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Feasibility and Acceptability of a 3-Day Group-Based Digital Storytelling Workshop among Caregivers of Allogeneic Hematopoietic Cell Transplantation Patients: A Mixed-Methods Approach

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Family caregivers are essential partners for patients undergoing hematopoietic cell transplantation (HCT). The caregiving role is emotionally, physically, and financially demanding. Intervention efforts to provide relief for caregiver stress during HCT are highly warranted. Storytelling interventions are accruing evidence for efficacy in therapeutic contexts. The purpose of this study was to conduct a 3-full consecutive day digital storytelling (DST) workshop to build knowledge on caregivers' lived experiences during HCT, to pilot test DST with a small group of HCT caregivers, and to demonstrate feasibility and acceptability using qualitative and quantitative measures. Six adult caregivers of allogeneic HCT recipients (mean age, 60.2 years) attended a 3-day DST program (66% female, 83% white). All successfully created their personal audiovisual digital story (2 to 3 minutes long) and completed a survey. All participants rated the DST workshop as highly acceptable and therapeutic (mean score 5, on a scale of 1 to 5). Group discussions and interviews with participants further demonstrated high satisfaction and acceptability of the workshop format, setting, process, and structure. The survey results showed decreases in anxiety and depression from before to after the DST workshop with all participants showing change in the expected direction. This study demonstrates the feasibility and acceptability of a 3-day DST workshop as a distress-relieving tool for HCT caregivers. Future research is needed to test the efficacy of DST relative to a control condition.

INTRODUCTION

Hematopoietic cell transplantation (HCT) is a demanding and costly treatment used to treat multiple hematologic malignancies and some solid tumors. HCT is an intensive treatment that requires patients to endure physical, mental, and emotional trauma [1,2]. Caregivers play a critical role during the HCT process, and most transplantation centers require that HCT recipients have a caregiver available for 24 hours a day for 30 to 100 days post-transplantation. Caregivers monitor side effects, compliance with medication, diet, and activity, in addition to taking significant precautions to help patients avoid infection [3,4]. During the pretransplantation period and for months to years after HCT, caregivers are essential to patient recovery and quality of life, yet the stress places them at heightened risk for physical health problems (eg, sleep and cognitive impairments) and psychological issues (eg, depression, anxiety) [5-11]. Caregivers also struggle to create meaning around their loved one's illness [5-11]. Taken together, this evidence highlights a growing need for a more in-depth understanding of how to support caregivers' psychosocial state.

Narrative forms of communication, informally known as storytelling, have been used interpersonally, culturally, and in research for various goals, including understanding patients' experiences of illness and as a therapeutic intervention in cancer care [12-16]. Studies have demonstrated the importance of emotional expression for cancer caregivers' emotional well-being, and some have directly explored modes for facilitating emotional expression through storytelling [17]. Most research examining emotional expression through narrative addresses the patient as the one doing the "storytelling" in therapeutic settings, whether through expressive writing [18,19], expressive group therapy [20], or telephone counseling [21]. However, there have been few rigorous tests of narrative elements for therapeutic purposes among caregivers of cancer patients. Moreover, storytelling has not been tested as a psychosocial

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therapeutic tool among HCT caregivers. If storytelling includes sharing thoughts, feelings, and meanings associated with traumatic experiences, they may facilitate emotional expression for patients and caregivers alike.

Technology-enabled visual and digital narrative methodologies are engaging and align with our present-day digital and visual culture. It represents a recognition that reliance on strictly text-based methods may yield decontextualized narratives that do not adequately capture the multifaceted nature of people and their lived experiences [22]. As a newer media form of storytelling, digital storytelling (DST) engages participants in creating and sharing brief, visually appealing narrative accounts of life events and health issues in the context of a supportive group environment [23]. In addition, active participation in the DST workshop may yield emotional acceptance that is psychologically and physically beneficial. As a group-based workshop approach, DST also offers helpful ways of highlighting narratives of resilience and hope, and provides a unique tool for expressing emotions, empathy, and group modeling of social support [23,24] that can ultimately bolster psychosocial well-being. DST has been successfully implemented among cancer patients [25,26] and oncology practitioners [27], but not specifically among cancer caregivers.

In this study, we sought to assess the feasibility and acceptability of a 3-day DST workshop among HCT caregivers using both qualitative and quantitative methods. The goals of this study were to conduct a DST workshop to understand caregivers' rich personal experiences during HCT, to pilot test DST with a small group of HCT caregivers to preliminarily examine a direction of change in process measures, and to gather digital stories as material for future interventions. If feasible, these digital stories could be viewed and discussed by other HCT caregivers as a therapeutic intervention and to examine the influence of DST on their psychosocial outcomes.

METHODS

Participant Recruitment and Samples

Adult primary caregivers of allogeneic adult HCT patients (18 years or older) who (1) had completed a transplant within the past 2 years; (2) were of any gender, race, or ethnicity; and (3) spoke, read, and wrote in English were invited to participate in this study using an Institutional Review Board-approved flyer. Exclusion criteria included inability to comply with the study protocol, such as attendance at a 3-day workshop. Participants were recruited between February 2017 and April 2017. The study was approved by the Institutional Review Boards at both a National Cancer Institute-designated cancer center and a partnering university in the Phoenix Metropolitan area. Initial screening was conducted via medical records to identify potential participants. The study coordinator explained the details of the workshop over the phone or in the transplant clinic. Caregivers who agreed to participate were screened for eligibility, and full informed consent was provided in person. The confidential nature of material produced during the workshop (eg, story scripts, digital images, transcripts from group discussions) was emphasized to participants, and participants had the option to remain anonymous within their stories by omitting names and dates and blurring images. Each participant received a $150 gift card for attending the workshop.

Design Overview

This study used a single-group, pretest/post-test design with a small sample of caregivers of HCT patients in a DST workshop. The DST workshop is designed to conduct over the course of 3 consecutive 8-hour days to create personal digital stories [23]. During the workshop process, selected group sessions and group discussions were recorded to qualitatively determine feasibility, acceptability, and satisfaction of DST workshop and process. The survey questionnaire was also assessed at baseline (before the workshop at day 1) and at the completion of the workshop (end of day 3) to test feasibility of the DST workshop process and evaluate changes in process measures of DST program among storytellers as a component of acceptability.

DST Workshop and Associated Qualitative Data Collection

The DST workshop format was designed by StoryCenter, a California-based organization considered to be the founders of the DST movement. DST workshops are most easily and effectively facilitated with a small number of participants (fewer than 6 to 10 people) [23]. DST comprises 3 components: an individual process, a group process, and a process co-mediated by participants, researchers, and facilitators (Figure 1) [23]. Digital stories, produced by the individual attending the workshop, are short first-person visual narratives that synthesize digital images, audio recording, music, and text to document personal experiences. The process is person-centered, with the participant retaining control over the story that is told.

Participants who attend the workshop were asked to share verbally with other group members a story in a "story circle" activity. They were then asked to write their own script and storyboard (with feedback and guidance if preferred), record the story into a microphone, choose or take photos and video clips to illustrate the story, and work with the workshop facilitators to combine these materials into short digital videos called "digital stories." In this activity, each participant introduces his or her final personal digital story with other members in a group "screening," with facilitators guiding a group discussion around the content of individual stories, as well as the entire collection of stories produced in that particular workshop [23]. Here we focus on the "storytelling" side of the therapeutic model, in which a participant shares a life experience with others throughout the steps of the workshop. The experience of sharing in a common community is thought to provide potential for inner discovery and growth [23]. In addition, as these workshops bring together those with some common experience or community investment, the experience of sharing extends to the listening to others' communalities, thereby engaging in dialogic expression more fully.

A team of 4 researchers observed and assisted with the DST workshop. Each researcher wrote field notes to capture the entire process, including components that were not audio recorded (with only the story circle and story screening recorded). Three researchers conducted a semistructured group discussion after the workshop to better understand participants' experiences during the workshop. The semistructured questions included "What is your overall experience during the 3-day workshop?," "What did you feel was most valuable about this workshop?," "Was there anything about the workshop that inspired you?," "How would you improve this workshop?," "What would be the potential strengths and weakness of the workshop?," and "Is there anything else you would like to tell me concerning your experiences with the workshop?"

Feasibility and Acceptability

Demographics

Project participants were asked to self-report on age, gender, race and ethnicity, relationship to the patient, marital status, educational level, and employment status, as well as utilization of any psychosocial support programs or services.

Feasibility

Feasibility was measured by recruitment and retention rates, survey completion, and direct feedback from participants from group discussion and one-on-one in-depth interview with participants following the DST

Figure 1. Three elements of the DST process [23].

workshop. Benchmark criteria for feasibility data were set in accordance with the goals of a future study that will test the intervention in a larger population. We aimed to recruit an average of 4 participants per month, with a 60% uptake as our benchmark for consent. We then considered the proportion of participants who completed a 3-day workshop and assessment (baseline and post), with a 60% retention rate as our benchmark for retention.

Acceptability

We assessed acceptability based on participant satisfaction surveys conducted at the end of the workshop. On the final day of the DST (day 3), participants were asked to complete an 8-item questionnaire. Questions included "How satisfied were you with the DST workshop?"(overall satisfaction); "To what extent was attending this workshop worth your time?" (time commitment); questions related to perceived appropriateness, intent to attend, and willingness to attend another similar workshop and to recommend it to others; and 3 open-ended-questions regarding areas of improvement and overall experience. Response options for the closed-ended items assessed level of agreement using a 5-point Likert scale (1, strongly disagree to 5, strongly agree). We also assessed acceptability and satisfaction from field notes, qualitative data from transcripts of story circle, story screening, and follow-up debriefing group discussion recordings.

Self-reported data from surveys were used to understand the feasibility of DST workshop completion and evaluation of changes in process measures of the DST program among storytellers as a part of acceptability. Surveys were used to measure the process of the DST workshop on participants' emotional well-being using the Profile of Mood States subscales for depression and anxiety (4 items per subscale, 5-point Likert scale from 0, not at all to 5, extremely; $\alpha = .93$) [28] and the Patient-Reported Outcomes Measurement Information System Social Support scale (12 items rated on 5-point Likert scale from 1, never to 5, always; $\alpha = .86$) [29]. Emotional approach coping (on a 4-point Likert scale, from 1, "I usually don't do this at all" to 4, "I usually do this a lot"), including Emotional Processing (4 items; eg, "I take time to figure out what I'm really feeling," "I realize my feelings are valid and important"; $\alpha = .72$) and Emotional Expression (4 items; eg, "I let my feelings out freely," "I allow myself to express my emotions"; $\alpha = .82$) subscales [30], was also measured at baseline and post-DST program.

Data Analysis

Because the goals of this pilot study were primarily concerned with feasibility and acceptability of the DST workshop, power calculations and inferential statistical analysis were not used. Descriptive statistics were calculated and summarized by count, percentage, or mean to analyze whether changes moved in the expected directions across the 2 survey time points [31]. Feasibility data will be compared against benchmarks for success [32].

Our study is designed according to a constructivist grounded theory approach [33], which is particularly suitable for capturing the different angles of the DST workshop based on the conceptual model of the effects of DST on socioemotional well-being [34]. Steps in the qualitative analytical process included line-by-line coding, constant comparative analysis, and codebook development based on sorting and synthesis of codes into categories and major themes [35]. The codebook was further developed with exemplar quotes from participants, which supported the identified categories and themes. Four researchers independently reviewed transcripts of story circle, story screening, and follow-up debriefing focus group recordings; field notes; and participant responses to workshop evaluation. Emergent themes were then compared across all groups until the intercoder reliability was consistently at least 80% on 95% of the codes [36]. Intercoder reliability was calculated as the total number of agreements and disagreements for all codes combined over the total number of agreements for all codes [37]. Through this process, 4 coders were able to check coding agreement on focus group transcripts and consistently obtained 85% intercoder reliability. In this article, we present a triangulation of findings from the data to qualitatively analyze the DST process.

RESULTS

Sample Description

Six caregivers (mean age, 60.2 years; SD, 13.7) attended the 3-day DST workshop. All but 2 were female (66.6%; n = 4) and were the spouse of their HCT patient. All but 1 (83%; n = 5) were white and not currently employed (ie, full-time caregiving role). The median time from the most recent HCT for their patients was 5 months (range, 1 to 23 months). All but 1 (83%; n = 5) had not used any kind of psychosocial support program or services after HCT beyond the standard of care social work assessment.

Feasibility

A total of 10 caregivers agreed to be contacted and were approached during the 1-month recruitment period. Of these 10, 2 declined to participate because of their patient's poor physical health and 2 were ineligible due to inability to attend the 3-day workshop. Six caregivers (60%) consented and agreed to participate in the study. All 6 participants completed a survey questionnaire and successfully created their own digital story that synthesized written text, digital imagery, and sound using the WeVideo editing software program. Each video was 2 to 3 minutes long. Nearly all participants (83%; n = 5) completed the entire 3-day workshop. One participant completed 2 of the 3 workshop days with the completion of a digital story and a survey but could not attend the day 3 workshop for the story screening and group discussion due to a work schedule change. The lead investigator conducted an in-depth one-on-one interview (30 minutes) with this individual over the phone to gather his or her overall experiences during the workshop, satisfaction, and acceptability ratings. For our feasibility benchmark, all recruitment, retention, and data completion rates exceeded our goal of 60%.

According to the descriptive statistics, the DST program demonstrated decreases in anxiety and depression from before to after the DST workshop, with all participants showing a change in the expected direction. Changes in social support and emotional approach coping also occurred in the predicted direction, with participants reporting an increase in the levels of perceived social support and emotional expression/processing. Specifically, 5 of the 6 participants showed a change in the expected direction (Table 1).

Acceptability

DST demonstrated high acceptability among HCT caregivers. All participants reported a score of 5 on a 5-point Likert scale on overall satisfaction with the workshop and responded that they would like to attend a similar workshop again and would recommend this workshop to others. All but 1 participant indicated that it was worth their time and that the pace of the workshop was appropriate by responding "strongly agree" to both statements (mean score, 4.6).

The qualitative findings present a broader picture of the acceptability of DST. These responses were categorized as acceptability of the purpose of the DST and acceptability of the DST format. Participants indicated high satisfaction with the purpose of the DST, noting that it was especially important to create and share their stories among others who understood their caregiving experience. Although some caregivers initially expressed discomfort with sharing their stories, this proved to be an enjoyable part of the workshop.

> "*I think it was great when everyone talked. Number one, you heard their story you understood where they were coming from. When you see the actual outcome, you can actually feel from that, when they were telling the story. So it made a complete circle.*"

Table 1
Process Measures of the DST Program (n = 6)

Measure	Pre-DST	Post-DST
Anxiety	2.07 (.57)	.44 (.50)
Depression	1.53 (.36)	.33 (.74)
Social support	3.78 (1.01)	3.96 (.70)
Emotional approach coping	1.90 (.48)	2.96 (1.23)

Data are mean (SD).

"*It was good to hear other people's stories, I think, and we were all like, yeah, yeah. you know feeling a lot of the same things.*"

The participants stated that the stories shared were highly relatable and provided opportunity to engage in discussions in positive ways, unlike other traditional support groups.

"*I've been to a couple of care support groups, and I came back with negative feelings about the care groups because I felt people were more negative. But we weren't negative at all, we were just pouring out our hearts. And so I felt like that this was different, way different than the care groups."*

Responses demonstrated acceptability of DST format regarding the size of the group. "*I thought that was about the nice size of the group. I think we have enough time to talk to each other*." Participants also expressed satisfaction with the structure of the group as a group of allogeneic HCT caregivers; "*I think that keeping like-diseases makes you feel you are at home with each other*"; "*I think it helped that we were all bone marrow transplant people, you know. Where the care group that I was in, it was for any cancer. And so it was, so everyone's experiences were different.*"

Participants also expressed that they valued the group setting, and that this group structure gave them relief that they were not alone in their feelings or experience. One caregiver explained

"*Actually, I think the group support was probably better than even if it had been individual, because once again it's identifying with other people and knowing that your emotions are not isolated from other people's*."

Another participant also noted "*It was so nice to meet other patients who have gone through what you've gone through and hear what other people have gone through. It was more than talking and having a support group; it was very therapeutic for me*." Likewise, the caregivers explained that they appreciated the opportunity to participate in a DST workshop without the patient, noting that if the patient were involved, the DST would focus on the patient, not on the caregiver.

Finally, some participants discussed the technical skills (word processing and digital editing skills) that they needed to learn to construct a digital story, particularly for those individuals with low levels of print and/or media literacy. Specifically, participants expressed that they gained a sense of achievement and personal growth through the creation of the final stories, both their own and those of the group. As 1 participant noted, "*I don't know how I did it, but I'm pretty proud of mine. I think I did a great job, and everyone's turned out uniquely beautiful. Yeah!! We did it together*."

DISCUSSION

In this study, we sought to assess the feasibly and acceptability of a 3-day group-based DST workshop among HCT caregivers. Although several studies have examined the effects of DST on health outcomes, including decreased depression [18,38], this is 1 of the first studies using a mixed-methods approach to analyze the feasibility of a DST workshop among caregivers of HCT patients. Gubrium et al [23] noted that it is challenging to recruit and retain participants for a DST workshop in general due to the time commitment of 3 consecutive days. Consistent with this previous study, recruiting caregivers of patients who recently underwent HCT for a 3-day DST process was challenging, given that caregivers' post-HCT caregiving responsibilities. Despite those challenges, findings support the feasibility of recruitment. Among caregivers approached and deemed eligible, 60% agreed to participate. In addition, the retention rate for the 3-day DST workshop was high (83%), exceeding our benchmark goal of 60%.

Ratings of the workshop evaluation and qualitative data support acceptability of the DST purpose and format. Participants were quite satisfied with the DST program overall. Some of the most-popular aspects were sharing and telling the story and the elements of being listened to and listening to others who had similar experiences in a supportive group environment. In our case, caregivers were caring for patients who had undergone the same HCT procedure and were treated at the same medical center. This common experience may enhance the stories through personal relevance, mutual understanding, and positive benefits on psychosocial well-being. Participants also mentioned that the technical components of creating a digital story was one of the least-popular aspects of the DST process, but there is evidence from previous use of DST in a variety of populations indicating that developing, editing, producing, and sharing digital stories can build on participant's experience of mastery of technical and emotional expression skills [23]. As noted by some of our participants, the completed digital story gives a sense of efficacy and empowerment. Compared with the classic text-based storytelling workshop, participants use music or images to help express their own emotions and thoughts [39]. This process may empower participants to own their stories and their emotions [40,41]. With ownership of their emotions, participants are more likely to compare their story with other stories, connect more deeply one another, and commit to participation [41]. These specific mechanisms of the DST process and how stories may impact change over time merit systematic assessment in a future clinical trial.

The survey results showed changes in the levels of depression, anxiety, and emotional approach coping in the expected direction. These findings are consistent with previous studies on the importance of emotional expression as a means of improving psychosocial well-being [42,43]. The literature suggests that effective emotional expression and an individual's inner experience of emotions in response to stressful events are increasingly being understood as a core ingredient in resolution of stress-induced psychopathology [44-46]. Similarly, stress and anxiety may be decreased by reframing emotions and reflecting on the experience in the present study. In addition, the qualitative data identified several ways in which the storytelling process was useful as a distress-relieving tool. Most participants expressed positive feelings through telling their own story and listening to others' similar stories in a supportive group setting through mutual understanding, expression of emotions, empathy, and group modeling of social support. With a small sample, the quantitative findings are not able to, nor are they intended to, establish effectiveness of DST as an intervention. How DST can affect depression and anxiety symptoms, emotional approach coping, and social support for both short-term and longer-term sustained effects in a longitudinal study is an area ripe for additional investigation. At the current phase of this research program, we have no idea how distal the effects of DST might be. It could be that booster sessions are needed to maintain treatment gains. This could be systematically tested in the context of a randomized, even adaptive, trial design.

Moreover, the quantitative results on social support of caregivers who participated in the DST workshop showed changes in the expected direction, which is consistent with

the study of DiFulvio et al [23,47]. Through the story development process, the qualitative descriptions indicated that relationships were built and the participants engaged with one another's experiences, not unlike a support group environment. It appears that in the DST process, individuals can identify and strengthen their social support system by listening to others, being heard, and building solidarity through shared life experiences. Participants provide one another with positive encouragement and feedback and guide one another via social modeling and observational learning. Unlike traditional support groups, the facilitation process uses the production and sharing of stories as a way to co-construct and co-mediate knowledge and meaning, supporting participants throughout the process. That is, individuals leave the DST workshop with a tangible product that can be revisited, can be shared with friends and family, and can serve as a therapeutic tool long after HCT.

As with any research endeavor, this study has both strengths and limitations. The DST program was conducted at 1 cancer center with a small sample, with caregivers of a specialized patient population (recipients of allogeneic HCT), with post-transplantation time ranging from 1 month to 23 months. The emotional support needs of caregivers are likely to differ as a function of time post-transplantation [8,10]. Needs are acute during hospitalization and the immediate post-hospitalization outpatient phase, characterized by a high caregiving burden. Constructed stories are likely to change and evolve with extended time post-transplantation. It is possible that storytelling may be more beneficial later on in the trajectory (after the first 100 days, when families return home). Caregivers may have a clearer perspective at that point and thus may be better able to identify turning points and transitions through the narrative process of retrospective sense making. It is possible that other forms of expression may be more useful and practical earlier on in the trajectory, for example, emotional disclosure exercises that are brief, individual versus group-based, by design unfiltered, and, while potentially distressing in the short term, afford emotional expression and a working through of emotional experiences [48]. The timing and instructional set for both sets of interventions merit additional testing and research.

One purpose of the present study was to develop a set of stories that are interventive for others going through the HCT process, shifting the focus from story making and telling to receiving, that is, to examine impacts on the story listener. The recorded digital stories captured here could be used in systematic testing of story exposure, using a randomized longitudinal design. The stories could become a standardized intervention, portable for caregivers who have limited access to other psychosocial support services. If this investigation is successful, then a digital stories intervention could be reproduced and extended as an intervention for people at other transplantation centers and in other languages. Also worth exploring is whether an additional therapeutic benefit may be gained by an intervention for the HCT caregiver-patient dyad that is deeply affected by this process.

Although our recruitment and retention rates were strong, the 3 consecutive full-day workshop format (9 am to 5 pm) was challenging and time-intensive. It would be helpful to offer workshops with more flexible hours and fewer than 3 days, so that participants are not required to set aside 3 full days for workshop participation. In addition to a more flexible format, online workshops would better reach employed caregivers with limited schedules and resources and may help overcome geographic barriers to such an intervention. Nevertheless, our participants indicated that their time was well spent and they were extremely satisfied with their experience and the DST format. Importantly, the participants remained highly engaged and enthusiastic throughout the process.

Another limitation is that all participants were non-Hispanic white, and thus, our findings cannot be, nor are they intended to be, broadly generalized across different ethnic/racial populations. Future studies should attempt more purposeful sampling approaches to ensure more representative samples across different ethnic/racial populations.

Despite these limitations, this study demonstrates that the DST program was feasible and accepted by HCT caregivers. Although storytelling is a growing field of research, no storytelling studies have been tested as a potential psychosocial tool among HCT caregivers. Therefore, this work is novel and valuable for understanding alternative approaches to address psychosocial coping among HCT caregivers. Further research is needed to test the efficacy and effectiveness of the digital stories as an intervention for HCT caregivers as well as other populations. The DST program can be tested and applied to guide the development of similar supportive care materials for other cancers and in other languages to reproduce and extend the current study for even broader dissemination of this potentially distress-relieving tool. If findings are positive, then digital stories can be confidently distributed as an inexpensive yet effective supportive care tool for HCT caregivers in addition to the educational materials, especially low-income populations.

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