Palliative and Supportive Care

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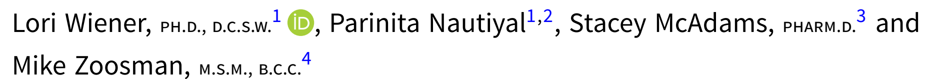
Making space for grief: The impact of remembrance programs for pediatric healthcare providers



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Original Article

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Abstract

Objectives. While caring for seriously ill children is a rewarding experience, pediatric healthcare providers may experience sadness and emotional distress when their patient dies. These feelings, particularly when not addressed, can lead to negative health and occupational outcomes. Remembrance practices can provide a safe space for staff to process their grief. This study explored pediatric healthcare providers' perceptions of an annual Pediatric Remembrance Ceremony (PRC) and a quarterly program, Good Grief and Chocolate at Noon (GGCN), to learn what components of the programs were considered meaningful and the personal impact on those who attended. The programs pivoted to a virtual platform during the COVID-19 pandemic, and the study also assessed providers' perspectives of attending the programs virtually.

Methods. A 19 multiple choice survey instrument was designed, reviewed, piloted, revised, and re-piloted by an interdisciplinary bereavement committee prior to administration. The survey included 2 open-ended questions, inviting additional insights into personal impact and future directions for remembrance programs. The survey was administered on an encrypted online platform.

Results. Components of the PRC respondents most valued included the opportunity for staff to choose a name of a patient they cared for and to light a candle for that patient as their name is read. Those who participated in GGCN found story sharing helpful, along with having a speaker address a topic around loss and grief during the second half of the session. Both programs provided reflection, solidarity, and memorialization. Most respondents prefer having both in-person and virtual options.

Significance of results. Healthcare providers are affected by the death of the children they care for and value opportunities provided to join colleagues in remembering their patients. The findings underscore the value of remembrance programs in supporting bereaved staff.

Introduction

It is well understood that healthcare workers who provide care to pediatric patients are greatly impacted following a patient's death. Such effects, if not addressed, can negatively impact healthcare workers' quality of life, including their well-being and occupational outcomes (Cocker and Joss 2016; International Work Group 2006; Davis et al. 1996; Tawfik and Ioannidis 2020; Zisook and Shear 2009). Remembrance programs held at healthcare institutions can allow a safe space for the staff to reflect, remember, process, and grieve together.

"Remembrance" can be seen as "an interdisciplinary approach to acknowledge and process the death of patients" (Morris et al. 2019). Remembrance activities pay particular attention to how the patients they cared for affect those who cared for them. Advocating for the incorporation of remembrance interventions in clinical services can be a part of how clinician self-care is provided (Morris et al. 2019; Sanchez-Reilly et al. 2013). Hosting recurring remembrance events can create a sense of community and support, reminding healthcare providers that their experiences are not unique, and that they are never alone in their grief.

The changes brought by the COVID-19 pandemic were difficult for pediatric healthcare providers, with many reports of moral distress (Schiff et al. 2021; Stephenson and Warner-Stidham 2024; Vig 2021). Moral distress has been defined as "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton 1984). Due to visitor restrictions, families were often separated, with only 1 family member present, resulting in key family members not being able to hold the hands of their loved ones during their final moments (Andrist et al. 2020; Feder et al 2021;

Wendlandt et al. 2021). Additionally, pediatric healthcare providers had to face heartbreaking situations, some having to tell a parent that their child would die over FaceTime (Sniderman et al. 2022; Wiener et al. 2021). Touch developed a deeper importance, especially with pediatric patients during end-of-life care (Andrist et al. 2020; Meijer et al. 2022).

The NIH Clinical Center, the largest hospital in the United States devoted entirely to clinical research, employs the practice of remembrance organized by an interdisciplinary committee. The Pediatric Remembrance Committee hosts 2 main pediatric programs each year for staff. The first is an annual *Pediatric Remembrance Ceremony* (PRC). This service is open to all hospital staff to remember and honor children and young adults who have died within the past year. Most of these young people had cancer, and more recently includes those who lived with other chronic and life limited conditions. The committee creates a unique theme for each program. Previous PRC themes are listed in Table 1.

There is a structured order of events for the annual PRC (Figure 1). As staff enter the hospital chapel where the ceremony is held, they pick up a name of a patient who had died in the past year. A hospital leader opens the event by welcoming the pediatric staff. Following this, a keynote speaker delivers a speech based on the program's theme. Afterward, poems chosen by staff members reflecting the theme of the ceremony are recited. Later, the names of the pediatric patients who have died in the past year are read aloud. As each name is read, the staff member who picked that name comes to the front of the chapel and lights a candle, memorializing that patient. Live music is performed by staff members throughout the event, and attendees are invited to join in a group song that concludes the ceremony. An informal reception is held immediately following the ceremony where desserts are provided, and staff have a chance to support one another.

During the post-ceremony receptions, and in the days following, Pediatric Remembrance Committee members would receive feedback from attendees about how important and meaningful the ceremony was to them. Often staff members would comment on how challenging it is to hear about the many patients who had died over the past year, and then return to the bedside without having had an opportunity to talk about the children they knew. In response, a second program, *Good Grief and Chocolate at Noon (GGCN)*, was initiated to provide an outlet for staff on a quarterly basis to share stories and memories about individual patients who have died within the past several months. It was hoped that holding these more frequent programs would prevent staff members from feeling so overwhelmed at the annual PRCs.

GGCN is a 1-hour program that integrates sharing and reflection with a didactic portion (Figure 2). Names of patients that died in the past several months are written on felt leaves. Felt flowers are also provided to represent someone a staff member is worried about, such as a patient, family member, friend, co-worker, or pet. Reflecting the name of the program, staff bring chocolate desserts to the session. During the first half of the program, staff members share stories and memories of the deceased patient they cared for, including feelings about their loss. The leaf with the patient's name

Table 1. Pediatric Remembrance Ceremony themes

• Hope	• Boats/River	• Stars	• Leaves
• Tree of Life	• Birds/Flight	• Dragonflies	• Seashells
• Light/Reflection	• Sand Mandala	• Imagine	• Forget-Me-Not Flowers
• Connections	• Invisible String	• Teddy Bears	
• Journeys	• Pathways	• Snowflakes	

PEDIATRIC REMEMBRANCE CEREMONY

Prelude Music

Welcome Remarks

Opening Song

Keynote Address

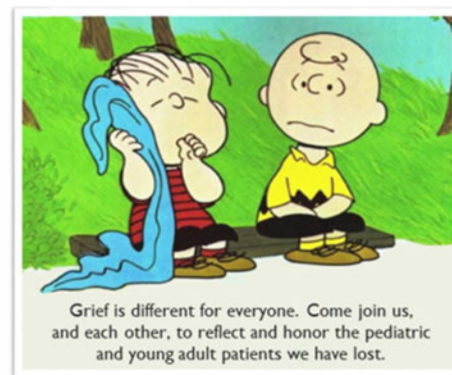
Poems

Reading of Names/Lighting of Candles

Closing Song – All are invited to join

Figure 1. Order of events for the Pediatric Remembrance Ceremony.

GOOD GRIEF AND CHOCOLATE AT NOON



Topic: Taking Time to Breathe

Chaplain Mike Zoosman will lead us through a mindful breathing meditation session during the second half of the program.

Hosted by the Pediatric Remembrance Committee

Figure 2. Sample flyer for Good Grief and Chocolate at Noon.

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Figure 3. Tree for Good Grief and Chocolate at Noon.

is then placed on a faux tree to honor them (Figure 3). After the sharing is finished and all names have been placed on the tree, staff who chose a flower share their story or concerns. They then place the flower at the base of the tree, creating a symbolic flower garden. A period of silence follows.

The second half of the GGCN program is a 30-minute presentation from a guest speaker. These talks address an aspect of grief and often include coping strategies for staff members. Speakers provided practical advice on issues such as legacy making and individual and team-based coping strategies, while others incorporated hands-on activities such as an art activity or creating a personal guided relaxation audio file. Recent GGCN topics are listed in Table 2.

During the COVID-19 pandemic, the PRC and GGCN were changed from in-person programs to virtual attendance via Zoom to reduce the spread of infection and maintain public health safety. The PRC was streamed live from the chapel to help remote attendees feel a communal connection of joining together in collective grief. Only direct participants, including speakers, musicians, and poem readers, were allowed on site. Most of the usual program elements were retained with slight modifications as needed to conform with COVID-19 guidelines. For example, a single staff member lit candles for all the patients. Beginning in 2024, the PRC was changed to a hybrid format allowing onsite attendance in the chapel while retaining a virtual option.

Because GGCN is more focused on active participation from attendees than the PRC, the COVID-19 pandemic prompted

Table 2. Good Grief and Chocolate at Noon topics

- The Building Blocks of Resilience: Staying Grounded when Managing Acute Grief
- Navigating Cumulative Grief at Work
- Coping with Personal Losses and Continuing our Bonds
- Personal Rituals for Loss and Healing
- Exploring Illness and Grief Through Faith and Culture
- Taking Time to Breathe
- A Creative Space for Remembering Our Patients
- Look for the Light

Figure 4. Adapted tree for virtual Good Grief and Chocolate at Noon.

moving GGCN to a fully virtual format. Chocolate is distributed to the pediatric units in advance of the programs. To replace the paper leaves and tree, a digital version of the tree and leaves is shared via Zoom. It includes animation so that when a patient's name is read, a leaf floats from the patient's name to a branch on the tree (Figure 4). Staff members who have joined remotely then take turns sharing stories and memories of that patient. For the second half, the guest speaker joins the Zoom session to present the didactic portion.

While the PRC has been provided to staff for 25 years and the GGCN for 11, there has never been a study at our hospital examining the usefulness of these remembrance programs. With the transition to a virtual or hybrid format, the Pediatric Remembrance Committee recognized the importance of better understanding how pediatric staff members perceive the programs and adaptation of these programs to virtual events. In response, a quality improvement research survey was developed to explore pediatric healthcare providers' perceptions of each program. Specifically, we wanted to learn what components of the programs were considered meaningful and their impact on those who attended. As the programs pivoted to a virtual platform during the COVID-19 pandemic, this paper also reports on the providers' perspectives of attending these potentially emotionally charged programs virtually rather than in-person, offering insight into future directions for remembrance programs.

Methods

Survey design

The Pediatric Remembrance Committee consists of 13 interdisciplinary healthcare members. Member roles at the Clinical Center include psychologist, dietitian, chaplain, social worker, recreational therapist, pharmacist, and nurse. There is also representation from The Children's Inn, the housing facility on campus, where up to 59 children and their family members are housed while receiving care at the hospital. The survey instrument was designed, reviewed, piloted, revised, and re-piloted by this committee prior to administration. The survey consisted of 19 multiple choice and 2 open-ended questions on an encrypted version of Survey Monkey. The questions explored the impact of the PRC and GGCN, what parts of the programs were found to be meaningful, and whether the programs had met their expectations. The survey invited staff to share anything that would be helpful to add to future programs. Additionally, participants were asked about their preference of an

in-person, hybrid, or virtual program and if they would attend a program in the future.

Data collection and analysis

Following the Office of Human Subjects Research Protections at the National Institutes of Health determination that the survey format and content qualified as exempt from full Institutional Review Board review, an invitation and link to the survey was emailed to the pediatric healthcare team members of the NIH Clinical Center. Data was collected between July and September of 2023. The analyses were descriptive and univariate in nature. The study team utilized counts for categorical variable responses. For missing responses due to skip patterns in the survey, the number of responders was used as the denominator (actual n).

Results

Pediatric Remembrance Ceremony

The survey included responses from 94 pediatric healthcare members. Out of the 94 participants, 77 (81.9%) indicated that they had attended a PRC. For those who indicated they had never attended a PRC, reasons included, “there has always been a time conflict” (46.7%), “I never received an invitation” (26.7%), “I don’t know the patients well” (26.7%), “it is too difficult/emotional for me” (6.7%), and “I prefer to grieve privately” (6.7%).

Participants were presented with a list of components included in past ceremonies and asked which they found meaningful and worthwhile to include in future ceremonies. Components deemed meaningful by over 90% of participants were the reading of names, welcome remarks, lighting of candles, piano music, and keynote address (Table 3).

All participants (100%) reported that the last PRC they attended met their expectations. When asked if there was anything not included in the ceremony that they would like to see in a future ceremony, all 100% reported “no.” When asked to reflect on the personal impact of the PRC, the majority of participants endorsed “a chance to memorialize those we cared for” and “an opportunity for reflection on patients who had died” (Table 4).

When asked if the participants would attend a future annual PRC, 85.7% of the participants reported that they would, with 14.3% reporting “maybe.” Reasons for the “maybe” response included “if time allows” (77.8%) and “only if I have a patient who died in the past year who will be remembered” (44.4%). In terms of the preferred platform, 58.5% of the participants preferred having an option for an in-person or virtual program, 36.9% preferred in-person only, 10.8% preferred virtual only, and 4.6% reported no preference.

Table 3. Meaningfulness of the annual Pediatric Remembrance Ceremony components

Ceremony component	Participants indicating component is “meaningful and worthwhile to include in future ceremonies” *N* (%)
Reading of names	65 (100%)
Welcome remarks from a pediatric hospital provider	64 (98.5%)
Lighting of candles	63 (96.9%)
Piano played by a hospital physician prior to the ceremony and throughout	60 (96.8%)
Keynote address tying the theme of the ceremony to the work pediatric healthcare workers provide	59 (93.7%)
Poem readings	57 (89.1%)
Songs performed by staff	53 (86.9%)
Picking up a memento with the child’s name on it and placing it when the name is read	51 (86.4%)
Closing song sung as a group by audience	42 (71.2%)

Table 4. Impact of the annual Pediatric Remembrance Ceremony on participants

“How much have the ceremonies provided the following for you?”	Participants responding “Quite a bit” and “Very Much” *N* (%)
Chance to memorialize those we cared for	62 (95.4%)
Opportunity for reflection on patients who had died	57 (87.7%)
Sense of solidarity (not being alone in your grief)	49 (75.4%)
Sense of closure	38 (58.5%)

Good Grief and Chocolate at Noon

Only one quarter (25.9%) of participants had participated in one of the quarterly GGCN programs. For those who had never attended this program, reasons included, “there has always been a time conflict” (43.4%), “I never received an invitation” (37.7%), “I prefer to grieve privately” (13.2%), “I am not involved in patient care/don’t know patients well” (7.6%), and “it is too difficult/emotional for me” (5.7%).

The participants’ reflections on the most meaningful components of GGCN are summarized in Table 5. Over 90% of

Table 5. Meaningfulness of Good Grief and Chocolate at Noon components

Program component	Participants indicating component is “meaningful and worthwhile to include in future ceremonies” *N* (%)
Having a speaker address a topic around loss and grief during the second half of the session	20 (100%)
Hearing stories about other children who were cared for at the hospital	20 (95.2%)
Opportunity to share or take part in a brief discussion about that child/family	18 (94.7%)
Picking up/choosing a leaf that has the name of a child you had known *(not available via virtual platform)*	14 (73.7%)

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participants endorsed, "having a speaker address a topic around loss and grief during the second half of the session," "hearing stories about other children who were cared for at the hospital," and "opportunity to share or take part in a brief discussion about that child/family."

Table 6 represents the participants' responses to the impact of the GGCN program with over 90% reporting the program provides "an opportunity for reflection on patients who had died" and "a chance to memorialize those we cared for."

Table 6. Impact of Good Grief and Chocolate at Noon programs on the participants

"How much have the programs provided the following for you?"	Participants responding "Quite a bit" and "Very Much" *N* (%)
Opportunity for reflection on patients who had died	18 (94.7%)
Chance to memorialize those we cared for	18 (90%)
Sense of solidarity (not being alone in your grief)	17 (85%)
Sense of closure	16 (80%)
Opportunity to learn more about coping with grief	12 (60%)
Opportunity to learn/practice coping/self-care strategies	12 (60%)

Table 7. Themes from the open-ended question and exemplary quotes from study participants

Theme	Phrases
Appreciation toward the programs	*I only attended the Remembrance ceremony once, in person, pre-pandemic. It was beautiful and much appreciated. I haven't attended virtually in the past few years. I very much appreciate the effort to pull this type of program together.*
	Thank you for having this annual remembrance ceremony. It means a lot to the staff who care for these children.
Reasons why programs are helpful to providers	*Thanks to all who are involved in the Pediatric Remembrance and Grief Programs. I appreciate all of the effort that goes into allowing staff to express their remembrances of the amazing children and their families in our care.*
	The Peds Remembrance Ceremony is a thoughtful and meaningful annual milestone. Especially enjoy the chaplains singing. Music is important in these types of events. I think it's important to make space for the staff to acknowledge their collective grief in this gathering.
	The pediatric remembrance committee does great work by allowing us an opportunity to honor and remember the patients we have lost as a community – very grateful for all of their efforts!
Offering comfort and safety to providers	*Thank you for all of the work from this committee. These programs help NIH feel like a safe and compassionate place to work.*
	There is a lot of comfort wrapped in being in the presence of others that are grieving in different ways but also understand the journey that requires no words.

The majority of survey participants (76.2%) would attend a future GGCN program. Of those who reported that they would "maybe" attend a session (23.8%), 60% answered attendance would be dependent on "if time allows," while 60% reflected they would attend "only if [they] have a patient who died in the past year who will be remembered." When asked about their preferred platform for the GGCN program, 81% preferred an option allowing either virtual or in-person attendance, 14.3% preferred virtual only, and 14.3% preferred in-person only.

An option was provided for participants to share any other thoughts that might be useful to the Pediatric Remembrance Committee. Twenty participants provided their additional comments. Common themes and exemplary quotes are presented in Table 7. In addition to the overall helpfulness of the programs, 3 suggestions were provided. One participant stated, "there were quite a bit of technical difficulties at the last ceremony that should be trouble shooted," a second shared that future events should, "maybe [share] names prior to [the] event," and a third wrote, "I don't think the keynote really needs to be too long – the music, poems, reading of the names is really what touches people."

Discussion

The responses from the survey indicate that both the *PRC* and *GGCN* are valued by the pediatric healthcare providers. The majority of participants expressed interest in attending a future PRC and/or GGCN event, underscoring the programs' purpose to provide healing, connection, and remembrance. Some found the PRC emotional or difficult, causing them to consider not attending a future program. Others expressed that they preferred to grieve privately. This aligns with the finding that when a ritual doesn't fulfill a need to grieve, the bereaved will seek their own, more effective way of remembering (Burrell and Selman 2020; Castle and Phillips 2003; Hunter 2008; Sas and Coman 2016). Moreover, some staff members felt inclined to attend a future program only if a patient they worked with was being remembered. This suggests that for some staff members, the decision to attend is based on their connection to the deceased patient.

Parts of the PRC that held the most significance to the pediatric healthcare members were the reading of names, welcome remarks, candle lighting, piano playing, and a keynote address connecting the theme to their daily work. Music in rituals has long been found to articulate sentiments and help create meaningful experiences for the bereaved (Adamson and Holloway 2012; Mills 2012; Viper et al. 2020). Both programs provided opportunities to reflect and remember patients who they cared for in the company of others who faced similar loss. Although the PRC did not provide the opportunity to talk about the patients, GGCN did. Having staff share and hear others' memories of their patients was perceived to be impactful. The overall popularity of the GGCN program can be attributed to the recognition that, although formal remembrance events are valued by most people, informal rituals, created by those who are also grieving, can hold importance (Bolton and Camp 1987; Vale-Taylor 2009). These types of informal rituals, where staff members come together to share stories, can hold more personal meaning than large-scale events (Bolton and Camp 1987). Exchanging stories about children who have died with colleagues can help people find connections to one another, while keeping the legacy of the deceased child alive in present day (Macpherson 2008; Vickio 1999). Moreover, speaking about the impact that such a loss

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has had on one's personal and/or professional life creates an outlet for staff to make meaning of their loss, look out for one another, and bond over commonalities (Bosticco and Thompson 2005; Klass et al. 1996; Vachon 1995).

Before the COVID-19 pandemic both programs were provided in-person. With the evaluation occurring prior to all staff returning to the hospital, the survey results reflect a positive impact of hosting the events on a virtual platform. In fact, more participants attended GGCN virtually than had typically occurred when in-person and the participants preferred the flexibility that a hybrid or virtual program provides. This suggests that bereavement programs for hospital staff members can be successfully hosted through a hybrid or virtual platform. Perhaps, for some, tears shed behind a computer screen may feel safer than in front of colleagues. While technical disruptions were noted, overall, the transition from in-person programs to virtual events was well received by the survey participants and may provide more equitable support to staff who wouldn't be able to attend due to solely remote post-pandemic work. With frequent staff changes, being more intentional about updating the email invitation list and using distribution lists rather than individual email addresses will reduce the number of staff members not being informed about upcoming programs.

This quality improvement study has several important limitations to note. The bereavement programs were available to staff at a single research institution that works with pediatric patients. To gain more generalizable consensus on the impacts of remembrance programs on pediatric healthcare providers, research at other institutions would be helpful. The survey questions were not forced choice, therefore not all participants responded to every question. While this reduced burden to participants who did not want to answer every question, this also resulted in some missing data. We did not ask which specific PRC or GGCN program(s) they attended and therefore were in their survey responses. Hence, some of the feedback may be biased due to participant recall if much time has passed. Adding a qualitative component to future studies can further explore the impact of remembrance programs on the well-being of pediatric healthcare providers. Such studies could include exploring the effects of these events on compassion fatigue, burnout, and the potential for secondary traumatic stress. Further studies of the role of virtual bereavement programs for staff may be warranted given the likelihood that online programming will continue in the wake of the COVID pandemic. These efforts will surely go a long way to intentionally promote the value of staff care in the pediatric, or any, healthcare environment.

Conclusion

The data from this study suggests that the provision of dedicated periodic opportunities for bereavement support for pediatric staff is invaluable. It honors the memories of those patients cared for, while also giving permission for communal grief. These programs provide meaning and inspiration to help motivate care providers in this inherently difficult work. The transition from in-person programming to virtual platforms was successful in keeping healthcare providers safe and allowing additional providers to attend. It is our hope that these types of bereavement programs, offered through hybrid models, can become integral in all pediatric healthcare facilities.

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