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Physicians' Conceptualization of "Closure" as a Benefit of Physician-Parent Follow-up Meetings after a Child's Death in the Pediatric Intensive Care Unit

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Abstract

We examined physicians' conceptualization of closure as a benefit of follow-up meetings with bereaved parents. The frequency of use and the meaning of the word "closure" were analyzed in transcripts of interviews with 67 critical care physicians affiliated with the Collaborative Pediatric

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Critical Care Research Network. In all, 38 physicians (57 percent) used the word “closure” at least once (median: 2; range: 1 to 7), for a total of 86 times. Physicians indicated that closure is a process or trajectory rather than an achievable goal. They also indicated that parents and physicians can move toward closure by gaining a better understanding of the causes and circumstances of the death and by reconnecting with, or resolving relationships between, parents and health professionals. Physicians suggested that a primary reason to conduct follow-up meetings is that such meetings offer parents and physicians an opportunity to move toward closure. Future research should attempt to determine whether follow-up meetings reduce the negative effects of bereavement for parents and physicians.

INTRODUCTION

Follow-up meetings have been proposed as a means by which physicians can provide information and emotional support to bereaved parents after their child’s death (1-7). Although no controlled trials evaluating the effects of physician-parent follow-up meetings have been conducted, descriptive studies point to the potential benefits of such meetings (1-5). In our prior study investigating physicians’ perspectives on follow-up meetings with parents after a child’s death in the pediatric intensive care unit (PICU), physicians reported their belief that for them and for bereaved parents, such meetings would facilitate a sense of closure (5). In our parallel study of bereaved parents’ perspectives on follow-up meetings, parents did not identify closure as one of the many anticipated benefits (4). Research suggests that most bereaved parents do not seek or experience closure in relation to their child’s death. Rather, they typically seek a connection to their child, or a sense of the child’s continued presence, through memories, mementos, rituals, altruistic acts, and relationships with others who knew the child (8-11). This discrepancy between the responses of physicians and those of parents is likely due to differences in the nature of the relationship each group had with the deceased child. For physicians, the child’s death often represents the end of the relationship; for parents, the death represents a change in the relationship, such that the death is acknowledged but the parent-child bond persists.

A clear understanding of the concept of closure, and the way in which the word is used, is elusive. Rather than specifically discussing closure, bereavement researchers refer to processes such as healing, acceptance, adjustment, recovery, resolution, post-traumatic growth, resilience, and moving forward (12-18). Among researchers who use the word “closure,” the concept is defined variably as an unnecessary and/or undesirable goal for bereaved parents (9), a coping strategy or transformative domain that allows bereaved individuals to move on with their lives (18-19), or a result of a compassionate end to the professional relationship between physicians and their deceased patients’ family members (20). The particular use of terminology often guides both conceptual understanding and practice (13). Thus, given that the physicians participating in our prior study believed that gaining closure is a potential benefit of follow-up meetings for both parents and physicians, and that this belief could shape their interactions with families before and after a child’s death, we sought to better understand physicians’ conceptualization of closure. We performed a content analysis to explore the frequency of use and meaning of the word “closure” during prior interviews conducted with pediatric critical care physicians in which their perspectives on follow-up meetings were elicited.

METHODS

This study is a secondary analysis of data collected by the Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN). At the time of data collection, the CPCCRN consisted of six

clinical centres and a data-coordinating centre (21). Details of the study methods are described elsewhere (5) and briefly here. The study was approved by each site's institutional review board. Informed consent was obtained from all participants.

Participants

Pediatric critical care attending physicians and fellows practising or training at a CPCCRN clinical centre between February 1, 2008, and June 30, 2008, were eligible for the study, with the exception of the principal investigator at each site. We mailed letters explaining the study to eligible physicians. Within two weeks of sending the letter, we attempted to make telephone contact with each physician to request participation and schedule an interview.

Interviews

A trained research assistant conducted semistructured, audio-recorded telephone interviews with each participating physician. Interview questions were designed to elicit physicians' experiences and perspectives related to meeting with bereaved parents after a child's death in the PICU. The interview questions were divided into three sections (5). The first section was comprised of open-ended questions regarding physicians' past experiences of participating in follow-up meetings with bereaved parents and the benefits that they perceived they and/or the parents had gained as a result of the meetings. The second section included open-ended questions about whether and how future meetings should be conducted, as well as potential benefits and barriers. The third section used a multiple-choice question format to obtain participants' demographic information.

Data Analysis

Interviews were transcribed verbatim, and a content analysis of the transcripts was performed. Content analysis is a method used in several disciplines to analyze text such as newspaper articles or transcripts of interviews, speeches, or interpersonal interactions. Content analytical procedures require the development of a theoretically driven, systematic approach to the identification, coding, and quantification of a clearly defined aspect of text (22). We chose physicians' use of the word "closure" as the unit of analysis.

Interview transcripts were imported into NVIVO 9 qualitative data analysis software (QSR International Pty Ltd., 2010). Using this software, we conducted an automated search for all occurrences of the word "closure," along with the context in which it occurred. In most cases, the context was the interview question that prompted the physician to use the word "closure" and the paragraph that contained the word. Two of the authors, one a communication scientist (SE) and one a pediatric critical care physician (KLM), recorded whether the word "closure" occurred in the first or second section of the interview and then used an iterative process to analyze the use of the word based on its context. This iterative process consisted of independently reading all relevant segments of text (that is, segments including the word "closure" and its context) to develop an initial list of categories representing all the ways physicians used "closure," discussing the list together to refine and operationally define the categories, and then returning to the text to ensure that the list was comprehensive. Once the list of categories was developed, the investigators independently coded each occurrence of the word "closure" based on whether it did or did not fit into each of the categories. After assessing intercoder reliability using Cohen's kappa, the investigators discussed and resolved disagreements. A final frequency count of the occurrences of "closure" in each category was conducted. Examples from each category are presented in italics.

Physician demographics were summarized as counts and percentages for nominal variables and medians and ranges for continuous variables. Relationships between use of the word

"closure" and physician demographics were evaluated by means of Fisher's exact test or the Mann-Whitney U test using SPSS 18.0 (SPSS Inc., 2009).

RESULTS

A total of 131 physicians were eligible for the study. Of these, 70 (53 percent) were interviewed, 1 (1 percent) refused, and 60 (46 percent) did not respond to attempts to contact them. Three audio recordings malfunctioned, leaving 67 transcripts available for analysis. The median age of those physicians for whom transcripts were available was 36 (range: 27 to 62 years); 37 (55 percent) were male; 48 (72 percent) were White, 14 (21 percent) Asian, and 5 (7 percent) Black; 3 (4 percent) were Hispanic; and 38 (57 percent) were attendings and 29 (43 percent) fellows. Physicians who used the word "closure" during the interview did not differ in age, gender, race, ethnicity, or career level from those who did not ($p>.05$).

Frequency

Of the 67 physician participants, 38 (57 percent) used the word "closure" at least once. Among those who used the word, the median number of occurrences was 2 (range: 1 to 7). Across all interviews, the word occurred 86 times: 50 occurrences (58 percent) were in response to questions about physicians' past experiences of participating in follow-up meetings with bereaved parents; and 36 occurrences (42 percent) were in response to questions about physicians' perspectives on future meetings.

Referents

In the 86 occurrences of the word "closure," participants referred to parents 69 times (80 percent). Other referents were physicians (n=11, 13 percent) or both parents and physicians (n=5, 6 percent); in one case, the referent was not specified (n=1, 1 percent). Intercoder reliability was acceptable (Cohen's kappa [κ]=0.8) regarding referents for each use of the word "closure."

Modifiers

"Closure" was used with a modifier in 53 occurrences (62 percent; κ=0.9). Modifiers indicated physicians' perception that closure exists as a process or trajectory rather than as a state or achievable goal. Of the 53 occurrences in which a modifier was used, 32 (60 percent) modified "closure" with a word or phrase that suggested closure occurs in degrees — such as "some," "a little bit," or "some degree of" closure.

> "When they come for the meeting, and the ice is broken, and finally we go through the specifics, I think there's a lot of sense of relief and some amount of **closure** in most of these meetings."

There were 14 modified uses of "closure" (26 percent) that indicated physicians' discomfort with the word, as though it did not accurately reflect the concept they wanted to describe. Examples include "a sense of," "sort of," or "a kind of" closure.

> "One [benefit] is, I think, some sense of kind of **closure** to the hospital process. That it's kind of officially over."

Five modified uses of "closure" (9 percent) described a quality such as "good," "better," or "fruitful" closure. Negative modifiers, such as "not," were used twice (4 percent) to describe circumstances in which closure was unnecessary for physicians.

> "I think now the benefit I get from [the meeting] is probably not so much **closure**, because...the effects of deaths are not as long-lasting for me now as they were 10 years ago."

Definitions

Rather than explicitly defining closure, physicians described the pathways along which parents and physicians move toward closure (Table 1). For parents, recurring themes related to these pathways included understanding the causes and circumstances of the child's death, considering the end of the child's life in retrospect, reconnecting or resolving relationships with health professionals, gaining reassurance, providing feedback, moving on, and accepting the reality of the death. For physicians, themes included reconnecting with families, further exploring the causes and circumstances of the death, and fulfilling professional duty.

Understanding the causes and circumstances of the child's death was a frequently mentioned pathway toward closure for both parents and physicians. In some cases, information not available at the time of death became available later through autopsies or other means. In other cases, parents had new or lingering questions following the death for which they sought answers.

> "I think it's good, 'cause it helps the families kind of gain a sense of **closure**, you know, get their questions answered, especially if it's going over autopsies or things of that nature."

> "Oftentimes, we kind of guess why the kid had died at that moment or whatnot, but, you know, we don't really usually get to have any sort of real **closure**, per se. I think it's just helpful to kind of review everything with everybody involved sometimes, and after some time has passed."

Reconnecting or resolving relationships was another often-referenced pathway toward closure for parents and physicians. The relationships between parents and the staff who cared for the child near the time of death are frequently intimate and intense, especially if the PICU stay was lengthy. An abrupt end to these relationships can be unsettling.

> "I think it's important for the family in many cases to come back and sort of get **closure** on the experience and also their relationship with us, which was, you know, usually a pretty intense one, certainly for the family a process, an experience that they'll never forget."

> "You enter into this relationship with these families
> you become part of their family. These meetings are helpful for the doctors too to get some kind of **closure** because you become so attached to these families and these kids."

Follow-up meetings held in the weeks to months after the child's death were also described as helping to move parents toward closure by giving them the opportunity to retrospectively consider the circumstances of the death with the assistance of the health professionals who cared for the child.

> "For the parents, it would probably help them after having some distance because of an obviously high-charged situation around a child's death. So it would help them achieve some **closure**."

Gaining reassurance that parents and health professionals did everything possible to benefit the child was described as another pathway toward closure for parents. Reassurance was thought to help relieve parental guilt and increase trust in the medical team.

> "I would like to think that it helped provide them with some **closure**
> One of the things that we talked about was that the dad was a little worried about could he have done something earlier, and, you know, the answer was no

> we were able to just reinforce the idea that he'd done everything that he could and we'd done everything that we could, and sometimes these things just happen."

Offering positive or negative feedback to health professionals at follow-up meetings was also described as a pathway toward closure for parents. Giving feedback allowed parents to contribute their experiences as information that would ultimately improve care for others.

> "I think that they would feel like, for one, they get some better **closure** that they would feel like they are important to the process and therefore have something to share. They can feel like, 'Okay, you know, we had a bad outcome, but I've hopefully helped for the next kid.'"

Accepting the reality of the death and moving on with life were two less frequently mentioned pathways toward closure for parents. Follow-up meetings were thought to represent a point in space and time in which the child's death could be confronted and from which parents could move forward.

> "I mean, it sounded like it brought some **closure**. They said it made things seem real."

> "I do think that it's beneficial to families in terms of **closure** for that particular child's death to help them move on a little bit."

Follow-up meetings helped physicians to proceed along a trajectory to closure by allowing them to fulfill their professional duties. Physicians described follow-up meetings as "part of my job" and said that their work was not complete until they had provided parents with final explanations.

> "I suppose it brings some **closure** for me as well. It just feels to me like the process isn't finished until at least you've sort of taken your last chance at finding out everything you can about the patient, making sure the family knows about that It just feels like I haven't quite finished the work if I don't do that."

DISCUSSION

We investigated pediatric critical care physicians' use of the word "closure" during previously conducted qualitative interviews designed to elicit physicians' perspectives on follow-up meetings with bereaved parents after a child's death in the PICU. Our findings demonstrate that physicians use the word "closure" frequently to refer to what they consider to be an important benefit of follow-up meetings for both parents and physicians. In contrast to these findings, prior research has shown that bereaved parents and bereavement scholars generally refrain from using the word "closure" in discussing adjustment following the death of a child (4, 9, 12-18).

The study of the use of single words in the context of personal journals, interviews, and daily interpersonal interactions is a method widely used in several disciplines. Studies have demonstrated that the words individuals use in daily life reflect how they think and feel, their personalities, their social identities and relationships, and their psychological states (23, 24). The pervasive use of the word "closure" by our study participants suggests that many physicians believe that parents and physicians need and desire closure after a child's death, and that the primary reason to conduct follow-up meetings is that they offer those involved an opportunity to move toward closure. Findings from our study also suggest that physicians view closure as existing on a trajectory rather than representing an achievable goal. Physicians frequently used modifiers with the word "closure"; they said that the word did not adequately describe the process, and they illustrated the process in various ways. They

perceived that parents and physicians move toward closure along multiple pathways — some specific to parents or physicians, and some common to both.

The most frequently mentioned way in which follow-up meetings allow parents and physicians to move along a trajectory toward closure is by offering an opportunity to discuss the causes and circumstances of the child's death. Physicians considered such discussion to be especially valuable for parents after the acute period of grief had passed. Indeed, the anxiety and distress that prevails at the time of the death may inhibit parents' ability to accurately and efficiently process information (25, 26). Participants also believed that it is valuable to physicians to talk about the cause of death, in part because preparing for the conversation requires them to contemplate the child's clinical course and the autopsy findings and reconcile this information with the child's outcome. Discussing these explanations with bereaved parents allows physicians to fulfill their professional obligations. Thus, follow-up meetings during which physicians and parents review details of the death, discuss new information, and address new or lingering questions may benefit both parents and physicians.

Another frequently mentioned way in which follow-up meetings can permit bereaved parents and physicians to move toward closure is by allowing them to reconnect with each other. In many cases, parents, physicians, and PICU staff develop intense relationships while caring for a dying child. When the child dies, these relationships often end abruptly. Parents may perceive this abrupt end as abandonment (20) and desire to reconnect with the people who cared for their child. Similarly, physicians and staff may wish to meet with parents to see how they are coping with the death. Thus, the chance to reconnect is another likely benefit of follow-up meetings for both parents and physicians.

Many of the pathways toward closure identified by physicians have also been described by bereaved parents as important needs that may be fulfilled through a follow-up meeting with the physician who cared for their child (4). However, parents typically seek fulfillment of such needs without considering closure to be their goal (4, 8-11). Pediatric critical care physicians often develop their understanding of bereavement processes through their extensive professional experience working with families of dying children rather than through formal training. The differences between the views of the physicians observed in this study and those of bereaved parents reported in the literature (4, 8-11) regarding parents' desire for closure suggest that physicians may need some formal training in the psychological processes of bereavement to broaden their understanding and better align their clinical approach with parents' goals.

LIMITATIONS

There were some limitations to this study. First, physicians were not specifically asked to discuss or reflect on closure; rather, our examination of the word "closure" was prompted, in part, by the fact that it occurred spontaneously and frequently. An analysis of responses to direct questions about closure might yield different results and, perhaps, provide more insight into the nature of closure in this context. Second, a large number of physicians (43 percent) did not mention closure; thus, information is not available about the extent to which these physicians' perspectives might have confirmed, extended, or contradicted the comments of the physicians who did so. Third, physicians interviewed for this study practise in academic tertiary care children's hospitals and may have perspectives that differ from those of physicians practising in other settings. Thus, findings from this study may not be generalizable.

CONCLUSION

Our findings support the need for further research that evaluates the ways in which physicians' beliefs about bereavement affect care for families before and after the death of a child. Prior studies have shown that bereaved parents are at high risk of complicated grief (27, 28). Further research should investigate whether follow-up meetings reduce the incidence of this and other disorders among bereaved parents. Similarly, health professionals who routinely care for dying patients and their families report a variety of work-related stressors that can lead to burnout and compassion fatigue (29-33). There is a need for studies to determine whether follow-up meetings affect the extent of work-related stress among such individuals. Other studies are required to investigate the processes and mechanisms through which the potential benefits of follow-up meetings occur. For example, Park (34) and others (35, 36) suggest that understanding the causes and circumstances of the death may help parents make sense of their experiences. Sense making, in turn, may facilitate healthier adjustment. Given that over 50,000 children die in the US each year (37), this type of research is clearly warranted.

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Table 1

Pathways to Closure

	Frequency n (%)*	Cohen's kappa
Closure for parents (n=69 usages)		
Understanding the cause and circumstances of the child's death	45 (65)	0.75
Considering the end of the child's life in retrospect	13 (19)	0.66
Reconnecting or resolving relationships with health professionals	10 (14)	0.65
Gaining reassurance	6 (9)	0.76
Providing feedback	4 (6)	0.79
Moving on	3 (4)	0.87
Accepting the reality of the death	2 (3)	0.87
Not specified	14 (20)	0.71
Other	7 (10)	0.68
Closure for physicians (n=11 usages)		
Reconnecting	5 (45)	0.84
Further exploring the cause and circumstances of the child's death	3 (27)	0.83
Fulfilling professional duty	3 (27)	**
Other	2 (18)	0.83
Not specified	6 (55)	0.77

* Each use of the word "closure" was categorized under one or more pathways.

** Cohen's kappa could not be computed because only one analyst identified the pathway prior to the consensus process.