there is not an acknowledgement. Acknowledgement [...] validates the value of your loved one with others [and] yourself...I just want to shout to the world "He is gone. He was special. I miss him."

Comments, especially about further illness diagnoses or additional deaths, were also considered abrupt triggers that agitated enduring sentiments regarding their caregiving experience and late loved one.

The abruptness of being alone was one of the most prolific triggers of loss shared by bereaved caregivers. Silence, uselessness, absence of joy, and loneliness were all used to summarize the void of loss. A primary post by one caregiver posed the question to others:

Ok....Not sure if this is just me or not [...] but I tend to do pretty well during the day. But nights?.....wow.... Not so much. Just seems like I've got more time to think and replay things. The quiet is quieter and the aloneness is a little more "alone".

Being alone was an abrupt trigger that reflected recognition and reflection of loss. Still, loneliness was also experienced when in the company of others, reminding caregivers of their loss and causing caregivers to feel alone in a crowd, as one caregiver shared:

The feeling of being alone isn't what I have a problem with it is being without [my] other half ... I had been part of a couple for 30 plus years and now no matter where or whom I am with, I am alone.

Unlike abrupt triggers that were unforeseen and emotionally distressing, bereaved caregivers also discussed anticipated triggers that reminded them to prepare for feelings of loss. Anticipated triggers included a loved one's well-known artifacts, family activities, estate planning, and holiday/family celebration preparations that evoked specific memories. Bereaved caregivers conversed about how to approach these with great intention and empathized with each other about the difficulty of preparing for these types of expected reminders of loss. Deliberate steps were shared about how best to cope and respect their deceased loved one. Many caregivers talked about the need to keep things consistent (such as leaving their loved one's things in place), especially in regard to clothing and personal items. Participation in organized support group discussions were also described as an anticipated trigger, yet bereaved caregivers continued to participate knowing ahead of time to prepare.

Preparation was a prevalent coping approach shared among caregivers to handle loss-oriented stressors resulting from anticipated triggers. Bereaved caregivers were aware that certain events would mean confronting loss and engaging in restoration (“The big days I am prepared - knowing I will feel sad and miss the person”). Regarding an upcoming holiday, one caregiver explained: “I’m trying to make some plans with friends so I won’t feel quite so alone.” Being aware of the “daily challenge to find purpose and meaning” was shared among caregivers who felt the “daily push to get out and about” without their loved one.

While coping efforts were intentionally described to navigate anticipated triggers and engage in restoration, caregivers described abrupt triggers as opportunities to embrace loss and deliberately seek out ways to obtain permission to grieve. One caregiver explained, “I keep cycling through mad, sad, acceptance and so forth [...] When I realized the tears wouldn’t stop I got out the pictures, cards, and albums and let it go, sometimes you just need to cry.” In a post to the Group one caregiver summarized: “‘Moving forward’ is, more times than not, a sideways, aimless stagger... occasionally falling forward just enough to call it a ‘step.’” Abrupt loss-oriented triggers enabled caregivers to contemplate their loss, as one caregiver articulated: “The concept of gone ‘forever’ is just a damned long time, and one that my emotional brain doesn’t want to accept even though my logical brain knows it to be true.”

Restoration

Bereaved caregivers participating in the Secret Facebook Group engaged in storytelling, advice giving and seeking, and encouraged restoration during online communication. Given that bereaved caregivers joined the group at different times over a six-month period, self-introduction posts included details of their caregiving story as part of their primer to the Facebook Group. Details included their relationship to the patient, how long they had been ill and/or receiving hospice care, the disease, date of death, story of getting to hospice, caregiving tasks, and sacrifices (“giving up my job”). These introductions concluded with summary statements about restoration efforts. One caregiver ended her introduction post by summarizing: “Now I can move on, and do for myself. Yes there is that void, but as each chapter of our lives draws to an end, the next chapter begins.” Throughout their participation the Facebook Group, several caregivers posted turning points in their own bereavement coping process, sharing personal of restoration (“I have to share this...”), coping mechanisms such as re-arranging living room furniture (“somehow grief is easier”), difficult restorative tasks (“It was hard for me to deal with his clothes hanging in the closet and on the dresser”), and doing things to help ease the pain (“Music has always been my go to”). These posts and comments showcased restoration in progress and captured relatable experiences among participants.

By sharing similar stories and experiences with each other, bereaved caregivers established a sense of community without knowing each other personally. One caregiver posted, “I have personally found that ‘telling my story’ (to an appropriate audience) ... has really helped me.” Similar experiences created a synergy among participants who realized that they did not have to meet face-to-face to find support. Several caregivers posted comments directed to other caregivers (“I’ve never met you (caregiver’s name), but I’m thinking about you

today”), expressed concern (“I don’t know you but you have my sympathies”), and acknowledged turning points. “Thank you for your kind thoughts and thank you for this page which allows me to voice my thoughts and know I am not alone and my feelings are normal,” shared one caregiver.

Bereaved caregivers also offered and sought advice from group members. Online communication between group members included suggestions on ways to celebrate memories of loved ones lost, to make new friends, and to attend the hospice memorial event. All of the suggestions were meant to assist each other with loss-oriented stressors (“When the feelings come up, acknowledge them”) and providing coping suggestions (“just let the people who love you help you through it”). Still, several caregivers used the Group as a place to seek advice from similar others (“I need advice, thoughts, something...”). In a post by one caregiver, she inquired about the impact of caregiving:

It has been 3 1/2 months since (loved one’s name) passed and I am starting to have minor problems with my health ... It is like the stress of the last 2 years has slammed into me ... I didn’t have any problems when (husband’s name) was sick - almost like I wouldn’t allow myself to be ill because he need me. Anyone else having the same problems?

Caregivers used the Facebook Group to seek advice on how to engage in restoration.

Supporting and encouraging restoration was also a prominent message throughout the group’s online communication. Caregivers talked about the various ways that they grieved, sharing whether or not they cried at funerals and instances where uncontrollable crying occurred. Posts and comments reflected the idea that “everyone grieves differently”, as one caregiver informed another, “Don’t let anyone tell you that your [sic] doing it wrong.” Supportive words were offered (“keep smiling and be kind to yourself”) and shared understanding about the difficulty of the process (“the first time... was kind of hard... but it won’t be as bad next time”). Caregivers shared personal memories, including poems, videos, and artwork. “One day it will bring more happiness than sorrow,” reminded one caregiver.

Reported Outcomes

Data related to participants’ scores on anxiety (GAD-7) and depression (PHQ-9) measures are summarized in Table 2. Overall participants reported low levels of anxiety at both Time 1 and Time 2. The mean GAD-7 score was 4.6 at Time 1 and 3.4 at Time 2; both of these scores correspond to a minimal level of anxiety. Only one person at Time 1 and one person at Time 2 were determined to be moderately anxious; no participants’ reports were consistent with severe anxiety at either point in time. The mean PHQ-9 score at Time 1 (7.8) corresponded to a mild level of depression, while at Time 2 the mean PHQ-9 (4.3) fell into the range of minimal severity. Six of the 16 participants reported moderate or higher levels of depression at Time 1 compared with only one at Time 2.

Discussion

This study extends work on the DPM by analyzing the longitudinal bereavement experiences of hospice caregivers, going beyond outcome measures to discern stressors

shared among a community of bereaved caregivers (Stroebe & Schut, 2010). Bereaved caregivers in this study predominantly engaged in restoration-oriented online communication, suggesting that caregivers are acutely aware of their restoration efforts in the first six months of bereavement. While bereaved individuals may consult supportive others (friends, family) for restorative issues and restorative coping may be individualistic (Carr, 2010), our findings suggests that an online asynchronous platform that unites individuals with similar experiences can sustain a supportive environment where face-to-face meetings are not required to establish a community.

The majority of interaction in the Secret Facebook Group came through comments rather than posts, depicting new roles and relationships developed post-bereavement, an area of DPM research that has gone unaccounted (Carr, 2010). The large variation between posts and comments indicates that the majority of interaction came from caregivers responding to other caregivers. External support resources, informational and social support that comes from outside of the caregiver's personal support system of family and friends, may be helpful as caregivers report not wanting to burden family and friends with talk about bereavement (Diamond, Llewelyn, Relf, & Bruce, 2012). More research is needed to explore how unknown supportive others (i.e., not personally known through face-to-face interaction) are beneficial to the bereavement process.

According to DPM, oscillation is a process where loss-orientation and restoration-orientation stressors are either confronted or avoided. However, it has been proffered that these two types of stressors are not separate but rather overlap and activate each other (Shear, 2010). Our analysis of online communication depicts coping processes triggered by one of the stress types, with engagement in both loss and restoration as a cognitive process that is intentional. Although the certainty of emotional loss was recognized by bereaved caregivers as they described anticipated triggers, and the uncertainty of abrupt triggers were also described as emotionally distressing, caregivers in this study did not disclose avoidance as a coping strategy. Rather, this study illustrated bereaved individuals actively and purposely chose coping strategies.

The restricted sample size and exploratory design of this small pilot study limit conclusions that can be drawn from the available data. Still, the study has similar findings to an earlier study of an online hospice community that also had a small sample, a similar number of posts, and a majority of emotional support messages (Buis, 2008). Scores for anxiety and depression should be regarded as descriptive only and cannot be attributed to participants' involvement in the Secret Facebook Group. There is no causality between the intervention and related outcome measures; the outcome assessment merely served as pilot measures for possible use in future controlled studies. The innovative study approach facilitated data collection during active bereavement rather than retrospective accounts. One of the strengths of the study was the length of time involved in the group (all caregivers participated for at least three months, with the majority participated for more than six months). Caregivers were able to use the Facebook Group to share events as they unfolded in their life (compared to recalled events captured through retrospective interview). The length of time in study participation allowed us to capture bereavement experiences as they occurred across the

bereavement trajectory, which has been noted as a research strength (Bennett, Gibbons, & Mackenzie-Smith, 2010).

There remains a strong need to establish guidelines for hospice bereavement care and to minimize the resources used to provide bereavement services (Barry et al., 2012). This study shows the promise of using a Secret Facebook Group to facilitate comprehensive services for hospice bereavement. Future research should include measuring the benefits of discussing loss and restoration-oriented stressors and explore the positive impact on health outcomes in addition to changes in negative outcomes.

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Table 1**Participant Characteristics**

Characteristic^a	
Age, mean (<i>SD</i>)	48.6 (16.1)
Gender, <i>n</i>	
Female	11
Male	5
Race, <i>n</i>	
Caucasian	15
Native American	1
Relationship to patient, <i>n</i>	
Spouse or Partner	7
Adult Child	6
Other	3
Employment Status, <i>n</i>	
Employed full-time	8
Employed part-time	2
Unemployed or Retired	6
Highest Education Attained, <i>n</i>	
High School	3
Some College or Technical School	5
Undergraduate Degree	6
Graduate Degree	2
Annual Household Income, <i>n</i>	
Under \$20,000	4
\$20,001–40,000	6
\$40,001–70,000	2
Over \$70,000	4
Method of Accessing Group, <i>n^b</i>	
Personal Computer	16
Smartphone	7
Tablet	4

^a Demographic information is provided as it was reported upon entry to the group.

^b Values exceed total sample size due to some participants accessing the group via multiple methods.

Table 2Participant Anxiety (GAD-7)^a and Depression (PHQ-9)^b Scores

	Time 1 ^c (<i>n</i> = 16)	Time 2 ^d (<i>n</i> = 11) ^e
Anxiety Score, mean	4.6	3.4
Anxiety Severity, <i>n</i>		
None or Minimal (0–4)	7	8
Mild (5–9)	8	2
Moderate (10–14)	1	1
Severe (15–21)	0	0
Depression Score, mean	7.8	4.3
Depression Severity, <i>n</i>		
None or Minimal (0–4)	5	6
Mild (5–9)	5	3
Moderate (10–14)	3	1
Moderately Severe (15–19)	3	0
Severe (20–27)	0	0

^aGAD-7 = Generalized Anxiety Disorder 7-item scale^bPHQ-9 = Patient Health Questionnaire 9-item scale^cTime 1 = Date on which participant joined group^dTime 2 = Date on which participant completed final measures^e*n* = 10 for the PHQ-9 at Time 2