Communication With Families After the Death of a Child

A Pilot Study

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Anecdotal evidence reveals that bereaved parents often feel cut off from the healthcare community they have come to depend on during an intimate time: the final months or days of their child's life. There is a scarcity of literature that addresses the topic of condolence letters in both adult and pediatric populations. The purpose of this study was to identify what practices are used by nurses trained in end-of-life care for communication with parents after the death of a child. A total of 24 of 40 nurses (60%) who are End-of-Life Nursing Education Consortium–Pediatric Palliative Care trainers completed a short four-question Web-based survey regarding their practices in the use of condolence letters and other forms of communication within the population of parents of deceased pediatric patients. Nearly all participants (92%) said they send a sympathy card with a handwritten note, and a majority (58%) called the parents personally. Most participants (67%) felt a sense of closure after sending a card or letter, and 71% reported hearing back from the parents after they have received the card or letter. All of the nurses who responded to the survey used some type of condolence correspondence, and many used more than one form of communication.

KEY WORDS

bereavement, condolence letter, end of life, nurse, pediatric

How does the healthcare community handle communicating with parents after a death? Do clinicians attend funerals or write personal condolence letters? After hearing parents speak of their experiences both good and bad in parent panels during End-of-Life Nursing Education Consortium–Pediatric Palliative Care (ELNEC-PPC) courses, the first author (S.T.) wondered how clinicians were communicating with parents after the death of a child. The relationship formed with children, parents, and families at the end of life is often very intimate and intense. This is especially true when clinicians and families have long relationships that may have lasted from months to years when battling diseases such as cancer, cystic fibrosis, or muscular dystrophy or during the perinatal/neonatal period.

The ELNEC project is a training program that provides education to nurses and other healthcare providers in palliative care. The first national ELNEC course was held in February 2000 and since that time has trained over 12,750 nurses and other healthcare professionals.[1] A pediatric palliative care (PPC) course was developed and piloted in 2003, and since that time, over 1680 nurses have attended a national ELNEC-PPC course.[1] The modules presented during the 2-day training include Introduction to Pediatric Palliative Nursing Care; Perinatal and Neonatal Palliative Care; Communication; Ethical/Legal Issues; Cultural and Spiritual Considerations in Pediatric Palliative Care; Pain Management; Symptom Management; Care at Time of Death in Pediatric Palliative Care; Loss, Grief and Bereavement; and Models of Excellence.[2] Since ELNEC-PPC uses a train-the-trainer model, nurses return to their institutions and educate their staff in palliative care.[3] At most national courses and often during a local course, a 1-hour parent panel is held. The panels are composed of parents who have lost a child. During the session, the parents tell their story and answer questions from attendees. These sessions are usually very well received, and those in attendance have a chance to learn from the bereaved parents. The participants from this study were chosen from the population of ELNEC-PPC–trained nurses who have all received specialized education in bereavement.

There have been very few studies on the specific topic of condolence letters sent to families after a death. Twenty-five articles from 1986 through 2011 addressed this topic. Eleven of those articles were related to pediatrics (including perinatal/neonatal), 11 were adult specific, and three either addressed both populations or

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were generic. Several studies focused exclusively on physician[4-9] behavior, while others included or at least mentioned nurses.[10-17] The articles were contributed by authors from the United States, Australia, Italy, Israel, Canada, and Sweden. The literature consistently echoed the authors' experiences in communications from parents: very few clinicians contacted the parents or attended funerals. Practices have often been confined to an institution-based bereavement service sending a preprinted card or a clinician providing the parents with a business card before they leave the hospital.

LITERATURE REVIEW

Research in pediatric clinician bereavement practices tends to fall in two areas: perinatal/neonatal and general pediatrics. In the area of perinatal/neonatal death, parent needs are very clear: parents want truth and open communication both during the dying process and after the death.[14] Parents in this population often report feeling forgotten by clinicians.[18] A survey of bereaved parents in the United Kingdom found that the majority of parents appreciated receiving a copy of the medical summary after the death of their infant along with a letter inviting them to discuss the summary with their physician.[6] Other studies have found that most parents appreciated autopsy reports if they had consented to the procedure.[14] In the case of perinatal/neonatal death, knowing the truth appears to be an important part of the bereavement process in Western cultures.

According to the literature, the bereavement practices of pediatric clinicians vary widely. In one study of 376 pediatric critical care physicians, 76% of the physicians agreed that physician follow-up helps the family, but just over 20% of physicians actually contact parents of children who have died, and almost the same number never contact the families after a death.[5] In this same study, 37% of the physicians reported calling the family, 33% meet with the family several weeks after the death, 27% provide their contact information before the parents leave the hospital immediately after the death, 25% write to the family, and 34% discuss the autopsy findings with the family.[5] The main barrier to bereavement communication cited by physicians, nurses, and other clinicians was lack of time.[5,8,16,19] Ellison and Ptacek[7] found that medical records were often missing contact data for the family and that 71% of responding physicians would like to have the contact information provided so that they could communicate with the family.

In the majority of the studies surrounding communication with bereaved parents of pediatric patients, it was clear that parents appreciated all contact following the death, but the majority wanted to talk with the physician who cared for their child.[4,10,11,13] Parents want to meet with physicians to discuss the facts of their child's death, but they were more likely to want to receive emotional support from the nurse, chaplain, social worker, or other hospital personnel.[13] Many children's hospitals host annual memorial services for all the children who have died.[5,11,20] Many parents attend the service: some find it an opportunity to formally recognize their loss year after year, and some find a sense of community with other parents.[11] Studies have found that parents also return to the hospital to visit the staff to reconnect, to express thanks, to ask for explanation of medical information, or to seek bereavement support.[12,13]

International clinician bereavement practices have many similarities. In a survey of adult hospices in the United Kingdom, all hospices offered bereavement services, but they were not standardized: all hospices surveyed offered a bereavement booklet and follow-up contact, most offered a memorial event and grief support, and a few sent a condolence letter or a card on the anniversary of the death.[21] A Canadian study found that palliative care physicians were most likely to sometimes or usually call the family (68%), send a card or letter (46%), or attend the funeral (30%), and oncologists were least likely to participate in these activities (61%, 34%, and 5%, respectively).[8] In a study of 126 medical, surgical, or radiation oncologists in Israel, researchers found that more than 90% never attended funerals or memorial services, and a majority (57%) never sent a card, letter, or e-mail.[19] However, physicians in this study were most likely (70%) to call the family.[19] Physicians who said they were religious were likely (50%) to either telephone or send a card, while those who said they were spiritual but not religious were the most likely (39%) to go to funerals, visitations, or memorial services.[19]

METHODS

A four-question survey was developed using SurveyMonkey (www.surveymonkey.com). Two questions allowed participants to select as many choices as were applicable. Many participants chose multiple answers to describe their practice, so percentages are greater than 100%. Question 1 asked how participants contact parents after the death of a child (Table 1). Question 2 asked how participants felt after sending a card or letter and if they heard from the parents (Table 2).

The remaining two questions were optional and allowed free text. Question 3 asked participants about their experiences of sending a card or letter, and Question 4 allowed participants to add any additional thoughts about parental bereavement. The survey was sent to 40 active national ELNEC pediatric trainers from 22 states in all regions of the country as an embedded link in an e-mail. The participants were selected from the American

TABLE 1 Question 1 (Choose All Applicable Answers)

After the Death of a Child, How Do You Handle Contact With Parents?	n	%
• A preformatted letter with some personalization	6	25
• A preformatted letter with no personalization	2	8
• A sympathy card with a handwritten note	22	92
• A personal, handwritten letter	9	38
• A sympathy card with only a signature(s)	2	8
• An e-mail	2	8
• I call the parents personally	14	58
• Someone from my facility calls the parents	9	28
• None of the above	0	0

Association of Colleges of Nursing ELNEC trainer Web site (http://www.aacn.nche.edu/ELNEC/trainer.htm) for PPC trainers. This sample was chosen because it was expected that potential participants would be active in bereavement support or at least aware of the importance of bereavement support for parents after the death of a child. Data for the first two questions are shown as percentages. The free-text, qualitative data were analyzed for general themes and shared as direct quotes.

RESULTS

Twenty four of 40 nurses (60%) responded to the survey. The first two questions had multiple choices. Because participants could choose more than one answer, percentages add up to more than 100%. The first question asked how participants contact parents after the death of a child. Most participants (92%) said they send a sympathy card with a handwritten note, and a majority (58%) call the parents personally. Many respondents send a personal, handwritten letter (38%), or someone from their facility calls the parents (38%). A few respondents send a preformatted letter with some personalization (25%). Only two participants said they send a preformatted letter with no personalization (8%), send a sympathy card with only signatures (8%), or send an e-mail (8%).

The second required question asked how the participants felt after sending the correspondence and if they heard from the parents. A majority of participants (67%) said they felt a sense of closure after sending a card or letter to the parents. Most of the participants (71%) heard from the parents after they received the card or letter. All participants had some communication with the parents after the death.

An open-ended question, asked: "Would you share your general experience of sending cards and letters?" Seventy-five percent of study participants shared further thoughts on this topic. The themes that emerged were as follows: a sense of closure, nurses show their caring of the families, families appreciate the contact and support, and bereavement support does not end with the initial sympathy card. Most of the respondents said they feel a sense of closure by sending a card. One participant said, "For some families, I do feel a sense of closure, …[for others] I don't ever feel a complete sense of closure." Many participants have a sympathy card that nurses working on the unit may sign and include a message as a group. Often, primary nurses send their own card and also attend funerals. One nurse said, "I often send cards at holidays, birthdays, etc. I try to include a personal message for the siblings." This thought was echoed several times. Several of the respondents mentioned how much the families they hear from appreciate receiving the card or letter. Some participants indicated a sense of personal growth through communication with families. As one nurse explained:

> Writing a sympathy letter allowed me not only a sense of closure but also an opportunity to share special moments that I have had with their child and how it helped me grow not only as a nurse but also as a human being. Many times, these are the things that are often left unsaid during the time when I am preoccupied with caring for their loved one.

Many nurses send cards periodically for a year or more including birthday, anniversary date, and holidays and report that families appreciate the contact.

The final open-ended question asked participants to "Please share any thoughts or additional experiences relating to parental bereavement." Most of the study participants (71%) described how they felt about bereavement. This question led to an outpouring of experiences that were captured in the following themes: a sense of closure for nurses, a feeling of appreciation from parents, and an acknowledgement that parents often feel abandoned by the healthcare team. One nurse said, "I feel a

TABLE 2 Question 2 (Choose All Applicable Answers)

Would You Share Your General Experience of Sending Cards and Letters?	n	%
• Did you feel a sense of closure after sending the card/letter?	16	67
• Did you hear from the parent after they received the card/letter?	17	71
• I do not send a card or letter.	0	0

better sense of closure if I actually get to speak with the parents." Along with the possibility of closure for the nurses, another nurse spoke of how it is "difficult to express your sorrow to a family when you are also grieving the loss of a child that you cared for." Several nurses said that they attend funerals whenever possible.

According to the participants, parents often express appreciation of being remembered either by calling or coming by the hospital to visit. Many facilities have yearly remembrance services. One nurse said of her experience of this event, "We have people who come once, and then others attend for years… if you leave the connection possibilities open for families, they will seek you when they need you." Another nurse explained that continued contact between parents and nurses "helps the parents to… keep the memory of the child through the nurses."

Several participants acknowledged that parents often feel abandoned by the healthcare team. One nurse explained:

> After spending such an intimate time such as the loss of a child, I find that many times parents feel as if we just move on after they leave. I think that sending them a note and letting them know how their child ['s life] touched mine and others' lives make them realize that they and their family are not forgotten.

Families with longer relationships with the healthcare team seemed to experience greater feeling of abandonment according to another nurse with over 15 years of experience who stated that families feel abandoned most "when a team has worked with a family for long periods of time, months to several years."

LIMITATIONS

The limitations to the study include small sample size and sample bias related to choosing only ELNEC-PPC trainers: a population likely to have experienced a heightened awareness of bereavement issues. Data were self-reported, and those with more experience with grief and loss may have been more inclined to answer the survey. The questions asked in the Web-based survey were meant to be exploratory, and a validated tool was not used. While the results may not be generalizable to all clinicians, they do report on the practice of these pediatric nurses.

DISCUSSION

Bereavement practices vary widely from facility to facility and among clinicians. Most studies regarding bereavement communication practices have been conducted with physicians or with parents and families. The role of nurses has not often been included in this literature. While nurses are mentioned in eight of the studies, none focus exclusively on nurse communication with the parents of a deceased child. This pilot study specifically looked at the bereavement practices of nurses across many settings from bedside to advance practice about their practice regarding communication with families after the death of a child.

Meaning making is a theoretical framework that speaks to grief and guides this topic.[22,23] In the meaning-making framework, parents strive to find a sense of meaning after their child's death and to "preserve the significance of their child's life."[22(p793)] Receiving a letter, phone call, or other communication from the nurse, physician, or healthcare team may help parents know that their child is remembered and had an impact on their healthcare providers.

There does not seem to be a consensus or any evidence that speaks to a "best practice" or "standard of care." One common finding is that parents desire contact from the healthcare team after the death of their child. They want to hear not only an acknowledgement of the death of their child but also the medical facts surrounding the death. Parents appreciate hearing from the nurses who cared for their child and will come by the hospital to visit with them often more than once. More than one study found that parents come back to the hospital to visit staff.[12,13] It seems likely that the ritual of funeral attendance helps both the family and the nurse. A thought heard from parents during ELNEC-PPC parent panels is that sometimes parents feel more comfortable talking about the death of their child with the healthcare providers than with family and friends. One study participant said that people "tend to not want to bring the death up because it may upset the grieving parent," but in fact, many find that talking about the child and the death experience is helpful in bereavement.

An interesting difference between the attitudes of families of adult patients versus pediatric patients is that, in adult patients, families are happy to have contact from any member of the healthcare team.[4,10,11,13,16,17,24] For pediatric patients, however, physician contact is essential. In one study, parents said that having their child's pediatrician acknowledge the death in some way was very important to them because it acknowledged their child's life.[4] Another reason parents wanted the physician to contact them is that they often had medical questions that only the physician could answer[4,13] and to receive emotional support after the death.[13]

More research is needed to determine the best standard of care for bereavement support of both adult and pediatric families. In particular, further study is needed to determine the role of nurses in communicating with families after a death. One study found that parents and families sought nurses, social workers, and chaplains for

support after the death of a child.[13] Research should explore if and how nurse communication may benefit parents after the death of a child. In addition, research could examine when contact is best initiated and how long it remains helpful for families. The literature and clinical consensus indicate that there is no one single practice that fits all families. However, there is strong consensus that families desire follow-up communication after the death such as through a handwritten note expressing the physician's and the team's heartfelt condolences.

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