The Experience of Pediatric Palliative Caregiving: A Qualitative Analysis From the Photographs of Meaning Program

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Abstract
The Photographs of Meaning Program for pediatric palliative caregivers (POM-PPCG) is an innovative, meaning-based intervention utilizing photovoice and social media components. In 2017, 9 pediatric palliative caregivers participated in this intervention. During the social media portion of the POM-PPCG, participants were presented with weekly themes based on a meaning-making curriculum. In response, they took photographs, applied either audio or typed narratives, and shared them via social media. Ninety-five photographs with narratives were produced during the intervention. Through thematic qualitative analysis with consensual qualitative research components, 5 themes were identified: Love, Challenges, Loss, Coping, and The New Normal. This study adds to existing literature by shedding light on the experiences of caregivers of children with palliative care needs. Findings from this research contribute not only to the innovative use of qualitative methods but also to the clinical knowledge and practice regarding the pediatric palliative caregiver experience.

Keywords
caregiving, pediatrics, pediatric caregivers, palliative care, qualitative, photovoice, social media, Photographs of Meaning Program

Introduction
Pediatric palliative caregivers (PPCGs) provide care to children/adolescents with life-limiting and life-threatening illness. A study conducted in 2015 found that over 21 million children worldwide could benefit from palliative care based on selected diagnoses. Compared to caregivers of adults, PPCGs are younger, less educated, less financially stable, feel less supported, and have higher levels of burden. Studies of PPCGs have found physical and psychosocial difficulties including role strain, lack of social support, social isolation, and long-term health concerns. While outcomes for PPCGs are worse than their adult caregiver counterparts, less research has been conducted and fewer resources are available. They are left at a constant disadvantage due to their unique life circumstance of becoming a caregiver before fully integrating into society. Further, as they represent only a small subset of caregivers, they are often inappropriately judged and misunderstood by their communities.

Meaning-Centered Psychotherapy
Meaning-centered psychotherapy (MCP) is an intervention originally conceptualized for patients with cancer to enhance meaning, mindfulness, and purpose. Offered as either an individual or a group intervention, MCP explores various aspects of meaning over the course of 8 weeks. Meaning-centered psychotherapy has been found to increase quality of life and decrease depression, hopelessness, and symptom-related distress. Modified MCP for cancer caregivers found burden, meaning, and the importance of personal connections positively impacted. Testing of a web-based format for cancer caregivers found the intervention to be feasible and a potential way to meet the unmet needs of caregivers.

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Photovoice and Social Media

To help reduce the effects of PPCG burden and isolation, participatory-based intervention strategies should be utilized. Photovoice is a research method that supports the sharing of the personal realities of its participants. This methodology promotes self-expression, helps overlooked populations normalize their experiences, and offers learning opportunities for the community at large. This is especially important for PPCGs, as their role is often minimalized due to a lack of understanding. Participants in photovoice-based programs take photographs and are traditionally asked to share about what they see in their photos in group discussions with individuals having similar life circumstances. Later, these photographs are shared publicly in order to enhance understanding of the participants and inspire multilevel change within communities. Photovoice has been used successfully in child caregiving populations including caregivers of children with cancer and asthma.

Caregivers have noted that time/scheduling difficulties and guilt leaving their care recipient hinder accessing psychosocial services. Considering that PPCGs spend significantly more time providing care than their adult caregiver counterparts, traditional therapeutic measures may be unrealistic. Applying photovoice to social media may act as a solution to this barrier, as active social media users increased to an all-time high of 2.8 billion or 37% of the world population in 2016. When photovoice is attached to social media, participants instead create narratives that explain the image through their own eyes instead of discussing photographs in the traditional group setting. Preliminary research combining photovoice with social media has shown to be an effective means of storytelling and intervention in populations of adolescents with type 1 diabetes and young adult cancer survivors.

The combination of MCP, photovoice, and social media has created the basis for the Photographs of Meaning Program for PPCGs (POM-PPCG). Integration of MCP and photovoice into POM-PPCG provided participants with expressive opportunities through photo narratives to share with each other and their community. It also serves as a way to collect and learn from caregiver experiences. The aim of this study is to qualitatively analyze the narratives collected during POM-PPCG in order to enhance the clinical and community-based knowledge of life as a PPCG.

Method

Study Design

This is a qualitative analysis of photo narrative data from POM-PPCG. Data were collected between July and September 2017. This project was approved by the Social and Behavioral Institutional Review Board of a midsize public university (FWA0008824) on March 15, 2017.

Table 1. Weekly Themes Covered in POM-PPCG.*

<table>
<thead>
<tr>
<th>Week</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Identity exploration and reflection</td>
</tr>
<tr>
<td>2</td>
<td>Awareness regarding sources of meaning</td>
</tr>
<tr>
<td>3</td>
<td>Historical sources of meaning and identity</td>
</tr>
<tr>
<td>4</td>
<td>Present and future sources of meaning, identity, and legacy</td>
</tr>
<tr>
<td>5</td>
<td>No new topic—participants are encouraged to complete unfinished topics and view posts of other participants</td>
</tr>
<tr>
<td>6</td>
<td>Attitudinal sources of meaning: barriers and burdens</td>
</tr>
<tr>
<td>7</td>
<td>Creative sources of meaning: engagement in life beyond caregiving</td>
</tr>
<tr>
<td>8</td>
<td>Exploration of engagement with life</td>
</tr>
<tr>
<td>9</td>
<td>Reflection on experience and hopes for the future</td>
</tr>
</tbody>
</table>

Abbreviation: POM-PPCG, Photographs of Meaning Program for pediatric palliative caregivers.

*This table includes the weekly themes sent to participants during POM-PPCG. Themes were dispersed via text or e-mail twice a week during the intervention, with the exception of week 5. During this week, participants received reminders that they could catch up on posts if they had fallen behind.

Inclusion Criteria and Recruitment

Potential participants were identified to the research team by the interdisciplinary care team of a pediatric palliative care program in Western New York. Inclusion criteria included primary caregiver of a child enrolled in the pediatric palliative care program, at least 18 years old, owned an Apple iOS smart device (the app utilized in POM-PPCG was only accessible through iOS devices at the time of the intervention), and a method to receive weekly information pertaining to the intervention. Participants with language barriers were excluded from recruitment.

Referred potential participants were approached by members of the research team through phone contact, followed by a home visit to further discuss the study and obtain written consent. Participants were also asked at this time to complete a media waiver so that the photographs and narratives could later be used in a community photo exhibition as part of the larger intervention.

Procedure

The POM-PPCG was conducted during the summer 2017. The intervention has 2 distinct portions: a 9-week curriculum based on MCP was completed over social media and a community viewing of participant photo narratives. During the social media portion of the intervention, participants were prompted weekly with specific themes (Table 1). Participants would reply with photographs and either typed or audio narratives (based on participant preference) to a private Pixstori (a social media app) web portal. Throughout the intervention and afterward, participants could access each other’s posts, but there were no interactive features on the app as too not overwhelm participants. After completing the 9 weeks over social media, each participant was asked to select a photograph and narrative they felt was a good representation of their experiences to share.
Data Analysis

All narrative files were extracted from the web portal, de-identified, and transcribed as needed. A team of 3 core members met biweekly to analyze all data, with a fourth team member conducting audits. Data were randomized so that weekly intervention themes were not considered when determining themes of the narrative content.

Thematic analysis with consensual qualitative research components was utilized to evaluate the data. Prior to analysis, the core team met to discuss individual biases and expectations that may affect the process. After familiarization with the data, initial codes were generated and data were organized. Next, themes were generated and reviewed based on how they related to the original codes and the overall data set. Analysis continued by refining and defining themes. Full consensus of themes and definitions were reached by the core team, while the auditor provided perspectives as an objective party. Finally, a report including definitions and excerpts from the data was generated.

Results

Study Participants

Nine caregivers participated in POM-PPCG. All participants were female and identified as the mother/stepmother of the care recipient. Participant ages ranged from 32 to 52 years with a mean age of 40.11 years (standard deviation = 6.74 years). All but 2 participants identified as white/Caucasian. Care recipient ages, diagnoses, and length of stay in the pediatric palliative care program varied greatly. See Table 2 for complete demographic information.

Photovoice Themes

From 95 collected photo narratives, the following themes emerged: Love, Challenges, Loss, Coping, and The New Normal. Table 3 includes a complete list of themes and subthemes.

Love. Many photo narratives expressed love or the affection for another/between individuals. Subthemes of explicit and implicit love arose from the data. The most common form of explicit love was for the participant’s love of their care recipient. One caregiver said, “The special love between a mother and daughter is forever...I’ll always be there to show you love and encouraging you to live your dream.” Participants also expressed love for their family, significant others, friends, and between the care recipient and their siblings. Implicit love is more subjective and was identified based on actions described by the participant. When referring to her child, one participant said, “I can’t let them down. Everything I do is to make life better for them...I have to keep him safe; I’m all he’s got.”

Challenges. Challenges were defined as difficulties directly relating to caregiving. Subthemes here are challenges of medical, psychological, social, and uncertainty. Medical challenges denote struggles associated with the care recipient’s diagnosis, condition, or care. One caregiver described the experience of her daughter being diagnosed:

We went for a simple eval at a local clinic due to her losing weight, vision, fine and gross motor skills along with her lack of speech. About 2 hours into her appointment, they admitted her. The next day she went for the first of numerous MRIs and within
Table 3. List of Themes and Subthemes.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Love</td>
<td>Explicit</td>
</tr>
<tr>
<td></td>
<td>Implicit</td>
</tr>
<tr>
<td>Challenges</td>
<td>Medical</td>
</tr>
<tr>
<td></td>
<td>Psychological</td>
</tr>
<tr>
<td></td>
<td>Social</td>
</tr>
<tr>
<td></td>
<td>Uncertainty</td>
</tr>
<tr>
<td>Loss</td>
<td>Freedom/spontaneity</td>
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<tr>
<td></td>
<td>Time for self</td>
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<tr>
<td></td>
<td>Social</td>
</tr>
<tr>
<td></td>
<td>Control/role</td>
</tr>
<tr>
<td>Coping</td>
<td>Problem-solving/action facilitated</td>
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<tr>
<td></td>
<td>Emotional adjustment</td>
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<tr>
<td></td>
<td>Self-care</td>
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<tr>
<td></td>
<td>Network support</td>
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<tr>
<td></td>
<td>Religious</td>
</tr>
<tr>
<td>The New Normal</td>
<td>Lifestyle changes</td>
</tr>
<tr>
<td></td>
<td>Growth</td>
</tr>
<tr>
<td></td>
<td>Identity</td>
</tr>
</tbody>
</table>

*aThis table includes a listing of the emerging themes and subthemes from the qualitative analysis. Examples of each theme are included in their subsequent section.

an hour we had the devastating news. My then 2-year-old baby had brain cancer.

Several participants expressed negative ways in which caregiving affected their psychological well-being. One participant outlined several struggles in one narrative:

When he isn’t doing well I find myself struggling with depression and helplessness. My mood has always depended on how he is doing…over the last 6 years he has become more and more unstable. My grief counselor says I have anticipatory grief; I am anticipating his death instead of appreciating his life.

For some caregivers, social challenges between individuals and beyond were illustrated. In one post, a participant shared, “Trying to get the necessary equipment, therapies, school services, etc, is so hard and usually takes several phone calls, letters, and threats…Others think it is just so easy to get what you want. They have no idea.”

Caregiving comes with a certain amount of uncertainty, ranging from the daily unknowns to unclear futures. One participant described planning a birthday for her son, saying “I remember feeling so scared when making plans for the coming birthday because we didn’t know if he was gonna make it to the next birthday, which it was just a few months down the road.”

Loss. Losses considered here are in direct relation to being a PPCG and included subthemes of freedom/spontaneity, time for self, social, and control/role. Freedom/spontaneity becomes difficult and sometimes impossible with a sick child. One participant shared a memory of playing in a creek before her son was diagnosed:

We had no towels with us; we didn’t have swimsuits. No worries about germs in the water…about being able to have full balance. If we fall, hit the head—how far is the closest hospital? Or his Mediport, or having a seizure. Those moments are long gone because now and there’s a lot more things we have to think about whenever we plan any outing.

Being a PPCG also leaves little time for self. One caregiver explained why making time for yoga, her favorite activity, is difficult, saying,

I need to be home for my kids. It’s a 90-minute commitment and a half-hour to yoga and a half-hour back, so it is two and a half hours of working out that I just don’t have time for.

Participants described situations where they had endured social loss, such as relationships and employment. One caregiver said, “I attempted to work 1 day a week, but couldn’t juggle work, 18 therapists visits, chemotherapy, doctors, VNA nurse, and much more plus having a baby too.” While caregivers are often more controlling due to the nature of their child’s diagnoses, there are times where control/role is lost or has to be given up. One participant shares her fear of losing control as her son grows:

I just fear that he is going to outgrow me and I will not be strong enough to help him in a time of need. Not just in a way that he would need help in the bathroom or in the shower or out of bed physically. I just worry if he falls I’m not gonna be able to lift him.

Coping. In managing challenge- and loss-based stress, participants described several adopted forms of coping. Themes of coping in the data were problem-solving/action facilitated, emotional adjustment, self-care, network support, and religion. Taking advantage of the things that can be done through problem-solving/action-facilitated behaviors was helpful to many. One caregiver described this subtheme, saying,

Something that is very meaningful to me is my passion to help other people in similar situations. I want to share what I have learned with others so they don’t have to go through the same struggles I have.

Participants also utilized emotional adjustment, or working with their emotions, often reframing the situation in a positive way. For one mother, this meant focusing solely on the present:

We never know when our time is up on this earth. We need to take one day at a time. Sometimes thinking about the future takes up a lot of unnecessary energy and the focus needs to be on the moment.

Though participants expressed issues with finding time for themselves, self-care was still important. One participant describes scrapbooking for self-care:
I personally scrapbook to document everything that is important to me. This way when they get older, they will understand and see the struggles they went through. This is also a way to give me a breather and my husband will watch the kids.

Many caregivers described utilizing network support as a way to cope, with network size varying from the care recipient to the community at large. In one narrative, this crucial moment of support is illustrated:

She was going for her surgery and I was very scared. This is her telling me that everything is going to be okay. I felt like I had to be strong and that day I was not—she was being strong for me. That day something inside of me changed. I don’t feel that I have to be strong all the time . . . I can cry sometimes in front of her.

Some participants used religious coping mechanisms often in tandem with their care recipient and family. In a post about routinely praying the rosary, one caregiver says:

I think in a crazy state of life when you have a child that is high maintenance you need a place where you can just unplug from everything and even as a family plug into peace. We use the rosary to plug into peace.

The New Normal. This theme refers to how life is different as a PPCG. Lifestyle changes, growth, and identity make up the new normal. Lifestyle changes denote the modifications made to everyday life that directly stem from their role. One mother described this experience:

I was forced to learn and understand medical things I’d never even heard of. If I didn’t, my son could suffer and possibly die. I realized this was nothing like when my boys wanted a snack or to read the same book over and over or go outside. Those were things I could say no to or just do another time. Now I couldn’t say no or wait for another time.

Many participants identified growth within themselves directly stemming from being a caregiver. One participant illustrates this new growth, saying “I have learned so much about myself and my ability to be completely selfless for another person, even when she doesn’t always want me. I am stronger than I ever imagined I could be.” Participants also discussed identity, or the roles and qualities ascribed to them. Being seen as a parent versus a caregiver was common, with one participant saying, “As a caregiver it just says I am a mom, first and foremost. I may be a caregiver, but I really just call myself a mom.” Posts about being and becoming an advocate were also common. One mother stated, “It is my duty and responsibility to step in as her representative and her voice.”

Discussion

Photographs of Meaning Program is an original intervention, with this iteration aimed at supporting PPCGs.21 Photo narratives collected are unlike any data we have seen on PPCGs and can therefore inform better practice and policy when working with this population.

For PPCGs, love for their child serves as a driving force in everyday life. It is love that motivates caregivers to create a new normal for themselves and their child. Being a parent fundamentally restructures the brain, making mothers more attentive and better at caring and therefore more willing to change based on their child’s needs.24 It was noted by the data analysis team that love was not only strong enough to stand as its own theme but was also interwoven into the narratives of all other themes and subthemes. Every aspect of each caregiver journey is influenced by love, giving both meaning and purpose to their actions and experiences.

Challenges that arise for PPCGs vary greatly: unexpected to long term, simple to complex, and individual to community based. As photovoice aims to reflect community strengths and concerns and promote dialogue about important issues,13 bringing to light issues of accessibility and disparity through photo narratives coincides well with this objective. Further, POM-PPCG may help caregivers overcome the challenges related to social isolation through community integration.

From the moment of diagnosis of their child’s condition, PPCGs begin to experience loss. Disenfranchised grief is one way to make sense of this, as their losses can go unnoticed, be misunderstood, or are not generally supported.25 Isolation complicates socially based losses, as PPCGs retreat from jobs and relationships but not due to a lack of care or interest. Finding ways to support and validate loss is essential in the support of caregivers. The POM-PPCG offers the opportunity for caregivers to explore and name their losses without stigma or shame while forging new connections.

The POM-PPCG identifies how caregivers cope with role-based stressors. While self-care is crucial, it can be hard for caregivers to find time for themselves while meeting the needs of their child. The focus and attention of this program is on the caregiver, helping redirect some of their energy and thoughts on themselves. Further, the choice to participate allows for caregivers to recognize their limits, opt out, return, and assert control over their time as another facet of self-care.

Several aspects of post-traumatic growth26,27 are described within the new normal theme. Appreciation for life and a change in priorities are evident, as well as recognition of personal strength. Relationships forged in the life of PPCGs also appear more meaningful, intimate, and cherished. The assumption that posttraumatic growth enhances wisdom and narrative development28,29 is also of note, as wisdom is clearly reflected within the photo narratives.

Although not identified as a direct theme, time appears as a latent component of narratives analyzed. Across participants, the journey to their child’s diagnosis was commonly shared. These moments feel particularly critical, highly structured, and incredibly detailed. With traumatic events such as the life-threatening or life-limiting diagnosis of a child, memory and details of that moment might be heightened and easier to recall.30 Pediatric palliative caregivers, commonly referred to...
events of the past, described appreciation for the time that they have with their child and look to the future with fear, optimism, and uncertainty. When working with PPCGs and their families clinically, time (in past, present, and future contexts) undoubtedly holds great importance and should be discussed.

**Limitations and Future Directions**

Participants were recruited from one pediatric palliative care program and therefore may not represent all PPCGs. Although the majority of PPCGs from the program where the sample was obtained were female, future studies should aim to capture the experiences of a wider range of PPCGs including males and diverse racial/ethnic backgrounds. As social media is used by a wide range of adults, it is possible that POM-PPCG would be a useful tool in capturing the experiences of other groups. Additionally, inclusion criteria for this study proved to be a limitation to sampling. The intervention itself was created using a social media app that could only be accessed through iOS smart devices. During recruitment, it became clear that some PPCGs were interested in participating but did not meet inclusion criteria due to a lack of access to these devices. It is possible that narratives of these caregivers would be different, as it may indicate different financial and social challenges that did not present in this qualitative analysis.

**Conclusion**

Examination through qualitative analysis of the photo narratives collected during POM-PPCG greatly contributes to what is known about the PPCG experience. Participants were able to share their experiences with each other and the greater community (including clinicians) using their own photo narratives, eliciting greater understanding of the needs of PPCGs. The use of modified photovoice methodology allowed for sharing that may not have occurred in traditional therapeutic settings. Beyond the positive effect and experiences reported by participants, information stemming from this analysis can be utilized to inform clinical practice with this population. In addition to the therapeutic benefits of POM-PPCG, utilizing social in tandem with MCP and photovoice-based methods helps caregivers put into words what often goes unspoken. Continuing efforts should be made so that POM-PPCG becomes commonly available, furthering clinical and community knowledge of this disadvantaged population and creating new therapeutic avenues where underserved and overlooked PPCGs can share their stories.

**Authors’ Note**

The authors alone are responsible for the conceptualization, execution, and/or drafting of this project and manuscript. 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.

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