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Preliminary Results of Caregiver Speaks: A Storytelling Intervention for Bereaved Family Caregivers

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Abstract

When bereaved cancer caregivers have the opportunity to tell stories about their caregiving and bereavement journey, they are better able to make meaning of these experiences. Creating a space where they can share stories with other bereaved caregivers increases social validation, facilitates the meaning-making process, and reduces distress and risk for complicated grief. This study explored the feasibility and acceptability of an innovative storytelling intervention for bereaved family caregivers of cancer patients. Twenty-one participants engaged in the intervention, and eleven were interviewed about their experience. Results indicated study feasibility and intervention acceptability. Suggestions for future intervention were also provided.

Keywords

Cancer; Caregiving; Bereavement; Meaning-making; Storytelling

Introduction

For each of the nearly 610,000 Americans who die from cancer each year, countless spouses, children, grandchildren, and friends are left to grieve their loss (Mooney-Doyle, 2018). Many of these bereaved individuals previously played a significant role in caring for their now-deceased family member or friend, providing considerable physical, practical, emotional, and social support as unpaid family caregivers. These now-bereaved family caregivers may experience a tremendous amount of emotional distress, including depressive symptoms that can be prolonged even after the patient's death (Kastenbaum, 2008; Kuo et al., 2019; MacKinnon et al., 2013).

There is a robust literature documenting the psychological, physical, and social burdens associated with cancer caregiving and their impact on a bereaved family caregiver's ability to cope post-death (Götze et al., 2018). The demands of cancer caregiving place family caregivers at risk for clinical depression, anxiety, disruptive sleep patterns, and poor social

support with the tendency to increase with intensity as the patient nears death (Williams & McCorkle, 2011). Caregivers who experience clinical depression, anxiety, and poor social support during active caregiving are predisposed for complicated grief post-death (Nielsen et al., 2017), which is characterized as a persistent and debilitating form of grief that disrupts one's ability to cope and heal with the loss (Shear et al., 2011). While grief is a normal and healthy reaction to losing a family member or friend to cancer, approximately 20–30% of bereaved cancer caregivers experience complicated grief during bereavement (Guldin, Vedsted, Zachariae, Olesen, & Jensen, 2012).

Storytelling and Meaning-Making in Bereavement

Research suggests that when bereaved caregivers make meaning of their caregiving and bereavement experiences they may exhibit lower depression and anxiety, and thus lower their risk for complicated grief post-death (Bellet, Neimeyer, & Berman, 2018; Gillies & Neimeyer, 2006; Park & Folkman, 1997b). There is a large body of literature exploring the significance of meaning-making for individuals coping with adverse life events, like the death of a family member or close friend (Kauffman, 2013). Studies suggest that when given the opportunity to tell personal stories of caregiving and death, bereaved caregivers are able to understand the purpose of these events in their life, and are thus able to make meaning of these experiences (Barnato et al., 2017; Rolbiecki, Washington, & Bitsicas, 2017; Rosner, 2015).

Research on storytelling's psychological and emotional benefits has shown that the process of developing a story and sharing it with others in a safe and supportive environment may reduce depression and anxiety among caregivers (Chidubem, 2012; Fels & Astell, 2011), as well as increase their connections with others who share a similar experience, reduce isolation, and potentially increase social support. Having a tangible tool, like a photo, to help bereaved caregivers communicate their stories of caregiving and loss has been shown to facilitate storytelling and meaning-making (Rolbiecki, Washington, & Bitsicas, 2019). Photo-elicitation – the use of photos to elicit one's thoughts and feelings about a particular issue – has been identified as an effective strategy to facilitate sharing personal stories of caregiving and loss (Angelo & Egan, 2015; Waldman, 2005).

Despite the rich literature that exists describing the psychological benefits of storytelling, few studies have examined the impact of photo-elicitation as a vehicle for delivering these stories via an online social network (Rolbiecki et al., 2018). Therefore, the overarching aim of this mixed-method pilot was to assess the feasibility and acceptability of Caregiver Speaks (CS), a novel online intervention that utilizes photo-elicitation as a tool to facilitate the exchange of personal stories among bereaved cancer caregivers. The specific research questions guiding this aim included: 1) What percentage of bereaved caregivers approached to join the study consented to participate? 2) Of the number of consenting participants, what percentage was retained through completion of the intervention? 3) What did study participants cite as the benefits and challenges of the CS intervention? and 4) What suggestions did participants provide for future iterations of the CS intervention.

Theoretical Underpinnings of Caregiver Speaks

Narrative theorists have described the role of storytelling in helping individuals organize life experiences and memories in a coherent and chronological timeline (Frank, 2013; Mattingly & Garro, 2000). Research suggests that, after a traumatic or adverse life event, the process of developing a story and sharing it with others promotes meaning-making, healing, and personal growth (Frank, 2013; Tedeschi & Calhoun, 2004). There is empirical evidence to underscore the effectiveness of storytelling in reducing depression and anxiety among individuals who experienced trauma (Rolbiecki, Anderson, Teti, & Albright, 2016), chronic illness (Cangelosi & Sorrell, 2008; Frank, 2013), and caregiving (Chidubem, 2012; Fels & Astell, 2011).

The CS intervention is informed by Park and Folkman's meaning-making model of coping, which assumes that individuals cope with adverse life events (e.g., the death of a family member) by reconstructing and transforming the event's meaning, then incorporating this new meaning into one's larger self-narrative (Park & Folkman, 1997a). In this study, participants photographed people, places, and things that were connected to or represented some aspect of their caregiving or bereavement experiences and then shared and discussed those images and corresponding stories with other bereaved caregivers in a private Facebook group. According to the model, the sharing of photos and facilitated discussion would support individual exploration and reconstruction of pre and post-loss meanings, changing the individual's definition of the situation, and strengthening their ability to cope with death.

Methods

Study Design and Data Collection

Though heavily qualitative, this mixed-method design elicited participants' reflections via open-ended, semi-structured phone interviews. Interviews were conducted among 11 of the 31 total participants, resulting in 55 pages of transcription. All interviews were audio-recorded and transcribed verbatim for qualitative data analysis. Recruitment statistics and demographic information was obtained via REDCap (Harris et al., 2009), a secure online data collection tool.

Participants and Ethical Approval

Research activities were approved by the primary author's Institutional Review Board before investigators began recruitment. All study participants had previously taken part in a randomized controlled trial (RCT) of a caregiver support intervention funded by the National Cancer Institute (R01CA203999). Upon exiting the RCT, 93 bereaved caregivers were invited to take part in a separate bereavement group intervention. Of that number, 31 (33.3%) gave verbal consent to participate, and 11 completed individual phone interviews about their experiences in the bereavement group intervention (Mean length: 7:52 minutes, SD = 3:30 minutes) at study exit. Eligibility criteria included previous participation in the aforementioned RCT as well as willingness to participate in a facilitated Facebook group and complete periodic surveys.

Demographics

All consented participants were bereaved family caregivers of cancer patients who utilized services from a national hospice organization located in the Midwestern United States. Participants were primarily female (90.3 %) and Caucasian (96.8%). Participants' bereavement experiences varied, as many were bereaved spouses (45.2%), and adult children (41.9%), in addition to two bereaved parents and two bereaved siblings. Variation also existed in participants' education levels, access to internet, and their use and understanding of photo elicitation and Facebook. The mean participant age was 57.8 years (SD = 10.7 years).

Project Procedures

Once eligibility was determined and consent given, a research staff person scheduled an initial phone call with each participant to further explain the intervention procedures. At this time, the staff person provided an overview of photo-elicitation (participants were informed that their de-identified personal images could potentially be used for publication purposes at this time), and answered any questions participants had about what to photograph and how to upload images to a secret Facebook group created specifically for the study. Secret Facebook groups are designed with the highest level of Facebook security, meaning only invited persons could join and view the discussions occurring within the group. Facebook was the chosen social network for this study because of its ready availability and free access for participants. Furthermore, participants were already familiar with the use of Facebook because of their participation in the RCT cited above, which also used the platform as a tool for delivering an intervention.

Outcome Measures

To measure feasibility of the intervention relative to recruitment and retention, authors captured the number of people approached to participate in the intervention, the number of people who consented to join the study, and the number of people who completed the intervention (i.e., the number of participants retained). Acceptability was qualitatively captured via participant noted benefits and challenges to participation, as well as participant-cited suggestions for future intervention.

Caregiver speaks intervention protocol.—Upon admission to the Facebook group caregivers were asked to introduce themselves and given the opportunity to share a photo. The group facilitator—a masters-prepared social worker—also asked other group members to welcome new caregivers and to actively engage in the discussion.

Over the next six weeks, caregivers were asked to share photos related to specific weekly themes which correspond to the model of meaning-making. The research staff facilitated discussions of the photos and corresponding stories, including reactions to sharing and observing other participants' photos and stories. To ensure caregivers had the opportunity to participate in the full experience, they engaged in the 6-week cycle four times before being asked to participate in a semi-structured exit interview via phone. Caregivers were given the option to remain in the Facebook group and continue sharing photos and stories after they

participated in the exit interview, as active facilitation would continue each time a new caregiver entered the group.

Analysis

Quantitative analysis.—Feasibility was determined via descriptive statistics (means, SD) regarding study recruitment and participant retention. All data were downloaded via REDCap, and analyzed using Microsoft Excel©.

Qualitative analysis.—All exit interviews were recorded and transcribed by a professional company (Rev©) before being imported into Dedoose© (Manhattan Beach, CA), a web application for qualitative data analysis. Two members of the research team utilized a deductive, framework analysis approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013) that was informed by Sekhon and colleagues' (2017) framework for acceptability of healthcare interventions, which defines acceptability as the extent to which people receiving a healthcare intervention consider it to be appropriate based on their experience participating in the intervention, and noted response. In order to address the intervention's acceptability, the authors focused their analysis on participant-noted benefits and challenges to participation and suggestions for future intervention, all of which were provided in participants' exit interviews.

First, both researchers individually read three randomly chosen interview transcripts to familiarize themselves with the data, and noted any additional content that provided deeper insight beyond the framework. Next, both researchers engaged in a process of coding where they applied codes based on the framework (i.e., acceptability: benefits and challenges; suggestions) to all of the transcripts, debriefing only if one coder had questions or concerns. The lead researcher (AR) then interpreted the data, and presented the final themes to additional researchers to ensure credibility. The themes are further described below, with supportive key quotes from participants (pseudonyms were assigned to protect confidentiality).

Results

Feasibility

Feasibility of the intervention was confirmed in multiple ways. Ninety-three bereaved caregivers were contacted for recruitment with 31 (33.3%) of those contacted verbally consenting to join the study. This indicates a large interest in the intervention. Additionally, of those verbally consented, 21 (67.7%) were retained in the group through the conclusion of the study, suggesting that the participants found the intervention to be useful and beneficial.

Acceptability: Participant-Noted Benefits

To assess acceptability of CS, researchers sought to better understand bereaved caregivers' perceptions of its benefits and challenges. Bereaved caregivers reflected on their participation in CS, specifically noting how comfortable they were with sharing, the benefits of *sharing stories through photo elicitation*, and how this facilitated *connection among group members through a shared experience*.

Sharing stories through photo-elicitation.—When asked what she liked most about the intervention, Victoria, a 49 year-old bereaved spouse said, “I liked the part where we got to share photos, and leave comments for each other.” They continued, “...the fact that I could see what other people were going through really helped.” Similarly, Marilyn, a 64 year-old bereaved spouse, expressed, “I thought it was interesting to see what other people [posted]...I guess seeing how other people were dealing with things, and what their lives had been like prior to the death of their loved one.” Stephanie, a 42 year-old bereaved adult child, noted, “It was nice to have a place to go where I could talk to, or more listen to, other people’s perceptions of what they were going through, and deal with my own [feelings]...” Finally, Bethany, a 61 year-old bereaved adult child said, “I enjoyed being able to see people’s families, or see, you know, this is what [life] was like before mom got sick, or dad got sick and passed away. It was nice to see that.”

When specifically asked how comfortable he was with sharing photos, Mark, a 79 year-old bereaved spouse, expressed, “I’m not so sure it was the other people’s photos, as much as it was thinking about my own photos and experiences...Maybe even the ones I didn’t share...” Victoria noted, “[photo elicitation] let me be able to express myself with the pictures. It was really neat because we were able to show different phases we had been through, and the ways that they were before and after...” Similarly, Laurel, a 63 year-old bereaved spouse, engaged in photo elicitation, but mentioned feeling more comfortable with sharing only some of the weeks. She said, “I remember one time feeling like I wanted to do it, and other times being in a mood where I didn’t want to. It just kind of depends on where you’re at that particular day, you know?”

Deepened connection.—As a consequence of viewing and commenting on others’ photos, participants mentioned a shared or deepened connection with other participants as a beneficial aspect of their participation. For example, to emphasize the value of shared connection with other group members, Blaire, a 37 year-old bereaved adult child, expressed the following when asked what they liked most about participation: “There were several people [in the group]...it was nice to see their photos, then comment with them and know their stories of what they had gone through, and how they got through it. I found it very inspiring.” They continued, “That’s the most beneficial thing. Having those other people to talk to and grieve with and reflect with...just knowing that you’re not alone.” Similarly, Marilyn said, “I guess seeing other peoples’ [photos]...how they were dealing with things, and what their lives had been like prior to the death of their loved one.” She continued to note how one photo elicitation piece in particular helped facilitate a shared experience with other members in the group:

“I think the most beneficial part was sharing and having other people...actually saying my feelings, and how things had been, and what my plans were for the future. I learned [from the group] that just writing [my feelings] down was helpful.”

Likewise, another participant said, “Seeing what other people are going through really helped. It makes you feel like you’re not the only person that’s going through this, and that there’s other people that feel the same way that you do.” Finally, when asked what they liked most about the intervention, Bethany noted how validating it was to be in the group:

“Probably the validation of what I was going through...Everybody else is feeling that way too, everybody has experienced a loss, and we’re all stepping through it one step at a time, as it comes. You feel some camaraderie there.”

Acceptability: Participant-Noted Challenges

In addition to participant-noted benefits, researchers also sought to understand participant perceptions of the challenges of the intervention as a way to ascertain suitability of the CS intervention. Bereaved caregivers noted that the *creative aspect of photo-elicitation* made it difficult at times to participate. And while many agreed that the shared connection with other participants was a beneficial aspect of CS, some noted a *lack of connection* with others as a challenge to their participation. Finally, one participant expressed that the material became *redundant* over time. These subthemes are fully described below with supportive quotes from participants.

Creative aspect of photo-elicitation.—Despite the fact that the facilitator explained that participants would have complete creative freedom in regards to what pictures they would share (meaning, they could be pictures of the deceased individual, or pictures that were symbolic or representative in nature), many expressed that the creative aspect of CS was challenging. For example, Blaire expressed, “sometimes it’s just hard to find photos... like, my dad wasn’t big on photos, and so I don’t have a lot with him, or of him. Sometimes not everyone is big on pictures...so it is hard to find the right picture. So, some of the photos that I shared were of things that remind me of him.” Similarly, Stacy, a 62 year-old bereaved spouse, said, “The photos are challenging...some of the questions, you know, to think of a photo that would express [what I am feeling]...it’s a very visual kind of expression. That was challenging.” Finally, Laurel expressed how their mood sometimes impacted their willingness to be creative and post pictures in the group. They said, “I remember one time feeling like I wanted to [post photos], and another time being in a mood where I didn’t want to. [It depends] on where you are at.”

Lack of connection.—While many participants expressed the group connection was a primary benefit of participating in CS, others noted a lack of connection with group members being a challenge. Kristen, a 56 year-old bereaved sibling, shared that her relationship to the deceased individual contributed to a lack of shared connection with other group participants. They expressed, “I feel different than everybody else. This was my brother, he and I weren’t very, you know, we weren’t very close, and I have a lot of other issues I’m dealing with. I feel so bad for the people who lost spouses or children...I know [it was] mostly spouses that I read about.” Similarly, Bethany said, “I just don’t feel like I know anybody in the group. It’s an odd feeling to be vocalizing your feelings when you don’t know any of these people.” Josette, a 71 year-old bereaved parent, noted that the lack of in-person meeting made it difficult to connect with other members in the group. They said, “[I don’t like that] we don’t meet. We don’t sit there and look at each other.”

Redundancy.—Caregiver Speaks followed a 6-week cycle that corresponded with the Park and Folkman model of meaning-making (Park & Folkman, 1997a). At the point of data analysis, each participant had been through the 6-week cycle four times. As a result of

cycling through each of the weeks at least four times, one participant, Stacy, noted that the material became redundant over time. They emphasized, “It was kind of the same stuff over and over. I was about ready to say, you know, ‘been there, done that. I’m ready to move on.’”

Suggestions for Future Intervention

To further understand participant perceptions of the intervention, researchers asked them to reflect on their suggestions for future intervention. The most commonly provided suggestion was the need for additional components to the intervention, beyond photo elicitation and group support. For example, Stacy expressed, “I wish there had been other challenges besides just pictures. You know, I mean I can see why the pictures really work in that format. But I enjoy journaling-type assignments to get you thinking.” Similarly, Josette suggested having the facilitator encourage writing as a way for participants to process. She said, “It helps me to sit down and type stuff out. I’m like, ‘Oh gosh, is that what I really mean?’ Just keep encouraging them to feel free to write...express their thoughts.” Tina, a 56 year-old bereaved adult child, reflected on the need for an in-person meet-up to help people connect, and possibly open up to share more. They said, “you can’t force anyone, but maybe [create] meetings, or set some things up locally in their hometown where they could actually have more options to meet with others...make it easy for them.” Blaire suggested the facilitator share articles and other relevant research with the group. She said, “I think it would be really beneficial to read articles about...how to cope, how to get family and friends to understand what you are going through, how to ask for help, how to reach out for help...to remind you that you are not alone. This is normal, and it’s ok if people don’t get it.” Finally, one participant reflected on the need for more focused facilitation in the group. For example, Kristen expressed that they wished others would talk more specifically about what happened, and said, “Maybe on a [Facebook] memory, or something.”

Discussion

The burden of cancer caregiving is significant and presents numerous challenges both physically and mentally that can affect how one copes after a family member dies. Bereaved cancer caregivers who are distressed during active caregiving and after death are at risk for prolonged or complicated grief. Making meaning of one’s caregiving and bereavement experiences has been shown to reduce post death distress, which can ultimately lead to more adaptive coping during bereavement, and can potentially reduce risk for complicated grief. Research suggests that developing and sharing stories about one’s experiences while caregiving and during bereavement is one way to make meaning. Using photos to help facilitate the sharing of stories in a safe and supportive group can not only foster meaning making, but can also increase social support.

Caregiver Speaks (CS) is a supportive intervention that utilizes photo-elicitation as a way for bereaved caregivers to construct and share their stories of caregiving and bereavement in an online facilitated group via Facebook. This study demonstrated the feasibility of study recruitment and retention, and captured acceptability of CS via bereaved cancer caregivers’ perceptions of the benefits and challenges of participating. Notably, participants found the

sharing of photos and bearing witness to others' stories via their photos to be beneficial in terms of their participation. They elaborated that this enhanced their connection with other individuals who shared similar experiences, which was noted as a benefit. Participants expressed that at times the creative aspect of photo elicitation was challenging, and they sometimes struggled to feel connected to others in the group. Participants also shared that the redundancy of the material made it challenging from them to remain engaged in the intervention. Finally, the participants shared suggestions to improve CS. Particularly, they expressed the need for additional components, beyond the photo elicitation, to the intervention. Some mentioned journaling or creating options to meet in person. Additionally, one participant expressed a desire for the facilitator to share more material like research articles and other supportive literature. Finally, one participant suggested the facilitator offer more focused facilitation of the group.

Clinical Implications and Ethical Considerations

Our findings contribute to a growing body of literature that examines the potential usefulness of storytelling and meaning-centered grief therapies (Neimeyer, 2019). Additionally, Caregiver Speaks is innovative in that the intervention uses photos as a vehicle for bereaved caregivers to deliver their stories of caregiving and loss in the safe and supportive environment of the group. This intervention may be particularly appropriate for use in hospice agencies, which are required by law to provide bereavement care for up to one year following the death of a patient (US Department of Health and Human Services, 2008). However, there is no standard of care for this requirement, and hospices have limited resources to meet this demand. Considering bereaved family caregivers are likely overwhelmed with bereavement-related tasks (e.g., handling finances, memorials, etc.) and are likely still experiencing the ramifications of demands of caring for someone in their final days, there is a need for interventions to designed to reach a large body of individuals are likely unable to come to an in-person support group. Facebook is a free and readily available tool that most individuals have access to; therefore, Caregiver Speaks provides hospices a unique opportunity to extend their bereavement services in an affordable, yet efficient way.

The use of a third-party social media site also introduces the need to seriously attend to issues of participant privacy. Given the revelations about Facebook's unauthorized sharing of personal data (Herrman, 2018), discussions with group participants regarding the social media platform's privacy policies, including the sharing of personal information with third parties, is necessary. Typically social media platforms have an option for users to opt out of the sale of their personal information, therefore group facilitators should have a discussion with all participants about these options prior to them entering the group. For Facebook specifically, facilitators can direct participants to Facebook's terms and conditions, or they could provide their own language summarizing these policies and terms. It is recommended that participants are explicitly informed that it is their individual responsibility to manage their privacy settings within their own individual profiles.

Finally, it is well understood that grief is a unique and highly personal experience for the bereaved. The same argument could be made regarding the bereaved and their meaning-making process. Given this intervention is one that heavily relies on the sharing of personal

stories as a way to facilitate meaning-making, facilitators of Caregiver Speaks should be aware of how this might or might not affect the culture of the group, group cohesion, and collective meaning-making. Active and ongoing facilitation is imperative to ensure that the group remains a safe and supportive space for all participants..

Study Limitations

Despite the challenges that existed with participation, bereaved caregivers perceived CS to be acceptable in terms of it offering a benefit to them. These results cannot, however, be generalized to other populations, and do not suggest a definite impact on outcomes of interest, like complicated grief. Study limitations include size and homogeneity of the sample. The majority of the 31 participants were white and female, and therefore do not represent the broader population of caregivers. Had the study included a more diverse sample in terms of race, ethnicity, gender, age, and understanding of and access to technology, barriers to adoption and utilization might have existed (e.g., internet access and connectivity, social media literacy, data usage). However, regardless of race, gender, age, and social-economic status (SES), most (70%) adult a smartphone, and over 72% of American adults use social media (Center, 2018). To address these limitations, it is recommended that future trials of this intervention include a more diverse sample of sufficient size to ensure that the study is adequately powered to detect differences in outcomes meaningfully related to bereaved caregiver wellbeing (e.g., depression, anxiety, complicated grief).

Conclusion

Bereaved family caregivers of cancer patients were generally accepting of the CS intervention, and their suggestions for modifications to the intervention provided useful data researchers can reflect upon prior to large-scale testing of this promising approach to bereavement support. Specifically, participants supported the intervention as a tool for facilitating storytelling and ultimately meaning-making. Many also indicated that CS can increase connection, and thus social support for bereaved individuals. Additional testing of this intervention approach is needed.

Our findings contribute to the growing body of literature that explores the use of technologically-mediated storytelling interventions as a tool for facilitating meaning-making among bereaved family caregivers. This work was conducted as a preliminary pilot for a forthcoming multi-site RCT designed to test the impact of Caregiver Speaks on important outcomes like depression, anxiety, meaning-making, and grief intensity for bereaved family caregivers.

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