The Photographs of Meaning Program for Pediatric Palliative Caregivers: Feasibility of a Novel Meaning-Making Intervention

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Abstract

Background: Research indicates that informal caregiving can have intense physical and mental impact on the individual. Relative to caregivers of adults, pediatric palliative caregivers appear less in literature despite experiencing greater mental, physical, financial, and social strain. There is limited research on the creation and evaluation of interventions specifically for this population despite clear need. Objective: This study aims to evaluate the feasibility and engagement of the Photographs of Meaning Program, a modified meaning-making intervention for pediatric palliative caregivers. Design: Participants completed a pre–post intervention meaning-in-life measure. Over a 9-week period, participants followed a meaning-making curriculum whereby they created and shared photo narratives via social media. As part of the intervention, a community photo exhibition was held featuring these photo narratives. Exit interviews were also conducted at study close. Setting/Participants: Nine individuals providing informal care to children in a pediatric palliative care program participated in the intervention. All participants were female and are older than 18 years. Settings for research include participant homes and at The Center for Hospice and Palliative Care in Cheektowaga, New York. Results: Participants posted 95 photographs and 96 narratives during the intervention, posting on average once each week. Statistical analysis within the small sample indicated an increased presence of meaning in the lives of participants (P = .022). Exit interviews conveyed satisfaction with the intervention. Conclusions: Findings suggest that the Photographs of Meaning Program is a practical intervention with life-enhancing potential for pediatric palliative. Future research should aim to collect additional evidence of the intervention's effectiveness.

Keywords
pediatric palliative care, pediatric, pediatric caregiver, caregiver, meaning-centered psychotherapy, photovoice, social media

Introduction

Informal caregiving is the support given to an individual with an illness by a person with whom they have a significant relationship.1 These individuals play an important role in the health-care system as a main provider of care across cultures, settings, and generations.2 As of 2015, roughly 43.5 million adults in the United States function as informal caregivers.3 In Australia, approximately 14% of the working-age population takes on informal caregiving, while similar percentages are reported in Sweden (15.7%) and the United Kingdom (12.9%).4

The potential negative outcomes of caregiving are extensive. Stress,5,6 anxiety,6,7 and depression5,8 are common, as well as a decrease in overall health status9 and cognitive abilities.6,10 Caregivers may also experience role entrapment,11 decreased self-esteem,5 feelings of loneliness and isolation,8,12 and unmet needs.8,13 Additionally, it is not uncommon for caregiving to interfere with employment14 or to have lasting effects on depressive symptoms and functional limitations.15

Despite the potential for negative psychosocial outcomes, nearly two-thirds of caregivers (64%) report that they do not receive any therapy or counseling.16 Of this group, 92% report...
interest in these services. Difficulty with time and scheduling was identified by nearly half (48%) of caregivers as a barrier. Feelings of guilt related to leaving their care recipient were also reported. Phone or online delivery with a flexible schedule was identified as a preferred method of psychosocial services.

**Pediatric Palliative Caregiving**

Great strides have been made in improving care for adults with serious illness and supporting their caregivers. In contrast, the research on pediatric palliative caregivers (PPCGs) has been lagging despite this population having unique and different needs. Compared to their adult caregiver counterparts, time and activities are not only different, but they compound on top of traditional childcare. The PPCGs are significantly younger than the overall caregiver population (40 years old vs 49 years old)\(^1\) and are more likely to be caring for someone with a rare disease with less treatment options.\(^18\) More time is spent caregiving; 24% report providing over 41 hours of care per week.\(^17\) Poorer health outcomes are reported by PPCGs compared to both the adult caregiver population and the general adult population.\(^17,19\) The PPCGs also report having significantly less education, lower household incomes, and lower rates of full-time employment,\(^17\) which translates to greater financial hardships. Social well-being is also more strained, as PPCGs report having less time for relationships. This combination can leave PPCGs isolated from their community. The PPCGs also express interest in supportive services and are more likely to search for information on self-care, managing stress, and work–life balance than the typical caregiver.\(^17\) The demand for an intervention targeting the distinctive needs of PPCGs, while keeping in mind their level of burden, is evident.

**Aims and Purpose**

The purpose of this research is to evaluate the feasibility and engagement of a new intervention for PPCGs through a mixed-methods study. Being mindful of the available literature on the burdens of PPCGs, their interest in receiving therapeutic services, and the deterrents to receiving services, a program, called the Photographs of Meaning Program (POM) was developed. Photographs of Meaning Program is an innovative intervention that combines meaning-centered psychotherapy (MCP), photovoice, and social media as a way to reach a variety of populations, such as the PPCGs. This program aims to be an effective clinical tool with strong treatment adherence and this article details the development and feasibility of executing this program in the PPCG population.

**Methods**

**Participants**

Participants were recruited from a home-based pediatric palliative care program serving 3 counties in Western New York, ranging from urban to rural settings. This program provides coordination of medical, psychosocial, and spiritual services to children with chronic and/or life-threatening illnesses and their families and partners closely with the local children's hospital. Inclusion criteria for the study were as follows: (1) primary caregiver; (2) care recipient was enrolled in the home-based pediatric palliative care program at consent; (3) age 18 years or older; (4) access to an iOS smart device with social media capabilities (ie, Apple iphones and ipads); and (5) access to an intervention delivery system, that is, e-mail, text messaging, and so on. Potential participants were only excluded if there was a barrier of language or communication.

Twelve PPCGs meeting the inclusion criteria agreed to participate and completed consent documents. Ultimately, 9 participants took part in the intervention due to unforeseen circumstances arising prior to the beginning of the social media intervention. Participants were compensated with gift cards: $15 at consent and $35 at study closure.

**Development of the POM-PPCG**

The POM is a novel intervention that utilizes 2 evidence basic approaches: (1) MCP and (2) photovoice over social media as a way to reach a variety of populations. This particular adaptation of POM was designed specifically for use by PPCGs (POM-PPCG), while feasibility testing of POM for adolescent and young cancer survivors has been conducted.\(^26\) Based on research identifying the need for a less burdensome and easily accessible psychosocial support,\(^16\) the intervention takes place mainly over social media. Participants upload photographs and narratives through a social media platform, Pixstori, as a way to answer questions from the meaning-centered curriculum. The intervention concludes with a community photo exhibit, where PPCGs express themselves within their community through these photographs and narratives. Each facet of POM-PPCG’s conceptualization is described below.

**Building the meaning-centered curriculum: MCP**

The MCP is a therapeutic intervention originally designed to enhance meaning,\(^21-23\) spiritual well-being,\(^22,23\) and overall quality of life\(^21,24\) for patients with terminal cancer. Beyond these outcomes, MCP can also decrease depression symptoms\(^23,24\) and hopelessness.\(^22,24\) The use of MCP for informal cancer caregivers has been explored.\(^16\) In a case study with an adult caregiver, meaning-centered techniques brought about significant growth, better understanding of the caregiving role, and recognition of the need for improved self-care.\(^25\) Recently, a web-based version of MCP for informal cancer caregivers was reported as a feasible intervention.\(^26\)

Initial drafts of the POM-PPCG curriculum adapted the language and theme of traditional MCP\(^27\) to better fit the population being served. Additionally, a “bye-week” was added to the curriculum to allow flexibility for participants due to potential unforeseen life circumstances. A focus group comprised of 6 PPCGs was held to further assess the language and content of the modified curriculum by the intended population. Three members of the focus group later became members of the POM-PPCG intervention group. Participants
were compensated for their time and contribution with gift cards. Following the focus group, the research team reviewed the feedback and finalized the curriculum. Information on the original MCP curriculum for groups\(^2^7\) and the modified themes utilized with this intervention can be found in Table 1.

**Incorporating photovoice.** Photovoice is a type of participatory action research in which individuals take photographs to illustrate their realities.\(^{2^8,2^9}\) It facilitates nontraditional documentary photography while challenging community assumptions of the narrating population.\(^{2^9,3^0}\) A key concept of photovoice is its ability to educate and bring awareness to marginalized populations through interpretation of photographs, normalizing the misunderstood and unseen.\(^{2^8}\) Previous photovoice research on the caregiver–child dyad has included Mexican American caregivers\(^3^1\) and young mothers who have experienced homelessness.\(^3^2\) Photovoice projects generally culminate with a photo exhibition where participants can share their photographs with the greater community to create multilevel change.\(^{2^8}\) In traditional photovoice, participants are asked to share and express their points of view in their photographs in small and large group discussions with other fellow participants. This component was adapted for POM-PPCG; in this intervention, photographs were shared through social media with the larger group. Discussion of the photographs occurred freely during the community photo exhibit.

**Applying a social media overlay.** Social media is an ideal platform for distributing an intervention to burdened populations due to its wide reach and capacity for direct, fluid communication.\(^3^3\) In 2016, active social media use increased by approximately 482 million worldwide to an all-time high of 2.8 billion (37% of the world population).\(^3^4\) Of all users of Facebook, the most popular social media site worldwide, 55% report being active daily. Social media is also commonly used to locate health-based information (75% of adult Internet users in the United States use social media for this purpose).\(^3^5\) Social media is already being used as a platform for several interventions, including smoking and health promotion.\(^3^6\) Using social media as the intervention mechanism to meet the expressed desires of PPCGs needing online support heavily influenced the design of POM. A social media application that had the feature of taking a photo and adding an audio narrative was chosen to facilitate the intervention, as participants used social media to share their photographs and narratives with each other.

**Measures**

Meaning in life was measured using the Meaning in Life Questionnaire (MLQ) developed by Steger et al.\(^3^7\) The survey consists of 10 items scored using a 7-point scale (from 1 [absolutely untrue] to 7 [absolutely true]). Within the MLQ are subscales on the presence of meaning and search for meaning. The former measures fullness of meaning in the lives of respondents, while the latter measures a respondent’s engagement and motivation in finding or deepening meaning. Reliability ranged from 0.81 to 0.86 for presence and 0.84 to 0.92 for search, representing good internal consistency. Additional testing has supported the convergent and discriminant validity of both subscales. This survey was administered to participants at consent and at the close of the intervention.

Additionally, a short demographic measure designed for this study was administered to participants at consent. This included information on both the participant and their care recipient.

**Procedures**

**Project approval.** This project was approved by the State University of New York at Buffalo Social and Behavioral institutional review board (FWA00008824) on March 15, 2017.

**Recruitment.** Clinicians of the home-based pediatric palliative care program were introduced to the research study and asked to refer any potential participants that met all recruitment criteria and expressed interest in the intervention. Based on clinician referral, phone recruitments were conducted by a member of the research team to interested caregivers. If these individuals expressed interest once again in the program, a member of the research team would plan a recruitment visit at the potential participant’s home. During recruitment visits, participants completed written consent, a media waiver, pretest measures, and training on the social media being used in this intervention.

<table>
<thead>
<tr>
<th>Week</th>
<th>Group MCP</th>
<th>POM-PPCG</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Concepts and sources of meaning</td>
<td>Identity exploration and reflection</td>
</tr>
<tr>
<td>2</td>
<td>Cancer and meaning</td>
<td>Awareness regarding sources of meaning</td>
</tr>
<tr>
<td>3</td>
<td>Historical sources of meaning (legacy: past)</td>
<td>Historical sources of meaning and identity</td>
</tr>
<tr>
<td>4</td>
<td>Historical sources of meaning (legacy: present and future)</td>
<td>Present and future sources of meaning, identity, and legacy</td>
</tr>
<tr>
<td>5</td>
<td>Attitudinal sources of meaning: encountering life’s limitations</td>
<td><em>No new topic: Participants are encouraged to complete unfinished topics and view posts of other participants</em></td>
</tr>
<tr>
<td>6</td>
<td>Creative sources of meaning: creativity and responsibility</td>
<td>Attitudinal sources of meaning: barriers and burdens</td>
</tr>
<tr>
<td>7</td>
<td>Experiential sources of meaning: nature, art, and humor</td>
<td>Creative sources of meaning: engagement in life beyond caregiving</td>
</tr>
<tr>
<td>8</td>
<td>Termination: goodbyes and hopes for the future</td>
<td>Exploration of engagement with life</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>Reflection on experience and hopes for the future</td>
</tr>
</tbody>
</table>

Abbreviations: MCP, meaning-centered psychotherapy; POM-PPCG, Photographs of Meaning Program for pediatric palliative caregivers.
Social media portion of the intervention. To begin each week of the social media portion of the intervention, participants were sent the week’s curriculum (called a theme) and questions to answer through photo narrative posts based on that theme (Table 1). Toward the end of the week, participants were prompted again with the week’s content. Participants would then choose a photograph, add typed and/or audio narrative, and upload their post to a private and secure portal that could only be accessed by participants and the research team. Each weekly prompt would remind participants that there was no right or wrong way to respond to questions within each theme, but a modified version of the SHOWeD method (a structured form of questioning commonly used with photovoice)38 was included to assist in creating their narrative as needed. Safety monitoring was implemented for all photo narrative posts throughout the intervention.

Community photo exhibition. Following the social media intervention, participants were contacted to choose their favorite photo narrative to be printed on a large canvas and displayed at the community photo exhibition. To further showcase pediatric caregiver experiences at the event, a streaming slideshow of additional pictures and narratives was presented.

Exit interviews. Participants were asked to complete the postintervention MLQ and a semi-structured exit interview with a member of the research team at study close. Participants were asked their opinions on aspects of POM-PPCG, including overall experience, curriculum, the photo exhibition, and recommendations. Audio-recorded interviews were conducted with participants in their homes for later analysis.

Data analysis. All analyses were completed with SPSS Statistics version 25. Descriptive statistics including frequencies were conducted on all demographic and engagement variables. Cronbach z testing was conducted on both subscales to determine reliability. Pre- and posttest normality was determined using q-q plots. Paired samples t tests were used to analyze the differences between participants pre- and postintervention based on data normality. An z level of .05 was utilized to assess statistical significance. Exit interviews were transcribed verbatim and analyzed through summarization.

Results

Demographic Data

All participants in POM-PPCG were female and either the mother (n = 89%) or stepmother (n = 11%) of the care recipient. The majority of participants identified as white/Caucasian (n = 78%), married (n = 67%), and Christian/Catholic (n = 78%). Participants were between 32 and 52 years, with an average age of 40 (standard deviation [SD] = 6.735).

The average care recipient was identified as male (n = 56%) and approximately 11 years old (SD = 4.610). Two-thirds of care recipients had a genetic or neurological primary diagnosis. Refer to Table 2 for complete demographic information.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Group</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>Age</td>
<td>4</td>
<td>44.40</td>
</tr>
<tr>
<td></td>
<td>32-37</td>
<td>4</td>
<td>44.40</td>
</tr>
<tr>
<td></td>
<td>38-43</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td></td>
<td>44-49</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td></td>
<td>50-55</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>9</td>
<td>100</td>
</tr>
<tr>
<td>Race</td>
<td>White/Caucasian</td>
<td>7</td>
<td>77.80</td>
</tr>
<tr>
<td></td>
<td>Hispanic/Latino</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>6</td>
<td>66.70</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td></td>
<td>Long-term relationship</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td>Religion</td>
<td>Christian/Catholic</td>
<td>7</td>
<td>77.80</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td>Relationship to care recipient</td>
<td>Mother</td>
<td>8</td>
<td>88.90</td>
</tr>
<tr>
<td></td>
<td>Stepmother</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Age</td>
<td>4-7</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>8-11</td>
<td>3</td>
<td>33.30</td>
</tr>
<tr>
<td></td>
<td>12-15</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td></td>
<td>16-19</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>5</td>
<td>55.60</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>4</td>
<td>44.40</td>
</tr>
<tr>
<td>Race</td>
<td>White/Caucasian</td>
<td>8</td>
<td>88.90</td>
</tr>
<tr>
<td></td>
<td>Biracial/Multiracial</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td>Genetic</td>
<td>3</td>
<td>33.30</td>
</tr>
<tr>
<td></td>
<td>Neurological</td>
<td>3</td>
<td>33.30</td>
</tr>
<tr>
<td></td>
<td>Muscular</td>
<td>2</td>
<td>22.20</td>
</tr>
<tr>
<td></td>
<td>Cardiac</td>
<td>1</td>
<td>11.10</td>
</tr>
<tr>
<td>Length of stay in the pediatric palliative care program (in years)</td>
<td>0-1</td>
<td>4</td>
<td>44.40</td>
</tr>
<tr>
<td></td>
<td>1-2</td>
<td>3</td>
<td>33.30</td>
</tr>
<tr>
<td></td>
<td>&gt;2-4</td>
<td>2</td>
<td>22.20</td>
</tr>
</tbody>
</table>

Engagement

A total of 95 photographs and 96 narrative reflections were posted during the intervention. On average, participants submitted 10.56 posts (1.17 per week). Of the narratives submitted, 50.5% were typed, 48.4% were audio, and 1.1% included both. Audio narratives ranged from 10 seconds to almost 3 minutes with an average length of 70 seconds. Prior to the “bye week,” approximately 14.5 posts were submitted each week (1.61 per participant). Following the “bye week,” there was a decrease in posting to an average of 8.5 per week (0.94 per participant). Throughout the monitoring of photo narrative posts, no instances arose where a staff member needed to intervene due to safety concerns.

Meaning in Life

Due to unforeseen medical circumstances of care recipients, only 7 PPCGs completed posttest measures. Cronbach z testing found that the presence of meaning subscale had an internal consistency of .90, while the search for meaning subscale had an internal consistency of .89 There was a significant increase
in the presence of meaning for participants, with scores increasing from 28.86 to 31.86 ($P = .022$). The program had no significant impact on search for meaning. Refer to Table 3 for complete statistical analysis.

**Satisfaction**

Seven participants completed the semi-structured exit interview. Names and other identifying information have been changed for confidentiality purposes. All participants described POM-PPCG as a positive experience. In terms of the curriculum’s therapeutic aspects, one participant, Lily, noted,

> It was healing. It was. It was really nice to tell other people about what I do to help me on bad days and even good days and it was nice to hear what other people do. I think you sort of go through the process alone but when you have something like that you are sort of reliving it with support, a different support group than you have had in the past. You learn from it.

In regard to the photo exhibition, participants noted the opportunity to teach the community as important. One caregiver, Wendy, said, “... helping bring more awareness. That is the main reason why I wanted to do it. Just make them more aware that this is happening and put faces with the name.” The photo exhibit was also a way for participants to connect with other caregivers. One participant, Alice, stated, “The photo exhibit made it real and at the same time looking at the people there you felt like you are not alone. There is more. There is more of us out there.” Over half of the participants stated that future iterations should include more time and opportunities for caregivers to interact with one another. Incorporating a theme of advice was also recommended.

**Discussion**

This study tests the feasibility, engagement, potential for meaning-making, and participant satisfaction of POM-PPCG. Participants of POM-PPCG experienced an increase in their presence of meaning while experiencing no change to their search for meaning. Based on the MLQ scoring guidelines available, the average scores of participants indicate that they feel their lives have meaning and purpose and are not actively seeking new sources of meaning. Anecdotally, these findings are not surprising; participants shared throughout the intervention that caring for their child was a major source of meaning, if not their primary source of meaning. Considering time spent caregiving, it makes sense that the continuous meaning derived from this activity would halt PPCGs from searching for additional sources of meaning. Still, POM-PPCG was perhaps able to introduce new purpose into the lives of participants without having to conduct a true search.

After consent, 3 participants were unable to begin the intervention due to unforeseen circumstances, including medical crises of care recipients and other family members. These participants informed the researchers of these circumstances following the distribution of the first week’s theme. In the case of these 3 participants, adding POM-PPCG to their schedule could have yielded the opposite of its intended effects and potentially increased feelings of burden. Considering this information, individual feasibility of the intervention will vary based the individual circumstances of each potential participant.

**Clinical Implications**

Understanding the experiences of PPCGs is essential in order for clinicians to offer the highest quality of care. The lives of PPCGs differ greatly from the overall caregiver population; their burden extends beyond physical and psychological impact. This research offers a glimpse into the lives of this caregiving population: their triumphs, hardships, and reality. Access to this information could prove an invaluable tool to clinicians working with PPCGs.

Beyond the learning opportunities awarded by the photo narrative data, POM-PPCG itself proves to be a practical feasible tool from the clinician perspective. The POM-PPCG curriculum has been modified by the study team, clinicians, and PPCGs in order to best fit this specific population. It allows for variability between participants based on interpretation and flexibility based on individual schedules. Additionally, POM-PPCG is not time-consuming for clinicians beyond monitoring portal content and therefore would not significantly add to clinician burden.

Although this intervention can be used to increase meaning in the lives of PPCGs, there is potential to use social media to distribute other interventions to this population as well. Although there is no direct evidence regarding adherence to a more classic therapeutic setting, past research demonstrates the difficulty this could possess. As the use of social media grows in health care and health interventions, clinicians

<table>
<thead>
<tr>
<th>Variables</th>
<th>Pretest Mean (SD)</th>
<th>Post-Test Mean (SD)</th>
<th>Difference (Post–Pretest) Mean (SD)</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of meaning</td>
<td>28.86 (4.140)</td>
<td>31.86 (3.485)</td>
<td>3 (2.582)</td>
<td>3.074</td>
<td>.022</td>
</tr>
<tr>
<td>Search for meaning</td>
<td>16.57 (7.635)</td>
<td>15.86 (7.647)</td>
<td>−0.714 (4.461)</td>
<td>−0.424</td>
<td>.687</td>
</tr>
</tbody>
</table>

Abbreviation: SD, standard deviation.

*N = 7.

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The photo exhibition was also a way for participants to connect with other caregivers. One participant, Alice, stated, “The photo exhibit was also a way for participants to connect with other caregivers. One participant, Alice, stated, “The photo exhibit made it real and at the same time looking at the people there you felt like you are not alone. There is more. There is more of us out there.” Over half of the participants stated that future iterations should include more time and opportunities for caregivers to interact with one another. Incorporating a theme of advice was also recommended.

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should consider offering additional interventions through online platforms.

Limitations
The current study has a number of limitations. First, the sample was composed of predominantly white, female mothers and stepmothers. Therefore, the findings may not be generalizable. Due to the small sample size, all quantitative findings must be viewed with caution. Future research with POM-PPCG should aim for a larger sample in order to assess quantifiable changes. Finally, inclusion into POM-PPCG depended on access to an iOS device. The differences between caregivers without access and those who acted as participants may go beyond their technological assets. Despite these limitations, POM-PPCG shows great potential as an accessible psychosocial intervention.

Conclusion
The results of this study indicate that POM-PPCG may be a practical intervention for the noted population due to patient engagement and expressed positive experiences. Through feedback, improvements for curriculum and participant interaction components of POM-PPCG have been identified. Further research utilizing POM-PPCG is warranted in order to continue exploration of efficacy with PPCGs.

Authors’ Note
In accordance with the State University of NY at Buffalo Social and Behavioral Research institutional review board approval of this project, all data including audio recordings and transcripts are to be kept secure, private, and not to be shared. The authors alone are responsible for the conceptualization, execution, and/or drafting of this project and manuscript. Lynda K. Beaupin is now affiliated with Department of Hematology/Oncology, Johns Hopkins All Children’s Hospital, St. Petersburg, FL, USA.

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