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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**

**A thesis presented in fulfilment of the requirements for the degree of  
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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.

# CHAPTER ONE

## INTRODUCTION TO THE RESEARCH

# CHAPTER 1

## INTRODUCTION TO THE RESEARCH

### Introduction

The withdrawal of medical treatment with curative or palliative intent involves complex and highly sensitive discussions between family members and the medical team. These conversations often occur in the setting of one or more ‘family meetings’ attended by several family members and staff from the Paediatric Intensive Care Unit (PICU), including doctors, nurses, social workers and cultural support workers. They also occur at the child’s bedside or less formally in hallways and are very difficult and complex conversations that require a high level of clinical skill (Fineberg, Asch, & Golden, 2007). Family members are often traumatised (Azoulay et al., 2005; Dyregrov, Nordanger, & Dyregrov, 2003) and the medical team have to explain complex medical terminology and support the family in decision-making. Family meetings are the central components of good medical decision-making between the medical team and the patient’s family in the PICU (Fineberg, 2005; Fineberg, Asch, & Golden, 2007; Hansen, Cornish, & Kayser, 1998)

There has been “surprisingly little research into the processes” of family meetings (Griffith, Brosnan, Lacey, Keeling, & Wilkinson, 2004, p. 577) and there are no reported studies of family meetings in the PICU. In 2003 the US Institute of Medicine published *When Children Die: Improving Palliative and End-of-life Care for Children* (Field & Behrman, 2003). The report recognised that systematic data on paediatric palliative care and end-of-life care for children was not available. The report went on to issue a call for research and particularly descriptive data to guide the provision of palliative, end-of-life, and bereavement care for children and families. This research is a timely contribution to the study of communication with families in the PICU.

The limited research on family meetings and interventions to improve end-of-life care in the PICU may be due to the small number of children who die in the PICU compared to the large number of adult patients who die in the intensive care unit (Truog, Meyer, & Burns, 2006). The primary purpose and goal of paediatric intensive care is almost always to restore a critically ill child to health. It is only when this fails that the medical

team and family shift their focus to the quality of the dying experience (Robinson, 2002).

Clarke (2003) conducted an in-depth literature review of articles that assessed the domains of quality of end-of life-care, (the majority of the experts involved were specialists in adult intensive care). It was acknowledged that there were unique features of caring for dying children and their families. Unfortunately, these unique features were not identified. The review went on to call for a consensus on the important distinctions for high quality end-of-life care in the paediatric and neonatal intensive care units. This study has responded to that call and identified some of the unique features of family meetings in the PICU.

Truog and Meyer (2006) advise against assuming that experiences in the adult ICU (Intensive care units) and the PICU are the same. The maxim that 'children are not just little adults' is true not only for matters related to pharmacology and patho-physiology, but also with regard to end-of-life issues (Hynson, 2008; Truog, Meyer, & Burns, 2006, p. S374). Much of the previous research in the PICU involved retrospective studies (Meert, Thurston, & Briller, 2005; Mello, Burns, Truog, Studdert, Puopolo, & Brennan, 2004; Meyer, Burns, Griffith, & Truog, 2002; Meyer, Snelling, & Myren-Manbeck, 1998) or simulated role-plays (Browning, Meyer, Truog, & Solomon, 2007; Browning & Solomon, 2005; Fineberg, 2005; Meert, Thurston, & Briller, 2005; Mello et al., 2004; Meyer, Burns, Griffith, & Truog, 2002; Meyer, Snelling, & Myren-Manbeck, 1998) to explore communication approaches. No published examples of recorded meetings in the PICU were found in the extensive literature review for this study, so the foundation of this research was the work of J.R. Curtis and his colleagues (Curtis & Burt, 2003; Curtis, Cook, Wall, Angus, Bion, Kacmarek, Kane-Gill, Kirchhoff, Levy, Mitchell, Moreno, Pronovost, & Puntillo, 2006; Curtis et al., 2002a; Curtis, Engelberg, Wenrich, Shannon, Treece, & Rubenfeld, 2005; Curtis, Patrick, Engelberg, Norris, Asp, & Byock, 2002b; Curtis, Patrick, Shannon, Treece, Engelberg, & Rubenfeld, 2001; Curtis & Rubenfeld, 2005; Griffith, Brosnan, Lacey, Keeling, & Wilkinson, 2004). It was anticipated that using the work of Curtis might also draw out some of the differences between family meetings in the paediatric and adult environment. There is a growing body of family meeting research set within the context of the adult intensive care unit and the work of Curtis and colleagues will be examined in more detail in the following chapter.

## **The Significance of this Research**

This research breaks new ground in the study of family meetings in the PICU. Past attempts to record and code family meetings in the PICU have been unsuccessful due to an inability to get consent from medical staff (pers.comm with Elaine Meyer from St. Jude's Hospital, Boston, US in January 2006). The principal investigator (PI) was aware of these potential difficulties and planned a series of meetings and discussed the research proposal with a number of key staff before embarking on the study. There were no problems with the recruitment of the medical team members who were familiar with the work of the PI and consented at an early stage to engage in the research. The only concern from the medical team was that recording meetings would increase medico-legal risk. This was addressed after consultation with the health board lawyer who allayed their fears. The decision was made to exclude families from the study where it was considered litigation could occur or where child protection issues were under investigation.

The major contribution of this research is the description of the content and process of discussions during a family meeting in the PICU. The description was achieved through the use of 28 codes and the results of the coding are presented in Chapter 4 and then discussed in detail in Chapter 5. The collection of information concerning family meeting characteristics has provided important data for comparison with the work of Curtis and colleagues (Curtis et al., 2002a) who studied family meetings in the adult intensive care unit (ICU) and this is also featured in Chapter 5. This study has begun to identify the unique features of family meetings in the PICU and explored how satisfied family members were with those meetings.

The research has also provided descriptive and evidence-based data for clinicians and educators who are supporting and training medical staff to facilitate family meetings. Ultimately it is hoped that this research improves the quality of communication experienced by family members during end-of-life meetings in paediatrics. This in turn may improve the likelihood of the family experiencing a 'good death' (Hynson, 2008) and reduce the level of trauma experienced by the family after their child has died. Recommendations are presented in Chapter 6 and a number of proposals for future research arising from this study are also discussed.

## Methodology

The overarching questions driving this study were:

What is the content and process of a family meeting in the PICU and what factors influence family satisfaction?

In an attempt to address this question, the following three aims were formulated:

1. Describe the content and process of 15 whanau/family meetings in the PICU
2. Identify family meeting characteristics and patient and family attributes that may influence family satisfaction.
3. Recommend guidelines, developed from this study, for health professionals participating in whanau/family meetings in the PICU.

These aims focus on the meetings that doctors have with families in the paediatric intensive care unit (PICU) of a children's hospital in New Zealand. The foundation of the research is the valid and trusted study of J. Randall Curtis MD, MPH and his colleagues at the *End of Life Care Research Programme* from Seattle in the United States (see website <http://depts.washington.edu/eolcare/>).

The PI engaged in a three year process to collect data and information about the process and content of family meetings in the PICU. The PI collected literature and consulted locally and internationally with inter-disciplinary health professionals involved in the PICU. After completing a rigorous ethics investigation and application the PI implemented a study of 15 family meetings in the PICU. Each meeting was recorded and families were asked about their satisfaction with the meeting using a questionnaire. Data were collected, transcribed and then analysed using a coding framework developed by Curtis (Curtis et al., 2002a). Questionnaire scores were compared with demographic information and meeting attributes to identify any associations that might predict increased satisfaction from family participants. The findings were combined with the recent literature and recommendations for guidelines were proposed.

## Limitations of this study

The limitations of this study lay in its design, subjects, context, and resourcing. Each of the limitations will be elaborated on in the following paragraphs.

The sample size of 15 family groups limited the potential of the study to demonstrate significant relationships that are more widely applicable. However, 15 family groups and medical staff consented to participating in the research and that is regarded as a good sized sample for such a sensitive topic. The foundation of the work is a study by Curtis (2002a) with a sample of 51 family meetings from four hospitals whereas this study recruited 15 family meetings from one hospital.

The nature of the study and the sensitivity of the research did not allow for a representative selection. In order to achieve a representative sample it was proposed that the study sample would reflect the ethnic break down of the mortality statistics for the year 2007. It was anticipated that the ethnicity of the sample would reflect the same ethnic make up of the mortality statistics for the year 2007. Maori and European patients' families were well represented in the sample but Pacific Island families were underrepresented. The Maori Research Review Committee requested that at least one third of the families participating be Maori and this was achieved.

The sample may also have been influenced by the staff in the PICU who contacted the PI when a family meeting was being held. It is not possible to identify the family groups who were eligible to enter the study but were not passed on to the PI. Families who did enter the study may have had better relationships with the PICU staff and therefore may have felt obligated to rate the medical team more highly to preserve their relationship with the team. This potential bias has been taken into account and caution exercised in the interpretation of findings.

The Curtis framework (Curtis et al., 2002a) has been used to code the various content discussions that occurred during a particular meeting. However, it has not been possible to record the content of previous meetings that may have been held with the family and this might account for specific codes not being filled. For example, the introduction phase of one meeting may appear to have been neglected but this might also reflect the medical team's familiarity with the family and the continuation of an ongoing discussion rather than a stand-alone meeting. During the consultation phase of the research the PI considered adopting an approach that would involve recording all meetings with a family. This was ruled out due to constraints that would have required the PI to be permanently stationed in the PICU.



The coding of the transcripts was validated by two independent coders but only four of the transcripts were crosschecked by two coders for accuracy in this study. This may limit the accuracy and reporting of the coding. The foundation of this study was the research by Curtis (Curtis et al., 2002a) and this relied on eight coders who scrupulously double checked all transcripts, with 10% of all the transcripts being reviewed by all the coders. The resources required to employ additional coders were not available for this study. Yet the use of voluntary coders proved to be very effective with high inter-coder reliability.

Family meetings in the PICU are regular occurrences during a child's admission. These meetings often occur at the bedside during a medical consultation or in a corridor or more formally in a private space away from the bedside. At each meeting, the medical team learns more about the family. The family learns about the medical team's intentions and is updated about their child's condition. This study was not able to assess the satisfaction of family members with these meetings or to assess whether these meetings differ to the 'sit-down' meetings described by this study.

Finally the researcher acknowledges the universal possibility of a 'Hawthorne effect' (Campbell, Maxey, & Watson, 1995) that may have influenced the findings as the medical team and family may have altered their behaviour or modified their responses because they realised they were being recorded and scrutinised. The 'Hawthorne effect' postulates that the performance of individuals improves whilst they are aware of being observed for research purposes.

## **Outline of the thesis**

The results and findings of the family meeting research in the PICU are detailed in this thesis as follows:

**Chapter 1** provides an introduction to the research identifying the significance of the research and briefly acknowledging the research aims, questions and limitations.

**Chapter 2** provides an overview of the significant literature related to this research and the foundation of the research methodology.

**Chapter 3** details the research methodology and procedures. The preparation and process of the research is comprehensively described.

**Chapter 4** outlines the results and includes the processing, analysis and first interpretation of data.

**Chapter 5** presents a discussion and analysis of the coding framework and a discussion of the findings.

**Chapter 6** concludes the thesis with a summary of the key findings and, recommendations arising from the research including practice implications, guidelines for health practitioners and future research opportunities.

## **Conclusion**

In this chapter the subject of the research has been introduced and the timely significance of the research has been indicated. An overview of the research methodology has been given and the rationale for choosing a methodology employed in an adult setting was explained. The following chapter will contextualise the study and report a review of the literature in end-of-life decision-making and family meetings. This will inform the development of the methodology and provide important data for the third aim of the research which is to recommend guidelines, developed from this study, for health professionals participating in whanau/family meetings in the PICU.

## CHAPTER TWO LITERATURE REVIEW

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **Introduction**

The majority of the literature reviewed for this study emerged from the United States and is related to the adult intensive care unit (ICU). It may be helpful to acknowledge the differences between the delivery of socialised health care in New Zealand and the delivery of healthcare in the United States. The New Zealand healthcare system provides subsidised hospitalisations and pharmaceuticals. It also has a universal no-fault accident compensation system that may contribute to low rates of litigation and medical indemnity insurance premiums (Glasgow, McLennan, High, & Celi, 2008). The United States does not have a no-fault accident compensation system and does have high rates of litigation and medical indemnity insurance premiums. The research generated during the last ten years in the United States may have been influenced by the litigation that can arise because of difficult or inadequate communication between the doctor, patient, and family. However, the purpose of this review is to identify the evidence-based findings related to family meetings in health rather than an analysis of the financial motivation for improving communication or the differences in healthcare delivery systems.

The aim of this chapter is to review the literature relating to family meetings and end-of-life discussions in the paediatric intensive care unit (PICU). It explores the relevant studies and articles that have helped to shape this research. The selection of material included in this literature review includes the background to this research and additional material that will continue to inform the future analysis of data generated by this study.

The parameters of the review were set between 1997 and 2008 but also include other significant research and articles before that time. The key words that were used for the search: paediatric intensive care unit (PICU), neonatal intensive care unit (NICU), critical care, intensive care unit (ICU), family conferences, family meetings, end-of-life (EOL), communication, decision-making. Internet databases searched were Ovid, CINAHL, and Medline. This search uncovered 89 articles that included some landmark

materials predating 1997. Additional cited articles were sourced and reviewed as they emerged from the original search material.

## **Definition of family meetings in the PICU**

Family meetings are most commonly the forum in which family members (including extended family and friends) and members of the multi-disciplinary team meet together to exchange information about the patient's condition and to plan for the future. The international literature describes the forum in which a family communicates with the medical team as a Family Conference (Curtis et al., 2001, p. 796; Hansen, Cornish, & Kayser, 1998; Powazki, Walsh, Davis, & Bauer, 2006). The family conference is known as a family meeting in New Zealand with the term 'Family Group Conference' having a specific meaning in the context of care and protection of children.

In a rare social work article on 'Family Conferences as forums for Decision making in Hospital Settings' (Hansen, Cornish, & Kayser, 1998) the family conference is defined as:

*...a meeting which involves a number of family members, the patient and hospital personnel in discussions concerning the patient's illness, treatment and plans for their discharge or their care outside the hospital. (p.58)*

The discussions that occur during these meetings aim to ensure that the family and patient understand the patient's condition and prognosis, and facilitate decision-making. Hansen and colleagues do not address the important role of family meetings during end-of-life care, referring only to 'discharge' and 'care outside the hospital'. Fineberg (2005) also uses Hansen's definition of family meetings and goes on to describe the family conference as a clinical tool that enables patients, families and providers to discuss together the illness experience, care options and end-of-life care. Moneymaker (2005) developed a patient information sheet for families that described the family meeting as a forum in which healthcare professionals have the chance to meet with the family, to discuss information about the patient's illness, the response to treatment, and what to expect. Moneymaker suggested that the family meeting fosters communication and is an opportunity to share concerns, and provide information to help provide family-centred care.

Family meetings and family-centred care are the central components of good medical decision-making between the medical system and the patient's family in the PICU (Fineberg, 2005; Fineberg, Asch, & Golden, 2007; Hansen, Cornish, & Kayser, 1998). Family meetings are a reflection of the commitment to family-centred care. Family-centred care helps to establish the parents as partners with the medical team and encourages trust and cooperation. It can reduce fear and anxiety in the family and patient and at best create an environment of mutual respect and understanding (Ridling, Hofmann, & Deshler, 1992). Family centred care also places the family, rather than the hospital staff, at the centre of the health care delivery system (Hostler, 1991). Family centred care also ensures that the family are no longer considered as visitors in the ICU by the medical team and are active participants in the care of the patient (Lautrette, Cioldi, Ksibi, & Azoulay, 2006). The Initiative for Paediatric Palliative Care (Browning & Solomon, 2005) identified six domains of high quality family-centred care that included: support of the family unit; communication with the child and family about treatment goals and plans; ethics and shared decision-making; relief of pain and other symptoms; continuity of care; grief and bereavement support.

For the purpose of this research, the family meeting is defined as a meeting that involves the patient's family and the PICU team in discussions concerning the child's medical condition, plans for future care, and family wellbeing. This builds on the work of Hansen (1998) and acknowledges that the patient in this instance is a child and that family meetings may also be about end-of-life care. It acknowledges family wellbeing and the important task of supporting the family during such difficult discussions about their child's life.

## **Factors influencing clinicians during family meetings**

There are a number of different factors that can influence the process and content of family meetings, not least the personality and attributes that the medical team bring and their training experiences. Curtis and Patrick (2004) suggested two important aspects of end-of-life communication for consideration by clinicians. Firstly, that clinicians examine and seek to understand their own discomfort with death. Secondly, that effective communication requires training and practice similar to any technical skill. Fineberg (2005) states that 'like other clinical procedures and skills, family conferences must be taught' (p. 858). The following paragraphs will review some interesting material

presented by Peter Barr and then explore some of the recent training initiatives that are influencing the practice of medical teams in the PICU.

Barr (2007) has addressed the issue of a clinician's discomfort with death. He studied the relationship between neonatologists' personal fear of death and their treatment of newborns with severe disability for whom further treatment was considered non-beneficial or over-burdensome. Barr found that neonatologists with greater fear of their own dying process and premature death were more likely to hasten an infant's death using analgesia-sedation when further treatment was considered futile. Those neonatologists who feared being destroyed (for example being cremated) were less likely to intentionally hasten death, even though this could alleviate pain and suffering. Barr's work identified the link between doctors fear and the influence on clinical decision-making and this connects with Curtis and Patrick's suggestion that clinicians to examine their own discomfort with death.

A number of training initiatives have developed in paediatric and adult medicine to address effective communication with families. Participants at the Program to Enhance Relational and Communication Skills (PERCS) (Browning, Meyer, Truog, & Solomon, 2007) are encouraged to 'leave one's badge at the door', learn to be genuine and real, encourage colleagues from other disciplines into difficult conversations and attend to the emotional care of patients and families. Browning refers to this as relational learning and has identified some of the 'hidden curriculum' (Haidet & Stein, 2006) value premises underlying the culture of medicine that can complicate difficult conversations during family meetings. The 'hidden curriculum' refers to the value based assumptions such as 'Doctors must be perfect', or 'Uncertainty and complexity are to be avoided' or 'Medicine takes priority over everything else' and 'Hierarchy is necessary' (Browning & Solomon, 2006, p. 796). Browning and other commentators argue that today's culture of medicine is shaped by powerful economic forces that are hostile to the more traditional virtues of 'altruism, accountability, excellence, duty, service, integrity and respect for others' (Coulehan, 2005). Browning (2007) concludes that:

*Experience has taught us that it is indeed possible, in the busiest of hospital environments, to fashion learning experiences that promote moral reflection and reconnection with one's humanness, and that participation in this kind of relational learning can be transformative, both personally and professionally.*

(P. 910)

Preparing clinicians for difficult conversations became the focus of communication research marking the shift from descriptive studies to evidence-based interventions. This shift began in 2007 with the publication of Alexandre Lautrette's work with 126 dying patients and their families in 22 ICUs in France (Lautrette et al., 2007). Patients were randomly assigned to two groups, one of which involved a pro-active intervention utilising a Family Conference, the other a control group following the customary practices of the ICU. In the intervention group, the Family Conference was held in accordance with detailed guidelines and training drawn up by Curtis from his previous research (Curtis et al., 2001; Curtis & Rubenfeld, 2005; McDonagh et al., 2004). Curtis (Lautrette et al., 2007) developed the following mnemonic from the evidence base to guide clinicians in their discussions with families:

- V**...Value family statements
- A**...Acknowledge family emotion
- L**...Listen to the family
- U**...Understand the patient as a person
- E**...Elicit family questions

The families in the intervention group also received a brochure on bereavement. Participants were interviewed 90 days after the death and screened for post-traumatic stress disorder (PTSD), anxiety, and depression. The participants in the intervention group spent more time talking during the conference than those in the control group (median, 14 minutes vs. 5 minutes) and the meeting was of a longer duration (median, 30 minutes vs. 20 minutes). Participants in the intervention group also reported lower levels of PTSD, anxiety and depression than the control group. Lautrette concluded that providing relatives with a bereavement brochure and using a pro-active communication strategy might lessen the burden of bereavement.

## **Factors influencing parents during family meetings**

There are a number of factors that influence family members in the PICU including continued exposure to traumatic events and life threatening experiences that are known to precipitate post traumatic stress (Azoulay et al., 2005; Dyregrov, Nordanger, & Dyregrov, 2003). There is a considerable amount of literature dedicated to the topic of the impact of paediatric critical illness on a family, including an excellent review (Shudy et al., 2006) that details the vital needs of the family as rest, nutrition, hydration,



communication and a sense of partnership with the staff. This section will focus on what parents have identified as important during their stay in the PICU, what they identify as the factors that assist them with decision-making, and what their priorities are for end-of-life care. The following studies employed a retrospective methodology and relied on focus groups, clinical observations and self reported questionnaires from family members.

Truog, Meyer and Burns (2006) presented the descriptive data drawn from a literature review, clinician and patient surveys, interviews and expert practitioner workshops to identify six domains considered critical to high-quality family-centred care:

1. Support of the family unit
2. Communication with the child and family about treatment goals and plans, ethics and shared decision-making
3. Relief of pain and other symptoms
4. Continuity of care
5. Grief and bereavement support

This work was reinforced with a qualitative study (Meyer, Ritholz, Burns, & Truog, 2006) of 56 parents whose child had died in the PICU. The parents were sent a self-administered questionnaire with open-ended questions. The parents identified six priorities for end-of-life care that have implications for the delivery of family meetings:

1. **Honest and complete information**- the parents stressed that they wanted the broadest possible picture. As one parent wrote, 'Listen. Answer all questions. Give all information – parents can handle it. What we cannot handle, is not knowing what is going on. If something is wrong, tell us.' (Meyer, Ritholz, Burns, & Truog, 2006, p. 651)
2. **Ready access to staff** – parents emphasised that ready access to staff increased emotional peace of mind, provided information and fostered trust and reassurance. Inability to contact staff resulted in considerable stress for parents.
3. **Communication and care coordination** – the parents indicated that they wanted consistent information from the teams supporting their children's care. Some families wanted one primary doctor as the source of information and others wished to hear from all viewpoints. As one parent commented,

*There were many different MDs involved in my child's care. This became difficult when information was given to me. They sometimes had very different opinions and ways of dealing with the critical illness of my child. If there was a way of meeting together with all of them and myself it would have been helpful.*

(Meyer, Ritholz, Burns, & Truog, 2006, p. 652)

4. **Emotional expression and support by staff** – the verbal and behavioural expression of emotion was perceived by parents as authentic and reflecting a level of care beyond that required by the professional role. Staff who were seen as aloof, detached, or 'stone faced' were viewed as less empathic. Parents also acknowledged and valued the actions staff took to soften and humanise the clinical environment.
5. **Preservation of the integrity of the parent-child relationship** – parents wanted to be recognised by the medical team for their vital role, responsibility, and contribution to their children's care. They wished to be included in the decision-making process. In addition, most parents expressed a strong desire to be physically close to their child and have private times with their child.
6. **Faith** – many parents acknowledged the importance of their faith as a way of making meaning of their child's predicament. They also utilised their faith to find guidance, permission and assist in decision-making at end-of-life.

These six priorities provide some important guidance to the medical team on how to conduct their relationships with families in the PICU. Sharman and colleagues (2005) conducted semi-structured interviews with 14 parents of ten children whose PICU doctor had recommended the limiting or withdrawing of life support. The factors influencing the parent's decisions included their previous experience with making end-of-life decisions and making comparisons with the deaths of other family members. They also used their experience having directly witnessed the deaths of other children. A major determinant in their decision-making was their personal observations of their child's pain and suffering. Parents reported receiving help from their family and from God and faith was extremely important to this group. Parents reported that they did not relinquish their decision-making power to their wider family but felt the need to make

decisions themselves rather than depend on the views of other family members. Wider family support was shown in understanding and acceptance of the parents' decisions.

## **Decision-making in the ICU and PICU**

The family meeting is the key forum for decision-making in the PICU and there does not appear to be any decision-making literature specifically dedicated to the PICU in New Zealand. The following section details some of the international literature about decision-making and during this section the various approaches to decision-making are explored with reference to the New Zealand context.

A central function of the family meeting in the PICU is the requirement to explain and therefore justify the decision-making of the medical team and provide the family with the information about their child's condition so that they can also participate in the decision-making process. A number of studies have shown that families value their contribution to the decision-making process (Meert, Thurston, & Sarnaik, 2000; Meyer, Burns, Griffith, & Truog, 2002; Sharman, Meert, & Sarnaik, 2005).

Decision-making differs round the world but health is underpinned by the ethical principles of autonomy, beneficence, non-maleficence, and justice. Sarnaik and Meert (2007) state that almost all religions and cultures share these principles of health-care ethics. For centuries, decisions were left in the hands of doctors but as the principle of autonomy has developed, the role of the family in decision-making has also moved to the fore.

The Hippocratic Oath recognised the importance of beneficence, non-maleficence and medical futility but did not address autonomy or distributive justice (Yaguchi et al., 2005). Yaguchi and colleagues point out that over the last four decades autonomy and distributive justice have become increasingly predominant during end-of-life decision-making. The ethical principle of distributive justice is concerned with the fair allocation of resources among diverse members of a community. This is particularly significant for the healthcare system in the United States where the risk of litigation has increased the sensitivity of health-care providers as they navigate complex decision-making with family members. The ethical principle of respect for autonomy refers to the right of the individual to make his or her own decisions. This right is based on the individual's competence or capacity to understand the medical information that they are given by

the healthcare provider (McConnell & Frager, 2004). The ethic of autonomy is complicated when an individual's rights are held by a surrogate decision-maker, such as a caregiver, a family group, or friends. A previous study (Lautrette, Ciroldi, Ksibi, & Azoulay, 2006) has stated that less than 5% of adult ICU patients are able to communicate with clinicians at the time that decisions are made about withholding or withdrawing of life sustaining treatments. The family meeting in the adult environment will require the doctor to assess the family's ability and authority to act on behalf of a patient (Curtis & White, 2008). This is not the case in the PICU where the family - and specifically parents - are immediately recognised as legal representatives of their child.

Due to issues of competence and capacity to act, it is unlikely that children would be called upon to make decisions during their time in the PICU. If a child under the age of sixteen years wished to make their own decision independent of the family, they would first require assessment by a child psychiatrist. This assessment sometimes known as the 'Gillick test', should prove that the child 'can demonstrate sufficient maturity and intelligence to understand and appraise the nature and implications of the proposed treatment, including the risks and alternative courses of actions' (Wheeler, 2006, p. 807). This is a rare event in the PICU and responsibility for decision-making normally rests with the medical team and the family.

The family meeting has a decision-making function but approaches to decision-making differ around the world. Within the context of the New Zealand PICU, the decisional-authority rests with the medical team but they may also involve the family in shared decision-making. International studies of decision-making indicate a spectrum of models predominating in different areas of the world (Yaguchi et al., 2005). This spectrum extends at one extreme from paternalism (also referred to as parentalism) or doctor decides (predominantly a New Zealand approach) to the other extreme of autonomy or patient/family decides. The mid ground on this spectrum is shared decision-making (Curtis & White, 2008) where the family and medical team work together to achieve a consensus.

Orfali (2003) explored parental roles in decision-making in French and American NICUs. In France, a paternalistic model was evident, and Orfali notes that the parents were considered too emotional to make decisions and therefore the doctors acted on the child's best interest as the guiding criteria for decision-making. The American model of decision-making was based on autonomy and informed consent, and parents

were regarded as the appropriate decision makers. The role of the doctor in this context was to provide information and treatment options.

Research by Carnevale (2007) in France and Quebec, also indicated that a paternalistic model of decision-making operated in France and whilst decisional authority was more varied in Quebec, parents were the most common decision-makers. Parents in France appeared to be more satisfied, with their communication and relationships with their medical team, than were the parents from Quebec. Carnevale notes that a level of paternalism in decision-making was unavoidable in both countries, regardless of the ethical and legal norms in place.

The complexities of decision-making were reviewed in 2005 by five European and North American critical care societies who issued a joint consensus statement advocating shared decision-making about life support in ICUs (Carlet, Thijs, Antonelli, Cassell, Cox, Hill, Hinds, Pimentel, Reinhart, & Thompson, 2004). The consensus states that 'responsibility for decisions is shared jointly by the treating physician and the patient's family' (cited Curtis & White, 2008, p. 836). The practice of shared decision-making was then followed up with guidance on how to enact shared decision-making through a three step process; assessing prognosis and certainty of prognosis, assessing family preference for role in decision-making and adapting a communication strategy based on patient and family factors (Curtis & White, 2008; White, Braddock, Berekenyei, & Curtis, 2007).

The dilemmas associated with shared decision-making are reflected in the literature and a review by Sarnaik and Meert (2007) advocates the merits of shared decision-making and the importance of eliciting parental views. However the authors round off their review of shared decision-making reflecting the approach of the New Zealand PICU doctors:

*It should be understood that the final ethical and moral responsibility for end-of-life care decisions is borne by the physician.*

(Sarnaik & Meert, 2007, p. 106)

## **The End-of-Life Care Research Programme**

The following section details the work of Curtis including the methodology that has shaped this research and the findings from the End-of-Life Care Research Programme. The adult ICU is a setting where discussions about death and end-of-life care are common, yet in the 1990s, the quality of communication at end of life was under scrutiny in the United States. The poor quality of physician-patient communication was identified during a two year observational study (Connors, Dawson, Desbiens, & Fulkerson, 1995) of family members impressions of the dying experience (4804 hospitalised patients were involved). A further study (Azoulay, Chevret, Leleu, Pochard, Barboteu, Adrie, Canoui, Le Gall, & Schlemmer, 2000) evaluating doctor-family meetings in the ICU identified that 54% of family members did not adequately understand basic information about the patient's diagnosis, prognosis, or treatment after a conference with the doctor. The lack of evidence to support communication strategies in the ICU led to the formation of a working group of experts in palliative care, critical care, medical ethics and medical law who developed a research and education agenda for improving the quality of end-of-life care in the ICU (Clarke et al., 2003; Rubenfeld & Curtis, 2001). The working group laid the foundation for a research agenda for end-of-life care in the ICU. A key item on this agenda was 'communication in the patient-family-staff triad' (Rubenfeld & Curtis, 2001, p. 2003). This led to a focus on the family conference as an opportunity to improve communication in the ICU (Curtis et al., 2001).

Curtis and his colleagues embarked on an ambitious study to record family meetings (Curtis et al., 2002a). The research began in four ICUs in the Seattle area of the United States and 51 family meetings were recorded and then transcribed. At the close of the meetings, the participants (family and medical staff) completed questionnaires relating to their satisfaction with the meeting. The meeting transcripts were checked, anonymised and finally coded using grounded theory. Grounded theory and the process of analysing the transcripts is detailed here because the framework generated by Curtis will guide the coding of this study.

Grounded theory is a general methodology for developing theory that is based on qualitative data, systematically gathered, analysed and conceptualised. There are two particular steps in grounded theory, known as open and axial coding, in which the coding categories and frameworks are developed, defined, and described. To develop

concepts requires an opening-up, or open coding, of the text 'to expose the thoughts, ideas and meanings contained therein' (Strauss & Corbin, 1998, p. 102). In axial coding the open codes are grouped under higher-level concepts and explanatory principles (Curtis et al., 2002a, p. 149).

A team of eight investigators (including Curtis) were recruited to ensure a high level of trustworthiness and represented critical care medicine, critical care nursing, health services research, and anthropology. They were asked to develop a draft framework and were directed to identify codes for domains that described the content, interactions, and issues that surfaced during a family meeting. The codes were discussed and it was decided to develop two frameworks; one for content of the meeting and the second for style of communication. The initial group of eight investigators broke down into two groups of four. The first group focused on the content and the second group focused on style of communication.

The two subgroups independently reviewed three additional transcripts, using a draft framework to code the speech. Each group met in pairs to review their coding and resolve differences. New codes were generated when important new text was identified that had not been captured by the initial coding scheme. The sub-group met together to review their coding and reach a consensus. In addition, some codes were combined and others deleted when there was overlap in the code meanings. This process continued until the investigators achieved agreement on the coding. Pairs of investigators coded the remaining transcripts and every fifth transcript was reviewed by four investigators. The codes were used as the foundation for the frameworks.

The first framework generated by the team described communication content (Table 1), including introductions, informational exchange, decisions, discussions of the future, discussions of death and dying and closings. The second framework described the medical team's style of communication and support as they interacted with the family. This included behaviours such as active listening, acknowledging informational complexity and emotional difficulty of the situation, and supporting family decision-making. These frameworks identified the content of doctors' discussions, how they presented themselves and responded to issues, and how they supported families during these conferences (Curtis et al., 2002a). The first framework (Table 1) serves as the coding framework for this study.

**Table 1: Coding framework developed for the content of discussions during family conferences in the ICU.**

### **Introductions and openings**

Introductions	Introduces the family and team members; determination of the relevant decision makers and review of who is missing.
Purpose	Discusses the purpose of the conference, what to expect, and defining duration or other parameters.
Elicit agenda	Elicits issues or items for discussion.

### **Informational exchange**

Review patient's condition	Reviews the medical history up to the conference including past medical history, conditions, and ICU course leading to the conference.
Discuss patient's baseline	Discusses baseline physical and mental abilities, and quality of life including ability to carry out activities of daily living and other activities.
Values history	Obtains a values history of the patient including personality traits, values, generic treatment preferences; often involves acknowledging the family as the experts on these questions.
Clarification of terms	Explanations in lay terms of diagnostic tests, treatments, and medical terms.
Significance of information	Describes the significance of the details of medical history, current condition, tests, or treatments; provides interpretation of medical facts as good or bad and the integration of medical details into the big picture.
Symptoms	Discusses the patient's current comfort, symptoms, or experience in the ICU.
Affirming experiences	Affirms, acknowledges, or restates the family experience of the ICU stay or the course of the patient's disease or treatments.



Table 1: continued

## Discussions of what the future might hold

Prognosis for survival	Makes statements about the future (except predictions about quality of life—see later); includes predictions of death, duration of mechanical ventilation, dependency, and discharge location.
Prognosis regarding future quality of life	Makes statements about future quality of life and future neurologic function including cognition, and activities of daily living.
Uncertainty	Makes explicit statements about the inability of knowing the prognosis or course or the uncertainty of the prognosis.

## Decisions

Surrogate decision making	Discusses the principles of surrogate decision making.
Discussions of existing advance directives	Specific discussions of durable power of attorney, living will, and other advanced directives.
Options	Discusses procedures, treatments, or tests that might be performed in the future.
Choices	Discusses specific treatment options that are indicated, recommended, or selected.
Code	Discusses resuscitation status or emergent care.
Transitions from curative to palliative care	Discusses differences between life-supporting care and palliative care and their goals.
Burden and benefit	Discusses or balances both the burdens and benefits of treatment options.
Withdraw life-sustaining treatments	Discusses the possibility of stopping, withdrawing, withholding life support or any of the treatments linked to life-sustaining treatments.

Table 1: continued

## Discussions of dying and death

Dying	Discusses what withdrawal of life support might be like and what dying might be like including symptoms, process of care, location, physiology, and spiritual aspects.
Death	Directly raises the possibility that the patient may die.

## Closing

Summary of conference	Summarizes or reviews the treatment decisions made in the conference.
Family control of timing	Gives family control over time for private conversations, timing of decisions, and implementing the plan.
Assure patient comfort	Reassurance that patient will be made comfortable.
Further discussions	Plans for further discussions.
Continuity issues	Discusses physicians or nursing continuity of care issues.
Contact information	Provides contact information for physicians and/or nurses or express availability for future contact.
Gratitude	Acknowledges or shows appreciation for the value of the conference or care that the patient has received.
Next steps	Discusses what happens immediately after the conference.

(Curtis et al., 2002a)

This work had a number of limitations that has significance for this study. Firstly, the framework coding does not include any frequency scores so it is difficult to establish how frequently a code was identified from a transcript and therefore at what point it became identified as a valid code. Secondly all the meetings refer to patients who were 18 years of age or older; the rationale for excluding younger patient meetings is not stated.

Having established the frameworks, Curtis and his team from the *End of Life Care Research Programme* then conducted further analysis of the 51 meetings and developed a number of findings:

- **Increased family speech may be associated with increased family satisfaction.**

The team measured the duration of time that families and clinicians spoke during the conference and found that doctors spoke, on average, for 71% of the time. Increased proportion of family speech during the meeting was significantly associated with increased family satisfaction. Increased proportion of family speech during the meeting was also associated with decreased family ratings of conflict with the physician (McDonagh et al., 2004). These findings were consistent with a previous study of medical residents who spoke for 75% of the time during DNR discussions (Tulsky & Chesney, 1995). In reviewing McDonagh's contribution Meyer noted that providers who speak less also listen more (Meyer, 2004). A more recent study (Fassier, Darmon, Laplace, Chevret, Schlemmer, Pochard, & Azoulay, 2006) of 90 ICUs in France showed that in one day the median time spent giving information to families was 16 minutes (range 8-30 min.) minutes per patient and that family members spoke for 33% of the time. This study did not gauge family satisfaction but identified that doctors gave less information to a family and patient when more than one bed was in the room. None of these studies included paediatric patients.

- **Identifying commonly missed opportunities to provide support for, or information to families during a Family Conference.**

Curtis (2005) continued to analyse the data from the programme (Curtis, Engelberg et al., 2002) and using grounded theory identified and categorised missed opportunities. These were defined as occurrences when the doctor had an opportunity to provide information or support to

the family and did not. These missed opportunities fell into three occurrences:

1. **Missed opportunities to listen and respond to family questions.** This was the most common occurrence of missed opportunities. In this category, doctors failed to answer questions or avoided the question completely. At times, they misunderstood the question or failed to seek clarification from the family about the question. These unanswered questions would slow a meeting down and become the focus of repeated or unresolved questioning from the family.
  2. **Missed opportunities to acknowledge and address emotions.** The expression of emotion was very common during a family meeting whilst critical decisions were being made about a relative's life. Crying occurred with or without any verbal expression and the doctor did not always acknowledge this. The language that was used during these times by family members presented an opportunity to explore the meaning, significance, or impact of the news.
  3. **Missed opportunities to explain key tenets of medical ethics and palliative care.** These missed opportunities referred to the key tenets of medical ethics that the doctor would be aware of but about which the patient's family had no knowledge. The expression of these tenets and explanation of them could assist in complex decision-making. One example of this would be the doctor's explanation of patient 'autonomy' and the role of surrogate decision-making by the family.
- **The effect of expressions of nonabandonment during family meetings.**

Fear of abandonment was identified in the research as a key feature of the care of critically ill patients and their families. Addressing this fear became a point of quality improvement and during this study Curtis and

his team identified expressions of nonabandonment in the ICU (West, Engelberg, Wenrich, & Curtis, 2005). They identified three ways that clinicians expressed nonabandonment to families: alleviating suffering/ensuring comfort, allowing family members to be present at the bedside for the death, and being accessible to families and patients. They also identified how families expressed their own concerns about nonabandonment through: ensuring that the patient's wishes regarding end-of-life care are honoured, ensuring that the patient is comfortable, and being present at the bedside.

- **Prognostication during doctor-family discussions about limiting life support in the adult ICU**

During this study the team analysed the same data set of 51 family meetings and the objective was to identify the types of prognostic information delivered (White, Engelberg, Wenrich, Lo, & Curtis, 2007). Of the family conferences that were recorded 86% contained discussions about the patient's anticipated function or quality of life, compared with 63% in which the chances of survival were discussed. It appeared that less educated families received less information about prognosis, and the increasing educational level of the family was associated with more prognostic statements by the doctor.

Curtis and his team (Stapleton, Engelberg, Wenrich, Goss, & Curtis, 2006) were the first to provide an evidence base to illustrate the specific clinician behaviours and statements associated with family satisfaction during family conferences. In summary they reported higher levels of family satisfaction when clinicians:

- increased the time spent listening to the family
- assured family members that the patient would not be abandoned before death
- assured family members that the patient would be comfortable and would not suffer
- supported the family's decisions about end-of-life care

This concludes the report on the work of Curtis and his team. The purpose of this has been to explain the development of the methodology that underpins this research and

identify some of the findings that have shaped the recent ICU family meeting literature and may shape the findings of this research in the future.

## **Conclusion**

In this chapter the development and history of the Curtis coding framework was discussed. The factors influencing family members and clinicians were presented and decision-making was explored in the context of the PICU in New Zealand. It was also acknowledged that there were no published studies that have focused on the content and process of family meetings in the PICU. The literature that has been reviewed in this chapter not only provided the foundation for this study's methodology but also provided evidence-based information for the guidelines featured in Chapter 6. The following chapter will detail the methodology used in this study.

## CHAPTER THREE METHODOLOGY

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### **METHODOLOGY**

#### **Introduction**

This chapter outlines the research methodology and procedures used in this study. In the previous chapter, the literature review identified the gap in paediatric research on family meetings in the Paediatric Intensive Care Unit (PICU) and detailed the family meeting research and methodology employed by Curtis and colleagues (2002) on which this study has been based.

The overarching questions driving this study were:

What is the content and process of a family meeting in the PICU and what factors influence family satisfaction?

In an attempt to address this question, the following three aims were formulated:

1. Describe the content and process of 15 whanau/family meetings in the PICU
2. Identify family meeting characteristics and patient and family attributes that may influence family satisfaction.
3. Recommend guidelines, developed from this study, for health professionals participating in whanau/family meetings in the PICU.

This study utilised a coding framework developed through a qualitative study of family meetings and a questionnaire providing a quantitative assessment of family satisfaction drawn from the same study (Curtis et al., 2002a). This material is detailed in Chapter 2. Demographic data for the study was collected from the patient's hospital record and combined with meeting recording data and transcript data to identify family meeting characteristics and attributes that might influence family satisfaction.

The research took place in a PICU in a university-affiliated children's hospital in New Zealand. The hospital has 176 beds of which 16 were in the PICU. The Principal Investigator (PI) was in an ideal position to undertake the study having established effective working relationships in the PICU. The PI was employed as a social worker at the hospital with the Consult Liaison Psychiatry Team coordinating and providing



clinical support to the Bereavement Service and the Paediatric Palliative Care Team. The PI had knowledge of the organisation and was familiar with the culture of the PICU.

## **Procedure**

The PI consulted with hospital staff and external experts in preparation of the research proposal and the application for ethical approval. Discussion about the study initially began with the Paediatric Palliative Care Team and the Consult Liaison Team at the hospital. Both teams supported the concept of studying family meetings in the PICU. The PI developed a methodology that would utilise the framework developed by Curtis (Curtis et al., 2002a; Curtis et al., 2001) and Curtis consented to the use of the framework and questionnaires. The PI contacted the PICU nursing and medical teams and outlined the proposed study, met with key members of the teams and received permission to continue from the PICU Clinical Director and Nursing Manager. The PI held meetings with the PICU nursing team personnel and briefed them about the research. The PI also consulted the Maori Health Team and submitted a copy of the research proposal to the Maori Research Review Committee who gave their support to the study. Approval was sought from the District Health Board managing the hospital and sign off was granted by the Chief Medical Officer. Finally, an application for ethical approval to proceed with the study was lodged with the New Zealand Ministry of Health and this was granted.

Additional support for the study was provided by a typist who transcribed the meeting recordings and two coders who cross checked the coding of four of the 15 meeting transcripts.

## **Identification and recruitment of family meetings**

The PI contacted the Clinical Charge Nurse of the PICU each morning and afternoon to identify eligible family meetings, from Monday to Friday for a 24 - month period. A notice was posted in the PICU nursing station and clinicians were encouraged to phone the PI. The availability of the PI was a major consideration in the recruitment process and this was assisted in the second year of the study when the PI received a research award to release him from some clinical duties.

The PI contacted the doctor and primary nurse for each whanau/family meeting identified and determined whether the family was eligible for inclusion in the study. The PI asked the doctor if this would be a 'sit-down meeting' with the family. The 'sit-down meeting' indicated that the medical team had some important decision-making or information to impart to the family that required a more structured approach than the more frequent bedside discussion.

All types of family meetings were eligible for inclusion except discharge planning meetings. No more than one meeting per patient was recorded to maximise the breadth of communication obtainable in 15 family Meetings. The doctors and nurses involved were eligible to participate in more than one meeting and written consent was only required once. Verbal consent was obtained for each subsequent meeting.

## **Sampling**

This study utilised purposive sampling. This type of sampling is referred to as homogenous sampling (Creswell & Plano Clark, 2007) whereby all participants have membership in a subgroup with distinctive characteristics. The distinctive characteristics of this group were that the family members involved had a child in the PICU with a life threatening medical condition and the medical team participants were all caring for a child with a life threatening condition.

Not all families admitted to the PICU were eligible for inclusion in the study. Those families where the risk of litigation or alleged child protection issues was present were excluded from the study. This exclusion was to avoid the possible use of meeting recordings for future legal proceedings. Those family members who were known to the PI in his capacity as a social worker were also excluded from the study. This was to ensure that the PI was not a participant in the study and could not therefore influence the data or the process of a meeting.

## **Participant Consent process**

Members of the medical team were given an Information Sheet and the research was explained to them by the PI. If they voluntarily consented to being recorded for the study, the PI gave them a consent form for completion. The family was given an information sheet (see appendix 2) and the PI explained the study. If the family

voluntarily gave consent, they also completed and signed a consent form (see appendix 3).

The consent forms were photocopied and one placed in the patient's medical file and the original stored in a research file. Each meeting was allocated a number and a separate research file that held consent documents, meeting participant's demographic data, the meeting transcript, completed questionnaires and the transcript analysis document. All data were stored in a locked cupboard in a locked room. Digital data were securely stored under password on a laptop and a USB memory device.

If the family consented to the family meeting being recorded, a digital recording device was placed in the meeting room. All family meeting participants including the medical team were informed that they could stop the recording at any time and the data would be withdrawn from the study. The PI operated the recording equipment at most of the meetings but in some it was operated by a social worker or nurse. The PI did not take any part in the meeting other than an initial reminder that the recording device could be turned off at any time.

At the close of the meeting, the family was asked if they would complete a confidential questionnaire (see appendix 4). The family was invited to seal the questionnaire in an envelope and leave it with their nurse or at the nursing station. The digital recording device was turned off and the meeting audio was downloaded on to a computer and USB memory device. The questionnaires were collected by the PI and all consent forms were transferred to a uniquely numbered research file. The family members and the medical team participants were then personally thanked for participating in the study.

The meeting audio recording was delivered to a transcriptionist who had signed a confidentiality agreement. When the transcript was complete, it was checked by the PI for accuracy and stored in the research file. The electronic version of the transcript was stored on a password-protected drive.

## **Ethical considerations**

The New Zealand Privacy Act of 1991 prescribes principles and procedures that govern the collection and use of data about identifiable people (Davidson & Tolich, 2003). Two of the most important principles include the participants right to be informed

that they are research participants and secondly that they know the purpose of the research and data that they generate. In order to achieve this, information sheets for medical staff and family were developed to ensure that informed consent was granted before continuing with the study. The PI also explained the research to all participants before recruiting them in to the study.

The ethical principles that underpinned this research were described in the words of Davidson and Tolich

1. Do no harm
2. All participation needs to be voluntary
3. Preserve the anonymity or confidentiality of participants
4. Avoid deceit
5. Analyse and report data faithfully

(Davidson & Tolich, 2003, p. 81)

A number of ethical issues were considered concerning the minimisation of harm to family and medical team participants. The District Health Board legal counsel advised that the recording of the family meeting was deemed the equivalent of patient information and was therefore available to family members, should they request it. To protect family members and guard against re-traumatisation it was decided that all recordings, if requested, would be replayed in the presence of a suitably qualified and supportive health professional and those family participants would be offered counselling if required.

Ethical consideration was also given to the administering of the questionnaires immediately after the family meeting. There was concern that family members would be too traumatised to complete a questionnaire immediately after a very difficult meeting with the medical team. The original questionnaire used by Curtis was 16 pages long with 36 questions, 28 of which involved a ten point Likert-like scale. This was considered too long and intrusive for a family as they processed important information about their critically ill child. The questionnaire was scaled back to five questions. Consideration was given to sending a questionnaire retrospectively but this was dismissed given the parents were more likely to rate their overall PICU experience rather than their experience of a single meeting.

Hospital staff were concerned that recorded meetings could be used by family members to complain about a staff member. Advice was sought from the district health board lawyer who advised:

*Where a transcript sheds light on a discussion, it is just as likely to benefit staff. This is particularly the case in PICU where family recall of discussions may be compromised by stressful circumstances*

This correspondence suggested there would be no greater risk to the medical team if a meeting were recorded. Whilst the district health board did not encourage recording of meetings, it was considered that the learning and benefit from this research outweighed any possible risks.

The PI addressed the Treaty of Waitangi during the ethics review process. The research included the participation and observation of Maori whanau in family meetings in the health environment. Where possible the PI sought the advice and support of the Maori health team in the hospital before approaching a whanau. The PI also committed to consulting with the Maori Research Review Committee on completion of the study and presenting any inequalities to them if they emerged from the research.

## **Measuring Instruments**

The analysis included four sources of data gathered from each meeting including: demographic data, the meeting recording, the transcript, and the questionnaire. These three data sources were then processed and results recorded on an MS Excel (Microsoft) spreadsheet and Word (Microsoft) documents. Data analysis was performed using Excel (Microsoft, USA) and JMP (SAS, USA) software.

The demographic data are illustrated in Table 2. The demographic data were collected from the patient's hospital record and PI observations. The number, designation, and gender of medical staff was collected by the PI and recorded on the research file. The number, role, and gender of family members attending the meetings were also recorded by the PI. The ethnicity of the family was identified using the patient's hospital record. The data were collected to identify family meeting characteristics and attributes that may have been associated with increased levels of satisfaction.

The meeting recording was used to establish the duration of the meeting. The total length of the meeting was recorded in minutes and was one of the four variables used to analyse family satisfaction.

The transcript produced from each recorded meeting was edited to remove any identifying features. The transcript was then coded by the PI. The PI reviewed each transcript using the Curtis framework (Curtis et al., 2002a) and ticked the relevant code when a particular process was covered. The full coding framework can be found in appendix 1 and an example of the coding can be seen in Figure 1. The reason the transcript was coded was to provide data that would identify the content and process of a family meeting in the PICU.

A binary (0-1) coding system was used where each item was coded either fulfilled (1) or not (0). Even partially fulfilled items were coded as fulfilled (1). As can be seen from the example of the coding sheet (Figure 1), the coding requirement is met because the team is introduced. The relevant text example from the transcript was then placed alongside the scored box as evidence. The 15 transcripts were scored in this way until all 31 codes were completed with a 0 or 1 score.

Figure 1: The coding sheet

Research Number 1  
Coder name AT

CODING FRAMEWORK FOR THE CONTENT OF FAMILY MEETINGS IN THE PICU

Please mark X in the boxes when specific areas are covered in the meeting and mark/highlight the relevant paragraphs in the transcription text with the number. On completion check and then mark 0 in uncoded boxes. Please ensure that the Patient Number corresponds with the transcript patient number

For example:

Social Worker: "Welcome everybody. Lets just go round the table and introduce ourselves and our relationship with XXXX (the child)."

1.1

Introductions and openings

1.1 Introductions: Introduces the family and team members; determination of the relevant decision makers and review of who is missing.

1

Dr: For those of you have haven't met me my name is (doctor's name) and I am the doctor that is in charge of the ICU for the next couple of days. This is (doctor's name) who's one of the Paediatric (doctor's designation) at this hospital and this is (nurse's name) who is looking after (patient's name) today.

Two independent coders took two transcripts at random from the sample and crosschecked the validity of the coding. Each coder worked on the two transcripts and then met with the PI to crosscheck results. It was anticipated that consistency of coding would be reflected in matching scores for no less than 90% of the codes. Where differences in coding occurred transcripts and original coding sheets were reviewed until agreement was reached between coders.

The transcript was also used to establish the proportion of speech from the medical team and family during the meeting. The number of words spoken by the family were counted using Microsoft Word and then approximated as a proportion (or percentage) of the overall word count. Using this method it was possible to calculate the proportion of time spent talking by the medical team and the family.

The purpose of the questionnaire was to establish the levels of family satisfaction to identify an association between levels of satisfaction and family meeting characteristics and family attributes. Family satisfaction with communication was assessed using five questions:

1. During the meeting, how well did the PICU team answer your questions about your child's illness and treatment? (previously not validated)
2. During the meeting, how well did the PICU team listen to what you have to say?
3. Overall, how well did the team communicate with you during the family meeting?
4. How well did this meeting help you understand the choices and decisions that may need to be made?
5. Overall, how well did this meeting meet your needs?

These questions had a 5 point response scale with the anchors of 1 = 'Not at all well' and 5 = 'Extremely well'. Four of the questions had been validated for an adult population in an earlier study (Curtis et al., 2002b).

## **Statistical analysis of data**

The analysis of the data were carried out to answer the question is there a relationship between family meeting characteristics and patient and family attributes that may lead to increased family satisfaction. The four family meeting characteristics (variables)

included: numbers of family present at a meeting, numbers of staff present, proportion of time spent talking by medical staff, and meeting length. The number of family and staff present at a meeting was collected by the PI. The proportion of time spent talking by medical staff and meeting length was collected from the original meeting recording and the transcript (as detailed earlier).

The relationship between the family meeting variables and total questionnaire scores were investigated by plotting the data and applying lines of best fit, R-squared values and p-values, to indicate the proportion of the variance of scores accounted for by the line of best fit, and the statistical significance, respectively. This analysis is detailed in Chapter 4.

It is acknowledged that the sample size of 15 family meetings was relatively low, which limited the potential of the study to demonstrate significant relationships that are more widely applicable. However, at the least these analyses served to demonstrate the trends observed.

## **Alternative research methods considered for this study**

Consideration was given to two alternative methodologies that might also answer the research questions posed at the beginning of this chapter.

The first was a retrospective study of family meetings based on the work of Elaine Meyer (Meyer, Ritholz, Burns, & Truog, 2006). In this study bereaved parents responded to open ended questions using anonymous self-administered questionnaires. The purpose of the study was to identify the priorities and recommendations for end-of-life care and communication from the parent's perspective. A similar approach with specific questions about family meetings could have been selected for this study. However, a retrospective approach could capture the family's overall experience of the PICU rather than the short and focused period of a family meeting.

The second alternative methodology was to simulate family meetings using actors and get feedback from the medical personnel involved. This would up-skill the team members involved and raise awareness about the process and content of family meetings. Studies of this type have been conducted using actors (Browning, 2002;



Browning, Meyer, Truog, & Solomon, 2007; Lautrette et al., 2007). Whilst this would have been an effective process, it arguably does not give an accurate reflection of the family's trauma. Earlier research (Field & Behrman, 2003) called on descriptive data and the work of Curtis (Curtis & White, 2008) points to the importance of establishing a descriptive study first before embarking on intervention based approaches.

## **Conclusion**

In this chapter, the research methodology and procedures were described. This chapter has also documented the research design, the instruments used, and outlined the procedures employed for data analysis in this study. The following chapter presents the results from the coding framework as it was applied to family meeting transcripts in the PICU and identifies the association between family satisfaction and family meeting characteristics.

## CHAPTER FOUR RESULTS

## **CHAPTER 4**

### **RESULTS**

#### **Introduction**

In the previous chapter, the research methodology was described and this chapter will detail the results of the study in the paediatric intensive care unit (PICU). The chapter following this will include a discussion of the findings.

The results chapter has three sections. The first section details the demographic data including the number of family meetings, who attended the meetings, and the study sample characteristics. The second section details the family meeting descriptive framework. The primary unit for analysis is the family meeting and this is identified by 28 codes spread across six domains. The frequency of each code is presented with an example from the transcripts. The aim of the first two sections is to provide data to describe the content and process of family meetings in the paediatric intensive care unit (PICU). The third section details the results of the statistical analysis comparing questionnaire scores with family meeting characteristics. Questionnaire totals were compared with four different family meeting characteristics to identify whether there was a relationship between family satisfaction and family meeting characteristics. The four characteristics (variables) included numbers of family present at a meeting, numbers of staff present, proportion of time spent talking by medical staff and meeting length. The aim of this final section is to identify process or content elements that might increase family satisfaction with meetings in the PICU. The chapter concludes with a summary of the key results.

#### **Descriptive data from the family meetings**

During the period of the study, fifteen family meetings were recorded, transcribed, and coded in the PICU unit between September 2006 and April 2008. Questionnaires were administered to 30 family members immediately after the meeting to gauge their satisfaction with the meeting. The 15 family meetings represented 15 unique patients, 67 family members were present in total, and 10 unique specialists or registrars led the

meetings. The meetings had a mean duration of 26 minutes with a range of ten to 49 minutes.

Extended family members were present at 11 (73%) meetings and 13 (87%) meetings had two parents present. A mean of 4.53 family members (range 2-16), attended the 15 meetings. Mothers were present in all meetings and in meetings where the father was absent, an extended family member was present. Female family members were three times more likely to be present than males.

The medical team present at the family meetings included doctors, nurses, cultural workers, and social work staff with a mean of 3.53 staff (range 2-6) per meeting. The doctors who lead the meetings were predominantly intensive care specialists or registrars and there was at least one doctor at every meeting, with three doctors present for five of the meetings and two doctors present for two of the meetings. At least one cultural worker was present at five of the six meetings involving Maori whanau and two cultural workers were present for two of those five meetings. A social worker was present at four of the 15 meetings. A nurse was present at 14 meetings and one of those meetings had two nurses in attendance.

The families of six male patients and nine female patients (n=15) participated in the study. The majority of the families (n=11) had a child who was aged 0 – 1 year of age. This was an extremely fragile group of children; nine children (60%) died during the study. The mean time of death after the family meeting was twelve days (range 1-37 days). The ethnic identity of the families included; eight (54%) European families, six (40%) Maori families and one (7%) Pacific Island family.

During the study period, 17 families were approached for inclusion in the study, one family member and one health professional did not consent to participate in the research. A number of families (not recorded) were excluded due to a previous professional relationship with the PI or were involved in proceedings likely to lead to some form of legal action.

## **The family meeting coding framework**

The coding framework (Curtis et al., 2002a) is detailed in Chapter 3 (the Literature Review) and served as the key tool for analysing and coding the content of a family

meeting. The primary unit for analysis is the family meeting and this is identified by six domains.

The following section presents the results of the coding. The 28 codes are recorded under six domains and are presented in the following six consecutive tables. Each table has three columns and is unique to each domain. The first column includes an abbreviated description of the code, the second column records the number of meetings where this code featured, and the third column provides a quote from one of the transcripts that relates to the code.

The six domains are presented in the order in which they would occur in a family meeting in the PICU. During the coding and analysis of the transcripts, the meetings varied in their format depending on previous discussions and meetings, but they shared similar content and process elements. The meeting would begin with introductions and a statement of purpose, often followed by questions to elicit the family's level of understanding. An informational exchange would take place including a discussion of the child's condition, symptoms, and a clarification or interpretation of the medical information given by the doctor. The significance of this medical information was then discussed and led the family and medical team to discuss, what the future might hold and the child's prognosis for survival. This opened up discussions on decision-making and the choices and options that were available or selected by the medical team. If discussions about withdrawing treatment were broached, this also led to further conversations about the possibility of death, or the inevitability of dying, and how this might occur. The meetings concluded with a range of approaches including a closing summary, reassurance to the family that their child would be made comfortable and openness to engage in further discussions.

## Domain one – Openings

The first domain described the opening period of a family meeting in the PICU and identified three content codes (Table 2). The **Introduction** was coded for 11 meetings and included any reference to introduction of the medical team, family, or extended family. It could also include a review of the relevant decision makers and of who was missing. **Purpose** was coded for 11 meetings and included any reference to the purpose of the meeting, what to expect, and a definition of the parameters of the meeting. **Elicit Agenda** was coded for nine meetings and included the eliciting of issues or items for discussion.

Table 2: Domain one – Openings

Code	Meetings/15	Example from transcript
<b>Introduction</b>	11	<i>For those of you who haven't met me my name is (doctor's name) and I am the doctor that is in charge of the PICU for the next couple of days. This is (doctor's name) who's one of the Paediatric Neurologists at this hospital and this is (nurse's name) who is the nurse looking after (patient's name) today.</i>
<b>Purpose</b>	11	<i>What I wanted to do now is to run through the current situation with (patient's name). I understand you have had a few talks already so I am not quite sure what you understand? But I would like to know what you understand and explain things from where I see them and then talk about what we need to do next and what is going to happen today, and to answer any questions for you.</i>
<b>Elicit agenda</b>	9	<i>What is your current understanding of what's happening? I am not quite sure what you have been told.</i>

## Domain two – Informational exchange

The second domain described the period of informational exchange during a family meeting in the PICU and identified seven content codes (Table 3). **Review condition** was coded for 14 meetings and included a review of the medical history leading up to the conference, discussions about past medical history and the time spent in the PICU leading to the conference. **Discuss baseline** was coded for five meetings and included discussions about baseline physical and mental abilities, and quality of life including the ability to carry out activities of daily living and other activities. **Clarification of terms** was coded for 15 meetings and included explanations in lay terms of diagnostic tests, treatments, and medical terms. **Significance of information** was coded for 15 meetings and included describing the significance of the details of medical history, current condition, tests, or treatments; providing interpretation of medical facts as good or bad and the integration of medical details into the big picture. **Symptoms** were coded for 11 meetings and included discussing the patient's current comfort, symptoms, or experience in the PICU. **Affirming experience** was coded for seven meetings and included affirming, acknowledging, or restating the family experience of the PICU stay or the course of the patient's disease or treatments.

Table 3: Domain two – Informational exchange

Code	Meetings/15	Example from transcript
<b>Review condition</b>	14	<i>... So she has never ended up being ventilated for very long, but she was on respiratory support for a long time. Then she went home on oxygen and got home for a little bit but then got into strife and ended up at XXXX and then got picked up by us and came up.</i>
<b>Discuss baseline</b>	5	<i>... most likely outcome is that she will survive this, but that she won't be the same little girl – that she will have some issues with brain function and development. But just how bad they are we don't yet know.</i>
<b>Values history</b>	0	
<b>Clarification of terms</b>	15	<i>He was bleeding from everywhere, his blood was very thin and his haemoglobin was very low and he had been bleeding so much and clotting so much that all of his platelets – platelets are part of your blood that helps stop the bleeding - and his platelets were very, very low.</i>
<b>Significance of information</b>	15	<i>... she has never been stable enough for us to look at it more closely. Normally in a baby that is this sick, we would try and take them to the CAT scan and scan their brain to try and get an idea of what it was like, and that doesn't answer all the questions but it sometimes helps. But she has never been well enough to be moved, she couldn't go on that oscillator breathing machine, you have to be on a normal breathing machine.</i>
<b>Symptoms</b>	11	<i>...that every time she tries to take a breath she pops another hole in her lungs. ... We are getting to the point where we are just not sure her lungs are going to be good enough for her survival.</i>
<b>Affirming experience</b>	7	<i>And I know as his Mum and Dad you love him very much and you would do anything you could to help him and to give him every chance in this life but unfortunately now, despite everything we have done and all the teams have been looking after him, his body is getting to the point where it doesn't want to go on</i>



### Domain three - Discussions of what the future might hold

The third domain described the period of discussions of what the future might hold during a family meeting in the PICU and identified three content codes (Table 4). **Prognosis for survival** was coded for 13 meetings and included predictions about the future (except predictions about quality of life); predictions of death, duration of mechanical ventilation, dependency, and discharge location. **Prognosis regarding future quality of life** was coded for eight meetings and included making statements about future quality of life, future neurological functioning including cognition, and activities of daily living. **Uncertainty** was coded for 11 meetings and included explicit statements about the inability of knowing the prognosis, the course of the disease, and the uncertainty of the prognosis.

Table 4: Domain three - Discussions of what the future might hold

Code	Meetings/15	Example from transcript
<b>Prognosis for survival</b>	13	<i>...his body is getting to the point where it doesn't want to go on any more which is very hard. It has been a gradual deterioration but it is now so bad that I think it is very likely he is going to die within the next short time, despite everything we are doing.</i>
<b>Prognosis regarding future quality of life</b>	8	<i>But at this stage it looks like she is not out of the woods – there is still a chance that she might not make it at all and if she does make it, we think she is going to be quite severely disabled by this.</i>
<b>Uncertainty</b>	11	<i>...today we went forward and had the scan and I showed it to you briefly and it does show some damage. Now the question we've got is how much and what does this mean. And I am not sure yet of all the answers to that and I have spoken to the neurologists and they have said there is some improvement, maybe there is not – we are not really sure. So I think the next step is to try and find some more information ...</i>

## Domain four – Decisions

The fourth domain (Table 5) described the period of decision-making during a family meeting in the PICU and identified six content codes (Curtis, 2002, identified two additional codes: **Surrogate decision making** and **Discussions of existing advance directives** that do not feature in this analysis). **Options** were coded for 12 meetings and included discussions about procedures, treatments, and tests that might be performed in the future. **Choices** were coded for 11 meetings and included discussions about specific treatment options that were indicated, recommended, or selected. **Code** was coded for one meeting and included a discussion about resuscitation status or emergent care. **Transition** was coded for three meetings and included discussions about differences between life-supporting care and palliative care and their goals. **Burden and benefit** was coded for five meetings and included discussions about the burdens and benefits of treatment options. **Withdraw** was coded for five meetings and included discussions about the possibility of stopping, withdrawing, withholding life support or any of the treatments linked to life-sustaining treatments.

Table 5: Domain four – Decisions

Code	Meetings/15	Example from transcript
<b>Surrogate Decision Making</b>	0	
<b>Discussions of existing Advance Directives</b>	0	
<b>Options</b>	12	<i>And so for your girl to be a viable candidate for the operation that needs to be done if we ultimately get to that stage, her blood pressure in her lungs needs to be low enough. If her blood pressure stays high in her lungs then that would be a bad thing also and time will tell. So we are in a holding pattern at the moment and we will do what we can do and hopefully things will get better.</i>
<b>Choices</b>	11	<i>Plan A is that we need to support her in the least invasive way we can and to not add in to her problems. So we want to ventilate and support her through this and we need to give her time for the steroids to work. So it is still early days yet and I would have thought that she still needs some time on the steroids and to give her time.</i>
<b>Code</b>	1	<i>If she does anything further we are not going to be trying to aggressively resuscitate her, do the chest compressions, because that is her saying 'no, this is it'. And it is not the right thing to do that any more, because we can't change what has already happened.</i>
<b>Transition</b>	3	<i>...even though we don't have any treatments left to save him, we still are here to care for him and to look after him and to support you and look after you as his parents. So that means that our focus changes a little now to making sure that as well as the things we have been doing, we are going to make sure that he is really comfortable and that he is not suffering</i>
<b>Burden and benefit</b>	5	<i>...where she is right now is we have got room to escalate on things but that in itself can be problematic because all the treatments we do have a good side and a bad side. So we are constantly balancing – is the good side going to be more good or more bad and we know that being on a breathing machine is not good for your lungs. It damages them just on its own.</i>
<b>Withdraw</b>	5	<i>And if we are not getting any improvements from the steroids then we are going to have to think about stopping what we are doing and then it is pretty likely that (patient's name) is not going to be able to manage without the support from the ventilator.</i>

## Domain five - Discussions about dying and death

The fifth domain described the period of discussions about dying and death during a family meeting in the PICU and identified two content codes (Table 6). **Dying** was coded for four meetings and included discussions concerning what withdrawal of life support might be like and what dying might be like including symptoms, process of care, location, physiology, and spiritual aspects. **Death** was coded for 11 meetings when the medical team directly raised the possibility that the patient may die.

Table 6: Domain five - Discussions about dying and death

Code	Meetings/15	Example from transcript
<b>Dying</b>	4	<p><i>And if there are particular things that you guys want, then it is important that we take those on board and try to do those things. I don't know whether you have thought about whether you want to get her baptised or christened or blessed or anything like that, but this would be a good time to think about doing those things too. ... If there is anything else particular that you want to do, play music, sing, anything like that. You just let us know. I think it would be a good thing to move her into a room by herself to give you guys a bit of privacy</i></p> <p><i>...I would then come to you and tell you and what we would tend to do is take out the breathing tube and the support and let her pass away in your arms</i></p>
<b>Death</b>	11	<p><i>If it comes to a stage when it is clear to everybody that what we are doing is just protracting his death, then we will sit down and talk to your family again. At the moment we are doing all our best to get him through this and to help him and try to get to the bottom of why and to do all the things we can to support his kidneys, his liver and his heart. We will do all those things and we hope that things will improve, but if it becomes obvious that we are just protracting him dying, then we would probably need to have a different discussion.</i></p>

## Domain six – Closings

The final domain described the closing stages during a family meeting in the PICU and identified eight content codes (Table 7). **Summary of Meeting** was coded for five meetings and included a summary or review of the treatment decisions made during the meeting. **Family control of timing** was coded for five meetings and included giving the family control over time for private conversations, timing of decisions, and implementing a plan. **Assure patient comfort** was coded for seven meetings and included reassurance that the patient would be made comfortable. **Further discussions** were coded for ten meetings and included plans for future discussions. **Continuity of care issues** was coded for one meeting and included a discussion about physician and nursing continuity of care issues. **Contact information** was coded for eight meetings and included discussions about contact information for physicians and/or nurses and expressing availability for future contact. **Gratitude** was coded for two meetings and included acknowledgment or appreciation for the value of the conference or care that the patient had received as expressed by the medical team. **Next steps** were coded for three meetings and included discussions about what would happen immediately after the meeting.

Table 7: Domain six – Closings

Code	Meetings/15	Example from transcript
<b>Summary of Meeting</b>	5	The plan that I have written is not for trachey at this stage, cardiology to remain involved and we will keep doing intermittent echoes.
<b>Family control of timing</b>	5	<i>So if it becomes obvious for us that things were futile, then we would get back to you and talk about how you would like things and for you to hold her and give you as much time as we can with you holding her in whatever circumstances you want</i>
<b>Assure patient comfort</b>	7	<i>The important issues are that we keep him comfortable at all times, we don't want him to be distressed or in pain, that we give you guys some time as a family to adjust, not that you ever adjust or are ever ready, but to have a bit of time as a family and to bring in other people – grandparents or other important people that you want to see him.</i>
<b>Further discussions</b>	10	<i>I am certainly around for the next couple of days and if you want to catch up at any stage – like I was very keen to catch up today just for the reasons I have explained. If you have any specific questions or if you want to sit down and have a bit more of a quiet chat ... then certainly just let somebody know.</i>
<b>Continuity of care issues</b>	1	<i>with all of the different physicians involved because of the genetic – there is metabolic – so there are a lot of teams which makes it probably harder as well because there are more people past the bed space looking at results. But while (patents name) is with us, the primary decisions are made by the intensive care team. They are made in conjunction with the other teams, but they are made by the intensive care team.</i>
<b>Contact information</b>	8	<i>Any time that you want to ask anything, if you have questions just let us know. We can either chat at the bedside or we can come and sit down, either way.</i>
<b>Gratitude</b>	2	<i>Well, this meeting has been very worthwhile because it has cleared a lot of things up which we were a little bit uncertain of.</i>
<b>Next steps</b>	3	<i>I think one of the most important things is actually now. Now is for you to be able to hold him while he is on the ventilator.</i>

## Questionnaire results

Family satisfaction was measured using a questionnaire that was given to the family immediately after they had attended a family meeting. Two family members from each meeting responded and 28 questionnaires were completed immediately after the meeting and returned to the PI, two further questionnaires relating to one particular meeting were returned after four weeks, resulting in a sum of 30 questionnaires. Each questionnaire was scored out of 25 and the two questionnaires were added together to give total satisfaction scores out of 50 for each meeting.

The questionnaires indicated a high level of family satisfaction with family meetings in the PICU with a mean score of 45.3 of 50. Six of the 15 meetings scored 50 of 50 for satisfaction. The lowest individual meeting score for satisfaction was 20 of 50. This was the only meeting where the questionnaires were not returned immediately after the meeting. Overall trends indicated that parents rated the medical team's ability to communicate the highest with a mean score of 9.6 of 10. The lowest score related to how well the Medical team 'meet your needs' with a mean score of 8.6 of 10 (Table 8).

Table 8: Mean and range scores of the questionnaires

<i>Question</i>	<i>Mean</i>	<i>Range</i>
<i>1. During the meeting, how well did the PICU team <u>answer your questions</u> about your child's illness and treatment?</i>	<i>8.8</i>	<i>2 to 10</i>
<i>2. During the meeting, how well did the PICU team <u>listen</u> to what you have to say?</i>	<i>9.4</i>	<i>6 to 10</i>
<i>3. Overall, how well did the team <u>communicate</u> with you during the family meeting?</i>	<i>9.6</i>	<i>7 to 10</i>
<i>4. How well did this meeting help you <u>understand the choices and decisions</u> that may need to be made?</i>	<i>8.8</i>	<i>2 to 10</i>
<i>5. Overall, how well did this meeting <u>meet your needs</u>?</i>	<i>8.6</i>	<i>2 to 10</i>
<i>Questionnaire Total</i>	<i>45.3</i>	<i>20 to 50</i>

## **Comparison of questionnaire totals with family meeting characteristics**

Questionnaire totals were compared with four different family meeting characteristics to identify whether there was a relationship between family satisfaction and family meeting characteristics. The four characteristics (variables) included numbers of family present at a meeting, numbers of staff present, proportion of time spent talking by medical staff and meeting length. There were no identifiable trends related to number of family present, number of staff present or time spent talking by medical staff.

The mean proportion of time spent talking by the six Maori whanau during a meeting was 11% of the total meeting time with the medical team speaking for 89 % of the time. The mean proportion of time spent talking by the eight Pakeha families during a meeting was 22% of the total meeting time with the medical team speaking for 78% of the time. There was no significant difference between the mean duration (26 minutes) of meetings for Maori whanau or Pakeha families.

The proportion of time spent talking by the family and medical team is noteworthy in this section because of comparisons with previous research (Fassier et al., 2006; McDonagh et al., 2004; Tulsy, 2005). This will be discussed in the following chapter. The mean family meeting time was 26 minutes with a range from 10-49 minutes. The mean proportion of family speech during a meeting was 16% of the total time with a range from 3-35% of the total time. There was no association between the proportion of time spent talking by the family and satisfaction.

## **Comparison of questionnaire totals with meeting length**

When satisfaction scores were correlated with meeting length a very interesting trend was noted. The data indicated that meetings of between 10 to 40 minutes scored highest for satisfaction, but longer meetings scored lower for satisfaction. Shorter meetings were also less satisfying, but overall longer meetings exceeding 40 minutes were much less satisfying. The following quadratic equation was developed for the curve that best illustrated the correlation between satisfaction scores and length of meetings:

$$\text{Satisfaction score} = 56.5 - 0.2 (\text{Meeting Length}) - 0.04 (\text{Meeting Length} - 26)^2$$

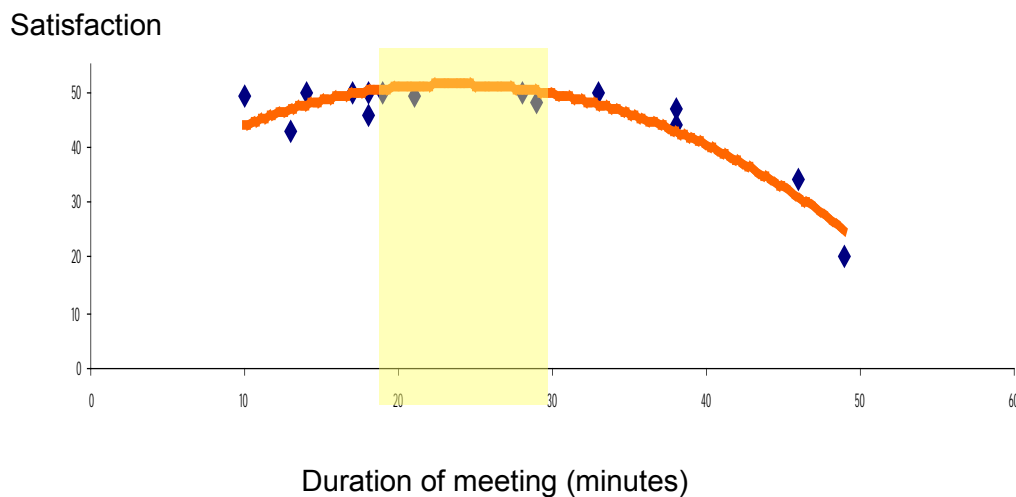


This equation yielded  $r=0.93$  and  $r^2=0.87$ ,  $p<.001$ . This very high correlation value suggests that the quadratic equation is a highly appropriate expression of the relationship between satisfaction and meeting length in this data set, and accounts for 87% of the data (Figure 2).

The equation was initially calculated using a straight-line (linear) fit to express the relationship between family meeting characteristics and satisfaction scores, but this was not appropriate because it suggested that no meeting at all (duration = 0) would provide the highest satisfaction.

Although the sample was small, the data were not normally distributed, and do not strictly meet the assumption for calculating the correlation statistic, there is no nonparametric alternative to this test (i.e., point-biserial, Spearman's rho or Kendall's tau) that can be used with these data (Pett, 1997). Therefore this statistic should be interpreted with caution

Figure 2: Comparison of questionnaire totals with meeting length



## **Comparison of questionnaire totals with patient and family attributes**

Questionnaire totals were compared with patient and family attributes. The patient and family attributes included gender, ethnicity, age, and mortality. There were no associations between satisfaction scores and patient attributes, possibly because of the small sample size. There were slightly higher satisfaction scores for male patients. Higher satisfaction scores were also recorded for family members whose child did not die during the period of the research but these were not considered noteworthy due to the small sample.

## **Summary of Results**

The measuring instruments that were used for this study included a coding framework and a questionnaire. Additional analysis included the data from 15 recorded family meetings, demographic information from the patient's hospital records, and PI reported observations of attendance at family meetings.

The coding framework was applied to the 15 transcripts generated by the study and answered one of the major research questions by describing the content and process of whanau/family meetings in the PICU. The framework was used to identify the frequency and content of 28 codes that are specific to the PICU. This described information and evidence based data that will inform the development of guidelines for whanau/family meetings in the PICU and for associated medical teams and health professionals. The following chapter will review the framework coding data in greater detail.

The questionnaire was used to measure the family member's level of satisfaction with a family meeting and identified a high level of family satisfaction with family meetings in the PICU with a mean score of 45.3 of 50. The satisfaction levels recorded from the questionnaires were also compared with meeting length and this indicated a trend suggesting family satisfaction may diminish as meetings extend beyond forty minutes. This answered the second research question and indicated that there is a relationship between family meeting characteristics, in this instance the length of the meeting, and family satisfaction.

The following chapter will discuss and interpret the clinical significance of these results and continue to answer the research questions. Findings will be integrated with the literature reviewed in Chapter 2.

## CHAPTER FIVE

# DISCUSSION OF THE RESULTS

## **CHAPTER 5**

### **DISCUSSION OF THE RESULTS**

#### **Introduction**

The first part of the chapter focuses on the content and process of family meetings in the paediatric intensive care unit (PICU). The second part of the chapter explores the relationship between family meeting characteristics and the patient and family attributes that may influence family satisfaction.

The purpose of this first section is to bring to life the 28 codes and the significance of the contents of each code. This is achieved with examples of speech that were originally recorded during family meetings in the PICU. Each example is discussed with reference to a specific code. The examples of speech are discussed so that the reader can observe different approaches to communication. Where possible approaches that may enhance communication are referenced back to the literature presented in Chapter 2.

The purpose of the second part of the chapter is to discuss the factors that may influence family satisfaction once again referencing the literature reviewed in chapter two. The chapter concludes with a summary of the unique features of meetings involving children in the PICU.

## The content and process of family meetings in the PICU

The following six content domains were identified as present during family meeting discussions in the PICU and are graphically represented in Figure 3;

1. Introductions and openings
2. Informational exchange
3. Discussions of what the future might hold.
4. Decisions
5. Discussions of dying and death
6. Closings

Each domain had a number of descriptive codes that provided further content detail. The following discussion will review the content and frequency of the codes in each domain and reflect on the specific textual examples provided.

Figure 3: Content domains of family meetings in the PICU

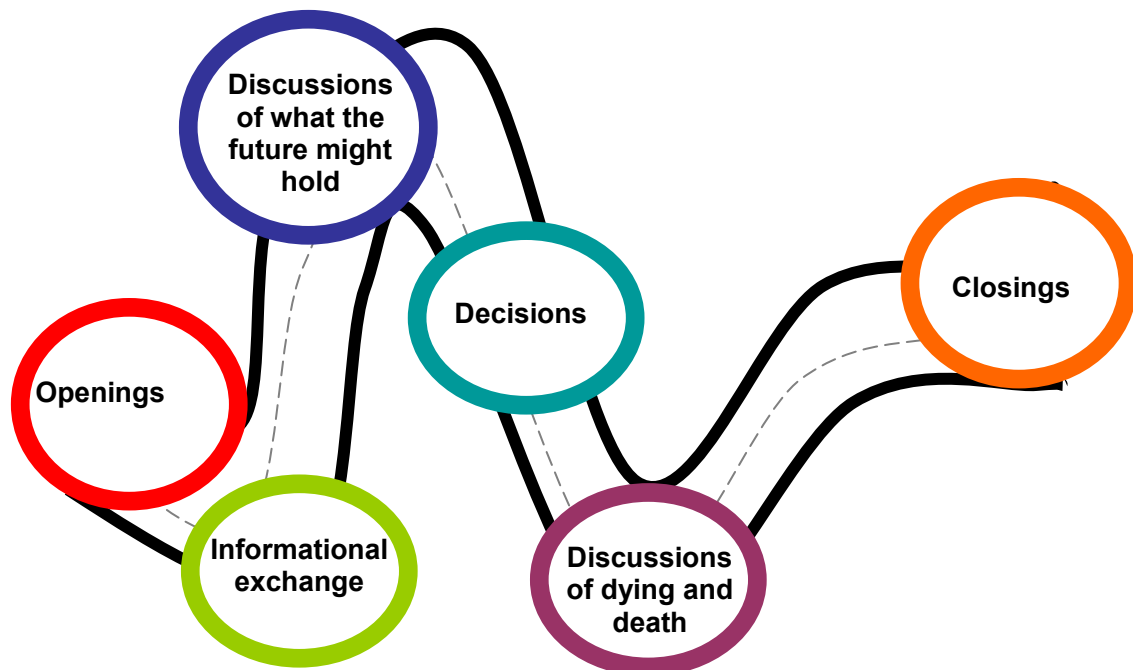
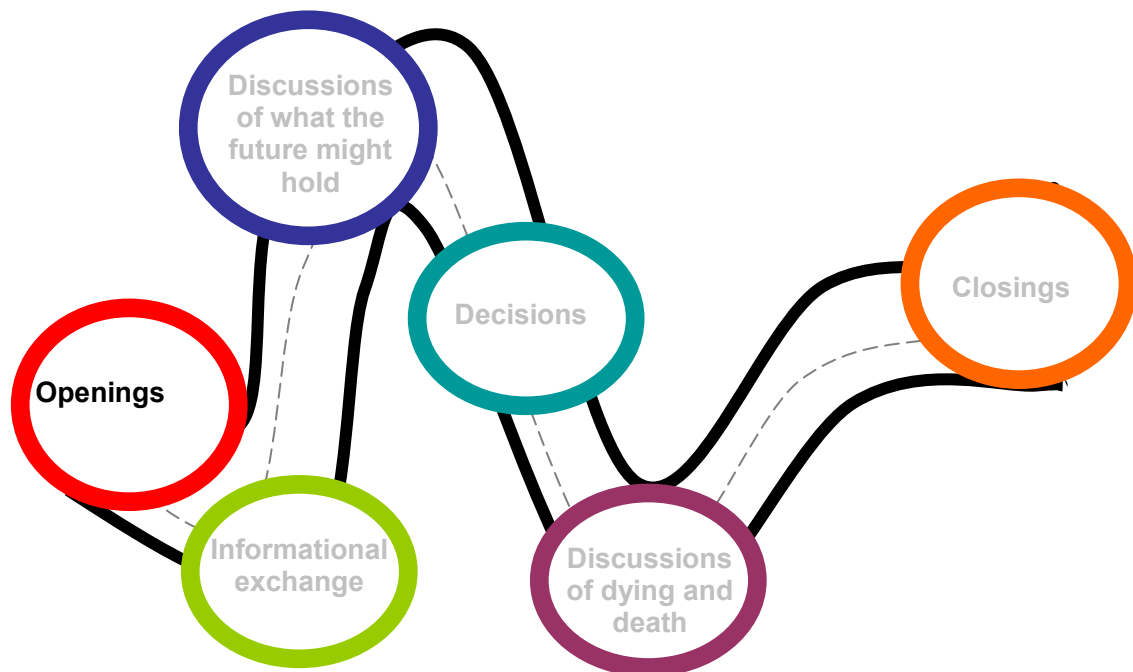


Figure 4: Domain one - Openings



## Domain One - Openings

### Code – Introduction

The majority of the family meetings began with an **introduction** (11 of 15 meetings hereafter indicated as 11/15) and this was lead by a doctor in all but three meetings (which began with a Maori prayer or karakia). A typical introduction by the doctor follows:

*Doctor: For those of you who haven't met me, my name is (doctor's name) and I am the doctor that is in charge of the PICU for the next couple of days. This is (doctor's name) who's one of the Paediatric Neurologists at (the hospital) and this is (nurse's name) who is the nurse looking after (patient's name) today.*

In this example the doctor introduces herself first, states her position as a decision maker in the PICU and goes on to introduce other team members. This was one of the most common patterns of introduction. In larger meetings, some of the doctors requested that other medical team members introduce themselves, usually followed by family members. It was less common for doctors to ask family members to introduce themselves.

## Code – **Purpose**

Following on from the introduction was a statement of **purpose** and this was coded in 11/15 meetings. The statement of purpose was frequently combined with a statement of process from the doctor. The following example illustrates this:

*Doctor: What I wanted to do now is to run through the current situation with (patient's name). I understand you have had a few talks already so I am not quite sure what you understand. But I would like to know what you understand and explain things from where I see them and then talk about what we need to do next and what is going to happen today, and to answer any questions for you.*

In this example, the doctor outlines that he will review the 'current' state of the patient's condition. He attempts to elicit a response from the family by posing the question 'I am not quite sure what you understand?' The doctor then goes on to suggest a process that proposes the family share their knowledge about their child and then he will follow up with his understanding.

This statement of purpose and process was a common approach during the opening phase of a meeting and could be accompanied by a reflection on the type of communication style employed by the doctor as this example indicates:

*Doctor: I haven't met everyone. I am Dr (doctor's name). I am one of the doctors working here over the next few days. I understand the workings in this unit. There are lots of people coming and going and although it can be good, it can also be bad in that you get confused information. Having said that I am going to be quite blunt. It is not because I am awful, it is just that I think that it is important that we all understand what is happening with (patient's name) and how she is.*

This approach not only indicates the process of the meeting but also prepares the family for the communication style of the doctor. It indicates that the doctor will be 'quite blunt' and will not be softening any information for the family. An earlier study (Meyer, Ritholz, Burns, & Truog, 2006) identified that PICU parents wanted honest and complete information and this is framed within the doctors honest statement of approach.



## Code - Elicit an agenda

The final stage of the introduction and openings included the doctor's attempt to elicit an agenda from the family for the meeting; 9/15 meetings evidenced this code with a range of approaches:

*Doctor: What is your current understanding of what's happening? I am not quite sure what you have been told.*

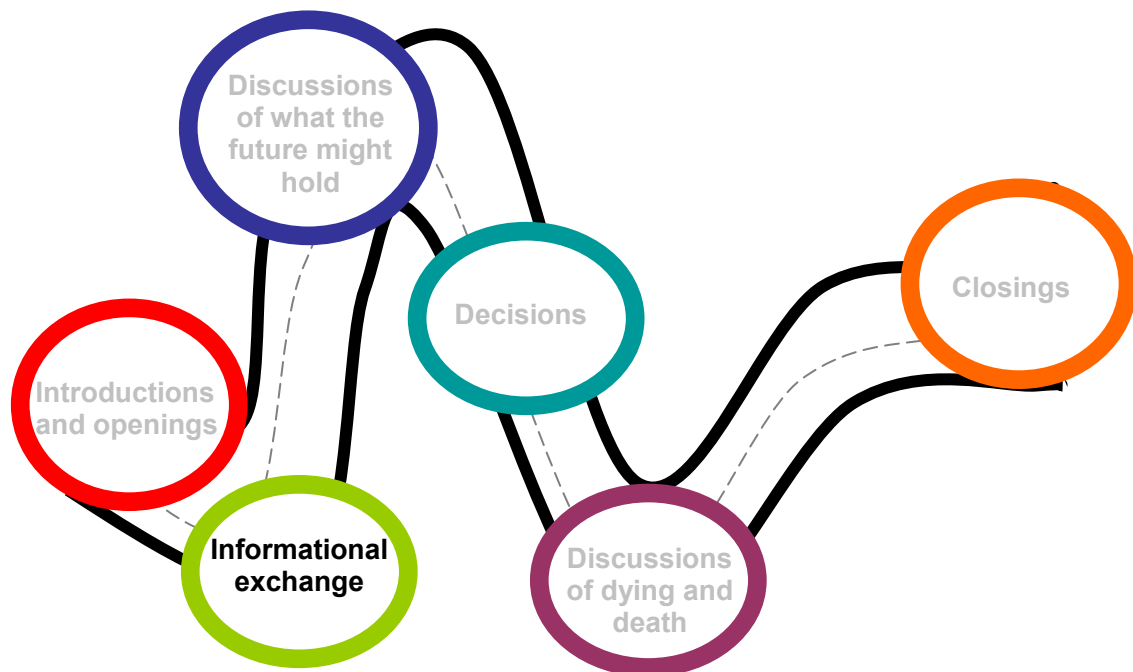
*Doctor: So that is things in a nutshell. So that is just an overview but I am sure, I know, you have a lot of questions and I am sure you want to ask myself or S or K.*

*Doctor: So if we could just start off by you letting me know what they told you in (city name) so I know what you have been told and you understand about (patient's name) injuries.*

These examples show the doctor's attempt to engage the family in the process of the meeting and to establish their knowledge of the patient's condition. The doctors commonly used open-ended questions to achieve this, which then allowed them to proceed with a review of the patient's condition and to deliver their review at the level of the family's understanding.

This approach to eliciting an agenda also potentially engaged the family in the meeting process and assisted them in finding a voice. The use of open ended questions encouraged more speaking in the meeting which may increase family satisfaction (Fassier et al., 2006; McDonagh et al., 2004; Tulsky, 2005).

Figure 5: Domain two – Informational exchange



## Domain two - Informational exchange

### Code - Review patient's condition

The review of the patient's condition usually involved a statement of the medical history leading up to the admission to the PICU and a review of the patient's condition whilst in the PICU. Having opened the meeting and attempted to elicit an agenda, 14/15 doctors began to review the patient's condition. The following example briefly reviews the child's history before admission to the hospital:

*Doctor: So she has never ended up being ventilated for very long, but she was on respiratory support for a long time. Then she went home on oxygen and got home for a little bit but then got into strife and ended up at (hospital name) and then got picked up by us and came up.*

The review of the patient's recent history enabled the doctor to bring the family up to date with the medical condition of their child and ensured that the family were able to understand why their child was in the PICU.

The task for the doctor at this point is to gauge the understanding of the family, bring them up to date with their child's condition, and begin to engage the family in a

collaborative working relationship. The following example illustrates the doctor's attempt to review the patient's condition and empathically engage the family, through evidencing what the family observed at the bedside:

*Doctor: Obviously everyone has been worried about him since he had his surgery in that at times he hasn't seemed to be wide awake even though occasionally he has been. And yesterday it looked like he was having some seizures so he was given some medicine which made him really sleep, and then when you came down here last night we were all worried that he wasn't waking up and moving around normally...*

The doctor carefully joins with the family, stating her concerns 'everyone has been worried' and 'we were all worried'. This encompassing approach may encourage the family that 'we' the PICU team, are vigilant and aware of the child's condition. This also prepared the family for the seriousness of the medical information that followed.

#### **Code - Discuss patient's baseline**

The discussion about the patient's baseline may be one of the first indicators for family members during the meeting that their child is critically ill and possibly facing death. In the following two separate examples, the doctors prepared the family members for the changes that may have occurred to their children:

*Doctor: ...the most likely outcome is that she will survive this, but that she won't be the same little girl – that she will have some issues with brain function and development. But just how bad they are we don't yet know.*

*Doctor: If he were to survive, he won't be the same boy you knew before he got unwell. There are parts of his brain that won't be working right and if he were to survive he would have problems. It is a bit hard to know yet, it is early days, what deficits he would have – he may not walk properly, he may not talk properly, he may not be able to feed himself, he may not be able to toilet himself – those sorts of things. It is not clear yet because his kidneys are getting more and more sick and his liver is getting more and more sick.*

These examples occurred in 5/15 meetings and were all accompanied by reserved prognostic statements such as 'But just how bad they are we don't yet know' or as

above 'he may not walk, he may not talk'. These statements by the medical team leave space for hope for the family whilst protecting the medical team should they have misdiagnosed the child. The latter statement 'he may not walk, he may not talk' is presented with a negative tone but could equally be perceived by the family as 'he may talk, he may walk'. The function of these reserved prognostic statements may also assist or prepare the family should the medical team have to consider withdrawing their child from life support.

#### Code - **Clarification of terms**

This code identifies one of the key skills for doctors, which is to interpret complex medical information for the family. All the meetings included examples of the doctor using layman's language and other devices to provide clarification of terms such as the following:

*Doctor: He was bleeding from everywhere, his blood was very thin and his haemoglobin was very low and he had been bleeding so much and clotting so much that all of his platelets – platelets are part of your blood that helps stop the bleeding- and his platelet's were very, very low.*

This example explains the purpose of platelets and the significance of having low platelets due to excessive bleeding. Some doctors used literal descriptions as this last example demonstrates and some doctors also used metaphors and imagery. The next example uses the image of a box to explain pressure in the brain:

*Doctor: The problem is that your brain is in a hard box, so as it swells up and the pressure goes up, it is harder for the blood and oxygen to get to the brain and the pressure in there causes damage... So we are monitoring pressure inside her head. She has two different monitors. She's got one actually sitting in her brain tissue, and one sitting in the fluid space inside her brain which means that when the pressure gets too high, we can also let some of the fluid out which just decreases the volume in the brain and lets the pressure go down a bit.*

The careful explanation, by the doctors, of these conditions, may have assisted the family to interpret complex medical information and begin to understand the significance of treatment decisions by the medical team.

### Code - **Significance of information**

This code was also present in all the meetings and often involved detailed statements about the status of the patient with the doctor's interpretation about whether these were good or bad indicators as in this example:

*Doctor: ...we know that his brain hasn't been working very well and that is also getting worse now with the seizures, which are a sign that there is a big problem there. And then the newer thing over night has been the fact that his bowels are not working either. The kind of bleeding that he is having from his bowel tells us that the bowel is probably dying. And once all of these parts of your body start to die, it means that he is going to die despite everything that we do.*

This important code is the third stage of a process of giving the family information. The first involves describing the medical condition of the child using layperson's terms and images to express complex medical conditions. The second, explaining the significance of these conditions and what they mean to the patients functioning. The third stage outlines whether these things are good or bad and integrates them into the prognostic outlook for the patient.

### Code – **Symptoms**

This code featured in 11/15 meetings and referred to the patient's current symptoms, comfort or experience in the PICU. It was an opportunity for the doctor to give the family a direct observation on their child's current condition in the PICU:

*Doctor: But her little body is just fighting away at the moment trying to breathe and trying to manage all the infection that has been in her brain.*

In this particular observation, the doctor frames the symptoms as the child's body fighting to breathe and manage the infection rather than the medical technology and medication. The inference of this comment could lead the family to perceive that their child's life depends on her ability to fight for her life, rather than her dependence on any medical intervention or life support measures.

## Code - **Affirming experiences**

This code appears at the end of the informational exchange section and is suitably placed to acknowledge the traumatic nature of the information that has been delivered to the parents. Having delivered the most difficult of news to a family an affirmation can provide some comfort and provide a bridge between the doctor and the family. Almost half the meetings (7/15) included affirming statements such as:

*Doctor: Unfortunately, it is a bit like a roller coaster thing and it is a very easy thing to say and it is a horrible thing to experience this.*

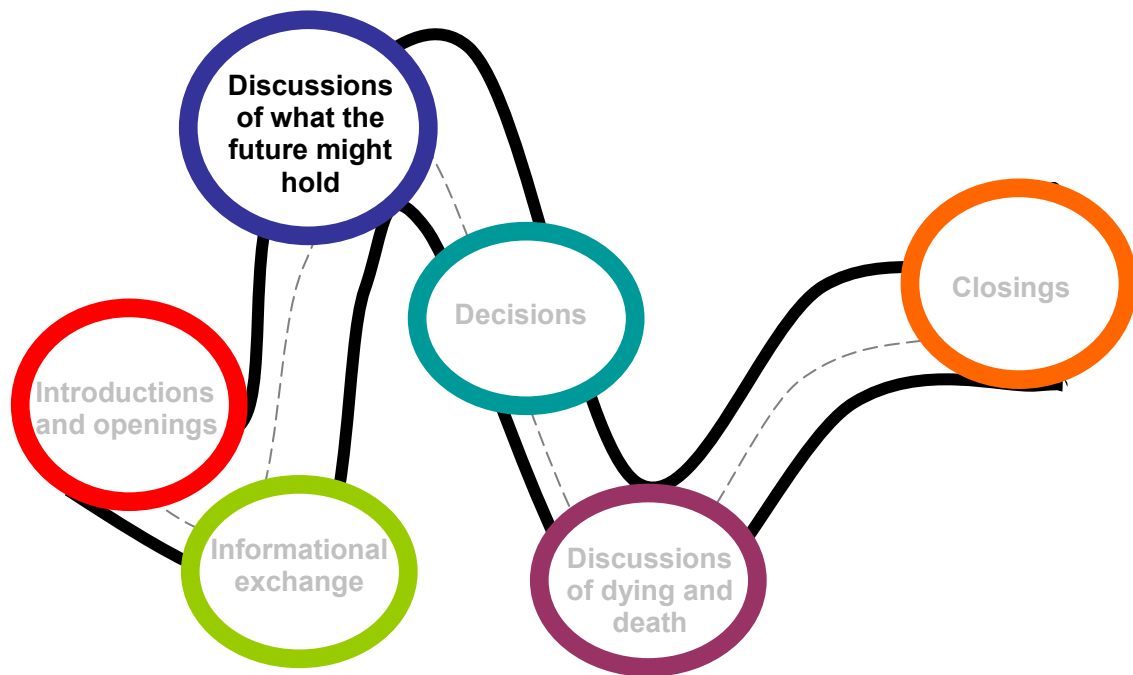
In this example, the doctor uses the metaphor of the rollercoaster to illustrate the sickening vicissitudes of parents' experiences and acknowledges his relatively easy task of explaining the medical information as opposed to being the recipient of such information. Boyle identified the importance of the medical team acknowledging the difficulty of the situation and the decisions for the family (Boyle, Miller, & Forbes-Thompson, 2005).

In the following example, the doctor acknowledges the experience of the child to provide comfort to the parents:

*Doctor: So even though you guys are suffering terribly from this, she is not, so she is not feeling any pain. She is not in any distress and that is an important thing.*

The importance of restating that a patient will be comfortable and will not suffer any pain is also identified in the literature as a statement that increases family satisfaction (Stapleton, Engelberg, Wenrich, Goss, & Curtis, 2006).

Figure 6: Domain three - Discussions of what the future might hold



### Domain three - Discussions of what the future might hold

#### Code - Prognosis for survival

This code reflects a change in the discussion from outlining the medical condition to reinforcing the seriousness of the child's condition and discussing the possibility of the child's death. Almost all the meetings (13/15) included statements about the future and some included predictions of death:

*Doctor: After fourteen or fifteen years of intensive care I have probably seen one or two other babies that have been like that and it hasn't got any better. We are getting to the point where we are just not sure her lungs are going to be good enough for her survival. So we thought we needed to sit down and let you know that and see what questions you have and how you are feeling about it all.*

*Parent: So if she was taken off life support her chance of survival is virtually nil?*

*Doctor: If we took her off right now she would die in a few minutes.*

In this example, the doctor stated her experience as a clinician and her experience with this particular medical condition. She introduced the seriousness of the child's condition and then invited response from the parents. The parent immediately responded to the invitation to ask a question and replies with her most important question and assumption.

#### Code - **Prognosis regarding future quality of life**

The parents immediate concern may have been their child's survival but the emerging reality may be that the child who lives is not the same child prior to the admission to the PICU. In this code the doctors addressed the implications of survival, should the child live. The following example illustrates the two scenarios that may face the family of a child, 8/15 meetings included this type of content:

*Doctor: But at this stage it looks like she is not out of the woods – there is still a chance that she might not make it at all and if she does make it, we think she is going to be quite severely disabled by this.*

This example is presented with three prognostic suggestions: the first 'she is not out of the woods' a term that is often used to indicate that a person is still at risk but may get 'out of the woods'; the second 'she might not make it' suggesting she will die, and the third suggesting she will be 'severely disabled' even if she does recover. This ebb and flow in the communication indicates the difficulty for the doctor to conclusively say this child will die or live.

#### Code – **Uncertainty**

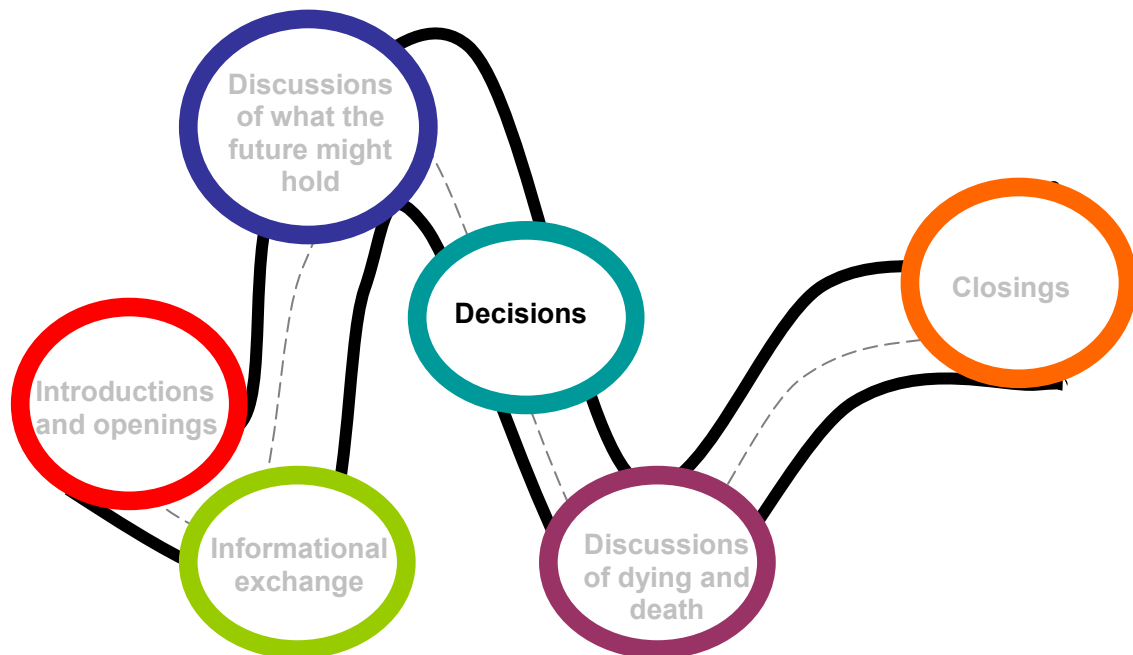
This domain of 'Discussions of what the future might hold' is underlined by the uncertain verb 'might'. It is very hard to judge when a child will die and 11/15 meetings reflected this uncertainty:

*Doctor: He is complicated for me and I have a whole team of heart surgeons and heart doctors and all the intensive care team here. It is hard to know which way to go with him, how to do it, and what the right thing is. There is no right or wrong answers. He is himself and we have got to do what he needs and tailor it to what he is doing and how he is.*



Uncertainty may be perceived by the doctor as an expression of failure. However, uncertainty from the doctor might also be perceived by the family as an expression of hope and humanness.

Figure 7: Domain four – Decisions



## Domain four – Decisions

### Code – Options

This code refers to the treatments that might be followed, depending on the condition of the patient. 12/15 meetings included these discussions and the following is an example:

*Doctor: And so for your girl to be a viable candidate for the operation that needs to be done, if we ultimately get to that stage, her blood pressure in her lungs needs to be low enough. If her blood pressure stays high in her lungs then that would be a bad thing also and time will tell. So we are in a holding pattern at the moment and we will do what we can do and hopefully things will get better.*

During this example, the doctor tentatively raised the possibility of surgery and identified one of the symptoms, 'the blood pressure' that has to come down before the medical team can proceed. The function of giving these treatment options to the family may be two fold. The first to provide an indicator (high blood pressure in the lungs) that the family can observe to predict their child's level of health and secondly as a sign of hope that the medical team is still proceeding with curative intent.

This second example illustrates the use of scenarios in end-of-life discussions

*Doctor: There are a number of scenarios. The worst-case scenario is where we look at the MRI and say, my goodness, this is really, really bad. I would then come to you and tell you, and what we would tend to do, is take out the breathing tube and the support and let her pass away in your arms.*

*The other things depend on how bad it is and whether we can get her off the breathing machine and get her off the drugs causing the fitting. Again, it would be a step down the line. The best case scenario would be to try and get rid of the drugs and the breathing tube and have her breathing quietly by herself and let her recover with time.*

Scenarios were used to express the dilemma associated with life and death situations. The doctor in this example provides two scenarios calling one 'the worst case' and, by omission, suggesting that the second scenario may be the best case. An expression of two scenarios allows discussion and acknowledges the possibility that the child may live or the child may die. The voicing of these two scenarios allows the family to consider both the options and to be prepared for either.

#### Code – **Choices**

This code refers to the treatments that have been selected by the medical team and is evident in 11/15 meetings. During this example, the doctor explained the treatment and its effect on the patient for the family:

*Doctor: In terms of her blood pressure, we are still giving her medicines to push her blood pressure higher to try and make sure her brain gets enough oxygen and is still protected. But I suspect she would have a normal blood pressure if we took her off those. We are pushing it higher on purpose at the moment.*

## Code – **Code**

This code only featured once (1/15) during the family meetings and refers to the immediate resuscitation status of a patient. The expression ‘Calling a code...’ is more commonly used in an adult hospital environment where sudden deaths are a more common occurrence. The following example fits the description for inclusion under this code and illustrates a form of paternalistic decision-making:

*Doctor: If she does anything further we are not going to be trying to aggressively resuscitate her, do the chest compressions, because that is her saying ‘no, this is it’. And it is not the right thing to do that any more because we can’t change what has already happened.*

This example illustrates the doctor’s belief that it would not be appropriate to resuscitate the patient due to her critical condition and history. He then checked this out with the family with the question ‘Does that make sense?’ This is also an example of the paternalistic approach to decision-making, similar to the French model (Carnevale et al., 2007) where the medical team makes the decision and informs the family. The discussion in a North American Hospital might be very different with the doctor seeking consent for a ‘DNR (Do not resuscitate) order’ and the family acting as the decision makers.

## Code - **Transitions from curative to palliative care**

When a decision is made to withdraw intensive treatment, the primary focus then changes from an interventionist approach aimed at sustaining life to a more patient and family directed process aimed at providing comfort and support of the child and their family (Longden & Mayer, 2007). The following examples occurred in 3/15 meetings and reflected the change in treatment discussions from curative to palliative care:

*Doctor: The important thing for you as his parents who love him and for all of us who have been trying to help and care for him is that even though we don’t have any treatments left to save him, we still are here to care for him and to look after him and to support you and look after you as his parents. So that means that our focus changes a little now to making sure that as well as the things we have been doing, we are going to make sure that he is really comfortable...*

*Doctor: ...then what we do, is, we change our focus from trying to save them to making sure that things are as good as they can be in a bad situation. So even if we stopped treating your girl, we are not going to stop caring for her and whatever we are going to do, we are going to do as well as we can and that is really important. We are going to give her, her dignity in this and that is important for us and for you.*

*Doctor: ... if we absolutely know this baby is not going to survive then you change your focus from doing everything to keep them alive to doing everything to keep them comfortable and making things right for the whole whanau and so if you reach that point then absolutely we would back off on the drugs and things that we are keeping her asleep and she could have cuddles and be with you guys and have lovely family time.*

The three doctors all referred to a change in 'focus' and illustrated what that would mean to the family and the medical team. This involved a shift of focus to caring, comfort and in the latter example, cuddles and family time.

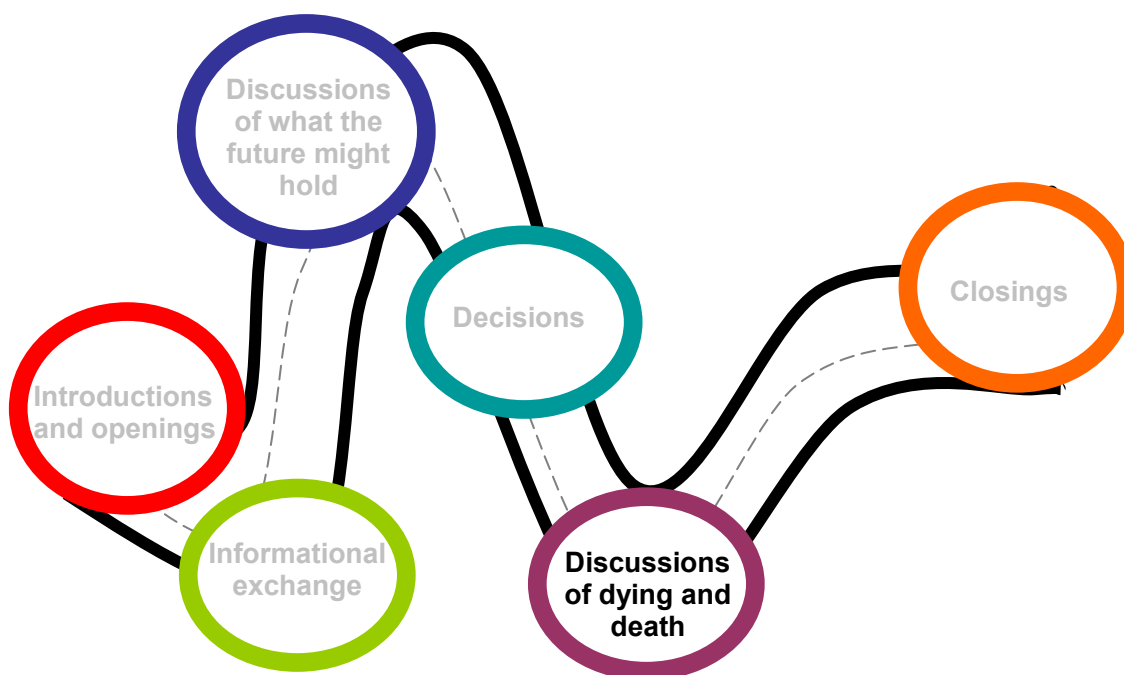
#### **Code - Withdraw life-sustaining treatments**

This may be one of the most difficult conversations for a doctor to have with a family and 5/15 meetings included a reference to the withdrawing of treatment. The following example demonstrates one approach to these difficult conversations:

*Doctor: So what we would do, is when you have had some time to talk, we would then come back and talk again and be looking at taking the breathing tube out so it is not uncomfortable in his mouth and so that you can hold him and cuddle him.*

In this example, the doctor acknowledges the family's need to talk and explains the process about withdrawing their child from life support. He sensitively shifts the focus to a palliative approach that emphasises comfort -the removal of the tube, presence- 'you can hold him' and love- 'cuddle him'. These are also important concepts in palliative care identified by Professor Ian Maddocks 'the hope affirmed by palliative care is different; it accepts the truth and its promise is not for longer life or recovery, but for comfort, presence, acceptance and love'(1990, page 538).

Figure 8: Domain five - Discussions of dying and death



## Domain five - Discussions of dying and death

### Code – Dying

The natural process of discussing withdrawing treatment leads to discussions about death and dying. During the Curtis study (2002) it was identified that doctors typically did not discuss dying or death in much detail. In this study the doctors also did not talk about dying in detail with only 4/15 meetings including discussions about dying.

The discussions about dying were brief with a focus on withdrawing the tubes and providing time, cultural support, or spiritual support. The brief nature of the discussions might also reflect the traumatic impact on family members who may be reeling from the information that they have been told. In the following examples, the doctors do not use the words death or dying but clearly acknowledge the importance of preparing before the death:

*Doctor: I don't know what is going to happen; I really honestly don't know what is going to happen over the next couple of days. Things look bad right here, right now, but do take this opportunity because your time is precious with her and do the things you would otherwise do. And if that involves getting her*

*christened or baptised or anything like that, I think you should take the opportunity.*

*Doctor: I would then come to you and tell you, and what we would tend to do is take out the breathing tube and the support and let her pass away in your arms...*

The four doctors who discussed dying correctly predicted that their patients would die. Discussions about dying were limited to offering support and acknowledging spiritual needs. There were no detailed discussions about what might occur during the dying process and how care might be managed. The research evidence from the paediatric literature suggests that higher parent ratings of physician care are associated with doctors giving clear information about what to expect in the end-of-life period (Mack et al., 2005)

The final example for this code illustrates the difficulty when a child is being kept alive by medical intervention and a doctor has to let the family know that the child's life is being artificially prolonged and they may be suffering:

*Doctor: ...we will get to the point that by keeping that breathing tube in and keeping him on the breathing machine, we are just making it harder for him and we are prolonging him dying. We are not helping him live any more, it just means that it is taking longer for him to die and we don't want him to suffer more like that.*

The inclusion of this example illustrates the difficulty for medical staff when a family is reluctant to withdraw their child from life support. The decision to withdraw a child from life support is made by the medical team and the family has to agree with this decision. The medical team will wait for the family and this may prolong suffering for a dying child.

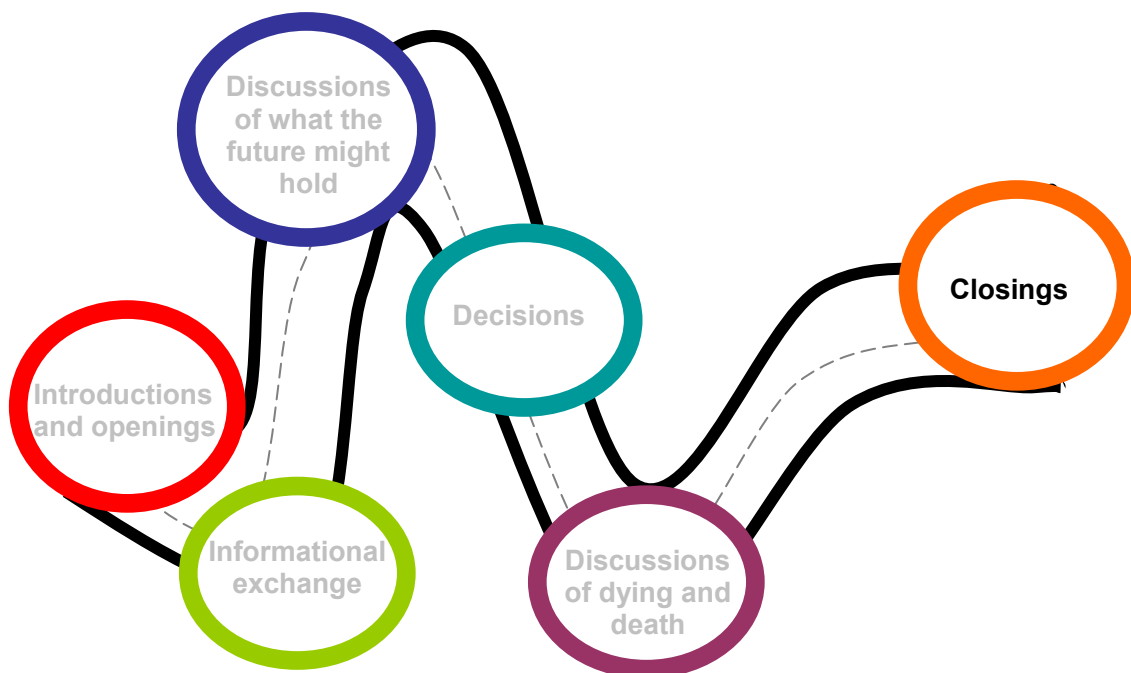
#### Code – **Death**

Discussions about the possibility (rather than the inevitability) of death occurred in 11/15 meetings and in this example, the doctor clearly indicates the possibility of death and the process that might occur:

*Doctor: If it comes to a stage when it is clear to everybody that what we are doing is just protracting his death, then we will sit down and talk to your family again. At the moment we are doing all our best to get him through this and to help him and try to get to the bottom of why and to do all the things we can to support his kidneys, his liver and his heart. We will do all those things and we hope that things will improve, but if it becomes obvious that we are just protracting him dying, then we would probably need to have a different discussion.*

This example also identifies the importance of limiting suffering with the expression 'protracting him dying'. The doctor also mentions twice the importance of discussing and talking before any further decision is made. This type of process discussion may prepare the family for the next step in the process of their child's treatment.

Figure 9: Domain six – Closings



## Domain six - Closings

### Code - Summary of meeting

A brief review or summary of the discussions occurred in 5/15 meetings shortly before the doctor left the meeting. This included repeating plans for future medical

procedures, reiterating the seriousness of the child's condition and making statements about the patient's level of comfort as this example demonstrates:

*Doctor: We have said that from the scan his brain is severely damaged and there are bad areas all over the place. We are keeping him very comfortable and I don't think he is suffering at all, but I don't know what place he is in and whether he can hear or not. I don't think he is suffering, but I am sure he would like to have his hand held and people to talk with him and to have familiar people around him.*

In this example the doctor highlights the difficulty of knowing 'what place he is in' and carefully attempts to comfort the family repeating 'I don't think he is suffering...I don't think he is suffering'. The use of the word 'place' almost has a spiritual quality as if the spirit of the child is no longer present. Family members may be reluctant to hold or approach their child for fear of causing pain or discomfort or even death, but this doctor encourages them to make contact with their child.

#### **Code - Family control of timing**

This closing activity was present in 5/15 meetings and acknowledged the family's need to process what they had been told and make plans for what was to come. In the following example, the doctor is conscious of extended family members who have arrived late:

*Doctor: We will give you some time and I will take you to a small room. Any one who would like to come, we will find a small room and we will leave everyone else here for a little while to have a bit of time here. We will go and I will tell you all the story again.*

The doctor not only provides time for the immediate family but also offers further time to the extended family so that the complete family is aware of the child's condition. One of the tasks of the medical team is to ensure that everyone has the same understanding about the patient's condition.

Offering time alone, or the opportunity to talk at the close of the meeting can also provide the medical team with the opportunity to disengage from the family and give the family time to process what they have been told.



#### Code - **Assure patient comfort**

Reassuring the family that their child will be made comfortable was mentioned in 7/15 meetings. The following example was typical of the comforting statements from the doctors involved:

*Doctor: The important issues are that we keep him comfortable at all times, we don't want him to be distressed or in pain...*

The literature identifies the importance of repeated reassurances that pain relief is a priority and the child will be made comfortable and will not suffer (Truog, Meyer, & Burns, 2006). Stapleton et al (2006) suggest that repeated use of this statement may also increase family satisfaction.

#### Code - **Further discussions**

Plans for further discussions were present in 10/15 meetings and were often brief closing statements as the following examples demonstrate:

*Doctor: Any time that you want to ask anything, if you have questions just let us know. We can either chat at the bedside or we can come and sit down, either way.*

*Doctor: You guys can ask for a family meeting any time you want as well. Any time you feel like it. And certainly if she gets worse we will talk to you.*

The examples reflect the open environment of the PICU and the parent's right to ask for a meeting with the medical team at any time. The examples also suggest an approachability and openness from the doctors involved.

#### Code - **Continuity issues**

Continuity of care issues were identified in one meeting with the following example:

*Doctor: ...so there are a lot of teams, which makes it probably harder as well, because there are more people past the bed space looking at results. But while (patient's name) is with us, the primary decisions are made by the intensive*

*care team. They are made in conjunction with the other teams, but they are made by the intensive care team.*

The code was not present in 14 meeting and even in this example the continuity of care issues are addressed with reference to decision-making rather than informing the family who specifically will be caring for their child. The continual rotations of nursing and medical staff can be perplexing for families and it is notable that this code did not feature more frequently. In findings from previous research in the PICU, parents emphasised that ready access to staff increased emotional peace of mind, provided information and fostered trust and reassurance. Inability to contact staff or knowing who to contact resulted in considerable stress for parents (Meyer, Burns, Griffith, & Truog, 2002).

#### Code - **Contact information**

The doctors in the study did not provide specific contact information such as phone numbers or email addresses, but in eight of the meetings demonstrated openness and approachability as this example demonstrates.

*Doctor: I am certainly around for the next couple of days and if you want to catch up at any stage – like I was very keen to catch up today just for the reasons I have explained. If you have any specific questions or if you want to sit down and have a bit more of a quiet chat ... then certainly just let somebody know.*

#### Code – **Gratitude**

There were two examples of gratitude coded from the transcripts and they were both spoken by the parents at the meeting rather than the medical staff as in this example:

*Parent: Well, this meeting has been very worthwhile because it has cleared a lot of things up which we were a little bit uncertain of.*

#### Code - **Next steps**

The final meeting code identifies the immediate action that is necessary after the conference and this featured in three meetings. The following example is drawn from

an end-of-life meeting and the doctor very sensitively identifies the mother's immediate wish to hold her child:

*Doctor: I think one of the most important things is actually now. Now is for you to be able to hold him while he is on the ventilator.*

*Parent: Yes, please we would like that.*

*Doctor: We will get that going now. Have we got a chair, a lazy-boy or something we can bring into the room?*

*Parent: Yes.*

This final example also illustrates the central importance of family meetings as doctors and family work together through the most difficult of times, in this case the death of a child.

## **Factors that may influence family satisfaction.**

This study identified a strong trend indicating an association between meeting length and family satisfaction. Longer meetings (extending beyond 40 minutes) were associated with lower satisfaction scores from families. This finding was supported by an earlier study by McDonagh who notes a trend towards longer meetings being associated with higher family ratings of conflict with the clinician, although this did not achieve statistical significance (McDonagh et al., 2004). This was also backed up by Curtis (Curtis et al., 2005) who identified that the most commonly missed opportunities during family conferences occurred when the medical team failed to listen or respond appropriately to family questions and this often slowed the progress of the meeting. It could therefore be argued that longer meetings may be because of failure to listen or respond appropriately to the family and failure to resolve conflicts between the medical team and family.

There is however evidence that longer consultations with patients may be more satisfying for the patient. In an interesting piece of research by Roter (2000) they compared the differing communication styles of 'expert' palliative care clinicians and community doctors. They found that the expert providers spent twice as much time talking with their patients and excelled in the use of a patient centred and partnership building communication style. This style appeared to invite the expression of patient opinions, expectations, and understandings and ultimately encouraged patients to talk more. This is a different patient group to the PICU sample but it raises some useful

approaches to end-of-life discussions and may challenge the notion that longer meetings may be less satisfying.

There was no association between the proportion of time spent talking by the family during a meeting and increased family satisfaction. This study was modelled on the family meeting research of Curtis. One of his co-investigators McDonagh (2004) found that allowing family members more opportunity to speak during conferences may improve family satisfaction. This theme has interested researchers over the last decade (Fassier et al., 2006; McDonagh et al., 2004; Tulsky & Chesney, 1995) as studies consistently argue that the more time family members speak during a family meeting the more satisfied they are. It should be noted that none of the previous studies involved paediatric patients.

Family members appeared to be satisfied with the family meetings during this study but spoke very little. Satisfaction scores were high with six of the 15 meetings scoring 50 of 50 (the highest point) for satisfaction and a mean score of 45.3. McDonagh (2004) also noted that family ratings of satisfaction after a meeting were high with a large proportion of family members rating individual communication items on the questionnaire at the highest point. This is consistent with two previous studies (Heyland, Rocker, Dodek, Kutsogiannis, Konopad, Cook, Peters, Tranmer, & O'Callaghan, 2002; Johnson, Wilson, Cavanaugh, Bryden, Gudmundson, & Moodley, 1998) surveying family members in the ICU.

Family members may have been very satisfied with the level of communication they received as a result of very competent medical team members in this study. However, the high scores in both studies may also indicate a limitation to the study design. Each family was handed a questionnaire immediately after a critical meeting. The content of the meetings in both studies included discussions about a life threatening condition and in some instances the death of a loved family member. These discussions were traumatic and at times shock and grief-inducing. It is to be expected that a number of the participants would find it very difficult to objectively reflect on the process of that meeting and they may have marked the highest possible rating for a number of possible reasons. Firstly, family members may have been concerned that the medical team would see the satisfaction scores and this might affect medical decision-making about their child. Secondly, family members may also have wanted to get the questionnaire out the way so that they could think about the important decisions ahead and process what they had just heard.

The content of family meetings may have a greater impact on family satisfaction than the proportion of time spent talking. This may be the case when the primary concern for parents is whether their child will live or die. A number of children died during the course of this study and their families ( $n = 9$ ) were slightly less satisfied (43.2 of 50) than those families ( $n = 6$ ) whose child did not die (48.3 of 50). This might suggest that the content of a meeting and the child's prognosis is more likely to influence satisfaction than the proportion of time that family members speak during a meeting. This is counter to findings that family members of adult patients who survived were less satisfied with the medical teams communication than the families of adult patients who died (Wall, Curtis, & Cooke, 2007). These studies occurred in North America (McDonagh et al., 2004; Tulskey & Chesney, 1995) and France (Fassier et al., 2006) who operate under different decision-making models. The model in North America is focused on patient and family autonomy whereas the paternalistic model in France is similar to New Zealand. It could be argued that a paternalistic decision-making approach might encourage doctors to speak more and family members to speak less. Fassier noted that family members spoke for 33 % of the time during the French study and this would appear to rule out the proposal that paternalistic models of decision-making might limit family speech or increase medical team speech.

The content of family meetings appear to be similar to the North American model described in Curtis (Curtis et al., 2002a), however there are differences between children and adults that might also account for the amount of time that families speak during these critical meetings. The context of the adult patient in the ICU is quite different from the context of the child in the PICU. Truog and Meyer (2006) advise against extrapolating that experiences in adult ICUs and PICUs are the same. The suggestion that *children are not just little adults* is true not only for matters related to treatment, but also with regard to end-of-life issues (Hynson, 2008). It is anticipated that at end-of-life older people will require hospitalisation before death but it is rarely anticipated that children will even die. The incidence of adult death in the ICU is frequent (Angus, Barnarto, Linde-Zwirble, Weissfeld, Watson, Rickert, & Rubenfeld, 2004) whereas the death of a child in the PICU is an infrequent event. Discussions at end-of-life concerning adults and children are times of grief and loss. However the death of an adult is arguably more likely to be understood as a natural part of the life-cycle as opposed to the death of a child which may be perceived as an unnatural event (Hendrickson & McCorkle, 2008; Hynson, 2008; McConnell & Frager, 2004). Therefore the discussions that occur in the adult ICU involve family reflections on the patient's

life, discussions of values history and discussions about surrogate decision-making (Curtis & White, 2008). These specific codes were not identified during the transcript analysis of this study. The findings from this study suggest that discussions in family meetings in the PICU are most likely to be focused on the child's medical condition and decision-making about treatment.

Parents may speak less during these meetings because they are experiencing higher levels of traumatic distress than their North American or French adult patient counterparts may. Family members in this study spoke for 16% of the total time during the family meeting with the doctor. Previous studies indicate the mean proportion of time spent talking by the family during family meetings as 29% (McDonagh et al., 2004), 25% (Tulsky & Chesney, 1995) and 33% (Fassier et al., 2006). None of these studies had paediatric patients as their focus but each of them focused on end-of-life meetings.

There are high levels of post-traumatic stress disorder (PTSD) in family members who have participated in end-of-life decisions about a relative (Azoulay et al., 2005). Nine of the children died during this study and previous research shows that to lose a child suddenly and in traumatic circumstances is a devastating experience for the survivors most often resulting in a tremendous and long-lasting impact (Dyregrov, Nordanger, & Dyregrov, 2003). The prevalence of PTSD amongst this vulnerable group of bereaved parents was also shown to be 57-78% (Dyregrov, Nordanger, & Dyregrov, 2003). The PICU experience may leave a long lasting impression on a bereaved parent. It is likely that the limited amount of time spent talking by a parent during a family meeting may be an indication of the high level of trauma being experienced by that parent.

There may be cultural factors associated with lower proportions of family speech during family meetings. In this study, Maori patients accounted for six of the family meetings and Pakeha patients for eight. However the findings from this study indicate that Maori whanau speak for 11 % of the time during family meetings, which is half of the time that Pakeha speak during family meetings in the PICU. Maori satisfaction with family meetings was high but such a disparity in the proportion of time spent talking between Maori and Pakeha requires some consideration. There are a number of factors that could be considered and the first is the confidence of the Maori whanau within the context of the PICU. Papaarangi Reid & Bridget Robson (2007) wrote about understanding health inequities, they said that there are

*...consistent, comprehensive and compelling disparities in health outcomes. They went on to say that despite the strength of these longstanding health inequalities, they do not create dismay, disbelief or horror. They have become expected.*

(Cited in Asher, 2008)

Pakeha may have accepted that Maori health outcomes will be lower but Maori also appear to be unable to respond when beset by poor health outcomes, such as the death of a child. The historic neglect of Maori health needs may have silenced Maori as they come face to face with the health system. The second consideration is the ethnic identity of the person leading the meeting and their ability to create a space that is culturally appropriate and accommodating of the whanau; this requires an awareness of protocols around the organisation of whanau hui (formal meeting) and family meetings in the health environment. Whilst it is not possible to state that all Maori organise family meetings in the same way, traditional Maori will have set protocols for different meetings depending on their local Iwi and the significance of the decisions being made. It may be that Pakeha are more vocal than Maori because they are more familiar with the cultural norms and values that structure European styles of communication. Finally, it was not possible to record nonverbal communication during these meetings and it could be argued that the Maori participants were engaged in a sophisticated nonverbal language structure that was not accessible to this PI.

The three meetings that were not automatically introduced by the doctor included a Karakia (prayer) and brief introduction from a Kaumatua or Maori cultural worker. The original framework (Curtis et al., 2002a) did not identify any culturally specific codes in the adult ICU and so this study did not code this content. However, the following example includes the introduction from a Kaumatua (Maori elder) having begun with a Maori Prayer followed by this introduction:

*I am (name). I am one of the Kaumatua for the Auckland District Health Board and I would just like to thank the doctors and the staff and everyone else. We are here as part of the Maori He Kamaka Oranga and the Kaiaatawhai and we liaise with whanau as well as the clinicians, doctors and if you need to ask anything regarding that we can assist you if you want. You don't have to. We are here to assist you with that and to work in with the doctors, nursing staff and whatever maybe within the hospital. So I won't hold you fellas up too long with this but I would like to thank Doctor and all the staff here, for being here, so we*

*are all singing the same tune and not mixing up the same words. I will hand you over to Doctor. Kia ora Doctor.*

The Kaumatua begins with a prayer, states his name and designation, and affirms the presence of the whanau (family) and medical team. He states his purpose to 'assist' the family and uses the metaphor of singing the same tune. This is a particularly appropriate metaphor given the difficult decision-making task faced by the medical team and family. The presence of cultural workers in the PICU may positively influence the process of family meetings, specifically in relation to spiritual and cultural practices. Despite the presence of cultural support at three meetings Maori whanau still spoke less than their Pakeha counterparts.

## **Conclusion**

During this chapter the six domains and 28 codes of have been discussed and provided an account of the content and process of family meetings in the PICU. In Chapter 1 it was noted that there are unique features of family meetings in the PICU. The following points identify some of the differences, between child and adult intensive care unit family meetings that have been highlighted during the course of this study:

- Parents spoke for a smaller proportion of time (16%) during family meetings in the PICU than their French and US counterparts in the adult ICU (25 -33%).
- The death of a child is rarely anticipated or planned and this was reflected in the discussions with the families. Discussions in PICU meetings were predominantly focused on the child's medical condition and treatment decisions, whereas adult meetings also reflected on the patient's life and values history acknowledging that family members may have anticipated the death of the adult patient.
- Children are not called upon to be decision makers in their own treatment as parents are naturally considered to be responsible for their child's well-being. Meetings in the adult ICU often require the identification of surrogate decision makers to act on the patient's behalf.



- Parents whose child died during this study were less satisfied with PICU meetings than those parents whose child lived. This is counter to findings in the ICU where family members where the patient died were more satisfied with family meetings than those families where the patient lived.
- It can be argued that the family members who attended family meetings in the PICU were more traumatised than their counterparts in the adult ICU. This might also account for the smaller proportion of time that family members spoke.

In the following chapter the outcomes from this research will be presented. The recommended guidelines are presented and future implementation and research options are proposed.

## CHAPTER SIX

# CONCLUSIONS AND RECOMMENDATIONS

# **CHAPTER 6**

## **CONCLUSIONS AND RECOMMENDATIONS**

### **Introduction**

During this final chapter the outcomes of the research are discussed, guidelines for practice during family meetings are presented, future research opportunities are proposed and significance of the study is stated.

### **Outcomes from this research**

The overarching questions driving this study were:

What is the content and process of a family meeting in the PICU and what factors influence family satisfaction?

In an attempt to address this question, the following three aims were formulated:

1. Describe the content and process of 15 whanau/family meetings in the PICU
2. Identify family meeting characteristics and patient and family attributes that may influence family satisfaction.
3. Recommend guidelines, developed from this study, for health professionals participating in whanau/family meetings in the PICU.

The following section will respond to each of these aims and summarise the major points of this study.

This research described the content and process of family meeting discussions in the paediatric intensive care unit (PICU) of a children's hospital in New Zealand. The six domains and 28 codes identified in Chapters 4 and 5 have provided a framework by which medical teams and allied staff can navigate the difficult territory of end-of-life family meetings. Each domain provided information and reminders that health professionals can reference to prepare themselves for a family meeting. The scope of this research has been in the PICU but the application of the framework can be adapted to a number of paediatric health environments and guide clinicians who are

required to hold difficult conversations with family members. During the course of this study, the framework was applied and adapted to conversations that audiologists have with parents of a child with a hearing loss (Thompson, 2008).

The second aim explored the family meeting characteristics and patient and family attributes that may influence family satisfaction. These factors were identified and analysed and the following significant points were discussed in Chapter 5:

- This study was the first to identify that when satisfaction scores were correlated with meeting length a very interesting trend was noted. The data indicated that meetings of between 10 to 40 minutes scored highest for satisfaction, but longer meetings scored lower for satisfaction. Shorter meetings were also less satisfying, but overall longer meetings exceeding 40 minutes were much less satisfying. Longer meetings (over 40 minutes) are associated with lower family satisfaction; this has been noted in two previous studies where longer meetings were associated with increased patient/doctor conflict and misunderstandings (Curtis, 2004; McDonagh et al., 2004).
- Family members caring for a child spoke less during family meetings than their United States (McDonagh et al., 2004) and French (Fassier et al., 2006) counterparts who were caring for an adult. It was argued that parents may speak less during family meetings in the PICU because they are traumatised and may be more traumatised than their adult counterparts. This observation was also supported by findings from the literature (Azoulay et al., 2005; Dyregrov, Nordanger, & Dyregrov, 2003; Shudy et al., 2006)
- Maori spoke for half of the time that Pakeha spoke during meetings and still scored slightly higher for satisfaction than Pakeha.
- There was no association in this study between increased proportion of time spent talking by family members and increased satisfaction unlike studies in the adult ICU (Fassier et al., 2006; McDonagh et al., 2004; Tulskey & Chesney, 1995). It was suggested that the content discussions of a meeting, such as whether a child would live or die, maybe more closely associated with levels of satisfaction than the proportion of time spent talking.

- Family members whose child died during the course of this study were slightly less satisfied than the family members whose child lived.

The final aim of this study was to provide recommendations for guidelines on whanau/family meetings in the PICU and for associated medical teams and health professionals. The contents of Table 9 were compiled and adapted from a range of sources (Boyle, Miller, & Forbes-Thompson, 2005; Curtis, 2005; Curtis et al., 2006; Curtis et al., 2001; Lautrette, Ciroidi, Ksibi, & Azoulay, 2006; Stapleton, Engelberg, Wenrich, Goss, & Curtis, 2006) and also includes the research material that emerged from the six domains featured in this study. These guidelines are presented only as recommendations with the understanding that they will have to be refined for implementation.

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**Table 9:** Guidelines for a family meeting in the PICU

**Preparation**

1. Consider what is known by the team about the patient and the family.
2. Acknowledge and address conflicts between physicians and within the PICU team.
3. Acknowledge clinicians' own anxiety or discomfort about the family meeting.
4. Plan where the discussion will take place and who will attend (quiet and private room, avoid being interrupted). All parties should be able to sit at the same level and be able to see each other.
5. Discuss with the family who will be present and let them know they can write down questions before the family meeting.
6. Consult staff members about whether they should be present.
7. Initiate an interdisciplinary pre-meeting to facilitate communication of consistent information and decide on roles. Decide who will start the meeting, who will close and who will deliver the medical information. Review what the family may know about the patient (diagnosis, treatments, outcomes).
8. Identify areas of uncertainty and disagreement between the family and the team.
9. Identify families at high risk for poor comprehension and conflict.
10. Identify specific cultural or spiritual requirements of the family.

**Opening the family meeting**

1. Check whether the family wants to start with a prayer or other cultural protocol.
2. Encourage people to introduce themselves and be sure that everyone knows each person's role and has heard each name.
3. Frame the discussion by stating the purpose of the meeting
4. Find out what the family understands; give them the opportunity to talk about their child's life and medical history.
5. Avoid the temptation to give too much detail about pathophysiology as a way to deal with our own discomfort (unless asked by the family).
6. Encourage the family to speak, use open-ended questions and set a non-threatening tone.

Table 9: Guidelines for a family meeting in the PICU continued

### **Informational exchange**

- 1) Listen to what families have to say.
- 2) Use reflection to show empathy and understanding.
- 3) Repeat what patients or families have said to acknowledge that they have been heard.
- 4) Acknowledge strong emotions (e.g., anger, anxiety, or sadness).
- 5) Tolerate silences that can precede difficult questions or expressions of emotions.
- 6) Discuss the patient's condition in a containing and sensitive manner.
- 7) Do not describe all possible treatment options as equally reasonable: make recommendations.

### **Discussions of what the future might hold**

1. Provide honest and meaningful information about the prognosis without discouraging hope
2. Provide scenarios to express the different prognostic outcomes that might occur.
3. Be prepared to acknowledge uncertainty

### **Decisions**

1. Do not let the family feel as if they have decided to withdraw their child from life support. This may require a discussion to address the ethics of end-of-life decision making.
2. Align the medical team and the families' views of what the goals of care should be.
3. Stress the specific palliative treatments that can be offered when the goals of care change from cure to comfort.

### **Discussions of dying and death**

1. Avoid unnecessary technical jargon, use the terms 'dying' or 'death'.
2. Make the family as comfortable as possible about discussing dying and death.
3. Be prepared to discuss the dying process or ensure the family knows with whom they can discuss process.

Table 9: Guidelines for a family meeting in the PICU continued

### **Closings**

1. Spend time exploring the family's reactions to what was discussed.
2. Family should understand that care is maintained, they will not be abandoned, even when treatments are limited.
3. Before finishing the discussion about end-of-life care, summarize the major points and ask family members if they have questions (tolerate silences, wait for questions).
4. Ensure that there is an adequate follow-up plan: when the clinician will meet with the family again and how the family may reach a clinician if questions arise before the next meeting.
5. Express the next steps and what has to be done now
6. Provide contact information.
7. Acknowledge the role of the family and the difficulty of the situation and decisions

### **After the meeting**

1. Document decision-making and rationale in the medical record.
  2. Briefly review the meeting with other staff present
  3. If the meeting exceeded 40 minutes, were there unresolved issues or difficulties that need to be addressed?
  4. Ensure there is follow-up support for the family
-



## **Recommendations for future research and implementation.**

This research has been a first in the study of family meetings in the PICU. A multi-centre study with international collaboration could replicate and refine the design with a larger data set.

The transcripts and recordings are a rich source of data for further analysis. Further investigation may provide findings that support or refute the findings of Curtis that have been featured in the literature review. The Curtis (2002a) coding framework has been tested in the PICU but further codes were evident and these require identification. Some of these additional codes included prayers or cultural protocols during opening of meetings and the use of scenarios to express uncertain medical prognosis.

The implementation of the guidelines would ideally be in the context of an interprofessional training tool bringing together nursing staff, doctors and allied health staff. The development of an interprofessional training tool based on this research would also be strengthened with pre and post evaluative research measures to test its effectiveness. The most effective training appears to include video-feedback modules that allow the participants to role-play, observe and reflect on their own practice whilst receiving constructive feedback from other course members and facilitators (Bylund, Brown, Di Ciccone, Levin, Gueguen, Hill, & Kissane, 2008). The literature in Chapter 2 reported on a range of evidence-based training models that could be adapted for this purpose (Browning, 2002; Browning, Meyer, Truog, & Solomon, 2007; Browning & Solomon, 2005, 2006; Fineberg, Asch, & Golden, 2007). The PERCS model brings together health professionals from different disciplines and provides them with an opportunity through simulated discussions with families, to develop their communication skills and learn about the distinct roles of their colleagues. The work of Fineberg directs the application of this research to medical, nursing and social work training schools where students can practice facilitating family meetings with their future colleagues. A synthesis of teaching approaches tailored for New Zealand, with specific cultural input, utilising this study, could be of benefit to the wider community of paediatric health professionals.

During the process of this study, a number of useful communication strategies emerged from the practice of the doctors involved. It may assist other health

professionals to expand on these practices with reference to the research transcripts and recordings. These practices included:

- Acknowledging emotion, containing affect and using empathy
- Stating that the family is not to blame for what has occurred to their child
- Expressing trustworthiness and integrity
- Taking time to pause and allow the family to process the information they have heard
- Using scenarios to express hope for life and the emerging reality of death
- Asking open-ended and information-seeking questions
- Shifting position from expert to learner during difficult conversations

A further exploration of what inhibits Maori from speaking more during family meetings may also be helpful, to ensure their voice is heard and guide the provision of appropriate cultural support. An analysis of the transcripts and specifically the questions asked by families during the family meetings may also reveal communication differences between Maori and Pakeha. It was not possible to record nonverbal communication during these meetings and a future study of nonverbal communication during difficult meetings would be a significant contribution to the family meeting literature.

The final research opportunity arising from this study is an exploration of the ethics of decision-making in paediatrics in New Zealand. The Doctors recruited for this research suggested that a paternalistic model of decision-making is practiced in New Zealand, but a further analysis of the transcripts may reveal another model of practice.

## Conclusion

The report of the US Institute of Medicine *When Children Die: Improving Palliative and End-of-life Care for Children* (Field & Behrman, 2003) called for research and particularly descriptive data to guide the provision of palliative, end-of-life and bereavement care for children and families. This is the first study to record and code the content of family meetings in the PICU. The description of the family meeting process and content will provide a foundation for future communication research in the PICU.

Communicating with families through tragic times is not an activity that can entirely be broken down into a prescribed series of events or codes. It is also not simply a matter

of communicating information about everything that is known or expected by the medical team, rather it is a series of relational interchanges between a medical team and a traumatised family (Truog, Christ, Browning, & Meyer, 2006). Each meeting, whether at the bedside or in a contained and private space, is contextual, requiring the medical team to be attuned to the shifting capacity of the family. This shifting capacity relates to the family's level of exhaustion, their ability to comprehend and to absorb the emotional impact of bad news (Browning, 2002). Being attuned to the family requires excellent communication and relational capacities, especially when the series of conversations shift from a curative to palliative focus. These relational capacities require careful practice and rehearsal and this study has provided vital descriptive data about the most complex end-of-life meetings to inform the development of such capacities.

The effectiveness of this study will be evidenced in its practical application to the PICU environment. The ability to reflect on, and explore the difficult terrain of end-of-life communication with traumatised family members will increase the knowledge and sensitivity of clinicians working in this field and ultimately improve the quality of care for families.

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# APPENDICES

## Appendix 1: Coding Sheet

Research Number: \_\_\_\_\_

Coder name \_\_\_\_\_

### CODING FRAMEWORK FOR THE CONTENT OF FAMILY MEETINGS IN THE PICU

Please tick the boxes when specific areas are covered in the meeting and mark/highlight the relevant paragraphs in the transcription text with the number. Please ensure that the Patient Number corresponds with the transcript patient number

For example:

Social Worker: "Welcome everybody. Let's just go round the table and introduce ourselves and our relationship with XXXX (the child)." 1.1

#### Introductions and openings

1.1 Introductions	Introduces the family and team members; determination of the relevant decision makers and review of who is missing.	<input type="checkbox"/>
1.2 Purpose	Discusses the purpose of the conference, what to expect, and defining duration or other parameters.	<input type="checkbox"/>
1.3 Elicit agenda	Elicits issues or items for discussion	<input type="checkbox"/>

#### Informational exchange

2.1 Review patient's condition	Reviews the medical history up to the conference including past medical history, conditions, and ICU course leading to the conference.	<input type="checkbox"/>
2.2 Discuss patient's baseline	Discusses baseline physical and mental abilities, and quality of life including ability to carry out activities of daily living and other activities.	<input type="checkbox"/>
2.3 Values history	Obtains a values history of the patient including personality traits, values, generic treatment preferences; often involves acknowledging the family as the experts on these questions.	<input type="checkbox"/>
2.4 Clarification of terms	Explanations in lay terms of diagnostic tests, treatments, and medical terms.	<input type="checkbox"/>
2.5 Significance of information	Describes the significance of the details of medical history, current condition, tests, or treatments; provides interpretation of medical facts as good or bad and the integration of medical details into the big picture.	<input type="checkbox"/>
2.6 Symptoms	Discusses the patient's current comfort, symptoms, or experience in the ICU.	<input type="checkbox"/>
2.7 Affirming experiences	Affirms, acknowledges, or restates the family experience of the ICU stay or the course of the patient's disease or treatments.	<input type="checkbox"/>

#### Discussions of what the future might hold

3.1 Prognosis for survival	Makes statements about the future (except predictions about quality of life—see later); includes predictions of death, duration of mechanical ventilation, dependency, and discharge location	<input type="checkbox"/>
3.2 Prognosis regarding future quality of life	Makes statements about future quality of life and future neurologic function including cognition, and activities of daily living and future quality of life	<input type="checkbox"/>
3.3 Uncertainty	Makes explicit statements about the inability of knowing the prognosis or course or the uncertainty of the prognosis.	<input type="checkbox"/>

## Decisions

4.1 Surrogate decision making	Discuss the principles of surrogate decision making	<input type="checkbox"/>
4.2 Discussions of existing advance directives	Specific discussions about previous advance directives such as an agreement not to resuscitate..	<input type="checkbox"/>
4.3 Options	Discusses procedures, treatments, or tests that might be performed in the future.	<input type="checkbox"/>
4.4 Choices	Discusses specific treatment options that are indicated, recommended, or selected,	<input type="checkbox"/>
4.5 Code	Discusses resuscitation status or emergent care.	<input type="checkbox"/>
4.6 Transitions from curative to palliative care	Discusses differences between life-supporting care and palliative care and their goals	<input type="checkbox"/>
4.7 Burden and benefit	Discusses or balances both the burdens and benefits of treatment options.	<input type="checkbox"/>
4.8 Withdraw life-sustaining treatments	Discusses the possibility of stopping, withdrawing, withholding life support or any of the treatments linked to life-sustaining treatments.	<input type="checkbox"/>

## Discussions of dying and death

5.1 Dying	Discusses what withdrawal of life support might be like and what dying might be like including symptoms, process of care, location, physiology, and spiritual aspects.	<input type="checkbox"/>
5.2 Death	Directly raises the possibility that the patient may die.	<input type="checkbox"/>

## Closings

6.1 Summary of conference	Summarizes or reviews the treatment decisions made in the conference.	<input type="checkbox"/>
6.2 Family control of timing	Gives family control over time for private conversations, timing of decisions, and implementing the plan.	<input type="checkbox"/>
6.3 Assure patient comfort	Reassurance that patient will be made comfortable.	<input type="checkbox"/>
6.4 Further discussions	Plans for further discussions,	<input type="checkbox"/>
6.5 Continuity Issues	Discusses physicians or nursing continuity of care Issues.	<input type="checkbox"/>
6.6 Contact information	Provides contact information for physicians and/or nurses or express availability for future contact.	<input type="checkbox"/>
6.7 Gratitude	Acknowledges or shows appreciation for the value of the conference or care that the patient has received.	<input type="checkbox"/>
6.8 Next steps	Discusses what happens immediately after the meeting.	<input type="checkbox"/>

## Appendix 2: Information sheet

# Increasing our Understanding of Whanau/Family Meetings in the PICU.

**Andrew Thompson – Principal Investigator**  
**Assoc. Prof. Christa Fouche – Research Supervisor**

Contact information deleted

### Information for the Whanau/Family

You are invited to take part in our study about the process of whanau/family meetings in the Paediatric Intensive Care Unit (PICU). During your child's stay in the PICU your whanau/family may be called to a meeting with the PICU team or you may request a meeting. With your permission we would like to audio tape one meeting, with your family, so that we can research the process of these meetings and improve our understanding of these meetings for the benefit of our patient's families. At the end of the meeting we will give two members of your family (as determined by you) a short questionnaire that will take 5 minutes to complete. This study is concerned with the process of a meeting and not the content.

Your participation is entirely voluntary (your choice). You do not have to participate in this study, and if you choose not to take part you will receive the standard treatment/care available and this will not affect any future care or treatment. If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your child's future care or treatment.

You may also want to show this information sheet to other members of your whanau/family who may attend a family meeting being audio taped. Their consent will also be requested before any meeting is recorded. The meeting will only be recorded if all members of the whanau/family in attendance have given their consent.

The study will be running in the PICU between September 2006 and August 2008.

### Researcher Introduction

**Andrew Thompson** - Principal Investigator and employed as a Counsellor Therapist at with the Consult Liaison Team and the Paediatric Palliative Care Team This research is a student project toward a Master of Philosophy at the Massey University, Albany and supervised by Assoc. Prof. **Christa Fouche**

### Participant Recruitment

- All new family admissions to PICU are eligible to join the study. The only exclusions are families who require an interpreter and families where there are pending investigations by Child Protection services.
- The research requires a minimum of 15 families.
- There are no anticipated risks to participants through taking part in this study; however should there be any unpredicted adverse psychological risks because of the research we will provide you with the appropriate support and follow up. Referral will be made to the Consult Liaison team at .

### **Project Procedures**

- The family meeting will be audio taped and then transcribed. All identifiable names and features will be removed to protect the privacy and confidentiality of all the meeting participants. No material that could personally identify you will be used in any reports on this study. The Principal Investigator will then code the transcript and the questionnaires relating to that transcription will be formulated.
- The data will be stored in a locked cabinet, in a locked room with restricted access for a minimum of 10 years. When the data is no longer required it will be shredded.
- The principal Investigator will write to all the families involved in the research after the results have been summarised.
- Data may be stored for future use and for which further ethical approval will be obtained from an accredited New Zealand Ethics Committee.

### **Participant involvement**

Participants will be audio taped during a family meeting and then 2 family members, as identified by the family, will complete one questionnaire each taking approximately 5 minutes.

### **Participant's Rights**

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question on the questionnaire;
- withdraw from the study before 31<sup>st</sup> July 2008
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used
- be given access to a summary of the project findings when it is concluded.
- ask for the audio tape to be turned off at any time during the interview.
- listen to the tape in the presence of a qualified and supportive health professional

### **Queries or Concerns**

If you have any queries or concerns regarding this study please do not hesitate to contact the Principal Investigator Andrew Thompson or the supervisor of this study Christa Fouche (numbers above).

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone

- Northland to Franklin 0800 555 050

### **Compensation for Injury**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

- **This Research has received approval from the Maori Research Review Committee.**
- **This study has received ethical approval from the Clinical Director of the PICU.**
- **This study has received ethical approval from the Northern X Regional Ethics Committee.**



## Appendix 3: Consent Form

### CONSENT FORM FOR FAMILY/WHANAU

#### Increasing our Understanding of Whanau/Family Meetings in the PICU

Thank you for agreeing to participate in this study

I have read and I understand the information sheet dated 11/09/2007 for volunteers taking part in the study designed to increase our understanding of family meetings in the PICU.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my child's future health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I will require an interpreter (please circle)	YES	NO
--	-----	----

I know whom to contact if I have any questions about the study.	YES	NO
---	-----	----

I consent to the whanau/family meeting being audio-taped.	YES	NO
---	-----	----

I wish to receive a copy of the study results	YES	NO
---	-----	----

A significant delay may occur between data collection and publication of the results.

I \_\_\_\_\_ (name) hereby consent to take part in this study and to my data being stored for future use for which ethical approval will be obtained from an accredited New Zealand Ethics Committee.

Date

Signature

Signature of witness

Project explained by  
Project role

Andrew Thompson  
Principal Investigator

(Note: 3 copies of the consent form: one to be retained by participant, one to be kept on the study records, and (in the case of patients) one copy to be placed in the clinical record.)

## Appendix 4: The Questionnaire

### Increasing our Understanding of Whanau/ Family Meetings in the PICU

#### Family Questionnaire

Date of Conference \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Hospital Number

Increasing our Understanding  
of  
Whanau/Family Meetings in the PICU

Family Questionnaire

## **DIRECTIONS**

Thank you for helping us with our study to improve the care of patients and their families in the Paediatric Intensive Care Unit (PICU). Please answer each question with the rating that seems best to you. There are no right or wrong answers. If you have any comments, feel free to write them on these pages. If you have any questions, a member of our research staff would be glad to answer them he can be reached by phone at (*phone number*)

**The information you provide on this survey is  
confidential and will not be shared with any of  
the hospital staff.**

**Before beginning, please fill in today's date:**

\_\_\_\_/\_\_\_\_/\_\_\_\_  
*Month Day Year*

## THE WHANAU/FAMILY MEETING

We would like to know how well the medical team communicated with you during this family meeting. Please **circle** the number that best describes how well the medical team communicated with you during the family meeting, with 0 = “the very worst I could imagine” and 5 = “the very best I could imagine”.

**During the meeting, how well did the PICU team answer your questions about your child’s illness and treatment. (Circle one number)**

Not at all well Extremely well

1 2 3 4 5

**2. During the meeting, how well did the PICU team listen to what you have to say. (Circle one number)**

Not at all well Extremely well

1 2 3 4 5

**3. Overall, how well did the team communicate with you during the family meeting? (Circle one number)**

Not at all well Extremely well

1 2 3 4 5

**4. How well did this meeting help you understand the choices and decisions that may need to be made? (Circle one number)**

Not at all well Extremely well

1 2 3 4 5

**5. Overall, how well did this meeting meet your needs? On the scale below, 1 = “not at all well” and 5 = “extremely well”. (Circle one number)**

Not at all well Extremely well

1 2 3 4 5

**THIS IS THE END OF THIS SURVEY. IF YOU HAVE ANY COMMENTS FOR US, PLEASE FEEL FREE TO USE THIS PAGE.**

**PLEASE HAND THIS COMPLETED SURVEY TO THE STUDY MEMBER OR PLACE IT IN THE SELF-ADDRESSED STAMPED ENVELOPE AND MAIL IT TO THE STUDY STAFF.**

***THANK YOU FOR YOUR TIME AND WILLINGNESS TO HELP US  
IMPROVE OUR ABILITY TO CARE  
FOR PATIENTS AND FAMILIES IN THE PICU***