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Brief Report

Parents' Experiences of Pediatric Palliative Transports: A Qualitative Case Series

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Abstract

Context. Pediatric palliative transports, the practice of transporting critically ill children home for end-of-life care including extubation, are an option for children requiring high levels of medical support at end of life. Little is known about the experience from the perspective of the children and families.

Objectives. To understand parents' perspectives on the experience of pediatric palliative transports.

Methods. Open-ended interviews were conducted using a qualitative descriptive design. Each parent was asked to reflect on the process of bringing their child home to die. Conventional content analysis was used for data analysis.

Results. Nine parents participated. The decision to transport the child home was a process motivated by promises to the child or a conviction that it was the right thing to do. The parents were gratified by the attention to safety and detail involved, but the actual transport home was stressful to them. The arrival home was typically recounted as a celebration. Being home provided time with the child in the context of their family and contributed to their lives. Memories of the experience brought comfort and a sense of fulfillment.

Conclusion. Each parent found the experience positive and meaningful. The child's experiences when alive, not events at the time of death, were remembered. All parents recommended palliative transports, emphasizing the importance of home and family, when desired. These interviews strongly suggest that palliative transports make a positive, important contribution to the care of at least some children facing end of life, and their families. J Pain Symptom Manage 2015;■:■−■. © *2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Pediatric, compassionate extubation, location of death, critical care transport, palliative care

Introduction

Among the many choices to be explored in the course of caring for dying patients are decisions related to preferences about location of death, when that choice is possible. Several reports describe trends and attitudes in adult patients nearing end of life,[1−4] indicating that most patients would prefer to die at home.[3,5] In pediatrics, most parents and their child's clinicians share this view.[6−8] A survey of health care providers found that parents benefitted when death at home was presented as an option.[9] In the U.S., home is increasingly the location of death for seriously ill children.[10]

Pediatric palliative transport (PPT) is the medical transport to home or inpatient hospice of children with levels of life-sustaining support demanding a critical care transport team, with the expectation of death within minutes to days after the cessation of that support. This relatively recent development allows for a critically ill child's death outside of a hospital. There have been case reports,[11,12] a case review,[13] and a

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case series of 12 children,[14] but no reports of this experience from the perspective of the family. Nothing is known about the decision-making process leading to the transport, the experience itself, and its influence on the child's process of dying and its aftermath.

In this study, we examined the perspectives of parents whose children died following PPTs. We interviewed parents who had chosen to take their child home to die in a medical transport requiring a critical care transport team, with the intent of better understanding their experiences.

Methods

Subject Recruitment and Consent

We reviewed transport logs from the Boston Children's Hospital (BCH) Critical Care Transport Team over the period January 2005 to December 2013, identifying all inpatients who had received a palliative transport. Excluded were children deemed ineligible for transport because of the likelihood of death during transport, patients discharged to home without requiring a critical care transport team, and "reverse" transports to local or referral hospitals.

Following approval from the Institutional Review Board at BCH, we sent a letter explaining the study to and requesting participation from each family that had experienced a PPT. The letter included a stamped, addressed postcard for parents to return if they did not wish to participate. Parents not declining were contacted by telephone, during which conversation the study was explained, questions were answered, and, if agreeable, an interview was scheduled. Before interviews, written consent was obtained. Participants received a $50 gift card.

Interviews

In-depth, open-ended interviews were conducted, each lasting 30–120 minutes. All interviews began with the prompt, "Please share with me your perspectives about the experience of bringing your child home before his/her death." Follow-up probes were used for clarification or further explanation, directing participants to explore the motivation behind the decision to go home; the overall experience; the effect of the experience on the parents' bereavement process; the effect of the experience on siblings and extended family; and whether participants would recommend a palliative transport to a family in a similar situation. Interviews were audio-recorded and transcribed verbatim, with all identifying information eliminated. The de-identified transcripts were used for data analysis.

Data Analysis

Transcripts were analyzed using conventional content analysis and open coding,[15] attempting to describe, not interpret, parents' perceptions using their everyday language to communicate what they stressed as important about the phenomenon of interest.[16,17] Investigators separately and then collectively reviewed transcripts of the participants, highlighting words and phrases conveying meaning and significance to the parents' experiences. Investigators discussed these first-level codes until consensus was reached on their significance, then similar codes were grouped together creating categories. Each category was defined, relabeled to reflect comprehensiveness of the category, and organized along a general time line of events.

Results

Parents of 10 children were contacted. The children ranged in age from six days to 24 years and represented a variety of medical and surgical diagnoses (Table 1). Nine parents of five children participated in the study, five mothers and four fathers. All but one of the interviews occurred in the parents' home, the one exception occurring at BCH. Three interviews were conducted with both parents present. All the deceased children had been intensive care unit patients.

Qualitative content analysis revealed six categories that emerged from the interview data: decision-making process, the transport, the homecoming, being home, the death, and life after. The sequence of these events was the same for all families (Fig. 1).

Decision-Making Process

Diverse motivations and processes behind making the decision to take their child home were recalled. The concepts of obligation to the child, advantages to the family, and the hospital as an undesirable location of death emerged. Parents were also commonly motivated by the idea that a return home held potential to be a more proper way for their child to die.

Some of the parents recalled asking the primary care team if going home was an option, whereas others remembered being presented options by the palliative care team. The parents of one infant recollected talking through three possibilities "that we could bring him home, that we could bring him to a hospice house or we could have him [die] at the hospital."

Parents varied in their expressed sense of obligation to their child for going home. Parents of newborns spoke about the goal since birth to take their baby home: