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# WHANAU/FAMILY MEETINGS IN THE PAEDIATRIC INTENSIVE CARE UNIT: CONTENT, PROCESS, AND FAMILY SATISFACTION

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## WHANAU/FAMILY MEETINGS IN THE PAEDIATRIC INTENSIVE CARE UNIT: CONTENT, PROCESS, AND FAMILY SATISFACTION

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#### **PREFACE**

I was drawn to this area of research in my role as a social worker and bereavement counsellor at a children's hospital. My motivation to complete this research was driven by a desire to improve family and medical team communication during critical end-of-life family meetings. The communication of bad news to a family can be perceived as a psychological assault that shatters their sense of a meaningful world and renders them physically, emotionally, and spiritually decimated. As one father said, 'Hope is dashed', and 'Hope is such an incredible commodity, keeps you going, and to lose it is an almost physical blow, one feels weak and shaky'. The communication of bad news to family members is a daily occurrence in large paediatric hospitals but there is limited data to guide clinicians in the delivery of this news.

During the course of my counselling work with bereaved parents, material emerged suggesting that the way in which the prognostic information was delivered to a family appeared to have some bearing on how parents coped with the death of their child. Those parents that experienced a chaotic death and who believed communication from the medical team was lacking, appeared to have greater difficulty making sense of their child's death. They would spend considerably more time ruminating over the events surrounding the death and would often be very angry with a member or members of the medical team. The perseverant reflection on the cause of death and events surrounding the death and accountability for the death created considerable distress that became interwoven with grief about the loss of the loved child. In contrast, those families who had maintained a good relationship with their medical team and where there had been good communication also tended to remember the death as a good death. They were also more likely to reframe the death experience as meaningful.

Breaking bad news to families who have a critically ill child is one of the hardest of tasks for paediatricians and one of the most traumatic experiences for parents. The decision to embark on a study of the content and process of family meetings in the PICU (hereon referred to as 'this study' or 'this research') comes as a response to improve the quality of family meetings at end-of-life and equip medical teams with information that will promote their discussions with family members.

This study has received ethical approval from the New Zealand Ministry of Health Northern X Regional Ethics Committee.

#### This work is dedicated to

Felix, Jo and Sean,

### The nine children who died during this research and their brave parents

Ruth and John

#### **ABSTRACT**

Family Meetings occur frequently in the Paediatric Intensive Care Unit (PICU) yet little data existed to guide clinicians in the conduct of these meetings. The medical team is required to deliver complex medical information and navigate complex decision-making with a traumatised family during a meeting. The objectives of this study were to describe the content and process of 15 whanau/family meetings in the PICU, identify family meeting characteristics and patient and family attributes that influence family satisfaction and recommend guidelines for health professionals working in the PICU.

The study was conducted in a PICU in a university-affiliated children's hospital in New Zealand (NZ). The process and content of 15 family meetings were analysed using a coding framework previously developed through a qualitative study of family meetings in the adult intensive care unit (Curtis, 2002a). A questionnaire providing a quantitative assessment of family satisfaction drawn from the same study was administered to 30 family members. Demographic data for the study were collected from the patient's hospital record and these were combined with data relating to the meeting recording and transcript to identify family meeting characteristics and attributes that might influence family satisfaction.

The content and process of family meetings in the PICU were described using a framework detailing 28 codes from the six domains: introductions, informational exchange, discussions of the future, decisions, discussions about death and dying, and closings. A comparison of family meeting characteristics and patient and family attributes revealed that longer meetings (40 minutes plus) were associated with lower family satisfaction and should therefore prompt clinicians to consider whether there are unresolved conflicts, difficulties or misunderstandings between the medical team and the family. Recommendations are proposed to guide health professionals in family meetings in the PICU.

This is the first study to record and code the content of family meetings in the PICU. The findings from this study will assist clinicians in their meetings with families. The description of the family meeting content will also provide a foundation for future communication training and research in the health environment.