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Bereavement Photography for Children: Program Development and Healthcare Professionals' Response

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Abstract

Reports of in-hospital bereavement photography focus largely on stillborns and neonates. Empiric data regarding the implementation of bereavement photography in pediatrics beyond the neonatal period and the impact of such programs on healthcare professionals (HCPs) is lacking. We describe the implementation of a pediatric intensive care unit (PICU) bereavement photography program and use questionnaire data from HCPs to describe HCPs' reflections on the program and to identify program barriers. From July, 2007 through April, 2010 families of 59 (36%) of the 164 patients who died in the PICU participated in our bereavement photography program. Forty questionnaires from 29 HCPs caring for 39 participating patients/families indicated that families seemed grateful for the service (n=34, 85%) and that the program helped HCPs feel better about their role (n=30, 70%). Many HCPs disagreed that the program consumed too much of his/her time (n=34, 85%) and that the photographer made his/her job difficult (n=37, 92.5%). Qualitative analysis of responses to open ended questions revealed four categories: the program's general value; positive aspects of the program; negative aspects of the program; and suggestions for improvements. Implementing bereavement photography in the PICU is feasible though some barriers exist. HCPs may benefit from such programs.

Since its inception, people have used photography to create images of the deceased. Photography of dead babies can be traced back to the 1850's (Van DerZee, 1978). For bereaved parents, photographs can help parents adjust to life without their child by providing opportunities to remember the child and his/her life, facilitating conversations with living relations such as siblings or friends, and introducing the deceased to those who did not know him/her (Riches & Dawson, 1998). Photographs help create physical,

emotional and spiritual histories for parents (Riches & Dawson, 1998). Some parents report that photographs have been paramount in their healing process (Alexander, 2001; Lundqvist, Nilstun, & Dykes, 2002; Riches & Dawson, 1998).

Published research and accounts of in-hospital bereavement photography focus largely on stillborns, neonates, and babies (Alexander, 2001; Gohlish, 1985; Harvey, Snowdon, & Elbourne, 2008; Mander & Marshall, 2003; Radestad, Nordin, Steineck, & Sjogren, 1996; Reddin, 1987). The use of bereavement photography with stillborns, neonates and babies is particularly compelling as families may not have any photographs of their child (Kolakowski, 1999); research studies have supported the use of photography in this group of patients (Gohlish, 1985; Mander & Marshall, 2003; Radestad, et al., 1996); and guidelines for bereavement photography involving babies exist ("Bereavement photography," 2006). The literature provides little information about the existence and extent of such programs beyond the neonatal period. Some challenges to introducing pediatric bereavement photography programs generally include: personal and cultural beliefs that photography is meant for happy occasions or photographing the dying or dead is macabre or voyeuristic; and concerns that the presence of a photographer could impair healthcare professionals (HCPs) caring for the patient and family during the dying and/or post-mortem period. HCP's reluctance to offer bereavement photography to families of patients beyond the neonatal period may reflect a presumption that families already have photographs of their children, or a concern that many children who die are significantly disfigured from traumatic injuries or prolonged illnesses.

To our knowledge, there are no empiric data regarding the implementation of bereavement photography in pediatrics beyond the neonatal period and the impact of such programs on HCPs or families. We describe the implementation of a Pediatric Intensive Care Unit (PICU) bereavement photography program at one hospital; provide reflections from HCPs on the program; and address barriers to implementing and sustaining such a program.

Methods

Program design/initiation

Children's Memorial Hospital (CMH) initiated the "Memories Held" bereavement photography program in 2006 in the Neonatal Intensive Care Unit (NICU). The program was started in the NICU because we assumed that it would be most readily accepted there, given published experiences, and because the NICU is predominately a self-contained unit, thus requiring "buy in" from a relatively homogeneous group of HCPs and few subspecialists. After anecdotally observing positive responses to the NICU program from HCPs and families and because approximately 60% of in-patient deaths at CMH occur in the PICU (determined by reviewing the hospital's database), we expanded the program to the PICU. The NICU experience served as a foundation for developing the PICU "Memories Held" bereavement photography program.

We developed the PICU protocol with input from a multidisciplinary group: the director of the hospital's bereavement program; the palliative care team social worker; members of both the PICU and NICU nurse bereavement committees; the photographer; and a PICU attending physician. Using the NICU protocol as a foundation, this team defined patient/family eligibility, described the process for informing families about the program, determined roles for PICU HCPs in facilitating the process, established a plan for contacting non-PICU subspecialists involved in the patient's care, and planned follow-up with the deceased patients' families. We educated staff about the program through presentations at regular meetings, information provided online through the hospital intranet, and individually.

Table 1 outlines the project protocol. Patient/family eligibility included: death; impending death (determined by the PICU physician); planned withdrawal of life-sustaining therapies with an expectation of subsequent death; or an examination consistent with brain death. The photographer was willing to photograph any time of the day or night, seven days a week. Because he had other responsibilities, we confirmed the photographer's availability before informing parents about the program. A member of the care team approached the parents with an informational brochure showing images of the photographer's work and explained the program. To be consistent with institutional and Health Insurance Portability and Accountability Act (HIPPA) guidelines, the hospital required families to sign a consent allowing the photographer (not a hospital employee) to take photographs and to be privy to private health information. The photographer asked families to sign a second consent form, giving the photographer permission to take and copyright the photographs.

The photographer has specific expertise in bereavement photography and training in bereavement support. He used documentary-style, available-light techniques without posing participants to create images reflecting the emotions of the situation and highlighting relationships and interactions of those involved. (See Figure 1.) He did make accommodations if the family requested a posed photograph. The photographer edited the photographs into an album which he presented to the family in person (unless a family requested otherwise).

Funding

We provided this service without cost to eligible families. The program was funded by internal grants, private foundation grants, and private donors. We stopped the program because funding ran out.

Healthcare professionals' feedback

We designed the HCP questionnaire (which included closed and open-ended items) with input from the program's multidisciplinary development group, described above. We gave any HCP caring for a participating patient/family at the time of a photography session or introduction of the program to the parents a questionnaire to complete and return via intra-office mail. We stopped collecting questionnaires after the first 39 patient/families because many responding HCPs submitted multiple questionnaires (about different patients) and we felt the responses to our open-ended questions had reached saturation (Patton, 2002).

We employed descriptive statistics to analyze closed-ended questionnaire data using SPSS 12.0 (SPSS inc., Chicago, Illinois). We analyzed data from the open-ended questions using standard methods of qualitative data analysis (Patton, 2002). Using ATLAS.ti Version 6.0.15 (ATLAS GmbH, Berlin, Germany), two study-team members (KM and KB) identified important ideas within the data set through separate review resulting in a list of codes. We then defined and finalized the codes through iterative discussion. The same reviewers then separately coded the data using the refined codes. We used the Coding Analysis Toolkit (Coding Analysis Toolkit, Texifter, LLC, <http://cat.ucsur.pitt.edu/app/main.aspx>) to examine the reliability of the two reviewers by calculating a Krippendorff's alpha coefficient. The Krippendorff's alpha value for all codes was 0.744, slightly less than 0.800, which some require to support reliability, but higher than 0.667, which many consider acceptable (Krippendorff, 2004). The two reviewers resolved coding discrepancies through discussion. Our final coding set defined 4 categories and we identified the major themes within those categories. We asked two study participants (two PICU HCPs) to review our findings. Both felt our results were appropriate and comprehensive. Thus we used "member checking" to further support the validity of our analysis (Janesick, 2000). In keeping with custom in

presenting qualitative analysis, we report themes without using numbers or proportions (Patton, 2002).

The hospital's institutional review board approved the study.

Results

The PICU program ran from July, 2007 through April, 2010. Families of 59 (36%) of the 164 patients who died during that time participated in the program. Table 2 describes demographic characteristics of the patients whose families participated.

We collected 40 questionnaires from 29 HCPs caring for the first 39 patient/family participants. Table 3 describes the demographics of the HCPs. Table 4 shows the responses from HCPs to our Likert-scale items. Most responses indicated that HCPs agreed that families seemed grateful for the service (n=34, 85%), that the program helped him/her feel better about his/her role in caring for the patient (n=30, 70%), and that we should continue to offer the program (n=37, 92.5%). Most responses indicated that HCPs disagreed that the program consumed too much of his/her time, (n=34, 85%) and that the presence of the photographer made his/her job difficult (n=37, 92.5%).

Responses to open-ended questions

We asked HCPs the following questions: 1) What is the value of the Memories Held Photography Program for you? 2) What seems to work well with the Memories Held Photography Program? 3) What does not work well with the Memories Held Photography Program? and 4) How can we improve the Memories Held Photography Program? Responses fell into 4 categories: 1) descriptions of the program's general value; 2) positive aspects of the program; 3) negative aspects of the program; and 4) suggestions for program improvements. We describe themes identified from each category below.

Category 1. General value of the program—Many responses reflected general program praise and included such adjectives as “unique,” “special,” and “amazing.” Respondents more specific descriptions of the program's value touched on three themes: family appreciation; benefits to families; and support to the HCPs. HCPs remarked that families seemed to appreciate the program. One person wrote, “To see their faces light up when his [the photographer's] services are offered, is really quite humbling.” HCPs reported that the program seemed to directly benefit families, including siblings, by offering a “tangible,” “touchable memory.” They indicated that such memory making was a way of helping families cope with the loss of their child and supported families' healing process. HCPs also noted the value of the program for themselves and reported that the program gave them the opportunity to offer what they considered a beneficial service. One person said, “... it is helpful for staff to be able to ‘do something’ when there are no more medical treatments available.” One person described how the program helped him/her initiate a discussion about grief with the family. Another person noted that while the photographer was with the family, the HCP could focus on other aspects of patient care. One person commented, “It was also a chance for me to sit quietly and take the time to emotionally deal with the nature of my patient.”

Category 2. Positive aspects of the program—Themes in this category included: attributes of the photographer and his availability; attributes of the photographic content; and praise for the program protocol. HCPs noted that the photographer is “adaptive, flexible, non-intrusive.” One person remarked, “He is so sensitive to the family's needs and space that his presence is never intrusive.” HCPs also lauded the photographer's availability, noting “willingness to come quickly and stay as long as it takes” and their ease of

communicating with him. Many praised the content of the images. One person noted, “The photos express both the profound grief of those present and the deep love and connection they shared with their child.” Another person wrote, “These photos were so full of life, even though the child had passed.” Multiple comments reflected positively on how the photographs were taken. “The photographer is virtually invisible while still meeting parents’ requests,” commented one person. Another wrote, “The manner in which the photographer worked...still allowed me access to the patient.” For issues related to the program protocol, some reported that brochures helped when introducing the program to families. One person noted the importance of giving families the choice to participate or not in the program. Several people commented that it was good that families leave the hospital without the photos and follow-up with the photographer later.

Category 3. Negative aspects of the program—The themes identified in this category related to: communicating with families; program logistics; program availability; and concerning events during or resulting from the photography “sessions.” Some respondents discussed a need to improve communication with families about the program. One person expressed concern that a family may not have adequately understood how the program worked because the family’s primary language was not English. Another person noted that one family had questions about the program which the HCP could not answer. In regard to program logistics, HCPs complained about the consent forms, describing them as “lengthy/obtrusive” and noting that “Signatures sort of get in the way of the moment.” Others noted lack of clarity about how to contact the photographer or disappointment that sometimes the photographer wasn’t available. Respondents also reported some general concerns, for example, not having the photographer on site delayed one patient’s planned extubation; in another case, the photographer continued to ask a family about taking pictures after being told that they did not want more photographs taken. One HCP noted that one family asked to be absent while the photographs were taken, and this seemed “odd.” Another HCP expressed concerns about taking photographs of an unhealthy appearing child. This person also noted that he/she had not seen any of the final images. Many HCPs reported that they perceived no negative aspects of the program.

Category 4. Suggestions for program improvements—Respondents made specific suggestions for program improvement focusing in three particular categories: staff education; program availability; and logistics. Multiple HCP’s requested increased education about the program for nurses and physicians to raise awareness about the program’s existence, to answer questions about the program protocol, and to help staff feel more comfortable introducing the program and providing appropriate information about the program to parents. Many people expressed the importance of expanding the program beyond the PICU and NICU. Some suggested having more photographers. Others made specific suggestions to improve the program logistics such as shortening the consent forms; reinforcing the need to verify the photographer’s availability prior to discussing the program with families; and ensuring that the photographer is updated on the family’s and patient’s situation.

Discussion

We describe the successful implementation of bereavement photography in the PICU for patients beyond the neonatal period. HCPs involved commented positively on the program’s impact both for the families and for themselves. Based on our experience, we believe the main barriers to implementing such a program include: maintaining financial support; having a skilled and accessible photographer(s) available at all times; streamlining consent processes; and adequately informing parents about the program.

Our experience supports the feasibility of successfully implementing bereavement photography in the PICU. While we attribute some of our success to the program protocol, undoubtedly, much of our success reflects the unique skill, character and techniques of our expert photographer. HCP's comments on the sensitive manner in which the photographer interacted with families suggest that he was able to establish a kind of therapeutic environment during his sessions. Indeed others have noted the importance of how photographs are taken ("Bereavement photography," 2006; Reddin, 1987). Also, our photographer used a documentary approach, which allows for integration of the photography into the dying and caring process. This documentary photography may also have contributed to our success and to the impact of the program on HCPs.

That HCPs perceive PICU bereavement photography as beneficial to families is not unexpected given available accounts in the literature regarding perinatal bereavement photography (Mander & Marshall, 2003; Radestad, et al., 1996; Riches & Dawson, 1998). But our results also highlight the potential benefits of bereavement photography to HCPs. Respondents suggested that benefits to HCPs came both from giving HCPs something positive to offer families in need and, for some, allowing HCPs time and opportunity to reflect emotionally on the situation, to interact with families in a more meaningful way, and to engage in other patient care tasks.

HCPs caring for critically ill and dying children can experience a range of emotions. Such work can create feelings of meaning, satisfaction, and renewal, but can also cause a sense of suffering, burden, and emotional fatigue (Rushton, 2004). Common syndromes that befall HCPs caring for dying children include burnout and compassion fatigue (Kearney, Weininger, Vachon, Harrison, & Mount, 2009). Our results suggest that bereavement photography has the potential to mitigate both syndromes. Burnout results, in part, from a sense of ineffectiveness and lack of personal accomplishment (Kearney, et al., 2009). Respondents in this study praised the bereavement photography program because it gave them something to offer families at a desperate time. The program provided an opportunity to introduce an intervention that was perceived to have a positive impact at a time when traditional medicine had less or nothing to offer. Respondents also reported receiving positive feedback from families, providing HCPs with a needed sense of accomplishment.

Compassion fatigue, also called vicarious trauma, is like post-traumatic stress disorder but affects those witnessing the suffering or trauma of others (Kearney, et al., 2009). Compassion fatigue itself can lead to burnout (Kearney, et al., 2009). Kearney, et al., (2009) propose several techniques to avoid compassion fatigue, including developing self-awareness and engaging in "exquisite empathy." Some describe exquisite empathy as an intimate therapeutic alliance that results from presence and heartfelt concern (Harrison & Westwood, 2009). In our study, one clinician specifically commented on how the photography session provided a chance to reflect on his/her own emotions. Photography may introduce a *pause* in the action, allowing HCPs time for reflection and nurturance of self-awareness. The extent to which any HCP might use the time during bereavement photography for self-reflection will vary depending on the individuals involved and the situation. But memory-making programs, such as bereavement photography, may present an opportunity for and acknowledgment of emotional work that might not otherwise occur.

Our experience highlights barriers to implementing such programs. Maintaining funds for the program was our greatest obstacle. Our program relied on grants and private philanthropy, limiting sustainability. Finding a photographer(s) with the needed interpersonal skills, technical expertise, and availability is clearly another barrier. Institutions could train hospital-based HCPs to do this work, though it may be hard to impart

the appropriate skills on individuals with no previous training in the area of bereavement photography.

Other important, though possibly more manageable, barriers included burdensome consent forms and challenges to providing families with adequate information about the project. To address the issue with consent forms, institutions could reconsider the need to obtain a signature on a legalistic document. Clearly, HCPs need extensive education on program logistics and training on how to communicate with families about bereavement photography. Also HCPs need access to examples of the photography. While we had brochures, perhaps access to more images and literature in multiple languages would be helpful.

We recognize that we are not the first to offer photography in the PICU setting. Other hospitals may offer this service, though the extent to which PICUs offer photography around the time of death is unknown. There are at least two non-for-profit organizations that provide photography services to patients in the hospital. However, both organizations rely on volunteer photographers with varying skill and expertise in bereavement photography. Neither organization has a program embedded into the processes of the institution as ours is. Both organizations provide portrait style photography, a very different approach compared to ours, with different goals for the resultant images as well as potentially different implications for and impact on HCPs and families.

While we received robust feedback from participants, our report has limitations. We only have information about our program from HCPs and no feedback from families. While most HCPs perceived our program as beneficial to families, we do not know families' actual reactions. However, prior research suggests that respondents' perceptions of parental benefits are likely accurate (Gohlish, 1985; Mander & Marshall, 2003; Radestad, et al., 1996; Riches & Dawson, 1998). Nonetheless, information on why some parents refused to participate in the program, what parents' actual responses to the program were, and how parents responded to the photographs would be helpful. Also we only have input from a limited number of PICU HCPs. Our results could reflect respondent bias. Finally, because our study was meant to be descriptive, our questionnaire was not formally validated, though it was reviewed by a group of experts.

Implications for policy, practice and future research

Implementing bereavement photography in the PICU is feasible. We describe important but manageable barriers to implementing such a program. The possibility of training HCPs or other hospital staff to do this important work should be explored to address the limitations associated with having only one person available to do the photography. HCPs may benefit from such programs, though more rigorous comparative studies are needed to fully understand the impact of bereavement photography and other similar kinds of memory making activities on the experiences of HCPs. Finally, more research is needed to understand the impact of bereavement photography on the end-of-life experience and bereavement process for families whose children die in the hospital.

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Figure 1.
Sue and Dave Hopkins spend precious time with their 6 1/2 year-old son, Will, in his last hours.

Table 1

Bereavement Photography Program Protocol

1	Determine patient/family eligibility
2	Confirm appropriateness of patient/family with study team
3	Confirm photographer availability
4	If photographer is available, a member of the medical team will inform the family about the program and obtain consent from interested parents.
5	Inform the photographer of parent's decision to accept or decline participation.
6	The program team member will identify and notify medical team members outside of the PICU about parents' decision to participate. Schedule permitting, PICU medical team members can help identify and notify medical team members outside of the PICU for parent's decision to participate.
7	Upon arrival to the PICU, the photographer is met by someone from the medical team and updated on the patient's and family's situation.
8	Someone from the medical team introduces the photographer to the family.
9	The photographer prepares an album of photographs for the family.
10	Approximately 4–6 weeks after the photographs are taken, the photographer contacts the family to discuss arrangements for presentation of the album (at the hospital, a neutral site, in their homes, via mail). Family may request to have specific hospital staff members present when they receive the album of photographs.

Table 2

Patient demographics

Patients – Total (n=59)*		
Gender	Female	29
	Male	30
Age	Range	2 days – 31 years
	Mean (SD)	5.2 years (6.1 years)

Patients - During Period of Health Care Provider Data Collection (n=39)		
Gender	Female	19
	Male	20
Age	Range	5 days - 31 years
	Mean (SD)	5.3 years (6.5 years)

* Includes the patients of all families who participated in the project

Table 3

Healthcare provider demographics

PICU Healthcare Professional	Forms Returned (n=40)	Individuals Represented (n=29)
Attending Physicians	4	3
Chaplains	5	4
Childlife Specialists	1	1
Fellow or Hospitalist Physicians	9	6
Nurses	17	13
Resident Physicians	1	1
Social Workers	3	1

Table 4

Responses to Likert-scale items

	Strongly Disagree or Disagree n (%)[*]	Neither Agree nor Disagree n (%)[*]	Strongly Agree or Agree n (%)[*]	No Response n (%)[*]
I am glad we are able to offer the Memories Held Photography Program to families.	0 (0)	0 (0)	37 (92.5)	3 (7.5)
Helping with the Memories Held Photography Program consumed too much of my time.	34 (85)	3 (7.5)	0 (0)	3 (7.5)
Families seemed grateful that we can provide this service.	0 (0)	2 (5)	34 (85)	4 (10)
The presence of the photographer made it difficult for me to do my job.	35 (87.5)	1 (2.5)	1 (2.5)	3 (7.5)
The Memories Held Photography Program helped me feel better about my role in caring for the dying child and his/her family.	0 (0)	7 (17.5)	30 (75)	3 (7.5)
I hope we can continue to offer the Memories Held Photography Program to families.	0 (0)	0 (0)	37 (92.5)	3 (7.5)

* Percentage of the 40 returned responses