Parents' Reflections on the Quality of the Dying and Death of Their Children in Pediatric Intensive Care

Abstract Information:
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Abstract

Presentation Preference: SNRS Poster Presentation
Abstract Categories: Interest Group: Parent-Child
Thematic Areas: End of life issues

Introduction:
Most children who die do so in the hospital, most often in the PICU. Little is known about how parents view or remember this experience. In this study parents who had a child die in one PICU during 2004 and 2005 (total of 84 children, one set of twins) were invited to share their memories of having a child die in the PICU and to rate the quality of various aspects of their experience.

Method(s):
In loosely structured audiotaped interviews parents discussed what they remembered about their experiences of having a child die in the PICU. Parents were also asked for their recommendations to improve this experience. Tapes were transcribed and analyzed. Evaluation of the quality of their child's dying and death in the PICU was determined using a modified version of the Quality of Dying and Death Questionnaire.

Results:
Results suggest that parents of dying children want: more direct communication and information about their child's condition; to remain both present and involved in caring for their child until and after they die; and, both want and need some follow-up contact after their child has died.

Discussion:
The families and parents participating in this study identified several areas of health care intervention that influenced their experience of their child's death in the pediatric intensive care unit: 1) How the health care team provided accurate, consistent and timely information, 2) How the health care team intervened to permit them to remain present with their child, and 3) How the health care team enabled them to remain involved in care and maintain their family roles. Conclusion: Health care team interventions affect parents' overall experience of their child's dying and death.

Research Completed: Yes
Abstract History:
-This material has been presented or accepted for presentation in whole or in part at this or another scientific meeting.
-Details: ENLEC Chicago IL, June 28 2008
Financial Disclosure:
Have a financial arrangement or affiliation with commercial companies whose products may be mentioned in this material?
No
FDA Disclosure: Cleared: Yes