

The Importance of Parental Connectedness and Relationships with Health Care.

Professionals in End-of-Life Care in the Pediatric Intensive Care Unit.

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Abstract

Objective: Support from health care professionals in a Pediatric Intensive Care Unit (PICU) is highly valuable for parents of dying children. The way they care for the patients and their families affects the parents' initial mourning process. This study explores what interaction with hospital staff is meaningful to parents in existential distress when their child is dying in the PICU.

Design: Qualitative interview study.

Setting: Level 3 pediatric intensive care unit in the Erasmus University Medical Center- Sophia Children's Hospital, Rotterdam, and the Netherlands.

Subjects: Thirty-six parents of 20 children who had died in this unit 5 years previously.

Interventions: Parents participated in audio recorded interviews in their own homes. The interviews were transcribed and analyzed using qualitative methods.

Measurements and main results: Parents' narratives of their child's end-of-life stage in the PICU bespeak experiences of estrangement, emotional distancing and loneliness. Significant moments shared with hospital staff that remained valuable even after five years primarily involved personal connectedness, reflected in frequent informational updates, personal commitment of professionals and interpersonal contact with doctors and nurses.

Conclusions: Parents whose children died in the PICU value personal connectedness to doctors and nurses when coping with existential distress.

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Medical and nursing training programs should raise awareness of parents' need for contact in all interactions, but especially in times of crisis and apprehension.

Keywords: parenting, communication, end-of-life care, pediatric intensive care unit, qualitative

Introduction

When parents are confronted with the unthinkable, the death of their child, they experience an immense impact on their lives. If this takes place in the Pediatric Intensive Care Unit (PICU), their mourning process starts right there. Compassionate care from health care professionals for both the dying child and the family influences the perception of parents of their stay in an Intensive Care Unit and mitigates the stress they experience.(1) It also affects the bereavement process, as memories of what happened in the PICU still comfort or distress them in the subsequent years.(2-4)

Different studies from (mostly) the United States have investigated the needs of parents who lost their child in the PICU and their priorities and recommendations for end-of-life care. (3,5) These studies made use of questionnaires with open-ended questions (5,6), focus groups (3,4,7), telephone interviews (8,9) and face-to-face interviews in the hospital(3). The time elapsed after the child's death varied between studies and the majority of participating parents were mothers. Through questions and prompts parents were invited to present their own perspective on the events. The results of these studies indicated that parents valued honest and complete information, good communication and empathic contacts with staff. (3-5,7,8,10) Parents not only have cognitive needs (to know and understand) but also affective needs (to feel known and understood).(11) Building a relationship between family and staff was found important. (7,12) Yet, it is not clear how health care professionals can help relieve parents' existential suffering when facing their child's death. Existential suffering or distress is hard to define, but the confrontation with the end of life, of existence, is associated with feelings of hopelessness, the shattering of meaning, fundamental loneliness and disruption of personal identity.(13,14) Existential suffering means 'being shaken to the core' and experiencing 'groundlessness'.(15) These issues are also at stake when a child dies. (16) To learn about parents' existential distress and what was important to them, we invited a number of parents whose child had died in our PICU to an interview. We visited them in their home environment to hear their personal narrative of happenings in the PICU. In their homes their child was present through photographs and mementoes. In the story they tell, parents in their own words express their concerns and the things that remain of value and significance to them, which is an important aspect of the mourning process.(6,17-19). Using qualitative analysis we examined how

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their natural narrative incorporated existential issues and what experiences with medical and nursing staff were meaningful.

This study is part of a larger (PhD) research project exploring meaningful experiences of parents whose child died in the PICU. We already published an article on the parental need for physical proximity to their child in End-of-Life care. (20) The aim of the present study was to learn what interactions of grieving parents with medical and nursing staff remain meaningful on the long term when facing the existential distress of their child's death in the PICU.

Materials and Methods

Design. To identify features of meaning and significance, we applied a qualitative research design with in-depth interviews. We contacted parents five years after the death of their son or daughter to understand what experiences are so branded on their minds that they still have meaning.

Setting. The setting for this study was the 34-bed multidisciplinary tertiary care PICU of the Erasmus MC-Sophia Children's Hospital, Rotterdam, the Netherlands. Interviews were conducted in 2013 and 2014 in the parents' home environment.

Participants. In the years 2008 and 2009, 92 children had died in the PICU. Parents of thirty-eight children were selected using a random number generator. Random selection was chosen because the interviewer worked in the department and we wanted to make sure that the selection of parents was not based on any kind of foreknowledge. Parents were invited by letter to be interviewed about their experiences in the PICU. The letter explained that they need not respond if they did not wish to participate and then would not be contacted again. Of the 38 invitations that were sent, six letters came back unopened, due to change of address. Twenty of the remaining thirty-two invitations were accepted (response rate 62.5 %). We approached the families one after the other and found after these twenty interviews that we need not include more respondents as data saturation was reached. The decision to be interviewed individually or as a couple was left to the parents themselves.

The study was approved by the Erasmus MC medical ethical review board (No. 2011-436). Written informed consent was obtained from all participants.

Interviews. All interviews were held at the homes of the families and lasted between 1 and 2 hours. The parents started the narrative in response to the main question: "Tell me about your child and what happened to him/her". The interviewer (JLF) followed the flow of the narrative and incorporated follow-up questions such as "Could you tell more about what happened to you at that moment" and probes such as "Please explain why you felt a loss" to encourage parental sharing and to get a better picture of the parents' intentions and

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feelings.(21) The interviews were audio-taped and transcribed verbatim. The interviews were held in Dutch.

Data analysis. The anonymized transcripts were analyzed by the interviewer (JLF) and a second investigator (MvD) independently, using Atlas-Ti 7.0 for coding and selection of themes. Any discrepancies between the coders were resolved through discussion until consensus was reached. In the first phase of coding, we looked at meaningful experiences in general and were struck by parents' feelings of estrangement and loneliness. We then investigated what had been meaningful to them in that situation. We discerned two major themes. First, parents needed to maintain connection with their child throughout the PICU admission, which we described elsewhere (20). The other meaningful theme was the value of being connected to both doctors and nurses, which is the topic of the current study. Contacts with psychosocial professionals and chaplains were occasionally mentioned, but the parents focused primarily on their relationships with physicians and nurses. We then analyzed the data set with a focus on interactions with PICU staff that conveyed meaning, both positive and negative. From the narratives we identified the dimensions 'information', 'non-verbal acts, behavior', and 'personal contact' and identified the importance of 'continuous updates' in the dimension of information provision, of 'personal commitment in professionalism' with respect to acts and behavior, and of both 'empathic support' and 'interpersonal contact' within personal contact. (Figure 1)

Relevant quotes related to these themes were selected and translated into English by an independent translator. If parents conveyed similar notions, the quote which expressed the issue at stake most explicitly was selected.

Results

Participant characteristics: Sixteen couples, and three mothers and one father individually participated. Parents were native Dutch, except for one mother who originally came from Pakistan. The children's age at the time of death varied from 2 weeks to 14 years. Length of stay in the PICU varied from 2 hours to over 5 months. Characteristics of the children are listed in Table 1.

Background: Impact of admission to the PICU. A striking element in the narratives was a feeling of alienation, estrangement from the events in the ward. One mother said: "It is as if you're standing beside, outside of yourself. You are conscious of things happening and yet you're standing beside it". (N15) Others described it as: standing at the side line, at a distance. (N11) A father said: "I strongly felt like watching from a distance. I still do. It is as if you're watching yourself, standing in a corner." (N2). These parents described it as a general feeling that remained during admission. In other narratives the feeling of disorientation was momentary. A mother who witnessed her son's resuscitation, said: "I entered into a kind of shock, I was there, and yet, it was as

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if I was pulled up.” (N10) Parents of children admitted after a trauma said it felt as if they were in a haze (N5), or daze (N3). A mother witnessing her son’s collapse felt ‘like a zombie’. (N2) Also the high-tech environment of the ICU and not knowing what was going to happen, made an overwhelming impression on some parents. It made them feel “a sort of plaything in a gigantic storm and you have no idea when it will end”. (N11, father)

N5: “ For you have to imagine: We never ‘come’ to the hospital. In any case, not before. But the light is somewhat dimmed, all the time you hear bleeps; your child is on 45 monitors. But next to it lies another child on 45 monitors. So it is rather an impressive scene, let’s say. Well....What is doing what and why are we doing it, huh?” Several fathers explained how they felt at a loss in the situation, having no control, being unable to interpret information and having no idea what to do. (N1, N2, N11, N14) Three mothers described the hours surrounding the delivery of their child, who was prenatally diagnosed with a life-threatening congenital anomaly as the loneliest in their lives. (N11, N14, N18) Their child was taken to the Intensive Care right after birth. The same mothers found it hard to connect to their child and never felt like being the mother.

N14: “But then you are actually labelled as the parent. Sure, you have a very important role, but it doesn’t feel like that. Because everybody is saying: You are the mother. But still... And then you start doubting yourself, like is something wrong with me then?... For in the beginning you feel like, let’s say, I am a perverted mother because I don’t have that feeling, which I should have. And everybody: you are the mother!”

N11: “So I was all the time between a kind of push and pull movement. Yeah, I happen to be the mother, they said every time in the unit. Then I thought: Ah yes, but what then... If your child happens to lie at that machine and I happen to be the mother. Well, what am I to do?”

To be able to connect to the situation, all parents had needed help from health care professionals in different dimensions of contact and support.

Information: the meaning of updates and contact.

For these parents to comprehend what was happening to their child, honest information was crucial. As long as doctors clearly explained what they thought and were about to do, parents could understand and interpret the situation, even if it hurt to hear “It’s not going well” (N20) Looking back, it helped them to make sense of the child’s death, which gave ‘peace’ or ‘rest’.(N8) Most parents were satisfied with the frequency in which they were given information. But to some parents being regularly informed of the medical situation was by no means sufficient. Especially in times of crisis parents had wished to know right at that moment what was happening.

N2: “ Then a whole bunch of people came in, and actually the only thing said was: he must be put on the ventilator.. Oh yes. And you’re standing next to it, literally. In the corner. Enters a whole team. At that moment, if only someone would take the lead and tell: ‘this we are going to do, because....’”

Several parents had wanted to ‘be taken by the hand’ (N2, N14), to be kept informed step by step, ‘to become part of what is happening’. (N2) Other parents explained that when there was no new information on the child’s condition, they still wanted some form of contact with doctors.. This is illustrated by a father expressing his dissatisfaction with a doctor who said he would only contact them if there was news on their son’s condition. On the other hand the father was grateful for this doctor’s colleague, who kept explaining what the medical staff was doing and said parents could always reach him: “Here is my card, you want to call, you have a question? Call me! It doesn’t matter when.”(N5)

Parents of children with a long admission said they sometimes had the feeling they were ‘forgotten’, because their child’s medical situation remained unchanged and thus apparently did not warrant communication. (N15, N18)

Non-verbal acts and gestures: meaning of personal commitment of professionals.

In the midst of uncertainties several parents perceived a professional urgency in doctors. Some of the parents had nicknames for their doctors, referring to how they acted professionally. ‘Dr. House’, for example, was always looking for new unconventional solutions to medical problems (N13). ‘Dr. Handyman’ always came up with ‘new creative ideas’. (N11) Their relentless efforts conveyed the message that ‘They didn’t give up on him’ (N13). An unconventional way of dressing sometimes in times of crisis made a similar impression. A doctor on night duty, who came in pajamas to support a colleague, unconsciously communicated: “I put everything aside to save his life”. (N7) This combination of professional skills with personal interest made a deep impression. (N10)

On the other hand, a doctor not showing up when parents had urgently asked for him in a crisis situation brought a lot of stress and made the parents feel they had to stay with their daughter day and night. They did not feel safe anymore. (N19) Besides, the nurses who said they would come to the funeral but did not show up are painfully remembered, too. (N6)

Personal contact: Meaning of empathic support and interpersonal contact.

1. Empathic support. Several parents mentioned they were being well cared for by the hospital team. This helped them cope with the situation. Food was often provided in times of crisis, a bed when a mother did not want to leave her son

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at all. (N6) Many narratives reflect feelings of gratitude for the way they were supported at the moment of death, and until they left the hospital.

N1: "Pretty much anything is possible. They also ask you: 'What would you like? Want to eat something?' That is something we found very positive. It stops there (for your child), but you are being seen there. This is why we actually don't find it difficult (to come to the hospital). Because we felt understood there."

The doctor who came to sit with the parents in the evening 'in his shirt-sleeves', was wellremembered for his show of care. (N12) On the other hand: a doctor who failed to make contact when parents entered the unit after having heard their child had already died appeared indifferent.

N10. "What was so peculiar, and these are things that are particularly stuck in my mind: that you enter, you know the reason why you come in, and this doctor was still behind the staff counter and he was just busy with colleagues. To discuss some things. And we are standing by our child, and instead... Then I had to go and ask, 'please can we have the curtain around us for a moment to just...' And: 'oh yes of course.' And that I found so bizarre that he did not come to us, join us, absolutely nothing."

It was also important that the child itself was seen as more than a patient. Parents remembered that nurses talked to the child even when she was totally sedated and explained softly what they were about to do. "Now I'm going to prick you', they said to her." (N12) Parents could tell that some nurses were conscious of the fact that it was a baby, a child and not just a sick patient they cared for. (N14) And several parents were grateful that the nurses told them they liked to take care of their particular child. (N19) "And then the nurse said something like: 'I was so happy I could take care of N.'" (N8)

2. Interpersonal contact. Most parents stressed the importance of interaction with hospital staff on a personal level. The memory of personal exchanges with (mostly) nurses was still cherished after 5 years. They still remembered names of nurses, who was getting married or soon leaving for a long trip, and they more than once had talked with nurses about the heavy job load. (N11, N13, N18, N19) In those situations any distance and difference between them disappeared. Several parents mentioned it had helped them to have normal conversations, "just having a chat". (N6, N8, N12)

Interpersonal contact occasionally was dearly missed. The parents of a child who had been readmitted many times and had known their doctor for years, said they found it difficult this doctor kept distance and did not want to be called by his first name. The parents had felt they formed a team with the medical staff and felt rejected as partners. (N19)

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Personal interaction was also reflected in the sharing of emotions, like crying together. Parents remembered the doctor's tear that dropped onto their dying son. (N8) Also physical contact with doctors or nurses had been very comforting. (N13) One mother started her narrative with: "I embraced the doctor who led my son's resuscitation."

N10."So you then see people who are doctors but also humans. Because you have to deliver a peak performance... You could see those emotions from their eyes. And you could see emotional release when everything was under control again. You just could tell from the body, you heard it, you felt it, you smelled it. From all these nurses who were standing there but also for example from the doctor as professional, who had to do her job. And I still remember that I asked her: 'Can I just hug you?' I had to let it go. Says she: 'of course'. And then we held each other for a moment and then moved apart. Because something was bleeping again, she had to go somewhere else again."

The caring attitude of physicians and nurses towards parents whose child was admitted for a long time made them feel at home. Doctors, but most of all nurses, were like friends and family; some parents even felt the PICU staff understood them better than did relatives and friends. With regard to the importance of connectedness to health care professionals there was no difference between the experiences of parents dealing with ECMO or resuscitation and parents who did not have that experience. Also, there were no striking differences between the data generated from single parents compared to the data from the couples.

Discussion

The personal narratives of parents whose children died in our PICU testify to the value of feeling connected to the doctors and nurses throughout their hardships. It was the personal contact that helped them bear the feelings of alienation, solitude, despair, and disconnectedness to their child. Some of these experiences of alienation are reminiscent of the psychological process of dissociation.

Several articles on existential suffering make clear that loneliness, fundamental aloneness, is one of the basic existential challenges.(14,22) The presence of others, a sense of being connected is therefore needed.(13) Our findings revealed this need for contact and connection in three aspects of pediatric palliative care.

First, adequate information provision was highly significant. In line with other research, honest and frequent information helped parents to understand what was happening and to make sense of the outcome.(5) Our study adds that besides medical technical information frequent contact is found indispensable,

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even when there is no news about the child's condition. In times of crisis direct contact and immediate information is crucial.

Second, the professionalism of medical staff as seen in their actions and behavior is another way of showing connection. Doctors trying their utmost or doing unconventional things communicate to parents that both their child and they themselves matter.(23) Third, personal contact with health care professionals was another significant feature emerging from the narratives. The memory of caring interventions by nurses, the sharing of emotions and the personal interactions were still meaningful in their mourning process after five years. The meaning that parents discern from these experiences is that they and their child had been seen, acknowledged, and found worthwhile. Knowing that you have been seen is an essential element of rebuilding the meaning of life when a trauma shatters the fundamental assumptions of life.(24) This is in line with findings that grieving parents need significant others, helpers, and witnesses to what happened. (19,25,26) Medical and nursing staff can fulfill this role when the mourning process starts when the child is still in the PICU. (9,23) In line with the conclusion of the study of Sand and Strang on existential loneliness, our study confirms that feelings of loneliness may decrease through empathic human encounters with care providers and experiences of mutual togetherness.(14) Our findings are in accordance with current literature on parental needs in end-of-life care, stressing the importance of relationship-centered care. Interpersonal sensitivity, and experiencing a bond with staff members conveying emotions and concern, can help families in their bereavement process (4 5). Caregivers also benefit from the relationships as a source of comfort and affirmation of their roles.(12)

Mutuality and reciprocity are important in relational communication.(27) At the same time, it is important to realize that the individual relationships between members of medical and nursing staff and families could affect the team as a whole. It is important that issues like the limits of personal contact and preserving professional distance can be openly discussed. This includes each caregiver's own way of interacting with parents. Moreover, parents could be asked how they would prefer to communicate and in which frequency.

For all parents, even those who stayed for just one or two days, having human contact with the health professionals in a direct and concrete way had been essential. A simple expression of this need is the meaning and importance of normal conversations. Coombs and Meyer pointed out that everyday conversations are important for both professionals and families in intensive care. (28) These will make it easier to communicate in more complicated situations, such as "the bringing of bad news".

We recommend our findings to be included in educational programs for both doctors and nurses.

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The first recommendation is addressing parents' need to make contact with the professionals in all interactions; especially in times of crisis and apprehension. For instance, in case of urgent medical invasive procedures or resuscitation with parents present, one of the health care professionals could acknowledge the presence of parents with a brief word of explanation, a touch or eye-contact to communicate they are aware of the impact of events on parents. Practice guidelines and education would help clinicians in supporting parents who are present during complex invasive procedures, as Curley et al showed (29). Secondly, in family conferences doctors could offer parents the opportunity to speak about their fears and hopes, their values and beliefs. This would help to increase the parental contribution to the dialogue that is often out of balance according to recent findings on communicative behavior of physicians and parents.(30,31) Third, practical training, such as interdisciplinary simulation sessions including parents, would help create awareness of parental existential needs and perspectives. Its value was also shown in Meyer's experiential training programs focusing on communication and relational learning for clinicians.(32) These approaches give clinicians not only the opportunity to practice challenging conversations, but also to practice and learn relationship skills and interprofessional teamwork in a safe setting. Also in the daily practice in the wards, it is important that health care professionals are aware of and response to the parental need for connectedness and their preferences in being informed.

A limitation of our research is the predominance of native Dutch parents. We tried to contact parents with a different cultural background, but they didn't respond. As culture and language may influence communication between hospital staff and parents from other cultural backgrounds, our findings may not reflect their experiences. The primary interviewer had supported two of the randomly selected families during their stay in the ward. This may in some way have influenced the interview process.

Another limitation is the single site of our data which limits generalization of the results. The interviews were held in Dutch and the quotes cited in this paper were translated into English, which might have caused loss of nuanced meaning. Strength of our research is that we analyzed parents' personal narratives told in their own words in their own homes. The home environment where the interviews were conducted may have helped the parents to tell the story of their loss and loneliness.

Speaking to parents after a time lapse of five years shows what remains significant to them in their mourning over time. Furthermore, the results reflect the experiences of both mothers and fathers, which is exceptional in most studies on the subject.

Conclusion

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Parents who lose a son or daughter on the PICU can face up to existential distress through personal connectedness to doctors and nurses. Medical and nursing training programs could raise awareness of parents' need for contact in all interactions, but especially in times of crisis and apprehension.

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