A FEASIBILITY STUDY OF A BOURDIEU-INFORMED PARENT BRIEFING INTERVENTION TO IMPROVE PARENTS’ SATISFACTION WITH DECISION MAKING FOR HOSPITALIZED CHILDREN WITH COMPLEX HEALTH CARE NEEDS

By

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A Thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Graduate Department of Nursing Science

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A feasibility study of a Bourdieu-informed parent briefing intervention to improve parents’ satisfaction with decision making for hospitalized children with complex health care needs

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Abstract

Children with complex health problems who are dependent upon medical technology require frequent hospitalizations, during which parents must make difficult decisions regarding their child’s care. Although principles of “family-centred care” have been widely adopted by paediatric hospitals, studies indicate that many parents are dissatisfied with their roles in decisions about their child’s care. Pierre Bourdieu’s Logic of Practice, specifically his concepts of field, capital, and habitus, as they relate to cultural and symbolic capital within the field of pediatric medicine, were used to guide the design of a parent briefing intervention aimed at improving parents’ satisfaction with decision making. Briefings were conducted during daily hospital rounds. Physicians and nurses were asked to sit while using a checklist as a communication guide.

A two-part study was conducted to determine feasibility of a randomized controlled trial of a parent briefing. One component was a psychometric evaluation of an instrument to measure parents’ satisfaction with decision making. The other was a phase I single group, post-test study of the parent briefing. Eighty-two parents of children admitted to an in-patient unit in a large metropolitan pediatric health centre, with an expected length of stay ≥ 3 days, completed the Family Satisfaction with Decision
Making (FS/DM) subscale and the Decisional Conflict Scale (DCS) prior to discharge. A subgroup of parents participated in the parent briefing study.

The Cronbach’s alpha reliability coefficient of the FS/DM was 0.87, and it was inversely correlated with the DCS ($r^2 = -0.635, p<0.0001$). Eighteen physicians, 25 nurses, and 31 parents participated in the phase I trial of the briefing intervention. Sixty-eight out of an expected 93 briefings were carried out as per study protocol. Nineteen parents did not receive the required “dose” of the study intervention. Mean time to complete the intervention was 11.9 minutes (SD = 6.9). Parents and nurses rated the acceptability and usefulness of the intervention favourably, whereas physicians’ ratings were mixed.

The FS/DM instrument is a suitable primary outcome measure for an RCT. However, more work needs to be done, to ensure the feasibility of the intervention, including more intensive clinician training.
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# Table of Contents

**CHAPTER: 1  INTRODUCTION & LITERATURE REVIEW**

- Background.......................................................................................................................... 1
- Literature Review .................................................................................................................. 5
  - Communication in a Hospital Setting .............................................................................. 6
  - Parent- or/Family-Professional Conflict during a Hospitalization ............................ 17
  - Decision Making .............................................................................................................. 25
  - Brief Structured Communication Processes .................................................................... 26
  - Patient and/or Parent Satisfaction with Care during a Hospital Admission ............ 27
  - Outcome Measurement
    - Family Satisfaction with Decision Making Subscale .................................................... 32
    - Decisional Conflict Scale ............................................................................................. 37
- Summary of Literature Review ............................................................................................ 39

**CHAPTER: 2  CONCEPTUAL ORIENTATION**

- Pierre Bourdieu: The “Logic of Practice” ......................................................................... 41
- Critique of Bourdieu’s Ideas ............................................................................................... 46
- Application of Bourdieu’s Concepts to a Pediatric Hospital Setting ............................. 47
- Forms of Symbolic/Cultural Capital during a Paediatric Hospitalization ..................... 49
- Social Positioning of Parents in Hospital Spaces ............................................................... 50
- Statement of the Problem .................................................................................................... 51
- Study Objectives .................................................................................................................. 53
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>54</td>
</tr>
<tr>
<td>Description of Study Setting</td>
<td>54</td>
</tr>
<tr>
<td>Description of Routine Unit Rounds</td>
<td>55</td>
</tr>
<tr>
<td>Study Schema</td>
<td>58</td>
</tr>
<tr>
<td>Psychometric Study</td>
<td></td>
</tr>
<tr>
<td>Eligibility Criteria</td>
<td>59</td>
</tr>
<tr>
<td>Sample Size</td>
<td>59</td>
</tr>
<tr>
<td>Phase I Single Group Post-test Study</td>
<td></td>
</tr>
<tr>
<td>Eligibility Criteria</td>
<td>60</td>
</tr>
<tr>
<td>Sample Size</td>
<td>61</td>
</tr>
<tr>
<td>Procedures Common to both the Concurrent Psychometric and Phase I Single Group</td>
<td></td>
</tr>
<tr>
<td>Post-test Components of the Study</td>
<td></td>
</tr>
<tr>
<td>Eligibility Screening</td>
<td>61</td>
</tr>
<tr>
<td>Recruitment and Consent</td>
<td>62</td>
</tr>
<tr>
<td>Study Enrolment</td>
<td>62</td>
</tr>
<tr>
<td>Followup</td>
<td>62</td>
</tr>
<tr>
<td>Methods for Data Collection</td>
<td>62</td>
</tr>
<tr>
<td>Demographic Data</td>
<td>62</td>
</tr>
<tr>
<td>Followup</td>
<td>63</td>
</tr>
<tr>
<td>Data Analysis Plan</td>
<td>64</td>
</tr>
<tr>
<td>Parent, Child, and Nurse Demographics</td>
<td>64</td>
</tr>
</tbody>
</table>
Procedures Specific to the Psychometric Component of the Study

Methods for Data Collection.................................................................65
Parents’ Satisfaction with Decision Making.........................................65
Parents’ Decisional Conflict.................................................................66
Data Analysis Plan...............................................................................67
Content Validity..................................................................................67
Construct Validity................................................................................68
Reliability..............................................................................................69
Distribution of Scores........................................................................69

Procedures Specific to the Phase I Single Group Post-test Component of the Study

Study Intervention................................................................................70
Elements of the Intervention...............................................................71
Nurse Training.....................................................................................74
Physician Participation........................................................................76
Methods for Data Collection...............................................................76
Data Analysis Plan................................................................................79

Feasibility for an Randomized Controlled Trial (RCT)............................81
Data Management and Data Validation.............................................83
Ethical Considerations..........................................................................83

CHAPTER 4: RESULTS

Derivation of Sample...........................................................................84
Psychometric Component of the Study..............................................84
Phase I Single Group Post-test Component of the Study.....................87
Descriptive Data about the Children, Parents, and Care Providers

Characteristics of the Children.................................................................88
Characteristics of the Parents.................................................................89
Characteristics of the Care Providers.....................................................90

Results

Study Objective #1.................................................................................92
  Distribution of Scores of the FS/DM.......................................................92
  Content Validity of the FS/DM...............................................................92
  Construct Validity of the FS/DM............................................................92
  Reliability of the FS/DM....................................................................93
  Distribution of Scores of the DCS.........................................................93
  Reliability of the DCS....................................................................93

Study Objective # 2

  Percentage of Eligible Physicians, Nurses who Agreed to Participate.....93
  Amount of Time Needed to Train the Nurses in the
  Study Intervention..............................................................................94
  Percentage of Eligible Parents who Agreed to Participate.................94
  Compliance of Clinicians and Parents with the Intervention.............94
  Length of Time Needed to Complete the Intervention......................99
  Parents and Clinicians Evaluation of the Study and the
  Intervention.......................................................................................99

Additional Analysis

  Relationship between LOS and Instrument Scores..........................103
Parents’ Satisfaction Scores Based on Participation in the Briefings…………………………………………………………………………104
Comparisons of the Number of Parents who Asked Questions when Physicians did and did not Sit during the Briefing………………105
Feasibility for a Randomized Controlled Trial…………………………………………………………………………………………………106

CHAPTER 5: DISCUSSION

Strengths and Limitations…………………………………………………………………………………………………………………………………109
Study Objective #1: Decision about a Primary Outcome Measure for a Proposed Trial……………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………112
FS/DM Instrument…………………………………………………………………………………………………………………………………………112
Measure of Patient/Parent Satisfaction as a Quality Care Outcome………………114
Study Objective # 2: Feasibility and Acceptability of a Parent Briefing Intervention……………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………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Implications for Practice.................................................................133

Conclusion....................................................................................134

Reference List..............................................................................136

APPENDICES..............................................................................151
List of Tables

Table 1: Communication in a Hospital Setting.............................................10
Table 2: Patient/Parent-Professional Conflict during a Hospitalization.............19
Table 3: Satisfaction with Care in the Hospital..............................................29
Table 4: Studies that support the importance of the domains of the FS/DM..........36
Table 5: Children’s Diagnoses.......................................................................89
Table 6: Characteristics of the Nurses..........................................................91
Table 7: Compliance with the Parent Briefing Intervention.............................97
Table 8: Nurses’ and Physicians’ Responses to Participating in the Phase I Single Group Post-test Component of the Study..............................................................100
Table 9: Parents’ Evaluations of the Parent Briefing Intervention.....................101
Table 10: Nurses’ and Physicians’ Evaluation of the Parent Briefing Intervention....103
Table 11: Satisfaction Scores of Parents who did and did not Participate
in the Parent Briefing Participation..............................................................104
Table 12: Frequency of Parent Questions During Parent Briefings: Providers were
Seated...........................................................................................................105
Table 13: Frequency of Parent Questions During Parent Briefings: Attending Physician
was Present....................................................................................................105

List of Figures

Figure 1: Study Schema...............................................................................58
Figure 2: Flow Diagram of Study Sample.....................................................86
List of Appendices

Appendix A: Confirmation of Entry Form ................................................. 151
Appendix B: Parent Consent Form I (Psychometric Study) .......................... 152
Appendix C: Parent Consent Form II (Phase I Single Group Post-test Study) .. 155
Appendix D: Family Form .......................................................................... 158
Appendix E: Child Form ........................................................................... 161
Appendix F: Nurse Form ........................................................................... 162
Appendix G: Nurse Consent Form ............................................................... 163
Appendix H: Family Satisfaction with Decision Making Instrument
(FS/DM) ..................................................................................................... 167
Appendix I: Decisional Conflict Scale (DCS) ............................................ 171
Appendix J: Parent Feasibility Questionnaire ............................................ 172
Appendix K: Physician/Nurse Feasibility Questionnaire ............................. 174
Appendix L: Nurse Education Session Outline .......................................... 176
Appendix M: OSCE Criteria ..................................................................... 178
Appendix N: Physician Consent Form ....................................................... 180
Appendix O: Compliance Data Collection Form ........................................ 183
Appendix P: Data Management & Data Validation .................................... 184
Appendix Q: Document Checklist .............................................................. 187
Appendix R: Parents’ Responses to Items on the FS/DM Instrument .......... 188
Appendix S: Parents’ Responses to Items on the DCS ............................... 189
CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

Background

Since the middle of the 1980’s, pediatric health care in North America has espoused to be family-centred. The elements of a family-centred-care (FCC) philosophy were delineated by the Association for the Care of Children’s Health (ACCH) and the Institute of Family-Centred Care (IFCC) (Shelton, Jeppson, & Johnson, 1987). Family-centred hospitals aim to promote mutually beneficial partnerships between families and staff in planning, delivery, and evaluation of services for children (Ahmann & Johnson, 2000; Franck & Callery, 2004; Hughes, Bamford & May, 2008). Parents become aware of FCC early in their health care experience as they are told on their child’s admission to hospital that they are partners in their child’s care. This philosophy is highly visible by posters on display in public spaces throughout paediatric health care organizations. However, despite the wide-spread adoption of this care philosophy, parents’ reports of their experiences during their child’s hospitalizations indicate that the collaborative activities that are central to FCC rarely are upheld.

Parents repeatedly have reported that relinquishing important aspects of their role is the most stressful aspect of a child’s hospitalization (Brown & Ritchie, 1990; Callery & Smith, 1991; Carnevale, 1990; Curley, 1988; Curley & Wallace, 1992; Dudley & Carr, 2004; Jay, 1977; Knox & Hayes, 1983; LaMontagne & Pawlak, 1990; Miles, 1979; Miles & Carter, 1982; Miles, Carter, Riddle, Hennessey, & Eberley, 1989; Miles, Carter, Spicher, & Hassanein, 1984; Ratcliffe, Harrigan, Haley, Tse, & Olson, 2002; Riddle, Hennessey, Eberley, Carter, & Miles, 1989). This stress is exacerbated when parents receive limited information regarding their child’s medical status and have little or no
opportunity to participate in decisions regarding their care (Balling & McCubbin, 2001; Board, 2004; Brown & Ritchie, 1990; Burke, Kauffman, Costello, & Dillon, 1991; Carnevale, 1990; Curley, 1988; Horn, Feldman, & Ploof, 1995; Kasper & Nyamathi, 1988; King, King, Rosenbaum, 1996; LaMontagne & Pawlak, 1990; Miceli & Clark, 2005; Miles, 1979; Miles & Carter, 1982; Robinson, 1987; Schaffer, Vaughan, Kenner, Donohue, & Longo, 2000; Seidman et al., 1997; Starke & Moller, 2002; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994; Thorne & Robinson, 1988).

Recent advances in medical knowledge and improved technologies have resulted in longer life expectancies for many children with serious congenital or acquired complex chronic conditions. These children have multiple ongoing health and developmental issues that may include functional impairments, neurodevelopmental disabilities, and dependence on medical technology (Rennick, 1995; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Their complex needs put substantial demands on various specialty paediatric services, care sectors, and care settings over the child’s life span (Cohen, Friedman, Nicholas, Adams, & Rosenbaum, 2008; Law & Rosenbaum, 2004; Perrin et al., 1993). Consequently, the prevalence of children with complex chronic conditions who require frequent and lengthy hospitalizations is increasing (Burns, Casey, Lyle, Bird, Fussell, & Robbins, 2010; Goldson, Louch, Washington, & Scheu, 2006; Gordon, Colby, Bartelt, Jablonski, Krauthoefer, & Havens, 2007; Horn et al., 1995; Newacheck, & Halfon, 1998; Perrin et al., 1993; Sieben-Hein & Steinmiller, 2005; Simon, et al., 2010; van der Lee, et al., 2007).

The admission of these children to hospital due to an acute illness is a highly emotional and stressful time for parents (Burke, Costello, & Handley-Derry, 1989; Burke
et al., 1991; Knox & Hayes, 1983). They are often faced with making decisions regarding their child’s care at a time when levels of stress and fatigue adversely affect cognitive functioning and therefore jeopardize their ability to problem solve (Board & Ryan-Wenger, 2000, 2002; Knox & Hayes, 1983; Noyes, 1998). Dealing with uncertainty, lack of structure, communication problems, and interpersonal conflict between these parents and members of health care teams, services, and programs are the dominant themes that emerge from parents’ reports of their hospital experience. (Bain, Rosenbaum, & King, 1995; Burke et al., 1989; Burke et al., 1991; Brown & Ritchie, 1990; Callery & Smith, 1991; Coffey, 2006; Dixon, 1996; Dodgson, Garwick, Blozis, & Patterson, 2000; Masri, Farrell, & Lacroix, 2000; Mello et al., 2004; Sieben-Hein & Steinmiller, 2005; Studdert, Burns et al., 2003; Thorne & Robinson, 1989).

Critiques of the concept of FCC illustrate its limitations (Bograd, 1984; Boss, Doherty, LaRossa, Schumm, & Steinmetz, 1993; Goldner, 1985; James & McIntyre, 1983; MacKinnon & Miller, 1987). The concept’s link with family therapy, which is based on systems theory, is the basis for the critique. Systems theory is interested in examining micro level circularity of interactions between family members (Piercy, Sprenkle, & Wetchler, 1996). Feminist critiques emphasize that this perspective disregards the importance of societal context and power relations in shaping the family. The main concern is that systems theory does not recognize the degree to which hierarchical structures are maintained by a family’s larger societal, economic, and political contexts. Limited attention is given to social constraints, external pressures, or society’s gender system and its influence on relations within families (James & MacIntyre, 1983). As a result, systems theory ignores the power of a larger system, such
as society, to shape a smaller system, such as the family (MacKinnon & Miller, 1987). Another main concern of systems theory is the disregard for power relations and their impact on the family. Systems theory assumes that mothers and fathers are equally powerful and responsible for maintaining family patterns. This perspective ignores power relations within families and the way in which these relations are influenced by societal institutions (Bograd, 1984; Goldner, 1985; MacKinnon & Miller, 1987).

Increasing parents’ satisfaction with the care their child receives and responding to their priorities is a key domain in improving quality of care (Dodek, Heyland, Rocker, & Cook, 2004; Fitzpatrick, 1991; Haines & Childs, 2005; Heyland & Tranmer, 2001; Heyland et al., 2002; Latour, Hazelzet, & van der Heijden, 2005; Miceli, & Clark, 2005; Wall, Engelberg, Downey, Heyland, & Curtis, 2007; Wensing, Grol, & Smits, 1994). However, despite this growing interest in parents’ perspectives regarding care (Hall & Doran, 1988a; Hall & Doran, 1988b), there have been few studies of parents’ satisfaction with care (Latour et al., 2005). Three instruments have been developed to measure global satisfaction with care among parents of hospitalized children, but none of these focus on communication and decision making processes. (Bragadottir & Reed, 2002; Haines & Childs, 2005; McPherson, Sacheva, & Jefferson, 2000). Heyland and colleagues’ (2001, 2002, 2003, & 2007) satisfaction with care instrument does focus on these processes; however, this instrument was designed for family members of critically ill adults.

In summary, given the prevalence of parents’ dissatisfaction with communication and decision making processes during a child’s hospitalization, there is a need to develop effective interventions to address this issue. The critiques of FCC suggest that such interventions should aim to mitigate the effects of the distribution of power in
hierarchical acute care hospitals. An important gap that must be addressed before evaluating such an intervention is the absence of a valid and reliable measure of parents’ satisfaction with parent-professional communication practices and decision making processes. Therefore, the purpose of this study will be to inform the decision about a primary outcome measure for a proposed trial and to assess the feasibility of a parent briefing intervention informed by Pierre Bourdieu’s central concepts.

Literature Review

A computer-generated search of English language publications and research reports as cited in the National Library of Medicine (MEDLINE) for the period 1950 to 2010, Nursing & Allied Health Literature (CINAHL) for the period 1982 to 2010, and Psychological Abstracts (PsycLIT) for the period 1985 to 2010 was conducted focusing upon family and/or parent satisfaction with communication and decision making processes for hospitalized children with complex health care needs. Key MeSH terms that were used in varying combinations in the search included: co-morbidity, chronic disease, neurodegenerative disease, neuromuscular disease, congenital disease, genetic disease, hospitalization, length of stay, hospitalized child, hospitalized adolescent, intensive care unit, critical care, intensive care, critical illness, paediatric care, paediatric nursing, childhood, adolescence, conflict, dissent and disputes, inter-professional relations, interdisciplinary communication, physician-nurse relations, professional-family relations, professional-patient relations, nurse-patient relations, physician-patient relations, trust, communication, consumer satisfaction, patient satisfaction, and maternal and paternal behaviour. The following literature review highlights those publications and reports that are most relevant to this study within the following categories: communication, conflict,
decision-making, parent-professional relationships, communication intervention studies and hospital stay, brief structured communication processes, patient and parent satisfaction with care, and outcome measures.

**Communication in a Hospital Setting**

Nineteen studies examined some aspect of communication within a hospital setting. Eight studies employed qualitative or descriptive methods and/or quality improvement initiatives (n=8); however, the majority of studies used an intervention design to address communication problems between family members and the care team. The majority of studies took place in the adult intensive care unit (n=11) and focused on end of life care (n=7). A detailed summary of the studies is provided in Table 1.

Two studies examined caregiver satisfaction with communication and decision making using a prospective descriptive study design (Hong, Murphy, & Connolly, 2008; LeClair, Oakes, & Weinert, 2005). Frequency of communication varied considerably (M=1.4 days, SD=1.7) with frequency declining as the intensive care unit length of stay increased (M=0.8, SD=0.7, LeClair et al.). Increased frequency of communication was strongly positively associated with increased satisfaction with communication overall (p>0.001) (LeClair et al.; Hong et al.); however, satisfaction with communication decreased significantly over the intensive care unit stay (p=0.006, LeClair et al.).

Three studies explored parent-professional communication when a chronically ill child was hospitalized (Burke et al., 1991; Horn et al., 1995; Stewart et al., 1994). All three studies were qualitative in nature using semi-structured interviews. Major themes expressed by parents related to the communication process such as omitting and/or withholding information, variations in the information provided, insufficient or
inappropriate information given, and having to seek out information or answers about their child’s medical condition.

Five studies (see Table 1) evaluated interventions to improve/enhance communication between and/or among healthcare providers and families in an ICU (Ahrens, Yancey, & Kollef, 2003; Eagle et al., 1990; Lilly et al., 2000; Lilly, Sonna, Haley, & Massaro, 2003; SUPPORT Principal Investigators et al., 1995). Interventions varied but were focused on a timely form of a structured communication process. All except one of the studies showed significant differences in their outcomes. Mean ICU length of stay (LOS) was reduced from 9.5 (SD 10.16) to 6.1 days (SD 5.41) (Ahrens et al.) and 2.45 to 2.23 days (p=0.07) (Eagle et al.); mean hospital stay was reduced 16.4 (SD 17.91) to 11.3 days (SD 9.88) (Ahrens et al.) and from 8.34 to 7.41 days (p=0.03) (Eagle et al.); median LOS was reduced from 4 to 3 days (Lilly et al., 2000 & 2003). The proportion of days in which team members disagreed with each other decreased from 65/1000 to 4/1000 patient days (Lilly et al., 2000 & 2003).

The SUPPORT trial (SUPPORT Principal Investigators et al., 1995) was the only study that found no differences in prevalence and timing of do-not-resuscitate (DNR) orders, ICU LOS, and use of hospital resources (see Table 1). The following issues with the study design are possible reasons why the intervention had no impact on any of the designated study outcomes: 1) although 95% of patients received the study intervention, the “dose” of the intervention was highly variable, 2) only 15% of physicians discussed the prognostic reports with patients and families, 3) while physicians were willing to have the SUPPORT nurse engage in conversations with patients and families, physicians’ behaviour appeared unchanged, and 4) the intervention may have been effective if
implemented earlier in the course of illness, if continued for a longer time or tested at later points in time.

Seven studies examined communication that took place during end-of-life discussions. Two studies examined the process of communication in an ICU context (McDonagh et al., 2004; Meyer, Ritholz, Burns, & Truog, 2006) while five studies evaluated an ethics and/or palliative care consultation process and its effect on communication and decision making processes in the ICU (Campbell & Guzman, 2003; Campbell & Guzman, 2004; Dowdy, Robertson, & Bander, 1998; Schneiderman, Gilmer, & Teetzel, 2000; Schneiderman et al., 2003). Important priorities identified by parents included honest and complete information and ready access to staff (Meyer et al.). McDonagh et al. found that physicians spent on average 70% (SD not reported) of the time speaking and 30% of the time listening to family members. Mean percentage of family speaking time was 29% (SD=15%). The percentage of family speaking time was found to be positively correlated with family satisfaction ratings. There were significantly more decisions to withhold or withdraw life-sustaining treatments (-1.7 days, p=0.01; Schneiderman et al., 2000, 2003) and significant reductions in both intensive care unit (-1.44 days, p=0.03; Schneiderman et al., 2003) and hospital length of stay (-2.95 days, p=0.01; Schneiderman et al., 2003) (8.6 versus 4.7 days, p=<0.001; Campbell & Guzman, 2003) for patients who received the ethics/palliative consultation.

In summary, the majority of studies that focused on communication and decision making processes took place in intensive care units during end-of-life discussions. Although four of the five intervention studies (Ahrens et al., 2003; Eagle et al., 1990; Lily et al., 2000; Lily et al., 2003) found that focused communication affected hospital
length of stay, they did not take into account the dyadic nature of the intervention. Given that the SUPPORT Trial (1995), a large scale RCT, found no significant differences in study outcomes, it would be important for any future intervention aimed at improving parent-physician/nurse communication to consider the distribution of power in the parent-professional relationship. Studies that focused on hospitalized children with complex health care needs (Burke et al., 1991; Horn et al., 1995; Stewart et al., 1994) highlighted the problematic nature of parent-professional communication. However, no intervention studies were found to address this problem.
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<tr>
<th>Author</th>
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<th>Outcome measure</th>
<th>Findings</th>
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<tr>
<td>Ahrens et al. (2003)</td>
<td>To evaluate the effect of a communication team on length of stay and costs for patients near the end of life in the ICU.</td>
<td>Quality improvement initiative</td>
<td>$N = 151$ Control $n = 108$ Intervention group $n = 43$</td>
<td>ICU LOS; Hospital LOS;</td>
<td>Mean ICU LOS was reduced from 9.5($SD = 10.16$) to 6.1($SD = 5.41$) days; Mean hospital LOS was also reduced from 16.4 ($SD =17.91$) to 11.3($SD = 9.88$) days</td>
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<td>Burke, Kauffman, Costello, &amp; Dillon (1991)</td>
<td>To gain a better understanding of the stressful process for parents involved in repeated hospitalizations of children with chronic conditions.</td>
<td>Grounded Theory Grounded Theory Grounded Theory</td>
<td>Theoretical sampling; 4 separate samples of mothers of disabled children</td>
<td>Stressful aspects of repeated hospitalization</td>
<td>Basic psychosocial problem: hazardous secrets, involved information of a negative nature; variations, gaps and/or omissions in management; inexperienced learning health care worker. Basic psychosocial process: reluctantly taking charge involved vigilance and taking over; negotiating rules and calling a halt; tenaciously seeking information; exhaustion; taking a break</td>
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### Table 1: Proactive Palliative Care Studies

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<tr>
<td>Campbell &amp; Guzman (2003)</td>
<td>To assess the impact of a proactive case finding approach to end-of-life care for critically ill pts in comparison to historical controls.</td>
<td>Comparison study</td>
<td>Retrospective cohorts (n = 40); Prospective cohorts (n = 41)</td>
<td>APACHE; TISS; Hospital LOS; ICU LOS; Frequency of DNR orders</td>
<td>Proactive palliative care approach significantly decreased the time spent in ICU ([7.1 (SD = 1.4) \text{ to } 3.7 (SD = 0.4), p = &lt;0.01])</td>
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<tr>
<td>Campbell &amp; Guzman (2004)</td>
<td>To compare usual care with a proactive case finding approach for critically ill pts with terminal dementia using an inpatient palliative care service.</td>
<td>Prospective comparison</td>
<td>(N = 52); Control group (n = 26); Experimental group (n = 26)</td>
<td>APACHE; TISS; ICU LOS; hospital LOS; Frequency and timing of DNR orders</td>
<td>Hospital LOS ([12.1 (SD = 1.6) \text{ to } 7.4 (SD = 1.4), p = &lt;0.007}) and ICU LOS ([6.8 (SD = 0.98) \text{ to } 3.5 (SD = 0.5), p = &lt;0.004]) was significantly reduced for the experimental group; All patients had DNR orders in the experimental group compared with 19 of 26 in the control group</td>
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<tr>
<td>Dowdy, Robertson, &amp; Bander (1998)</td>
<td>To evaluate the effectiveness of proactive ethics consultation on documented patient care communications &amp; on decisions regarding high-risk ICU patients.</td>
<td>Prospective controlled study</td>
<td>Baseline (n = 37); Control (n = 31); Experimental (n = 31)</td>
<td>Communication LOS</td>
<td>Ethics Group: 61% had DNR and other LST decisions made in the ICU compared to control groups; ethics group had ICU LOS of 7 days less than those who survived</td>
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<tr>
<td>Eagle et al., (1990)</td>
<td>To measure the effects of physician feedback on decision making</td>
<td>Prospective comparison</td>
<td>Control (n = 326); Experimental (n = 248)</td>
<td>ICU &amp; Hospital LOS; Post-ICU LOS</td>
<td>Hospital LOS: 8.34 to 7.41 days ((p = 0.03)); ICU LOS: 2.45 to 2.23 days ((p = )</td>
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<td>Hong, Murphy, &amp; Connolly (2008)</td>
<td>To investigate whether an in-service designed to improve nurse-parent communication would increase parent satisfaction.</td>
<td>Pre-post-survey design</td>
<td>50 parents were randomly selected out of 400 whose child was discharged.</td>
<td>Parent satisfaction with communication</td>
<td>Positive trends showing increased satisfaction ratings on the items of interest. None of the increases were statistically significant (i.e., <em>t</em>-test at 95% CI)</td>
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<td>Horn, Feldman, &amp; Ploof (1995)</td>
<td>To describe the stressors and coping strategies of families whose children with chronic illness require lengthy hospitalizations; and to compare family and professional perceptions.</td>
<td>Exploratory</td>
<td>13 families; 13 mothers; 5 fathers of children with chronic illnesses</td>
<td>Stress responses of families of children with chronic illnesses who endured lengthy hospitalizations</td>
<td>7 categories of family-reported stressors: Emotions; communication; routines; caregiving; relationships; hospital; finances. Communication: efforts securing information or answers about child’s medical condition, conflict-ting information, and learning professional terminology.</td>
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<td>LeClair, Oakes, &amp; Weinert (2005)</td>
<td>To determine whether the timing of prognostic information delivery by physicians was associated with caregiver satisfaction with communication or decision making in the ICU.</td>
<td>Multicentre, prospective, longitudinal, observational study</td>
<td>Substitute decision makers of adult ICU patients. Total 216 surveys for analysis; i.e. baseline 70 2nd – 43 3rd – 25 4th – 12</td>
<td>Actual and desired frequency of communication with physicians; Timing and content of physician</td>
<td>The mean prognostic interval was 1.7 (<em>SD</em> = 2.8); Reported rate of communication varied considerably(<em>M</em> = 1.4, <em>SD</em> = 1.7); Communication rate decreased as the ICU LOS increased</td>
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<td>Lilly et al., (2000)</td>
<td>To evaluate the effects of a communication process designed to limit the use of supportive technology when it is ineffective.</td>
<td>Prospective, change of practice intervention study</td>
<td>Pre-intervention group n = 134; Intervention Group n = 396</td>
<td>Patient/Family &amp; team consensus LOS</td>
<td>$(M = 0.8, SD = 0.7)$; Increased communication frequency was strongly positively associated with increased satisfaction with communication overall ($p &gt; 0.001$). Satisfaction with communication frequency decreased significantly over the ICU stay ($p = 0.006$).</td>
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<tr>
<td>Lilly, Sonna, Haley, &amp; Massaro (2003)</td>
<td>To assess a practice change designed to promote the use of advanced supportive technology when it was beneficial.</td>
<td>Extension of the change-of-practice intervention study</td>
<td>2891 consecutive adult patient admitted to a general ICU in a 4 year period</td>
<td>LOS; Family-team consensus</td>
<td>Team non-consensus days decreased from 65 to 4 days per 1,000 patient days; family non-consensus days decreased from 171 to 16 per 1,000 patient days; Median LOS was reduced from 4 to 3 days.</td>
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<td>Median LOS reduced from 4 days to 3; Median LOS in the 4 yr follow-up study was 3 days.</td>
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<td>McDonagh et al. (2004)</td>
<td>To describe the content and process of clinician-family communication about end-of-life care occurring as part of ICU family conferences and to evaluate the quality of this clinician-family communication about end-of-life care.</td>
<td>Cross-sectional study</td>
<td>Family conferences in ICU during which discussions about withdrawing life support were likely to occur. Total: 214 family members from 51 families.</td>
<td>Proportion of health care provider and family speech</td>
<td>Family speech 29% (SD = 15%); % family speech correlated positively with family satisfaction ratings; -0.31 correlation between % family speech and level of perceived conflict between family and physician ($p = .04$); Physicians spent 70% of the time speaking and 30% of the time listening to family members.</td>
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<td>Meyer, Burns, Griffith, &amp; Truog (2006)</td>
<td>To identify and describe the priorities and recommendations for end-of-life care and communication from parents’ perspective.</td>
<td>Descriptive</td>
<td>End-of-life care and communication</td>
<td></td>
<td>Priories:Honest, complete; information; Ready access to staff; Communication and care coordination; Emotional expression and support from staff; Preservation of the parent-child relationship</td>
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<td>Schneiderman et al. (2003)</td>
<td>To evaluate the effect of ethics consultation on LST in the adult ICU.</td>
<td>Multicentre, prospective, randomized controlled trial</td>
<td>ICU LOS; Hospital LOS; LST in those patients who did not survive to hospital discharge</td>
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<td>Reduction in hospital days ($-2.95, p = 0.01$) ICU days ($-1.44, p = 0.03$) and days receiving ventilation ($-1.7, p = 0.03$) for those patients who received the</td>
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<td>Schneiderman, Gilmer,</td>
<td>To evaluate the effect of an ethics consultation on patients, families,</td>
<td>Prospective randomized controlled trial</td>
<td>Control group $n = 35$; Experimental group</td>
<td>Satisfaction with ethics consultation process; LOS LST</td>
<td>Intervention but did not survive to discharge; no significant differences for patients who survived to discharge</td>
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<td>&amp; Teetzel (2000)</td>
<td>physicians, nurses, social workers, and on LOS and treatments.</td>
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<td>$n = 35$;</td>
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<td>&gt; 70% agreed that goals of ethics consultation were met; a reduction in ICU days, days receiving artificial nutrition &amp; hydration, and receiving ventilation for patients who died before discharge</td>
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<td>Stewart, Ritchie,</td>
<td>To describe the sources, types, and appraisal of social support that</td>
<td>Exploratory Descriptive</td>
<td>90 mothers of children with Spina Bifida</td>
<td>Stressful &amp; supportive interactions with health professionals</td>
<td>Stressful interactions with health professionals: Health professionals either gave insufficient or inappropriate information Conflicted Support: condescending interactions were encountered predominantly with health professionals; information was withheld; demeaning of parents’ care giving or knowledge</td>
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<td>McGrath, Thompson &amp; Bruce</td>
<td>mothers received in relation to specific types of demands of having a</td>
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<td>$(n = 30)$; diabetes $(n = 30)$; cystic</td>
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<td>(1994)</td>
<td>child with a chronic condition.</td>
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<td>fibrosis $(n = 30)$</td>
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<td>SUPPORT Principal Investigators et al. (1995)</td>
<td>To improve end-of-life decision making and reduce the frequency of mechanically supported, painful, and prolonged process of death.</td>
<td><em>Phase I</em> prospective observational study</td>
<td><em>Phase I</em>: 4301</td>
<td>Understanding of patient preferences; incidence and time of DNR orders; pain; ICU LOS; mechanical ventilation before death</td>
<td>48% of DNR orders were written within 2 days of death; no differences in prevalence and timing of documentation of DNR orders; no differences in LOS in ICU</td>
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<td><em>Phase II</em>: 4804 Randomized by specialty group</td>
<td>Experimental group</td>
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</table>

*Note.* APACHE = acute physiology and chronic health evaluation; DNR = do not resuscitate; ICU = intensive care unit; LOS = length of stay; LST = life sustaining treatment; TISS = therapeutic intervention scoring system.
Parent- or/Family-Professional Conflict during a Hospitalization

Nine studies focused on conflict between family members and health care professionals. The settings included general paediatric care (n=6), adult intensive care (ICU) (n=2), and paediatric intensive care (PICU) (n=1). The studies are summarized in Table 2.

Six studies have explored parent-professional relationships when a child was hospitalized. Four of the studies are from the parent’s perspective (Dudley & Carr, 2004; Knox & Hayes, 1983; Robinson, 1987; Thorne & Robinson, 1988) and two from the nurse’s perspective (Brown & Ritchie, 1990; Callery & Smith, 1991). All six studies were qualitative in nature, using semi-structured interviews with study participants. Two of the six studies focused on parents of children with complex health care needs (Robinson, 1987; Thorne & Robinson, 1988). Differing perspectives regarding their role in their child’s care was the dominant theme express by parents (Knox & Hayes, 1983; Robinson, 1987; Thorne & Robinson, 1988). These discrepant expectations between parents and health care providers led to interpersonal conflict that resulted in emotional distress and vigilant behavior on the part of parents (Brown & Ritchie, 1990; Callery & Smith, 1991; Dudley & Carr, 2004; Robinson, 1987; Thorne & Robinson, 1988).

Three studies focused on understanding conflict during a hospitalization. Two studies using a qualitative descriptive design to determine the type, frequency, source and predictors of conflict in caring for seriously ill patients in an ICU (Studdert, Mello et al., 2003) and children in a PICU (Studdert, Burns et al., 2003). The other study used a non-randomized clinical trial design to test an intervention to mitigate conflict in the ICU (Burns et al., 2003). Conflict occurred in half of the patients receiving care (n=51/110).
(Studdert, Burns et al.). Family-team conflict was reported most frequently (57.3% to 60%) (Studdert, Burns et al.; Studdert, Mello et al.). The most common sources of family-team conflict were breakdowns in communication, poor understanding of prognosis, language barriers, and disagreements over the plan of care (Studdert, Burns et al.; Studdert, Mello et al.). The intervention was associated with an increased likelihood of deciding to forgo resuscitation (OR=1.81, p=0.017) and choose comfort care only (OR=1.94, p=0.018) (Burns et al.).

In summary, the majority of studies identified conflictual relations when caring for critically ill patients. Although Burns et al (2003) found that a dyadic communication intervention affected decisions at end-of-life, the fact that the medical/nursing team decided upon the type of decisional support that would be provided to the family, highlights the power differential inherent in the parent/family relationship.
Table 2

*Summary of Literature Review: Parent- or Family-Professional Conflict during a Hospitalization*

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Purpose</th>
<th>Design</th>
<th>Sample</th>
<th>Outcome Measure</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brown &amp; Ritchie (1990)</td>
<td>To describe nurses’ perceptions of parent and nurse roles in caring for hospitalized children.</td>
<td>Qualitative Study</td>
<td>25 pediatric nurses</td>
<td>Nurses’ perceptions of parent and nurse roles</td>
<td>Conflict arose when parents did not meet the nurses’ expectations. Care activities: parent participation at the discretion of the nurse. Gatekeeper: nurse acted as gatekeepers to the parental role. Being an advocate: parents attempts to be an advocate unreasonable. Psychosocial care: recognized the value of providing parents with information.</td>
</tr>
<tr>
<td>Burns, Mello, Studdert, Puopolo, Truog, &amp; Brennan (2003)</td>
<td>To evaluate an intervention to identify and mitigate conflict in decision making in the ICU.</td>
<td>Phase I: prospective observational study</td>
<td>434 medical-surgical ICU cases</td>
<td>Patient and surrogate satisfaction with various dimensions of ICU care; probability that patients and their surrogates would choose a specific care plan for ICU care</td>
<td>No significant change in satisfaction with care ratings; Receiving the intervention increased the probability of deciding to forgo resuscitation (OR = 1.81, p = 0.017) and increased the likelihood of choosing comfort care.</td>
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<tr>
<td>Author</td>
<td>Purpose</td>
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<td>Outcome Measure</td>
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<tr>
<td>Callery &amp; Smith (1991)</td>
<td>To describe nurses’ perceptions that of parent’s involvement in their hospitalized child’s care.</td>
<td>Qualitative</td>
<td>64 pediatric nurses; 112 critical incidents</td>
<td>Nurses’ perception of parent involvement</td>
<td>Power in the nurse-parent relationship was weighted in the nurse’s favour</td>
</tr>
<tr>
<td>Dudley &amp; Carr (2004)</td>
<td>To explore the experience of vigilance; parents who stay at the bedside of their hospitalized children.</td>
<td>Qualitative</td>
<td>10 parents of children admitted to a medical surgical ward</td>
<td>Patterns of parents at the bedside</td>
<td>Commitment to Care feelings of responsibility, advocacy, and watching over their child Emotional Upheaval included anxiety, shock, and uncertainty, giving up control Dynamic Relationships changing nature of the relationship with health care providers</td>
</tr>
<tr>
<td>Knox &amp; Hayes (1983)</td>
<td>To examine the sources of parental stress during a child’s hospitalization</td>
<td>Descriptive exploratory</td>
<td>33 mothers, 7 fathers, &amp; 1 grandmother; Children hospitalized with long-term disabilities</td>
<td>Sources of parental stress during a child’s hospitalization</td>
<td>Change in parental role: Many of their usual tasks were now taken over by professionals, deleted, or replaced by new tasks; Parents described the need for open</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Purpose</td>
<td>Design</td>
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<td>Outcome Measure</td>
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<tr>
<td>Robinson (1987)</td>
<td>To elicit self-reports of parents’ experiences when their chronically ill children were hospitalized.</td>
<td>Phenomenology study</td>
<td>9 parents; child diagnosed with muscular dystrophy, spina bifida, toxoplasmosis</td>
<td>Parents’ perspective re: child’s hospitalization</td>
<td>Discreptant expectations arising from differing perspectives; disregard for family experience; parental involvement in decision making and caretaking was often restricted by lack of information.</td>
</tr>
<tr>
<td>Studdert, Burns, Mello, Puopolo, Troyen, Brennan (2003)</td>
<td>To determine the frequency, types, sources, and predictors of conflict surrounding the care of paediatric intensive care patients with prolonged length of stay.</td>
<td>Case-control design</td>
<td>PICU patients whose stay exceeded 8 days over an 11 month period</td>
<td>Type and source of conflict</td>
<td>Identification: Clinicians identified 55 conflicts involving 51 patients in this group. Types of Conflict: 33 (60%) were family-team disputes; 21 (38%) were among team members; 1 (2%) were among family</td>
</tr>
<tr>
<td>Author</td>
<td>Purpose</td>
<td>Design</td>
<td>Sample</td>
<td>Outcome measure</td>
<td>Findings</td>
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<tr>
<td>Studdert, Mello,</td>
<td>To determine types, sources, and predictors of conflict among patients</td>
<td>Case-control</td>
<td>Clinician reported conflicts in</td>
<td>Conflict: e.g. types and</td>
<td>Major Sources of Conflict:</td>
</tr>
<tr>
<td>Burns, Puopolo,</td>
<td>with prolonged stay in the intensive care unit.</td>
<td>design</td>
<td>656 pts with prolonged</td>
<td>sources</td>
<td>Team-Family: the substantive issue in 48% was attributed to poor</td>
</tr>
<tr>
<td>Galper, Truog,</td>
<td></td>
<td></td>
<td>length of stay</td>
<td></td>
<td>communication; also 39% cited disagreement over pt’s care plan; 39% was</td>
</tr>
<tr>
<td>Brennan (2003)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>attributed to unavailability of the parents/guardians to discuss</td>
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<td>treatment options and make decisions.</td>
</tr>
</tbody>
</table>

Intrateam: 38% were conflicts over poor communication, 33% were disagreements over the care plan
Intrafamily: 2% were related to care plan disagreements.

Identification: Clinicians identified 248 conflicts involving 209 pts in this group

Types of Conflict:
142 (57.3%) were family-team disputes;
76 (30.6%) were
<table>
<thead>
<tr>
<th>Author</th>
<th>Purpose</th>
<th>Design</th>
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<th>Findings</th>
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</thead>
</table>

among team members; 30 (12.1%) were among family members.

**Major Sources of Conflict:**

Team-Family: the substantive issue in 44% was a clash of preferences related to life sustaining therapy; also 44% cited poor communication (e.g. difficulty understanding the prognosis and outcomes, language barriers frustrated communication, and other communication breakdowns).

Intrateam: 55% were disagreements over aspects of medical management.

Intrafamily: majority were over life sustaining therapy or other decisions about the pts care plan.
<table>
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<tr>
<th>Author</th>
<th>Purpose</th>
<th>Design</th>
<th>Sample</th>
<th>Outcome Measure</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thorne &amp; Robinson (1988)</td>
<td>Analysis of the family members’ perspective of health care relationships when the context is chronic illness.</td>
<td>Phenomenology study</td>
<td>26 family members; 9/26 were parents of chronically ill child</td>
<td>Family-health care provider relationships</td>
<td>3 stages of relationships: <em>naive trusting</em> family’s assume that care will be collaborative <em>dissentment</em> dissatisfaction with care, difficulty obtaining information <em>guarded alliance</em> a reconstruction of trust that enabled cooperative caring</td>
</tr>
</tbody>
</table>
**Decision Making**

Eight reports of studies examined decision making within the context of an intensive care setting (Carnevale et al., 2007; Engelberg, 2006; Larson & Tobin, 2000; Laurette, Ciroldi, Ksibi, & Azoulay, 2006; Masri et al., 2000; Mello et al., 2004; Meyer, Burns, Griffith, & Truog, 2002; Truog, Meyer, & Burns, 2006). Of the eight reports, five were systematic reviews (Engelberg, 2006; Larson & Tobin, 2000; Laurette et al., 2006; Masri et al., 2000; Truog et al., 2006).

The remaining three studies examined decision making within a PICU. Two studies used qualitative methods to examine treatment decisions for critically ill children from the parents’ perspective (Carnevale et al., 2007; Meyer et al., 2002), and one was a non-randomized clinical trial of an intervention to facilitate decision making and improve parents’ satisfaction with care in a PICU (Mello et al., 2004). Parents identified a supportive decision making process as a factor that was important in their decision making (Mello et al., 2004; Meyer et al., 2002). Parents’ dissatisfaction was expressed in relation to their perception that physicians were not available to provide the information they needed and that physicians and nurses did not listen to them (Carnevale et al., 2007).

In summary, given that parents reported that they were dissatisfied with the dyadic communication processes professionals provided to them when making decision for their critically ill child, which speaks to their ‘lack of voice’ in the process, it will be important for any intervention aimed at improving parent-professional communication to include in its design a component to address this issue.
Brief Structured Communication Processes

In contrast to the interventions described above which examined communication processes over the course of the patient’s hospital stay, recent studies have evaluated brief structured communication interventions. Situational briefing tools provide a structured and organized approach to improve effective communication of accurate, relevant information between health care providers (Leonard, Graham, & Bonacum, 2004; Manning, 2006; Pope, Rodzen, & Spross, 2007). Situational briefing approaches have been developed for use between health care professionals such as a daily goals sheet (Agarwal, Frankel, Tourner, McMillan, & Sharek, 2008; Narasimhan, Eisen, Mahoney, Acerra, Rosen, 2006; Phipps & Thomas, 2007; Pronovost et al., 2003) and team briefings (Lingard et al., 2005; Lingard et al., 2006).

Four studies have evaluated the effectiveness of using a daily goals sheet to improve communication between nurses and physicians (Agarwal et al., 2008; Narasimhan et al., 2006; Phipps & Thomas, 2007; Pronovost et al., 2003). The use of the daily goals sheet enhanced physicians’ and nurses’ understanding of patients’ daily goals (p<0.001) (Agarwal et al.) (p=0.001) (Narasimhan et al.) that led to improved communication and better team work (Phipps & Thomas; Narasimhan et al.). A significant decrease in ICU length of stay from a mean of 2.2 to 1.1 days (SD not reported) (Pronovost et al.) and from a mean of 4.1 to 3.7 days (SD not reported) (p=0.36) (Agarwal et al.) was also found.

Lingard and colleagues (Lingard et al. 2005; Lingard et al., 2006) pilot tested preoperative team briefings to address communication failures in the operating room. Surgeons, anesthesiologists, and nurses conducted team briefings prior to each surgical
case, as a way to exchange information relevant to the patient’s surgery. The briefings had a direct effect on the work of the team by identifying problems and ambiguities, and facilitating decision-making and planning of patient care. Lingard and colleagues (2005, 2006) concluded that team members working in a hectic clinical environment can successfully implement a change in their communication practices.

In summary, although studies have demonstrated that situational briefing approaches can be useful communication tools for the inter-professional care team in clinical settings, no studies to date have tested a situational briefing approach with physicians, nurses, and parents of hospitalized children. The fact that such approaches have not included parents reinforces the hierarchical structures inherent in paediatric care settings.

**Patient and/or Parent Satisfaction with Care during a Hospital Admission**

Six studies examined patient and/or parent satisfaction with care during a hospital admission, which included adult intensive care (n=2), adult medical/surgical care (n=1), and paediatric intensive care (n=3). The studies are summarized in Table 3.

**Adult Intensive and In-patient Care**

Using a descriptive survey design, two studies addressed family satisfaction with care provided in the ICU (Dowling & Wang, 2005; Malacrida et al., 1998), and one study focused upon patient satisfaction with care during a medical/surgical admission (Charles et al., 1994). Communication was a key component of family members’ evaluations of their ICU experiences (Dowling et al., 2005). Patients and families were dissatisfied with information provided, their involvement in decisions, and that they received information only after requesting it (Charles et al.; Malacrida et al.).
Two studies and a quality improvement project examined parents’ satisfaction with their child’s care in a PICU by evaluating parent presence at bedside rounds of children admitted to a PICU (Klieber, Davenport, & Freyenberger, 2006; Landry, Lafrenaye, Roy, & Cyr, 2007; Phipps et al., 2007). Parents who were present during bedside rounds reported higher satisfaction, felt better informed about their child’s plan of care, had their questions answered, and felt that confidentiality was respected (Klieber et al., 2006; Landry et al., 2007; Phipps et al., 2007). Residents and physicians reported feeling more comfortable with parental presence at the bedside and felt that it did not affect the time spent in rounds and the rounds’ process (Landry et al., 2007; Phipps et al., 2007).

Given that Landrey et al. (2007) and Phipps et al. (2007) found higher parent satisfaction with communication when parents were present during the bedside rounds, it would be useful for any intervention aimed at improving parent-physician/nurse communication to consider this format for mitigating communication problems that can arise in clinical contexts.
Table 3

Summary of the Literature Review: Patient and/or Parent Satisfaction with Care during a Hospital Admission

<table>
<thead>
<tr>
<th>Author</th>
<th>Purpose</th>
<th>Design</th>
<th>Sample</th>
<th>Outcome measure</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Charles et al. (1994)</td>
<td>To describe Canadian patients’ satisfaction with their hospital care.</td>
<td>Cross-sectional survey design</td>
<td>4570 medical and surgical patients discharged home from 6 acute care Canadian hospitals</td>
<td>Patient Satisfaction with Care Survey</td>
<td>Dissatisfied with communication regarding: Daily routine (41%); Side effects of drugs (16%); Test results (15%); pain &amp; discomfort (26%); Understandable response to questions (8%); Not involved in decisions (10%)</td>
</tr>
<tr>
<td>Dowling &amp; Wang (2005)</td>
<td>To present results of the 3-year family satisfaction study at pilot sites.</td>
<td>Descriptive comparative</td>
<td>Pre- ( n = 154 ); Post- ( n = 383 )</td>
<td>Family satisfaction with care in the ICU</td>
<td>Significant differences were found in family ratings of their involvement in the decision-making process ( p &lt; 0.0071 )</td>
</tr>
<tr>
<td>Klieber, Davenport, &amp; Freyenberger (2006)</td>
<td>To encourage open access to bedside rounds for families of patients in the PICU.</td>
<td>Unit based policy change (QI Project)</td>
<td>Baseline: Parents 36/69 (52%); Nurses 23/39 (59%)</td>
<td>Experience and perception of participating in bedside rounds</td>
<td>Parents appreciated being present; never felt confidentiality was an issue; All physicians agreed that rounds were beneficial to parents; enhanced trust; was a time saver.</td>
</tr>
<tr>
<td>Author</td>
<td>Purpose</td>
<td>Design</td>
<td>Sample</td>
<td>Outcome measure</td>
<td>Findings</td>
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<tr>
<td>Landry, Lafrenaye, Roy, &amp; Cyr (2007)</td>
<td>To ascertain whether there is a difference of satisfaction and comfort between bedside case presentation and conference room case presentation for the parents of patients hospitalized in PICU</td>
<td>Randomized controlled trial</td>
<td>Day 1 mother $n = 21$; Father $n = 10$; Day 2 Mother $n = 19$; father $n = 8$</td>
<td>Parent satisfaction and preference for case presentation at the bedside versus conference room</td>
<td>Parents in bedside discussion group more likely to report they understood what doctor said ($p = 0.016$), felt confidentiality was respected ($p = 0.007$); their questions were answered ($p = 0.013$), and time spent with them was sufficient ($p = 0.016$)</td>
</tr>
<tr>
<td>Malacrida et al. (1998)</td>
<td>To analyze the degree of satisfaction of families regarding the assistance given to their relative and the information received.</td>
<td>Cross-sectional descriptive study</td>
<td>123/390 relatives of patients who died in the ICU over an 8 year period</td>
<td>Family satisfaction with care in the ICU</td>
<td>Dissatisfied with info given regarding: diagnosis (17.1%) and the consequences of the illness (18.3%); cause of death (30.4%); 25% claimed that they received information only after requesting it.</td>
</tr>
<tr>
<td>Phipps et al. (2007)</td>
<td>To objectively and subjectively evaluate parental presence during bedside medical rounds in PICU</td>
<td>Prospective, blinded, observational study</td>
<td>Parents of children admitted to the PICU Total $n = 81$; Medical team members $n = 187$; 105 observations were recorded on</td>
<td>Duration of Rounds; Teaching; Privacy</td>
<td>No significant differences between the time spent on rounds in the presence (13 minutes, $IQR = 7-20$) or absence of family (11 minutes, $IQR = 6-19$); No</td>
</tr>
</tbody>
</table>
89 PICU patients.

significant differences in time spent teaching in the presence ($mdn = 4$ minutes; $IQR = 2,10$) or absence ($mdn = 5$ minutes; $IQR = 2,10$) of family members; 85% of the medical team reported family members did not interfered with the discussion during rounds.

Note. PICU = paediatric intensive care unit; ICU = intensive care unit. See p. 5 for search terms used to identify relevant research studies. Only primary sources that measured family members’ satisfaction with communication with physicians and nurses were included.
Outcome Measurements

A review of the content and characteristics of satisfaction instruments related to paediatrics and/or intensive care settings (Latour et al., 2005) identified ten satisfaction instruments in the following clinical areas: ICU (n=2) (Heyland & Tranmer, 2001; Heyland et al., 2002; Wasser, Pasquale, Matchett, Bryan, & Pasquale, 2001), NICU (n=2) (Blackington, & McLauchlan, 1995; Mitchell-Dicenso et al., 1996), general paediatric hospitalization (n=5) (Bragadottir & Reed, 2002; Budreau & Chase, 1994; Marino & Marino, 2000; Moumtzoglou et al., 2000; Schaffer et al., 2000; Yge & Arnetz, 2001) and the PICU (n=2) (Haines & Childs, 2005; McPherson et al., 2000). Of the ten instruments reported, the Family Satisfaction with Decision Making subscale (FS-ICU/DM) of the Family Satisfaction with Care in the ICU instrument is the only one that has undergone further refinement and testing in a clinical context beyond its initial development and which measures aspects of care specific to communication and decision making processes.

Family Satisfaction with Decision Making Subscale

The FS-ICU instrument was developed to address a gap in the availability of valid and reliable instruments to measure family satisfaction with care in the ICU. Preliminary work was conducted by Heyland & Tranmer (2001) to pilot test the feasibility of administering the FS-ICU to measure family members’ level of satisfaction with care provided to them and their critically ill relative in the ICU. The FS-ICU (Part I) was developed based upon the Conference Board of Canada’s “Measuring Up: Patient Satisfaction Survey” utilizing the same format/response options but changing the nature of the questions to reflect the ICU setting (Heyland & Tranmer, 2001). The FS-ICU (Part
II) was developed based upon the work of Charles et al. (1998) who defined three analytic components to the decision making process: information exchange, deliberation, and deciding. Questions to assess the preferred and actual role of the substitute decision makers in the decision making process were added.

Face validity of the instrument was assessed with 16 health care providers and 21 family members of critically ill patients to test whether the questions made sense, were written clearly, and were comprehensive in scope. Heyland & Tranmer (2001) administered the FS-ICU to next of kin who had been in the ICU at least once to visit their critically ill ventilated adult family member who had been in the ICU for 48 hours or more. Twenty-five of 34 family members of ICU survivors completed the questionnaire at time of discharge from the ICU. Twenty-two of 33 of family members of ICU non-survivors completed the instrument 3 to 4 weeks after the family member’s death.

A test-retest assessment was carried out with family members of ICU survivors only to assess the reliability of the questionnaire (Heyland & Tranmer, 2001). The instrument was administered to 37 eligible family members when the patient was discharged from the ICU and again 7 to 10 days later to the same family member while in the hospital. The test-retest reliability coefficient was 0.85.

Internal consistency of the domains with the two subscales, assessed by the Cronbach’s alpha reliability coefficient, ranged from 0.74 (ICU environment), 0.91 (professional care), 0.95 (care of family), to 0.97 (care of patient) for domains within the satisfaction with care subscale, and ranged from 0.87 (deliberation) to .093 (information needs) for domains within the satisfaction with decision making subscale (Heyland &
Tranmer, 2001). In addition, there was a moderate correlation between satisfaction with overall care and satisfaction with the role of decision making \((r=0.64)\), indicating that communication and decision making are important components of the family member’s experience in the ICU.

Heyland and colleagues further refined and validated the FS-ICU instrument in subsequent studies (Heyland et al., 2002; Heyland et al., 2003; Wall et al., 2007). One such study was a multicentre prospective survey study with six tertiary care hospitals in Canada using the instrument (Heyland et al., 2002). Seventy percent (624/891) of family members of surviving and non-surviving adult ICU patients who had been ventilated for 48 hrs in an ICU completed the FS-ICU instrument post discharge from the ICU. The majority of respondents were satisfied with overall care \((\text{mean}=84.3, \text{SD}=15.7)\). Respondents were less satisfied with decision making \((\text{mean}=75.9, \text{SD}=26.4)\); 41% rated it as excellent, 34% rated it as very good, 17% rated it as good, 4% rated it as fair, and 4% rated it as poor.

Families were most satisfied with nursing skill and competence \((\text{mean}=92.4, \text{SD}=14.0)\), compassion and respect given the patient \((\text{mean}=91.8, \text{SD}=15.4)\), pain management \((\text{mean}=89.1, \text{SD}=18.3)\), and coordination of care \((\text{mean}=89.0, \text{SD}=16.5)\). Families were least satisfied with the waiting room atmosphere \((\text{mean}=65.0, \text{SD}=30.6)\) and frequency of physician communication \((\text{mean}=70.7, \text{SD}=29.0)\). In addition, respondents who rated the completeness of information provided by ICU staff as excellent \((\text{OR}=16.0; 95\% \text{ CI}, 5.8-43.9)\) or very good \((\text{OR}=5.3; 95\% \text{ CI}, 1.9-14.8)\) were much more likely to give an overall rating of their ICU experience as completely satisfactory (Heyland et al., 2002, 2003).
Heyland and colleagues (Wall et al., 2007) conducted a prospective cohort study, using six tertiary Canadian hospitals and one American tertiary hospital, to refine the FS-ICU instrument and develop a method for scoring the instrument. A total of 1,038 family members from seven medical centers completed the FS-ICU. The original survey contained 34 items. Further refinement identified 15 items for possible removal of which 10 were eventually removed (Wall et al., 2007). Factor analysis on the remaining 24 items revealed that 14 items loaded upon a first factor pertaining to satisfaction with care, and the remaining ten items loaded onto a second factor that focused upon satisfaction with decision making. Together the two factors explained 61.3% of the variance in scores. Reliability analysis revealed a Cronbach’s α coefficient of 0.92 for the Satisfaction with Care subscale and 0.88 for the Satisfaction with Decision Making subscale. Based upon the two-factor model, two subscale scores (i.e. FS-ICU/Care and FS-ICU/DM) and a total instrument score (i.e. FS-ICU/Total) were developed. Median scores and interquartile (IQR) ranges for the subscales and overall ICU experience were as follows: FS-ICU/Total score 85.4 (72.9, 93.8), FS-ICU/Care score 88.5 (75, 96.4), and FS-ICU/DM score 82.5 (70, 92.5).

Thus the Family Satisfaction with Decision Making Subscale includes components of communication and decision making processes that are important to parents during a child’s hospitalization. Table 4 outlines references to research evidence for the 10 items of the FS-ICU/DM subscale.
Table 4

*Studies that Support the Domains of the Family Satisfaction with Decision Making Subscale (FS-ICU/DM)*

<table>
<thead>
<tr>
<th>FS-ICU/DM subscale items</th>
<th>Literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of communication</td>
<td>Brown &amp; Ritchie (1990); Burke et al. (1991); Carnevale et al. (2007); LeClair et al. (2005).</td>
</tr>
<tr>
<td>Ease of getting information</td>
<td>Brown &amp; Ritchie (1990); Burke et al. (1991); Carnevale et al. (2007); Horn et al. (1995); King et al. (1996); Robinson (1983); Thorne &amp; Robinson (1988).</td>
</tr>
<tr>
<td>Understanding of information</td>
<td>Azoulay et al. (2000); King et al. (1996); Studdert, Burns, et al. (2003).</td>
</tr>
<tr>
<td>Honesty of information</td>
<td>Know &amp; Hayes (1983); Meyer et al. (2006).</td>
</tr>
<tr>
<td>Completeness of information</td>
<td>Burke et al (1991); Knafl et al. (1992); Meyer et al. (2006); Stewart et al. (1994).</td>
</tr>
<tr>
<td>Included in decision making process</td>
<td>Carnevale et al. (2007); King et al. (1996); Robinson (1983); Thorne &amp; Robinson (1988).</td>
</tr>
<tr>
<td>Supportive decision making process</td>
<td>Carnevale et al. (2007); King et al. (1996); Mello et al. (2004); Meyer et al. (2002).</td>
</tr>
<tr>
<td>Control over the care of your child</td>
<td>Balling &amp; McCubbin (2001).</td>
</tr>
<tr>
<td>Adequate time re. questions/concerns</td>
<td>Carnevale et al. (2007); King et al. (1996).</td>
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**Decisional Conflict Scale**

An examination of the evidence related to instruments measuring aspects of the decision making process found the Decisional Conflict Scale (DCS) (O’Connor, 1995) to be the gold standard to measure decisional conflict in clinical practice settings and clinical trials.

The Decisional Conflict Scale (DCS) was developed in response to the lack of instruments available to evaluate health-care consumer decision aids and to tailor decision-supporting interventions to particular needs. Preliminary work was conducted by O’Connor (1995) to develop and evaluate the psychometric properties of the DCS. The scale is designed to elicit health-care consumers’ uncertainty in making a health-related decision, the factors contributing to the uncertainty, and health-care consumers’ perceived effective decision making.

The scale was initially evaluated in two separate decision making contexts (O’Connor, 1995). The total sample size was 909. Four hundred and forty-three individuals considering influenza immunization were presented with information about the vaccine, asked for their intentions, and then asked to complete the scale. Likewise, 360 women aged 50-59 years old were asked what they would do if they received a letter inviting them to participate in breast cancer screening. Their responses were invited and then they were asked to complete the scale.

The test-retest correlation was 0.81. Internal consistency using Cronbach’s alpha ranged from 0.78 – 0.92 for the total scale and from 0.58 to 0.92 for the subscales. Construct validity was tested by using the known groups approach. The DCS was consistent in discriminating between those who accepted/rejected and those who
delayed/were unsure of the invitation to be immunized/screened \( (p<0.0002) \). In addition, there was a good correlation between satisfaction with overall care and satisfaction with the role of decision making \( (r=0.64) \). O’Connor and colleagues further validated the DCS in a subsequent study (O’Connor et al., 1998). They conducted a phase II randomized controlled trial to compare the efficacy of a tailored decision aid versus a general educational pamphlet to improve patient knowledge regarding hormone replacement therapy. One hundred and sixty-five women, aged 50 to 69 years, participated in the trial; 84 in the control group and 81 in the experimental group. The group who had the tailored decision aid reported less total decisional conflict \( (p=0.04) \) and had more realistic expectations \( (p=0.0001) \) regarding hormone replacement therapy.

The DCS has demonstrated satisfactory reliability, validity, and sensitivity to change for people making health decisions regarding immunizations (O’Connor, 1995), breast cancer screening (O’Connor, 1995), and hormone replacement therapy (O’Connor, 1998). Other studies supporting the establishment of the DCS as the gold standard of measurement include its use for people making health decisions regarding women’s health (O’Connor, Jacobsen, & Stacey, 2002), end-of-life decisions (Song & Sereika, 2006), prostate cancer (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004), cancer treatments (Keodoot et al., 2001), male sterilization (Balde, Legare, & Labrecque, 2006), and NICU care (Penticuff & Arheart, 2005).

Although the present study did not involve the use of a decision aid, the following systematic review by O’Connor and colleagues (1999) was felt to be relevant. As the DCS is used most frequently as an outcome measure in the context of evaluating decision aids, all of which include the transmission of information and knowledge as a key
element in satisfaction with decision-making, the review was included. O’Connor and colleagues (1999) conducted a systematic review of decision aids for people facing health treatment or screening and updated the review four years later (O’Connor et al., 2003). The initial review included a total of 17 studies, while the subsequent review in 2003 included 34 randomized controlled trials. The reviews concluded that when decisional aids are compared to usual care, decision aids performed better in terms of greater knowledge (WMD 19/100, 95% CI: 13 to 24), more realistic expectations (RR 1.4, 95% CI: 1.1 to 1.9), lower decisional conflict related to feeling informed (WMD -9.1/100, 95% CI: -12 to -6), and increased proportion of people active in decision making (RR 1.4, 95% CI: 1.0 to 2.3).

Summary of Literature Review

In summary, the hospital admission of a child with complex health care needs during an acute illness event is a stressful and emotional time for parents. Many parents have described alteration in their parental role and limited information and/or participation in decisions regarding their children’s care as the most distressing components of their hospital experience. These experiences occasionally led to stressful and tense interactions with physicians and nurses. The majority of studies used descriptive designs and involved small sample sizes. No studies were found which evaluated interventions aimed at improving parent-professional communication and decision making processes during a child’s hospitalization.

The intervention studies that did address family-team communication processes were based on dyadic communication practices that maintained traditional hierarchical physician/nurse-patient relationships. All the studies took place in adult intensive care
units within the context of end-of-life care. The study interventions were variations of a focused and timely structured dyadic communication process. No studies evaluated an intervention designed to mitigate the distribution of power in hierarchical acute care settings.

While no instrument measuring parents’ satisfaction with parent-professional communication practices and decision making processes for hospitalized children with complex health needs was found, an instrument developed to measure family members’ satisfaction in adult intensive care units has the potential to be suitable. However, before this instrument can be used in a future clinical trial, psychometric evaluation is needed, as the instrument has not been validated in a paediatric, non-ICU setting.
CHAPTER 2: CONCEPTUAL ORIENTATION

Paediatric hospitals are organizations containing multiple social spaces where care is provided by a host of professionals, allied health workers, volunteers, support personnel, and parents. Each social space has its own hierarchical structure, workflow patterns, and distribution of resources. Relative to parents, physicians and nurses hold powerful positions within the space because they have specialized knowledge of disease, technical skills, and because they are very familiar with institutional rules, routines, and policies. They are also well remunerated, especially physicians, and respected in society at-large.

Most parents lack these resources and struggle to find their “place” in the hospital setting. This is difficult for parents who, in most other contexts, especially within their families, are responsible for their children’s well-being. Parents of children with complex health care needs are sophisticated care providers and assume positions of great responsibility and authority when providing their child’s care at home; however, they report being placed in subordinate roles and having to struggle for position, power, and ultimately a voice in decisions regarding their child’s care while their child is in hospital (Brown & Ritchie, 1990; Callery & Smith, 1991; Carnevale, 2007; Dudley & Carr, 2004; Gatrell, Pompay, & Thomas, 2004; Mello et al., 2004; Robinson, 1987; Thorne & Robinson, 1988).

Pierre Bourdieu: The Logic of Practice

The late social theorist Pierre Bourdieu postulated that human behaviour is governed by the sense of how to behave in social contexts that individuals acquire through socialization processes that occur throughout their life (Schwartz, 1997, p. 141).
His theoretical opus is diverse and complex, but this study will focus on his key concepts of habitus, fields, and capital to hypothesize the physician/nurse-parent relationship during a child’s hospitalization. A Bourdieusian analysis illustrates how parents’ and professionals’ resources are not distributed equitably. This explains why they can’t work collaboratively as a team of equals. This postulation justifies an intervention aimed at redistributing resources to enhance parent-professional relationships.

In one of his major works, the “Logic of Practice”, Bourdieu outlined a general science of human behaviour (Swartz, 1997, p. 52). He posits that individuals’ or groups’ predispositions for certain behaviours, beliefs, and attitudes are a function of the resources available to them in specific social environments or fields. He uses the term “practices” to describe behaviours that flow from people’s positions relative to others in social hierarchies. Accordingly, Wacquant (1998, p. 2) describes Bourdieu’s theory as a science of human practice and a critique of the domination and submission that is inherent in all social arrangements. A more descriptive explanation is provided by Swartz (1997, p. 7) who states that Bourdieu views individuals as struggling over valued resources to maintain or enhance their position within fields. Bourdieu formulated his theory based upon three key concepts -- habitus, capital, and fields -- that are said to mediate the relationships between individuals (Swartz, 1997, p. 60-3).

**Habitus**

The concept of habitus allows an understanding of behaviour in the social field in which it occurs (Bourdieu, 1991, p. 13-14). Individuals are said to be born into and socialized within particular social positions and hence acquire a particular ‘habitus’ that shapes their experiences, beliefs, thoughts, attitudes, and behaviours. Individuals
internalize the fundamental social conditions of their existence in the form of personal dispositions (Swartz, 1997, p. 104). These dispositions shape master patterns of cognitive, normative, and corporeal dimensions of human behaviour and are expressed in language, non-verbal communication, tastes, values, perceptions and modes of reasoning (Marcoulatos, 2001, p. 3; Schwartz, 1997, p. 107-108).

Accordingly, Bourdieu states that individual behaviour is generated by the interaction between opportunities or constraints presented by situations and the dispositions that individuals bring to situations (Schwartz, 1997, p. 290). Bourdieu defines habitus as:

a system of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them (Bourdieu, 1990, p. 53; Swartz, 1997; p.100).

Therefore, habitus describes how individuals know or come to know their “place” (i.e. how to think, act, and feel) in various contexts.

Fields of Power

Bourdieu was particularly interested in the ways in which individuals and/or groups attain and maintain positions in different contexts (Bourdieu, 1991, p. 25). His concept of fields describes how social relations are subdivided around specific functions and valued resources (Swartz, 1997, p. 117). Societies are said to be composed of multiple overlapping institutional fields such as education, medicine, and the family.
Bourdieu describes two major competing principles of social hierarchies that shape the struggle for power. They are the distribution of economic capital, such as wealth, income, and property, and the distribution of cultural or symbolic capital, such as knowledge, social status, and credentials. Accordingly, individuals draw from accessible cultural or economic resources to maintain and enhance their position in particular fields (Swartz, 1997, p. 137) (e.g. fathers traditionally are powerful in families; he has valued resources, but much less so in the hospital).

Bourdieu speaks of structural properties that are characteristic of all fields (Swartz, 1997, p. 122-6; Wacquant, 1998, p. 6-7). Fields are structured spaces of dominant and subordinate positions based on types and amounts of capital where individuals must maintain or acquire certain types and amounts of capital to maintain their position. Individuals struggle over what are considered the most valued resources and pursue different strategies to obtain capital most favorable to their own situations. The use of different strategies is dependent upon the individual’s position in the field. Individuals who hold dominant positions use conservation strategies such as enforcing the status quo to ensure their power is maintained. New entrants use succession strategies to gain symbolic capital such as medical information to gain access to more powerful positions in a field. Those who believe they will gain very little from dominant persons use subversion strategies such as vigilance to challenge their legitimacy to define standards and behaviours (Swartz, 1997, p. 125; Wacquant, 1998, p. 7).

Additionally, fields impose on individuals specific forms of struggle (Schwartz, 1997, p. 125). Bourdieu likens the behaviours that occur within fields to games that are played according to tacit rules that the permanent occupants formulate and understand.
Each field has its own specific set of rules that are determined by the possession of certain types and amounts of capital, which precede the individual entering the game. Every field presupposes and produces a belief or acceptance of the values of the game as they are structured, which Bourdieu refers to as a type of ‘illusio’ because objectively they are arbitrary (Bourdieu, 1991, p. 22, p. 45; Swartz, 1997, p. 125). Players share a belief that the game is worth maintaining and enhancing their own position is worth pursuing and therefore share a common interest in preserving the field. Bourdieu refers to this deeply ingrained and implicit taken-for-granted understanding of the social field as “doxa” (Swartz, 1997, p. 125). The way things are is the way things should be.

Bourdieu refers to the field of power as a social space comprised of a system of relations (Bourdieu, 1989, p. 16). Individuals who occupy similar or neighbouring positions are subjected to similar conditions, and as a result, have every chance of producing practices that are themselves similar. Parents and physicians can be side by side spatially but separated by a ‘gulf’ in terms of things in common. Therefore, spatial distances do not coincide with social distances. Social distances are inscribed in bodies, or, more precisely, in relation to the body, to language and to time (Bourdieu, 1989, p. 17).

*Capital*

Individuals and groups draw on resources to maintain and enhance their positions in various fields. Bourdieu conceptualizes such resources as capital and describes four types of capital that enhance social status. The different types of capital are categorized as economic capital, which refers to money, wealth, and property; cultural capital, which includes knowledge, cultural goods and services, and credentials; social capital, which
includes acquaintances and networks; and symbolic capital, which refers to status, and position (Swartz, 1997, p. 73-4).

Bourdieu views linguistic practices, such as language skills and vocabulary, as a form of cultural and/or symbolic capital that is distributed in very similar ways to other forms of capital (Bourdieu, 1991, p. 9, 18). Within the field of pediatric hospital care, knowledge of medicine and technology and linguistic practices, such as language skills and vocabulary, are measured against the practices of physicians and nurses who hold higher field positions relative to most parents. Individuals who have not acquired a certain level of knowledge and learned to master necessary linguistic practices are usually excluded from the social interactions in which this competence is required (Bourdieu, 1991, p. 55). Therefore, successful use of cultural/symbolic capital within a hospital context is an important competency that can enhance an individuals’ social positioning in the field.

In summary, Bourdieu presents the following equation as a summary formula of his model: [(habitus)(capital)] + field = practice (i.e. behaviours and thoughts). Bourdieu conceptualizes behaviour as the outcome of the relationship between habitus, capital, and field. Therefore, practices cannot be reduced to either one or the other but grow out of the interrelationship between them (Swartz, 1997, p. 141).

Critique of Bourdieu’s Ideas

A presentation of Bourdieu’s concepts would not be complete without an acknowledgement of the critiques expressed by others related to his ideas. One of the main criticisms put forth is that his theory is overly deterministic with its strong emphasis on social reproduction that maintains the status quo rather than encouraging resistance
and forms of change (Berger, 1986; Gartmen, 1991; Lau, 2004; Sewell, 1992; Swartz, 1997). The critique is specifically focused on his concept of habitus which tends to reproduce those actions consistent with the conditions under which they were produced (Bourdieu, 1977, p.95). Thereby, individuals acquire particular dispositions and address situations in habituated ways, portraying an inescapable structural determinism (Kontos, 2006; Swartz, 1997, p. 211, p. 289).

Bourdieu does, however speak about mismatches between habitus and the opportunities offered in fields as one conceptual possibility for change, but the ways in which this would happen are not clearly specified (Swartz, 1997, p. 289). Scholars supporting the possibility for change view habitus as a mediating concept where practices occur through time and across situations that differ in the structural conditions from which they were formed; thereby, leaving room for modification and change (Swartz, 1997, p.212-213). The proposed study explores the possibility for change in parent, physician, and nurse communication practices during the patient care rounds process.

Application of Bourdieu’s Concepts to a Paediatric Hospital Setting

Health care settings are bureaucratic and hierarchical (Dracup & Bryan-Brown, 2006). The general paediatric ward, a subfield of medicine, is a highly-structured field where identity and social hierarchy are entrenched. Parents have stressed how the diminishment in their parental role in the family field and their lower social positioning in the field of medicine challenge their habitus as parents (Brown & Ritchie, 1990; Burke et al., 1991; Callery & Smith, 1991; Carnevale, 1990; Eberley, Miles, Carter, Hennessey, & Riddle, 1985; Miles, 1979; Miles & Carter, 1982; Miles et al., 1989; Miles et al., 1984; Riddle et al., 1989; Robinson, 1987).
Parents’ descriptions of their hospital experiences can be described as Bourdieusian because they are reminiscent of playing a game according to predetermined rules of conduct (Brown & Ritchie, 1990; Burke et al., 1991; Callery & Smith, 1991; Thorne & Robinson, 1988). Initially, parents do not know the rules of the game; however, they learn they must abide by the formal and informal rules to gain access to key players such as nurses and physicians who hold the majority of cultural/symbolic capital. Over the course of the child’s hospital stay, parents must quickly learn by trial and error the spoken and unspoken rules that are in place if they wish to maintain their subordinate social positioning in the hierarchical structure of the hospital unit. Parents report they are instructed on how to behave and when they can be present with their child (Ardley 2003; Berwick & Kotagal, 2004; Brown & Ritchie, 1990; Griffin, 2003; Rennick, 1986; Robinson, 1987). There is a hierarchical positioning of players, with physicians occupying the highest positions, parents occupying the lower positions, and nurses, depending upon their level of knowledge and linguistic style, occupying positions somewhere in between.

Bourdieu would argue that this arrangement of positions is formalized by the structural properties of the field of pediatric medicine that supports its own mechanisms of maintenance (Swartz, 1997, p. 126). These structural properties are reflected in the proliferation of distinct policies and procedures, processes of care, protocols, and guidelines for behaviour that produce and reproduce the hierarchical structures that maintain the dominant positions (Davidson et al., 2007; Pattison, 2006). Doctors and nurses know the rules of the game. Due to their social positioning relative to physicians, nurses are implicitly expected to enforce the rules of the game according to the structural
properties that are in place. Therefore, physicians’, nurses’, and parents’ relative positions are clearly distinguished and supported by the proliferation of structural properties giving the illusion of a family-centered care philosophy in the context of paediatric hospital care.

Forms of Symbolic/Cultural Capital during a Paediatric Hospitalization

The dominant discourse of the medical model and knowledge of disease and technologies functions as cultural/symbolic capital in the field of paediatrics, specifically in the care of children with complex health care needs. According to Bourdieu, all communication practices are measured against the practices of those who are in dominant positions (Bourdieu, 1991, p. 53). Physicians are the gatekeepers of medical knowledge and, as a result, have the highest weight and distribution of linguistic (symbolic) capital and knowledge (cultural) capital related to the disease process. Nurses are expected to acquire sufficient cultural/symbolic capital and linguistic style to enable them to engage in medical discussions and carry out the child’s medical care and therapies. Structures are in place for physicians to update nurses, who have enough of both forms of capital to play their roles and carry out the child’s ongoing plan of care. However, most parents have limited opportunities to acquire such capital and competency; as a result, they are excluded from domains in which this is required. This is evidenced by the multiple discussions regarding the child’s care that take place without the participation of their parents (Burke et al., 1991; Kerr, 2002; Kleiber et al., 2006; Robinson, 1987).

There is differential weight given to nursing and medical knowledge and linguistic styles relative to that of parents, which again speaks to the dominant habitus enjoyed by physicians and nurses relative to parents (Balling & McCubbin, 2001; Brown
& Ritchie, 1990; Callery, 1997; Callery & Smith, 1991). By establishing communication practices related to knowledge of disease and technology as the legitimate language, it symbolically formalizes distinctions between physicians, nurses, and parents. Therefore, knowledge of the diseased body of a general child versus knowledge of a particular child is accumulated and differentiated appropriately.

Social Positioning of Parents in Hospital Spaces

Many parents of children with complex health care needs experience numerous admissions to a paediatric hospital over the course of their child’s life. Parents’ dissatisfaction with their position relative to professional care providers in the health care system has been identified and described (Burke et al., 1991; Perkins, 1993; Robinson, 1987; Thorne & Robinson, 1988). The habitus of parents of these children is reflected in the language, non-verbal communication, perceptions and modes of functioning that they exhibit when that child is admitted to hospital. This predisposes them to behave in ways that are most likely to maintain or enhance their roles as parents considering the resources available to them and their past experiences in the health care field (Schwartz, 1997, p. 106). Attempts by parents to enhance their position are evidenced by their behaviours to maintain vigilance, negotiate rules, tenaciously seek information, and take charge of their child’s care (Burke et al. 1991; Perkins, 1993; Thorne & Robinson, 1988, 1989). Attempts by mothers to improve the social value of their child through the acquisition and deployment of various types of capital in various fields have also been described (McKeever & Miller, 2004, p. 1181). As parents acquire a linguistic style (symbolic capital) and relevant medical information and technical expertise (cultural capital), a path
is forged over time that reveals the strategies they employed to reach the social position they occupy (Wacquant 1998, p. 6).

When parents’ expectations of participation in their child’s care and involvement in decision making, formed by what they have been told, are not met, many become angry, frustrated, fearful, adversarial, and aggressive. Parents learn that they cannot win and that they or their child will suffer. Therefore, they come to accept their position in the social hierarchy and (re)formulate relationships with health care providers.

Several authors have postulated that transformations are possible when capital is redistributed and social positions are altered (Lahire, 2003; Marcoulatos, 2001; McKeever & Miller, 2004; Swartz, 1997). Therefore, it is hypothesized that an intervention aimed at increasing parents’ symbolic/cultural capital (i.e. linguistic competence and medical/technical knowledge) will improve parent-physician/nurse interactions thereby enhancing parents’ social positioning and increasing their satisfaction with their relationships with the health care team. In addition, it is hypothesized that physicians will gain/maintain valued forms of capital (i.e. time and status) because there will be less physician-parent conflict and more respect for parents. For the purposes of this study, enhancing parents’ social positioning to improve their satisfaction with communication and decision making processes is the desired outcome.

Statement of the Problem

Despite the rhetoric of a family-centred care philosophy to guide paediatric health care service delivery, parents of children with complex health care needs frequently report dissatisfaction with parent-professional communication practices and decision making processes, and with interpersonal conflict with physicians and nurses during their
children’s admission to hospital. Bourdieu’s theory, which acknowledges the power structures embedded in hierarchical settings, provides a framework from which to conceptualize parent-professional relationships. Parents of hospitalized children who lack the linguistic style and the knowledge of medicine and technologies that physician and nurses possess are excluded from the social domains in which this competence is required.

A parent briefing intervention designed to provide parents with an opportunity to obtain cultural-symbolic capital and thereby enhance their social positioning with physicians and nurses may improve parents’ relationships with health care providers. A reliable and valid instrument of family members’ satisfaction with communication and decision making in the adult intensive care unit has recently been developed and refined; however, a similar measure for paediatric settings is lacking.

Therefore, there is an urgent need for a valid and reliable parent satisfaction instrument that focuses on parent-professional communication so that rigorous testing of interventions can be completed. However, before a randomized controlled trial can be conducted, several important methodological issues need to be addressed. The proposed concurrent psychometric component of the study and phase I single group post-test component of the study will inform the decision about a primary outcome measure for a proposed trial, assess the feasibility and acceptability of the parent briefing intervention from clinicians’ and parents’ perspectives, and provide preliminary data about the relationship between hospital length of stay (LOS) and parents’ satisfaction with decision making.
Study Objectives

The study was guided by the following objectives:

1. To inform the decision about the primary outcome measure for the proposed trial by:
   a. Assessing the psychometric properties (i.e. content validity, construct validity, and reliability) and distribution of scores of the Family Satisfaction with Decision Making Subscale (FS-ICU/DM) of the Family Satisfaction with Care in the Intensive Care Unit (FS-ICU) instrument,
   b. Determining the reliability and distribution of scores of the Decisional Conflict Scale (DCS), and
   c. Assessing the relationship between the FS-ICU/DM, and the DCS.

2. To assess the feasibility and acceptability of a parent briefing intervention, from the perspective of clinicians carrying out the intervention and parents participating in the intervention, specifically:
   a. the percentage of eligible physicians and nurses who agree to participate,
   b. the amount of time needed to train nurses in the intervention,
   c. the percentage of eligible parents who agree to participate,
   d. compliance of parents and providers with the intervention,
   e. length of time needed to complete the intervention, and
   f. clinicians’ and parents’ evaluations of the intervention.
CHAPTER 3: RESEARCH DESIGN & METHODS

Design

A feasibility study was conducted with two related components: a psychometric study concurrent with a phase I single group post-test study of a parent briefing intervention to improve parents’ satisfaction with communication and decision making for hospitalized children with complex health care needs. The psychometric component of the study was conducted to determine the suitability of an instrument designed to measure satisfaction with communication and decision making. The phase I single group post-test component of the study was conducted to evaluate the feasibility and acceptability of a parent briefing intervention by parents who received the intervention and physicians and nurses who conducted the intervention. A subset of parents who participated in the psychometric component of the study also participated in the phase I single group post-test study intervention.

Description of Study Setting

The study was conducted in a Pediatric Medicine In-patient Unit (PMIU) in a university affiliated paediatric hospital in Toronto, Ontario, Canada over a nine month period in 2010. The PMIU is comprised of 60 in-patient beds for children admitted with a wide variety of medical problems and conditions. The 60 beds are divided among three geographically integrated units with each unit having a separate team of nurses and physicians. Occupying the 60 in-patient beds are a few children (i.e. up to ten) who receive medical care under specialty programs such as respiratory medicine and complex care.
The complex care service (CCS) is a specialty service within the hospital that provides comprehensive care to children with complex health care needs. Children are admitted to the CCS when they have met the following program criteria: a) health problem affecting ≥ 2 organ systems, b) ≥ 2 medical sub-specialists involved in child’s care, c) ≥ 2 allied health professionals involved in child’s care, d) ≥ 2 of: chronic prescription medication(s), special diet requirement, or medical technology dependence, and e) ≥ 2 or more hospitalizations, 10 or more clinic visits in the prior year (Cohen et al, 2008; Gordon et al., 2007). The program is comprised of six beds within the PMIU. The CCS has a program director and is staffed by four paediatricians, three advanced practice nurses, and one social worker, who all have specialty training and experience caring for this unique population.

As the CCS receives more referrals for their services than it can accommodate, the PMIU was chosen as the study site. Children who met the CCS program criteria but were unable to be admitted to the service were admitted to the PMIU. For those families whose child was referred to the CCS for the first time and were not admitted to the CCS but were scattered over the PMIU, there was a high potential for communication problems between the parent and the physician, and the nurse.

Description of Routine Unit Rounds

The paediatric medicine team of the PMIU conducted patient bedside rounds each day. The purpose of bedside rounds was to: a) review the child’s health status, current treatments and therapies, plan of care, b) make changes to the plan as needed, and c) communicate the plan to patients and families. The patient bedside rounds process began at 8:00am each morning, Monday to Friday. The first hour was dedicated to the medical
team and nurses receiving updates regarding each child’s care over the past 24 hours and to devising a plan of care for the next 24 hours. Once this update was complete, the paediatric medicine team then visited patients on their active patient care list in a priority setting manner where recently admitted or acutely ill and/or unstable patients were seen first.

The patient bedside rounds took place at the child’s bedside or in the corridor outside of the child’s hospital room. The child’s assigned nurse was not usually present during the medical team’s discussion and care planning. The discussion also took place with or without the parents present. Parents’ presence and active participation levels varied. Their participation was dependent upon the attending physician who conducted the patient bedside rounds and whether the parents were available at that time. Nurses’ and parents’ participation in the patient bedside rounds varied from no participation to varying degrees of participation. Therefore, there were inconsistencies in the level of parent and nursing participation and thus levels of communication and information transfer that took place between parents, nurses, and the medical team.

Outside of the patient bedside rounds, parents received varied amounts of information from various members of the clinical team at various times throughout the day, usually in a one-on-one fashion, that is, nurse to parent and physician to parent. Therefore, there was no systematic process for parents to have an opportunity to speak to key members of their child’s care team together at one time and to receive information in an organized fashion regarding their child’s illness, diagnosis, prognosis, short and long term treatment options, or to ask questions, and address concerns. Formal family-team meetings did take place but on an ad hoc basis and often in a reactive manner designed to
meet a specific purpose (e.g. to address parents’ questions and concerns), and/or facilitate a specific process (e.g. complex discharge planning).
Figure 1: Study Schema

Admission to PMIU

Assess Eligibility
Day 2

Obtain Consent
Day 2

Study Enrollment
PMIU LOS Day 2

Child does not meet
Complex Care
Service (CCS)
Criteria

Psychometric Study
(N=50)

Parents
Family
Demographics
FS-ICU/DM & DCS
1 Day Prior
Discharge

Child’s first
admission to
Complex Care
Service (CCS)

Psychometric Study
& Feasibility Study
(N=30)

Parents
Family
Demographics
FS-ICU/DM & DCS
Feasibility Survey
1 Day Prior
Discharge

Physicians/Nurses
Feasibility Survey
1 Week Post Data
Collection
Psychometric Study

For purposes of this study, a parent was defined as the legal guardian of the child.

*Eligibility Criteria*

*Inclusion Criteria*

1. a parent of a child (newborn to 17 years of age) who had a non-elective admission to the PMIU of a large metropolitan paediatric tertiary care centre,

2. a parent who was able to speak and read English and had primarily spent time with his or her child in hospital. If both parents met the criteria, the parent identified by the couple as the most involved in the child’s care was asked to participate.

*Exclusion Criteria*

1. the child was expected to be discharged from the hospital within the next 48-72 hours, as assessed by the PMIU attending physician.

*Sample Size*

The sample size consisted of one parent each from 80 children admitted to PMIU who met eligibility criteria for the study. According to Nunnally (1978), a psychometric evaluation of a scale requires 5-10 subjects per scale item. Eighty parents represented 8 parents for each item in the 10-item Family Satisfaction with Decision Making (FS-ICU/DM) subscale.
Phase I Single Group Posttest Study

Eligibility Criteria

Inclusion Criteria

1. a parent of a child (newborn to 18 years of age) who had a non-elective admission to the PMIU of a large metropolitan paediatric tertiary care centre,

2. the child’s health care needs met the criteria of the CCS: a) health problem that affected ≥ 2 organ systems, b) ≥ 2 medical sub-specialists were involved in child’s care, c) ≥ 2 allied health professionals were involved in child’s care, d) ≥ 2 of: chronic prescription medication(s), special diet requirement, or medical technology dependence, and e) ≥ 2 or more hospitalizations, or 10 or more clinic visits in the prior year (Cohen et al, 2008; Gordon et al., 2007),

3. the child had no previous admissions to the complex CCS at the hospital,

4. a parent was able to speak and read English, had primarily spent time with his or her child in the hospital, and was available to participate in the patient bedside rounds. If both parents met the criteria, the parent identified by the couple as the most involved in the child’s care was asked to participate.

Exclusion Criteria

1. the child was expected to be discharged from hospital within the next 48-72 hours, as assessed by the attending staff physician,

2. child was able to be involved in discussions about their care (i.e. the child did not have significant neurological impairment).
Sample Size

The first 30 parents (n=30), from the larger psychometric study sample (n=80), who met the above criteria and agreed to participate in the phase I single group post-test study participated in the evaluation of the study intervention. Enrolment for the psychometric sample was reached before 30 parents had participated in the evaluation of the study intervention, therefore recruitment continued until the sample size for the phase I single group post-test study was obtained.

Procedures Common to both the Concurrent Psychometric and the Phase I Single Group Post-test Components of the Study

Eligibility Screening

Following REB approval, all children and their parents who were admitted to the PMIU at the start of the study and all subsequent admissions to the PMIU during the study period were assessed daily for their eligibility by the PI and the Clinical Support Nurse In-Charge. Consultation with the CCS physician and/or inpatient nurse practitioner was carried out for the Phase I Single Group Post-test study for each eligible child. Children and parents who met the eligibility criteria for the study were approached by the Clinical Support Nurse In-Charge on the second day of the child’s admission to determine if the parents were interested in participating in the study. A pocket-sized laminated card was provided to ensure that the approach used by the Clinical Support Nurse In-Charge to identify interested parents was consistent.
Recruitment and Consent

Parents who indicated their interest were contacted by the PI who reviewed the study in detail, reviewed the expectations of parents, answered their questions and obtained a signed consent form. A copy of the signed consent form was placed on the child’s health record and a copy was given to a parent.

Study Enrollment

Upon confirmation of eligibility criteria and that consent had been obtained, parents were entered into the study on hospital day two. A table that recorded all parents who participated in the study was kept and continually updated. Enrolment numbers were calculated weekly and shared with nursing staff by email along with the monthly expected recruitment goals.

Follow Up

The PI contacted all parents entered into the study in person at point of follow-up to collect all outcome measure data. This took place on the day prior to discharge and/or transfer from the PMIU. This timeline was chosen as it allowed for parents to be contacted before being transferred to another care facility and/or discharged home and therefore reduced and/or eliminated the percentage of families lost to follow-up. The parents completed paper and pencil surveys while in hospital as instructed by the PI who later collected the envelope by hand from the parent the next day, prior to the child being transferred or discharge.

Methods for Data Collection

Demographic Data. A Confirmation of Entry Form (Appendix A) was completed by the PI on hospital day two after parents had consented (Appendix B) to participate in
the study. Parents who participated in the study intervention completed a separate consent form (Appendix C). All parents completed a family demographic form (Appendix D). A child demographic form was completed by the Clinical Research Project Assistant after the child was discharged from the hospital (Appendix E).

Information contained in the Family Form (Appendix D) included the parents’ age and level of education, marital status, number of other siblings in the family, ethnic origins, language spoken in the home, current place of residence, and length of time living in Canada. The most recent Statistics Canada information related to ethnic origins and mother tongue for Toronto and surrounding areas was used to construct data collection questions.

The Child Form (Appendix E) collected information upon discharge regarding the hospitalized child’s illness. This form included the hospitalized child’s date and time of admission to the PMIU, whether it was the child’s first admission to the PMIU, the child’s length of stay, and the markers of acuity and complexity of illness such as Resource Intensity Weighting (RIW) (Cohen, Austin, Weinstein, Matlow, & Redelmeier, 2008) and a nursing workload system (GRASP) (O’Brien-Pallas, et al., 1989; O’Brien-Pallas et al., 1992; Shullanberger, 2000) and the child’s diagnosis upon discharge.

A Nurse Form (Appendix F) was created to capture descriptive information about the nurses who provided the intervention in the study. The Nurse Form included nursing education completed and years of pediatric nursing experience. A nurse consent form (Appendix G) was created to record nurses’ informed consent to participate in the study.

Follow Up. The PI contacted all parents entered into the study one day prior to transfer or discharge to complete the Family Satisfaction with Decision Making
instruments (FS-ICU/DM) (Appendix H) and the Decisional Conflict Scale (DCS) (Appendix I). Parents who also participated in the study intervention were asked to complete a Parent Feasibility questionnaire (Appendix J). When the instruments were completed by the parents, they placed them in a sealed opaque envelope and gave the envelope to the PI by hand the next day or their assigned nurse where it was placed in a secure location at the nursing desk for pick up by the PI.

Feasibility outcomes related to clinicians’ acceptability and perceived satisfaction with participating in the study were completed at the end of data collection. Each staff physician/fellow/resident and nurse who participated in the parent briefings for the study completed a Physician/Nurse Feasibility questionnaire (Appendix K) within one week post data collection period for the study and returned the completed questionnaire in an opaque self addressed envelope that was provided.

Data Analysis Plan

All data for the concurrent psychometric study and the phase I single group post-test study were analyzed using the SAS™ software version 9.2 (SAS Institute, Cary, NC), where appropriate.

Parent, Child, and Nurse Demographics. Baseline and demographic variables contained in the family, child, and nurse forms were analyzed using descriptive statistics. Continuous measures such as the parent’s age, child’s age, child’s length of stay, and child’s GRASP and RIW scores were summarized using means, standard deviations, and ranges. Categorical measures such as parent’s marital status, parent’s level of education, siblings in the family, ethnic origins, language spoken in the home, current place of residence, length of time living in Canada, reason for child’s admission, whether it was
the child’s first admission to the hospital, nurses’ level of education, and years of pediatric nursing experience were summarized using frequencies and percentages.

Procedures Specific to the Psychometric Component of the Study

Methods for Data Collection

Parents’ Satisfaction with Decision Making. The purpose of the psychometric component of the study was to provide evidence of the reliability and validity of the “Family Satisfaction with Decision Making Subscale” (FS-ICU/DM) of the “Family Satisfaction with Care in the Intensive Care Unit” (FS-ICU) (Heyland & Tranmer, 2001) in the measurement of parents’ satisfaction with communication and decision-making.

The FS-ICU consists of 24 items contained within the two subscales of satisfaction with care and satisfaction with decision making. The subscale “Satisfaction with Decision Making” consists of 10 items that focus upon satisfaction with decision making and includes questions related to information needs and the decision-making process. The 10 items include six items related to information needs and four items related to the decision making process. The six items under information needs ask questions related to frequency of communication with ICU doctors, ease of getting information, understanding of information, honesty of information, completeness of information, and consistency of information. The four items under the decision making process ask questions related to feeling included in the decision making process, feeling supported during the decision making process, feeling they had control over the care of their family member, and if they had adequate time to have their concerns addressed and questions answered.
Parents were asked to rate their satisfaction for each item on the scale from 1 (excellent), 2 (very good), 3 (good), 4 (fair), to 5 (poor). Scoring for each item is equivalent to: excellent = 100, very good = 75%, good = 50%, fair = 25%, and poor = 0%. In addition, they can indicate whether or not they had experienced a particular item on the scale by indicating the “not applicable” option if needed. Scores range from a minimum of 0% to a maximum of 100%.

Since the setting for this study was a regular hospital ward and not an ICU, the FS-ICU/DM instrument will be referred from this point forward as the FS/DM.

Parents’ Decisional Conflict. Parents’ degree of decisional conflict was measured using the Decisional Conflict Scale (DCS) (O’Connor, 1995) (Appendix I). The Decisional Conflict Scale (DCS) is designed to elicit uncertainty about choosing among alternatives, modifiable factors contributing to uncertainty, and perceptions of effective decision making (O’Connor, 1995; O’Connor et al., 1998; O’Connor et al., 1999). The DCS consists of 16 items contained within the three subscales of uncertainty, factors contributing to uncertainty, and effective decision making. The three item uncertainty subscale focuses upon the degree of uncertainty surrounding the decision. The nine items comprising the uncertainty subscale focus on being informed about options, risks, and benefits, and feeling clear about values and trade offs in the decision. The four item effective decision making subscale focuses upon the extent to which consumers agreed that their decisions were informed, consistent with personal values, and would be implemented.

Parents were asked to reflect on the decisions they have just made or are about to make and to respond to statements using a five-point Likert scale. Responses to each
statement range from 1 (strongly agree), 2 (agree), 3 (neither agree or disagree), 4 (disagree) to 5 (strongly disagree), with negative statements having reverse scoring. Scores are standardized to range from zero (no decisional conflict) to 100 (extreme decisional conflict) points. Scores of 25 or lower are associated with follow-through with decisions, whereas scores that exceed 38 are associated with delay in decision making.

**Data Analysis Plan**

Assessment of the psychometric properties of the FS/DM instrument included: 1) content validity, 2) construct validity, 3) internal consistency reliability, and 4) a distribution of scores. Given the extensive evidence of reliability and validity of the DCS across a wide variety of populations, assessment of the psychometric properties of the DCS was limited to internal consistency using the Cronbach’s alpha reliability coefficient and an examination of the distribution of scores.

**Content Validity.** Content validity testing ensures that the instrument has enough items to adequately cover the domain(s) under investigation (Nunnally, 1978; Streiner & Norman, 2003). A number of strategies to assess content validity were carried out. First, a review of the literature and theoretical knowledge regarding parent/family satisfaction with communication and decision making during their medically complex child’s hospitalization and its relation to the 10 items of the FS/DM instrument was conducted. Table 5 reflects each of the items and the content areas represented through the literature and theoretical review.

Second, to ensure that the items appear on the surface to be measuring what respondents and other users of the test perceive it to be measuring, parents were asked a question related to the instruments’ suitability. This was accomplished by asking parents,
after they had completed the FS/DM and the DCS at time of follow-up, to simply rate the instrument on a five point scale ranging from extremely suitable to irrelevant (Nevo, 1985). Asking parents to assess the content validity of the instruments is in line with Streiner & Norman (2003) who state that because content validity pertains to how respondents and other users of the test perceive it, it should be judged by them and not experts in the field.

*Construct Validity.* Validity tests are undertaken to assess the extent to which a particular instrument relates to other instruments in a way that is consistent with theoretically derived hypothesis concerning the concepts that are being studied (Krishner & Guyatt, 1985; Nunnally, 1978). Construct validity of the Family Satisfaction with Decision Making instrument was assessed using the Decisional Conflict Scale (DCS) (O’Connor, 1995). The DCS discriminates significantly between those who make and those who delay or struggle with decisions and is inversely correlated to knowledge (O’Connor, 1995).

Construct validity was tested using the known groups approach (O’Connor, 1995). Therefore, it was hypothesized that low scores on the FS/DM instrument indicating dissatisfaction with communication and the decision making process would be moderately correlated with high scores on the DCS indicating high decisional uncertainty. Depending on the distribution of scores for the two measurement instruments, Pearson’s correlation was conducted if the scores were normally distributed, and Spearman’s correlation was conducted if the scores were not normally distributed. A correlation between -0.40 to -0.60 was considered to be a moderate inverse correlation for this study (Nunnally, 1978).
Reliability. Reliability is defined as how reproducible the results of an instrument are under different conditions. For this psychometric study, internal consistency, an estimation of reliability, was conducted using the FS/DM instrument and the DCS. Coefficient alpha is the basic formula for determining the reliability based on internal consistency (Nunnally, 1978). Therefore, calculating a Cronbach’s alpha coefficient, a good estimate of reliability which provides item-total correlations, was carried out for the FS/DM instrument and the DCS. A Cronbach’s alpha of 0.80 was considered an acceptable alpha for determining reliability of the FS/DM and the DCS (Nunnally, 1978; Streiner & Norman, 2003, Streiner, 2003). If an alpha of 0.80 is not achieved, the FS/DM instrument would not be recommended as a primary outcome of study for the main trial.

Reliability can also be measured by serial administration of a test to a group of subjects whose status on the dimension being examined is believed to be stable (Kirshner & Guyatt, 1985). However, parent’s perceptions of satisfaction can change with time resulting in vastly different scores between mothers and fathers at two different points in time. Therefore, other strategies to test reliability such as inter-rater reliability and test-retest reliability were not carried out in this study. The subsequent within-person and between-person variations would result in low stability of the measure over time (Nunnally, 1978; Streiner & Norman, 2003).

Distribution of Scores. For the FS/DM instruments and the DCS, a distribution of total scale scores that included frequencies, percentages, means, medians, inter-quartile ranges and standard deviations was generated. Reporting of satisfaction scores emphasized the frequency of responses that were less than “4” on the items, i.e. less than “good” or “very good,” as typically satisfaction scores are negatively skewed, and
researchers recommend paying particular attention to those who report they are less than very satisfied (Fitzpatrick, 1991; Fitzpatrick & Hopkins, 1983).

Procedures Specific to the Phase I Single Group Post-test Component of the Study

Study Intervention

Bourdieu’s ideas of symbolic/cultural capital, social positioning, and habitus provided the basis for the development of the parent briefing intervention. The intervention was a process that structures time for the physician/fellow/resident, nurse, and parent to engage in communication practices during the daily patient care rounds. Nurses and physicians, together with the parents, had an opportunity to participate in important communication practices regarding the child’s care. Parents had an opportunity to acquire important medical and technological knowledge about their child’s health care and to learn a linguistic style conducive to participating in physician-directed communication activities.

The attainment of medical and technological knowledge (cultural capital) and change in linguistic style (symbolic capital) by parents through communication practices with physicians and nurses had the potential to enhance parents’ social positioning within the acute care setting and to enable them to gain an active role in communication and decision making processes. By changing the habitus of physicians, nurses, and parents through their participation in the study intervention, it was anticipated that it would provide an opportunity for the establishment of new behaviours which had the potential to bring about long-lasting change in parent-physician/nurse relationships.
Elements of the Study Intervention

Content. A “Parent Briefing” communication process was designed to provide clinicians (e.g., nurses and physicians) with a template from which to guide a structured review for parents of their child’s health status and care needs. The briefing included the following elements to enhance parents symbolic/cultural capital: 1) a medical and nursing update of what was happening with their child on that day (i.e. medical/technical knowledge), 2) a review of the goals and plan of care for the next 12-24 hours (i.e., medical/technical knowledge), 3) a discussion about medical terminology, jargon, short forms, and acronyms and their use in communication practices (i.e. linguistic style), and 4) an opportunity to identify and answer/address parents’ questions and concerns (i.e., linguistic style),

Participants. The attending physician or his/her delegate (i.e., fellow, resident), assigned nurse, and the child’s parent participated in the parent briefing activity.

Location. The parent briefings were conducted daily at the bedside of the hospitalized child or in the corridor outside of the child’s room.

Timing. The intervention took place during the PMIU bedside rounds in the morning or in the afternoon when the physician or his/her delegate was available to conduct the briefing. The intervention period began on day two and took place daily for up to three days or longer when a study nurse was available.

Process. The parent was present during their child’s bedside rounds discussion. The attending staff physician/fellow/resident and study nurse met briefly with the parent after or during the health care team discussion of the child’s health status.
Chairs were placed in the child’s hospital room upon confirmation of enrolment in the study. The physician/fellow/resident, nurse and parent were asked to sit to conduct the briefing. This was an important component of the study intervention. Health care providers have been socialized into acquiring a certain habitus that has shaped their interactions with parents. The usual *modus operandi* was to stand while engaging in daily discussions with parents as it signified the briefness of the encounter to the parent and allowed the physician/nurse to easily take leave of the conversation in an efficient manner. The act of sitting to engage in the parent briefing process provided structured time for important communication practices to take place and physically positions the parent, the physician, and the nurse in the same horizontal plane (Marcoulatos, 2001). This physical manner and style of interaction is the result of the internalization of objective structures in the hospital setting that becomes incorporated into bodily form, which Bourdieu refers to as bodily hexis (Schwartz, 1997, p. 107-108). He states, “……the body has become a repository of ingrained dispositions that certain actions, certain ways of behaving and responding, seem altogether natural” (Bourdieu, 1991, p.13, 17). Therefore, the act of sitting to engage in communication practices with parents was changing the physical manner and style, or bodily hexis, of physicians and nurses.

The intervention proceeded as follows:

a) When the medical team arrived on the unit to begin the patient care rounds, a study nurse approached the attending physician and notified him/her of families enrolled in the study. Upon notification of families in the study, the attending physician understood to page the assigned study nurse when they were about ready to begin the parent briefing intervention.
b) As soon as the nurse arrived, the attending staff physician/fellow/resident began the briefing in which he/she reviewed for the parent the child’s medical status and plan of care for the next 24 hours,

b) The attending staff physician/fellow/resident then continued with their usual patient bedside round duties, and the parent and nurse completed the briefing,

c) Based on the parent briefing training the study nurse received (Appendix A & B), the nurse:

1. sat with the parent and reviewed the information the doctor had shared with them and any additional information to help them understand what was happening with their child. The nurse repeated medical and technical information, provided clarification as needed, and translated medical terminology as necessary.

2. reviewed the plan of care for the child which included relevant tests and procedures, and being mindful to explain any jargon, short forms, and acronyms that had been used and provided additional information as needed.

3. answered any questions and/or addressed any concerns the parents had.

4. discussed the use of medical terminology (i.e. jargon, acronyms, and short forms) in communication practices with physicians/nurses.

5. completed documentation in the data system for each briefing he or she completed highlighting the parent’s expressed questions and concerns. The information was available electronically for the attending staff physician to access.

d) When the study nurse was not able to complete the briefing process as required, he or she contacted a clinical support nurse in-charge who was trained in the study intervention that carried out the intervention.
**Nurse Training**

*Recruitment Process.* Five one hour presentations and many one-on-one discussions were conducted with nursing staff to provide them with an opportunity to learn about the study. A brief summary of the study, implementation of the “Parent Briefing” process, and expectations of nurse participants were presented. Nurses with a minimum of one year paediatric experience and interest in participating in the study contacted the PI. The PI met with each nurse and reviewed expectations of nursing participants, obtained informed consent, and arranged for the nurse to participate in one of the many scheduled study nurse training sessions.

The educational sessions took place at the hospital during days when the nurses were not scheduled to work. Each nurse was given an educational folder which contained an outline for the session along with important information necessary for their involvement in the study. Nurses completed the training session outside of their regularly scheduled shifts, and therefore were paid a total of five hours to cover the training session and the Objective Structured Clinical Exam (OSCE). Payment for the study nurses was provided by research funds obtained to complete the study. At the end of the study each study nurse received a certificate of acknowledgement and was invited to a celebratory event to acknowledge their efforts.

*Content of Training Session.* The study nurse training sessions involved the following information (Appendix L): 1) an overview of the study, 2) a summary of the evidence related to physician/nurse – parent communication and the decision making process, 3) a review of evidence regarding parent satisfaction with care during a child’s hospitalization, 4) a detailed description of the “Parent Briefing” process, 5) the process
for engaging parents, and 6) clinical application of the parent briefing in practice setting. The training session involved didactic presentations, case studies, and small group discussions.

The parent briefing intervention involved a variety of communication skills such as active listening, informing, and asking purposeful questions to solicit parent’s responses. It was supported by evidence related to brief communication processes in acute, highly structured clinical contexts that took place between inter-professional team members (Leonard et al., 2004; Lingard et al., 2005; Lingard et al., 2006). Examples of questions included: 1) Is there anything the doctor or nurse has said that you would like more information about?, 2) What other aspects of your child’s care do you need/wish to discuss at this time?, 3) What is concerning you the most right now regarding your child?, and 4) What additional information would help you the most at this time?

*Evaluating Nurses’ Competency.* Each study nurse participated in an OSCE of the parent briefing process within two to three weeks after he/she had attended one of the study training sessions. The study PI who has expertise in family-health care provider communication carried out the OSCE with each study nurse to ensure that they were competent in carrying out the study intervention. The study PI conducted the OSCE with the study nurse and provided feedback, using pre-determined sequentially structured criteria (Appendix M) regarding his/her implementation of the parent briefing process in a clinical practice scenario. The OSCE process enabled study nurses the time needed to acquire the necessary skills in carrying out the “Parent Briefing” process prior to the start of the feasibility study. All nurses demonstrated competence after completing the initial OSCE; therefore, a second OSCE was not required.
Physician Participation

Two sessions were conducted with physicians during regularly scheduled department meetings. The sessions were 30 minutes in length and involved: 1) an overview of the study, 2) a summary of the study intervention, and 3) expectations of physician participants. The main focus of the session was to provide physicians with a detailed description of the parent briefing intervention and to outline what physicians were asked to do that was different from their present practice, (e.g., having parent and nurse present during rounds discussion, following a briefing template to guide briefing, and sitting down with the parent and the nurse for the parent briefing). In addition, the PI met each attending physician individually prior to his/her on-call duties where the study and the parent briefing intervention were reviewed again and informed consent was obtained (Appendix N).

Follow up. The PI contacted each study nurse who was responsible for carrying out the study intervention on a daily basis during the study period. The PI checked in with the nurse and solicited their feedback, provided support, and answered any questions they had about the parent briefing process. Study nurses accessed the study PI as needed, by email, by telephone, or in person to have any immediate questions addressed.

Methods for Data Collection

Objective 2 (a): Percentage of eligible physicians and nurses who agreed to participate. A record of the number of physicians and nurses who participated in the study out of the total eligible to participate was kept by the study PI.

Objective 2 (b): Amount of time needed to train nurses in the intervention. The amount of time needed to train nurses in the study intervention included the time spent in
formal training sessions and time spent formally supporting study nurses who conducted the study intervention in clinical practice during a two week OSCE period. This information was collected and recorded in a training log by the PI.

Objective 2 (c): Percentage of eligible parents who agreed to participate. A record of the number of parents who participated in the study intervention out of the total eligible to participate was kept by the study PI.

Objective 2 (d): Compliance of clinicians and parents with the intervention.

Clinicians. Monitoring intervention compliance by clinicians on a daily basis for parents entered into the intervention group was carried out by the PI. The study nurse completed a Compliance Data Collection Form (Appendix O) after each parent briefing that he/she completed during the study intervention period. He/she indicated if the briefing took place and completed the form as required. The PI reviewed Compliance Data Collection Forms on a daily basis as needed. The total time to complete the study intervention was estimated to be approximately 20 minutes; duration of the intervention was recorded by the nurse who completed the briefing on the Compliance Data Collection Form.

The PI followed up with each study nurse in situations where the parent briefing process was not completed fully or not completed at all to track reasons for not completing the intervention as instructed. It was anticipated that study nurses would complete the study intervention a minimum of 85% of the time from the point of entry into the study through to the end of the data collection period. The 85% minimum was chosen to reflect the realities of everyday practice in a busy 20 bed paediatric inpatient
unit where nurses must adapt to the many unit activities/emergencies that dictated their nursing work load on a day to day basis.

*Parents.* Parents’ compliance with the parent briefing intervention was evident by the number of briefings in which they participated. Parental presence and other relevant information were collected using the Compliance Data Collection Form (Appendix O). Due to the challenges for families to be present during patient bedside rounds every day, it was anticipated that parent compliance with the study intervention would be at least 85% of the parent briefings available to them.

*Objective 2(e): Length of time needed to complete the intervention.* The length of time for the study nurse to complete the parent briefing intervention was recorded on the compliance data collection form at the end of each briefing by the study nurse. The time recorded began at initiation of the parent briefing and ended upon completion of all elements of the parent briefing process. It was anticipated that the parent briefing would take approximately 20 minutes to complete.

*Objective 2(f): Clinician’s and parents’ evaluations of the intervention.*

*Physicians and Nurses.* Staff physicians/fellows/residents and nurses who participated in the implementation of the parent briefing were asked to complete a Physician/Nurse Feasibility Questionnaire (Appendix K) designed for this study to elicit their perceptions of the timing and duration of the intervention, the clinical usefulness of the intervention to enhance communication and decision making between parents and physicians/fellows/residents and nurses, their satisfaction with study participation, and their preferences for future use of the intervention in clinical practice.
Parents. Parents who participated in the parent briefings were asked to complete a Parent Feasibility Questionnaire (Appendix J) designed to elicit their perceptions of the timing and duration of the study intervention, the usefulness of the intervention as it relates to enhanced communication and decision making between parents and the physicians and nurses, and their satisfaction with study participation.

Data Analysis Plan

The data analysis plan is described below, according to each of the objectives of the phase I evaluation of the parent briefing intervention.

Objective 2(a): Percentage of eligible physicians and nurses who agreed to participate. Data collected regarding eligible physicians and nurses who participated out of the total number of physicians and nurses who were eligible were analyzed using descriptive statistics such as frequencies and percentages.

Objective 2(b): Amount of time needed to train nurses in the intervention. Data collected related to the study training session and OSCE were analyzed using descriptive statistics.

Objective 2(c): Percentage of eligible parents who agreed to participate. Data collected regarding eligible parents who participated out of the total number of parents who were eligible were analyzed using descriptive statistics such as frequencies and percentages.

Objective 2(d): Compliance of clinicians and parents with the intervention. Data collected regarding clinicians’ and parents’ compliance with the intervention were analyzed using descriptive statistics such as frequencies and percentages.
during the briefings was analyzed using descriptive statistics such as frequencies and percentages.

**Objective 2(e): Length of time needed to complete the intervention.** Data collected regarding length of time needed to complete the intervention were analyzed using descriptive statistics such as mean, median, standard deviation, and range.

**Objective 2(f): Physicians’, Nurses’, and Parent’s Evaluations of the Study Intervention.** Staff physicians’, nurses’, and parents’ responses to questions about their experience in the study contained in the feasibility questionnaires were summarized using descriptive statistics, such as frequencies and percentages. Staff physicians’, nurses’, and parents’ responses to questions about the study intervention, using a Likert scale, that were contained in the feasibility surveys were summarized using descriptive statistics, such as frequencies and percentages.

Written comments provided by the physician, nurse, and parent were analyzed using content analysis. Participants’ responses to each question were analyzed for units of meaning, that is, words, phrases, and sentences that described physicians’ and nurses’ experiences. Data considered representative of similar patterns and themes were grouped into categories. Categories were then coded to develop coding schemes that guided the coding of qualitative data (Sandelowski, 1995, 1996, 2000; Skodel-Wilson, 1989). By using this approach, the questions in the survey served as an initial organizing framework where data was segmented according to each question and provided an organizing framework for analysis of data (Sandelowski, 1995).

**Additional Analysis: Explore relationship between LOS and scale scores.** To explore the relationship between hospital LOS and parents’ scores on the FS/DM
instrument and DCS scale, depending on the distribution of scores for the two measurement instruments, Pearson’s correlations would be conducted if the scores were normally distributed, and Spearman’s correlation would be conducted if the scores were not normally distributed. A range of 0.40 to 0.60 was considered a moderate correlation (Nunnally, 1978).

Additional Analysis: Comparison of Parents’ Satisfaction Scores on the FS/DM for parents who participated in the parent briefings and those who did not.

A distribution of FS/DM total instrument scores that included frequencies, percentages, means, medians, inter-quartile ranges and standard deviations was generated for parents who participated in the parent briefings and those who did not. A comparison of the total instrument scores between the two groups was analyzed using a t-test, with a two sided level of significance of 0.05.

Feasibility for a Randomized Controlled Trial (RCT)

For an RCT to be feasible, the following criteria would need to be met:

1. Decision about whether the FS/DM instrument is a suitable primary outcome measure:
   a. 80% of parents rated the FS/DM instrument as suitable (i.e. either 4 or 5 using a 5 point Likert scale) for asking parents to complete about their child’s hospital experience,
   b. A moderate inverse correlation within the range of approximately 0.40-0.60 with the DCS,
   c. A Cronbach’s alpha of at least 0.80, and
d. variability in respondents scores for each variable of the instrument.

2. Acceptability and feasibility of the study intervention:
   a. The training session and OSCE provided a sufficient amount of time to ensure 85% of study nurses were competent in carrying out the study intervention,
   b. Sufficient numbers of nurses (i.e. n=36, six staff nurses and 6 clinical support nurses per in-patient unit 7B, 7C, & 7D) and physicians (n=6) participated in the study to carry out the study intervention,
   c. At least 50% of the total number of eligible parents participated in the study intervention,
   d. PMIU physicians and nurses carried out the parent briefing intervention as per protocol 85% of the time and parents participated as per protocol 85% of the time,
   e. 80% of PMIU physicians, 80% of nurses, and 80% of parents reported that the amount of time needed to complete the parent briefing intervention was acceptable (i.e. rating 4 or 5 on a 5-point Likert scale),
   f. 80% of PMIU physicians, 80% of nurses, and 80% of parents rated their experience participating in the parent briefing intervention as a 4 or higher (using a 5 point Likert scale) on
all 5 questions related to the parent briefing experience of the feasibility survey.

Data Management & Data Validation

Detailed information pertaining to data management and data validation (Appendix P) for the feasibility study included a description of all data collection forms, set up and management of a computer database, outline of process when data was received, and procedure for data checking and data accuracy.

Ethical Considerations

The study received approval from the research ethics committee of the University of Toronto (i.e. January 19th, 2010) and The Hospital for Sick Children’s research ethics board (i.e. November 30th, 2009) before recruitment and data collection began. Once the trial began all families’ identifying information was kept in a separate storage location from data collection forms and was destroyed after follow-up data collection and data checking procedures were completed. Identification study numbers were used on all collection forms to ensure confidentiality of information and anonymity for the families. Data forms were treated like all other medical record forms. All data forms were kept in a locked filing cabinet in the Principal Investigator’s office or Clinical Research Project Assistant’s office at The Hospital for Sick Children.
CHAPTER 4: RESULTS

Derivation of the Sample

The feasibility study sample involved a total of 82 parents (see Figure 2). All parents participated in the psychometric component of the study, and a subset of 31 parents participated in the phase I single group post-test component of the study. It is important to note that the eligibility criteria for the psychometric component of the feasibility study were broader in scope than the eligibility criteria for the phase I single group post-test component of the study, and the sample sizes for both components were different. However, the two samples are not independent of one another, as there was some overlap. After a description of the derivation of the samples for the psychometric component of the study and the phase I single group post-test component of the study, the baseline characteristics of the children, their parents, and their care providers will be presented.

Psychometric Component of the Study

Eighty-one parents of children admitted to PMIU over a nine month period, who met the eligibility criteria, were approached to participate in the study. A small percentage of eligible parents did not wish to participate (n=8). Reasons parents stated for non-participation included being too tired, being too overwhelmed with the admission, and not wanting to share their story.

Of those parents who were enrolled in the study (n=73), 18 did not complete study surveys for the following reasons: hospital length of stay (LOS) was less than three days (n=6), hospital discharge was unexpected (n=6), parents did not complete surveys
prior to discharge (n=5), and lost to follow-up due to multiple intra-hospital transfers (n=1).

Therefore, fifty-five parents (75.3% of those eligible) completed two survey instruments, the Family Satisfaction with Decision Making instrument (FS/DM) and the Decisional Conflict Scale (DCS), prior to their child’s discharge from hospital. See Figure 2 for further details.
Figure 2. Flow Diagram of Study Sample

Psychometric Study ONLY

73 Enrolled

8 Refusals

18 Surveys not completed:
LOS < 3 days (n=6)
Did not complete surveys (n=5)
Discharged early (n=6)
Lost to Follow up (n=1)

Completed FS/DM Subscale & DCS

Total: 55

Psychometric Study & Phase I Single-Group Post-test Study

31 Enrolled

19 Non-Participants:
Not able to participate in rounds (n=8)
Refusals (n=11)

4 Surveys not completed:
Changed mind at follow up (n=1)
Withdrew from the study (n=1)
Did not complete surveys (n=2)

Completed FS/DM Subscale, DCS & Parent Briefing Feasibility Survey

Total: 27

Total Completed Psychometric Study: 82

Total Completed Phase I Single-Group Post-test Study: 27
**Phase I Single Group Post-test Component of the Study**

Fifty parents of children admitted to PMIU over a seven month period, who met the eligibility criteria, were approached to participate in the study (See Figure 2). Thirty-one parents (62.0% of those eligible) consented to participate in the study. Nineteen eligible parents did not participate. Eight out of 19 parents were unable to be present during the rounds process in the morning to participate in the briefings and 11 out of 19 parents did not wish to participate. Reasons stated by parents for non-participation included the child being quite anxious during the admission, feeling that they already have a very good understanding of what is happening to their child, and feeling that they are already involved in a number of research studies at the hospital. Six parents were not present in the hospital when the investigator sought to obtain informed consent and therefore are not included in the derivation of the sample in Figure 2.

Of those parents who were enrolled in the study (n=31), four parents did not complete the surveys for the following reasons: changed their mind about completing the surveys at follow up (n=1), parents chose to withdraw from the study as their child’s care changed from active treatment to palliative (n=1), and the child was transferred unexpectedly from the hospital (n=2).

Therefore, 27 parents (87.1% of those enrolled) participated in parent briefing(s) during their child’s hospitalization and completed three survey instruments, the Family Satisfaction with Decision Making instrument (FS/DM), the Decisional Conflict Scale (DCS), and a Parent Feasibility questionnaire prior to their child’s discharge from hospital. See Figure 2 for further details.
Descriptive Data About the Children, Parents, and Care Providers

Characteristics of the Children

Eighty-six children were enrolled in the psychometric study and a subset of these children (n=31) were enrolled in both the psychometric and the phase I single group post-test components of the study. The mean age of the children enrolled was 5.1 years ($SD = 5.6$, $Mdn = 2.3$, $IQR = 0.4, 8.3$), with a minimum age of a few days to a maximum of 17 years. For the majority of children, it was their first admission to hospital (59.3%). Two indices of the child’s acuity were recorded upon admission to hospital, and they included a nursing workload measurement (GRASP) score and a resource intensity weighted (RIW) score. The GRASP score reflects the number of hours and minutes of nursing care that a patient requires within a 12 hour shift; scores over 10 hours indicate a one-to-one assignment (Meyer, 1978; O’Brien-Pallas et al., 1992; O’Brien-Pallas et al., 1989; Shullanberger, 2000). The GRASP scores, for the 59 of 82 children who had a GRASP score recorded upon admission, ranged from a low of 1.5 to a high of 10.9; the mean score was 4.0 ($SD = 1.6$, $Mdn = 3.8$, $IQR = 2.9, 4.8$). The RIW score represents a measure of resource consumption that uses case mix group methodology to describe the average use of resources by a patient in the hospital relative to the ‘average hospital case’; 1.0 is normative and higher scores indicate increasing complexity and acuity (Cohen et al., 2008; Preyra & Sandor, 2002). The RIW scores ranged from a low of 0.35 to a high of 27.7, the mean score was 3.5 ($SD = 5.6$, $Mdn = 1.2$, $IQR = 0.6, 3.2$). The children’s diagnoses upon admission were categorized according to the International Classification of Diseases, 10th revision, Clinical Modification (ICD-10-CM) system that uses a body systems approach to classify diseases and injuries. Forty-two percent of the children
had two or more bodily systems involved on admission. See Table 5 for further details.

Table 5

*Children’s Diagnoses (N = 86)*

<table>
<thead>
<tr>
<th>Diagnosis (ICD-10 -CM)</th>
<th>Number of children (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory system</td>
<td>29 (33.7)</td>
</tr>
<tr>
<td>Congenital anomalies</td>
<td>23 (26.7)</td>
</tr>
<tr>
<td>Nervous system</td>
<td>15 (17.4)</td>
</tr>
<tr>
<td>Digestive system</td>
<td>14 (16.3)</td>
</tr>
<tr>
<td>Circulatory system</td>
<td>12 (13.9)</td>
</tr>
<tr>
<td>Infectious diseases</td>
<td>11 (12.8)</td>
</tr>
<tr>
<td>Muskuloskeletal system</td>
<td>8  (9.3)</td>
</tr>
<tr>
<td>Endocrine and metabolic</td>
<td>7  (8.1)</td>
</tr>
<tr>
<td>Diseases of the blood</td>
<td>5  (5.8)</td>
</tr>
<tr>
<td>Genitourinary system</td>
<td>3  (3.5)</td>
</tr>
<tr>
<td>Diseases of the skin</td>
<td>2  (2.3)</td>
</tr>
<tr>
<td>Mental disorders</td>
<td>1  (1.2)</td>
</tr>
</tbody>
</table>

*Note.* 36/86 (42.0%) of the children had a diagnosis that involved more than one body system.

**Characteristics of the Parents**

One parent for each child was asked to complete a demographic form. In all but seven cases it was the mother who reported the data. One family did not complete the demographic form. The mean age for mothers was 36.7 years (*SD* = 6.9, *Md* = 36.0, *IQR* = 32.0, 41.5), ranging from 21 years to 54 years. Fathers’ mean age was 39.1 years (*SD* = 7.7, *Md* = 39.0, *IQR* = 33.0, 46.0), ranging from 21 years to 53 years. Educational
levels tended to be high; 69.1% (n=56/81) of mothers and 69.0% (n=49/71) of fathers had a university or college degree.

The majority of parents were married or living in a common law arrangement (88.9%, 72/81). Most parents had other children (76.5%, 62/81) in addition to the child admitted to hospital. Over half of the parents identified their ethnic origin as Canadian (53.1%, 43/81). Although 86.0% of parents (70/81) primarily spoke English in their homes, many families indicated that they also spoke other languages such as Cantonese, French, Spanish, Italian, Portuguese, Polish, Punjabi, Tamil, Kutchi, Hindi, Tagalog, and Amharic. The majority of parents (82.7%, 67/81) lived in the Greater Toronto Area.

**Characteristics of Care Providers**

*Nurses.* Twenty-nine nurses completed the education sessions and successfully completed the OSCE. Four nurses dropped out of the study for the following reasons: 1) one nurse resigned from the hospital, 2) one nurse took an LOA for six months, and 3) two nurses transferred to other units/programs within the hospital. Twenty-five nurses participated in the study (see Table 6). Twenty-two out of 29 nurses (75.9%) had completed their Bachelor of Nursing degree, 26 out of 29 nurses (89.7%) had ≤ 10 years of experience; of the latter, 12 had between 1-3 years of experience.
Table 6

*Characteristics of the Nurses (N = 29)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of Nurses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing education completed</td>
<td></td>
</tr>
<tr>
<td>Diploma</td>
<td>6 (20.7)</td>
</tr>
<tr>
<td>Bachelor</td>
<td>22 (75.9)</td>
</tr>
<tr>
<td>Master</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>Doctoral</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Years of pediatric nursing experience</td>
<td></td>
</tr>
<tr>
<td>1-3yrs</td>
<td>12 (41.3)</td>
</tr>
<tr>
<td>4-7yrs</td>
<td>7 (24.1)</td>
</tr>
<tr>
<td>8-10yrs</td>
<td>7 (24.1)</td>
</tr>
<tr>
<td>10+ yrs</td>
<td>3 (10.3)</td>
</tr>
</tbody>
</table>

*Physicians.* Eighteen attending physicians consented and participated in the study. The participation of the physicians was determined by a rotating monthly on-call schedule where they participated in the study one month at a time. Therefore, depending on the staffing at any given time a minimum of four and a maximum of seven physicians each month carried out the study intervention on the units in collaboration with their nursing colleagues.
Results

Study Objective #1: To inform the decision about the primary outcome measure for the proposed trial by:

a) Assessing the psychometric properties of the Family Satisfaction with Decision Making Subscale (FS/DM)

Distribution of Scores for the FS/DM Instrument

Eighty-two FS/DM instruments were completed for the psychometric component of the study. Thirty-eight out of 82 parents (46.3%) scored their satisfaction with decision making to be “excellent=100%”, with a mean score of 78.6 (SD = 18.1, Mdn = 82.5, IQR = 65.0, 92.5). See Appendix R for a summary of parents’ responses for each individual item on the instrument and the total instrument score.

Content Validity of the FS-ICU/DM

The 82 parents who completed the FS/DM on discharge and/or transfer from the hospital were asked to rate the subscale’s suitability on a Likert scale from a maximum of 1 (agree) to a minimum of 5 (disagree). The parents were asked to rate whether they thought the instrument was suitable to ask parents to complete about their child’s hospital stay. Sixty-nine out of 82 parents (84.2%) felt that the instrument was highly suitable for parents to complete upon their child’s discharge and/or transfer from hospital.

Construct Validity of the FS/DM

A Test for Normality was rejected (p<0.001) for the FS/DM and therefore a non-parametric Spearman’s correlation coefficient was used. There was a moderate inverse correlation between the FS/DM and the DCS (Spearman’s r = -0.64, p<0.0001).
Reliability of the FS/DM

The internal consistency of the FS/DM instrument, as measured by the Cronbach’s $\alpha$ coefficient, was 0.87.

b) Determining the distribution of scores and the reliability of the Decisional Conflict Scale (DCS).

Distribution of Scores of the DCS

Eighty Decisional Conflict Scales were completed for the psychometric study as two parents chose not to complete the DCS upon discharge. The mean scale score was 21.6 ($SD = 17.0$, $IQR = 9.4, 30.5$). Thus most parents in this study were experiencing a low level of decisional conflict related to decisions regarding their child’s care while in hospital. See Appendix S for a summary of parents’ responses for each individual item on the scale and the total scale score.

Reliability of DCS

The internal consistency of the DCS, as measured by the Cronbach’s $\alpha$ coefficient, was 0.96.

Study Objective #2: Feasibility and Acceptability of Parent Briefing by Parents and Clinicians

The feasibility and acceptability of a structured communication intervention, from the perspective of clinicians who carried out the intervention and parents who participated in the intervention, was tested according to the following indices:

a) the percentage of eligible physicians and nurses who agreed to participate

All of the 18 eligible physicians participated in the study. Twenty-nine out of 76 eligible nurses (38.1%) participated in the study. In Unit 1, 10 out of 34 nurses (29.4%)
participated in the study. In Unit 2, 8 out of 27 nurses (29.6%) participated in the study, and in Unit 3, 11 out of 15 nurses (73.3%) participated in the study. As participation was voluntary, reasons are not known as to why nurses choose not to participate.

\[ b) \text{ the amount of time needed to train nurses in the intervention}\]

Of those nurses who participated in the training, 100% acquired the necessary knowledge and skill to be competent in the parent briefing intervention. Each nurse attended a one 3.5 hour education session to provide him/her with the necessary knowledge and skill to carry out the study intervention. Each session was attended by a minimum of one to a maximum of nine nurses at any one session. A total of ten education sessions were needed to ensure all study nurses had an opportunity to participate in a session. Competency was acquired through their involvement in the education session, completion of the OSCE, and clinical support provided by the study PI. Therefore subsequent OSCEs were not necessary.

\[ c) \text{ the percentage of eligible parents who agreed to participate}\]

Thirty-one out of 50 eligible parents (62.0%) participated in the study. Eleven parents did not wish to participate, and eight parents could not participate due to the nature of the study intervention taking place during rounds in the morning.

\[ d) \text{ compliance of parents and providers with the intervention}\]

\textbf{Parent Briefings:} Thirty-one parents participated in a minimum of one briefing to a maximum of five briefings during their child’s admission to hospital over a minimum LOS of 4 days to a maximum of 88 days. Twelve out of 31 parents (38.7%) participated
in three or more briefings. Therefore, the majority of parents did not receive the required “dose” of the study intervention.

Ninety-three briefings were expected to be carried out as per study protocol, that is, a minimum of three briefings per parent enrolled in the study (e.g. 3 briefings x 31 parents = 93 parent briefings). Sixty-eight out of an expected 93 parent briefings (73.1%) were conducted. See Table 7 for detailed information regarding the parent briefings completed in the study.

**Attendance.** The parent briefings were attended by 1) attending physicians and/or their delegates such as residents and/or fellows, 2) nurses and/or clinical support nurses, and 3) parents. All briefings were attended by a nurse and a parent and a physician. Sixty-six out of 68 briefings (97.1%) were attended by a resident and/or fellow and 24 out of 68 briefings (35.3%) were attended by the attending physician.

**Sitting.** In 47 out of 68 briefings (69.1%), the chairs provided for the intervention were used. Chairs were used at least once for 27 of the 31 parents.

**Content.** Key elements of the content of the briefings were carried out by the nurses for all 68 briefings. Questions were asked by parents in 38 out of 68 briefings (55.9%). Concerns were not expressed by parents about the plan of care in 39 out of 68 briefings (57.4%). None of the 31 parents involved in the parent briefings (100.0%) made a formal complaint to the unit manager or patient representative service of the hospital during their child’s admission to the hospital. Five out of 31 parents (16.1%) requested additional meetings with medical and/or nursing staff.

**Compliance.** Daily follow up with study nurses by the study PI regarding compliance with the parent briefings involved physicians’ and/or nurses’ participation in the briefing
(see Table 7). Twelve out of 31 parents received the full dose of the study intervention, (i.e., briefings were in complete compliance with the planned intervention). Twenty-five out of the expected 93 (26.9%) parent briefings were not completed as per study protocol. Table 7 lists the reasons why the briefings were not completed as scheduled.
Table 7

*Compliance with the Parent Briefing Intervention*

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Number of briefings (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Organizational barriers</strong></td>
<td></td>
</tr>
<tr>
<td>Study nurse not working</td>
<td>7 (28.0)</td>
</tr>
<tr>
<td>Patient was transferred or discharged</td>
<td>5 (20.0)</td>
</tr>
<tr>
<td>Study nurse not assigned</td>
<td>4 (16.0)</td>
</tr>
<tr>
<td>Unit too busy</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td><strong>Communication barriers</strong></td>
<td></td>
</tr>
<tr>
<td>Physician was not available</td>
<td>5 (20.0)</td>
</tr>
<tr>
<td>Physician did not page the nurse</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Parent was not available</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td><strong>n</strong></td>
<td>25 (26.9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent Briefing Items</th>
<th>Number of briefings (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attendance</strong></td>
<td></td>
</tr>
<tr>
<td>Attending physician</td>
<td>24 (35.3)</td>
</tr>
<tr>
<td>Resident/fellow</td>
<td>66 (96.7)</td>
</tr>
<tr>
<td>Nurse</td>
<td>68 (100.0)</td>
</tr>
<tr>
<td>Parent</td>
<td>68 (100.0)</td>
</tr>
<tr>
<td><strong>Sitting</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>47 (69.1)</td>
</tr>
<tr>
<td><strong>Key content</strong></td>
<td></td>
</tr>
<tr>
<td>Medical/nursing update</td>
<td>68 (100.0)</td>
</tr>
<tr>
<td>Review plan of care</td>
<td>68 (100.0)</td>
</tr>
<tr>
<td>Category</td>
<td>Count</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Review medical jargon</td>
<td>68</td>
</tr>
<tr>
<td>Parent’s questions</td>
<td>38</td>
</tr>
<tr>
<td>Parent’s concerns</td>
<td>29</td>
</tr>
<tr>
<td>Parents requested additional meetings</td>
<td>5</td>
</tr>
<tr>
<td>Parents made a formal compliant</td>
<td>0</td>
</tr>
</tbody>
</table>

| $n$                                           | 68    | (73.1)     |
e) length of time needed to complete the intervention

The mean length of time needed to complete the parent briefing intervention was 11.9 minutes ($SD = 6.9$), median 10.0 minutes, ranging from 5 minutes to 40 minutes ($IQR = 8.0, 15.0$).

f) parents’ and clinicians’ evaluations of the study and the intervention

Nurses, physicians, and parents were asked to provide feedback on their experience participating in the phase I single group post-test study and on their experience of carrying out the parent briefing intervention.

Evaluation of the Study. Twenty-seven of the 31 parents completed an evaluation of their experiences in the study. Twenty-six out of 27 parents (96.3%) liked being in the phase I single group post-test component of the study; fourteen (51.9%) liked that there were no extra demands on their time and energy, 13 (48.2%) felt reassured, 12 (44.4%) liked contact with study nurses, and 12 (44.4%) liked helping to find an answer to an important research question. Similarly, 22 parents (81.5%) reported that they disliked nothing about the study. Only one parent reported that being in the study caused her to feel worried. Twenty-six parents reported that they would definitely and/or probably choose to participate in the study again. Only one parent reported that she would definitely choose not to participate again.

Twenty-five out of 25 nurses completed the feasibility questionnaire. The most frequently reported response (from 20 out of 25) nurses was that the time set aside for parent-physician/nurse communication was reasonable. Thirteen out of 18 physicians completed the feasibility questionnaire. Nine out of 13 physicians (69.2%) reported that
they liked that there were few or no extra demands on my time and energy. However, less than half of the physicians rated other aspects of their experience in a similar manner (see Table 8).

Table 8

\textit{Nurses' and Physicians' Responses to Participating in the Phase I Single Group Post-test}

\begin{table}[h]
\centering
\begin{tabular}{lcc}
\hline
Response & Nurses \((n = 25)\) & Physicians \((n = 13)\) \\
\hline
Liked daily contact with study parents & 16 (64.0) & 5 (38.5) \\
Time set aside was reasonable & 20 (80.0) & 3 (23.1) \\
Few or no extra demands on my time & 13 (52.0) & 9 (69.2) \\
Find an answer to research question & 18 (72.0) & 3 (23.1) \\
Liked nothing & 0 (0.0) & 0 (0.0) \\
\hline
\end{tabular}
\end{table}

\textit{Evaluation of the Study Intervention.} Parents rated the parent briefings in a favourable manner. Parents rated the following statements as 3 or lower on a 5 point Likert scale (where 5 is “strongly agree” and 1 is “not at all”): the parent briefing was helpful \((n=5)\); recommend to other parents in the hospital \((n=4)\); recommend its use in the future \((n=4)\); the parent briefing was easy to participate in \((n=2)\) (see Table 9). Anecdotal comments provided by parents about their participation in the briefings included feeling like their input was important, that being present during the team discussion was helpful, that they were able to ask questions and state their concerns, and that they would have test and procedures explained to them.
Table 9

*Parents’ Evaluations of the Parent Briefing Intervention*

<table>
<thead>
<tr>
<th>Survey questions</th>
<th>Number of parents’ responses on a Likert scale (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Easy to participate in</td>
<td>21 (77.8)</td>
</tr>
<tr>
<td>Helpful</td>
<td>19 (70.4)</td>
</tr>
<tr>
<td>Recommend to parents</td>
<td>16 (59.3)</td>
</tr>
<tr>
<td>Recommend its future use</td>
<td>19 (70.4)</td>
</tr>
</tbody>
</table>

* A total of 27 parents completed the feasibility questionnaire.

Similar to parents, nurses also tended to rate all aspects of the parent briefing in a favourable manner (see Table 10). Few nurses rated the following statements as 3 or lower on a 5 point Likert scale (where 5 is “strongly agree” and 1 is “not at all”): the time it took to complete the briefing was reasonable (n=3); engaging in the parent briefing was helpful to my practice (n=3); the parent briefing was easy to carry out (n=2); recommend the use of the briefings in the hospital in the future (n=2). All nurse respondents rated the following statement as 4 or higher on the Likert scale: “the parent briefing enhanced parent-physician/nurse communication”. The content analysis of nurses’ comments about their participation in the study intervention supports this finding. A common theme throughout their comments concerned the challenges that they faced trying to attend to patient care while also being available to participate in the briefing (n=7). In addition, they also reported that they had to follow up with the physician/resident on more than one occasion to ensure the briefing was completed as per protocol (n=5).

Thirteen out of 18 physicians completed the Feasibility Questionnaire. Out of the 13 physicians, only 8 completed questions related to their participation in the briefing.
Contrary to parents’ and nurses’ responses, physicians’ ratings were more mixed (see Table 10). Only about one-half of the physicians rated the following items favourably, i.e. scoring them 4 or 5: enhanced parent-physician/nurse communication (n=6), and recommend briefings become part of usual clinical practice (n=4). All 8 physicians rated the following statement as 4 or higher on the Likert scale: “the parent briefing was easy to carry out”. Anecdotal comments provided by physicians who participated in the parent briefing were brief; however they are worth noting in light of the above results. Physicians stated the following: 1) that having the registered nurse present during rounds was helpful and contributed to the nurses’ enhanced role in facilitating effective parent-team communication (n=2), 2) the act of sitting down for the discussion changed the atmosphere of the interaction (n=2), and 3) that the briefing did not change their usual style of interacting with parents (n=2).
Table 10

Nurses’ and Physicians’ Evaluations of the Parent Briefing Intervention

<table>
<thead>
<tr>
<th>Survey question</th>
<th>Number of nurses’ responses on a Likert Scale&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Number of physicians’ responses on a Likert Scale&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5  4  3  2  1</td>
<td>5  4  3  2  1</td>
</tr>
<tr>
<td>Easy to carry out</td>
<td>9  14 1 1 0</td>
<td>4  4 0 0 0</td>
</tr>
<tr>
<td>Enhanced communication</td>
<td>15 10 0 0 0</td>
<td>1  5 0 1 1</td>
</tr>
<tr>
<td>Helpful to my practice</td>
<td>6  16 3 0 0</td>
<td>1  2 3 2 0</td>
</tr>
<tr>
<td>Time it took was reasonable</td>
<td>11 11 3 0 0</td>
<td>1  2 5 0 0</td>
</tr>
<tr>
<td>Recommend its use in the future</td>
<td>9  14 2 0 0</td>
<td>2  2 3 1 0</td>
</tr>
</tbody>
</table>

<sup>a</sup> n = 25. <sup>b</sup> n = 8.

Additional Analysis

Relationship between LOS and instrument scores

The mean length of stay in the hospital was 13.7 days (SD = 16.0, IQR = 5.0, 14.0), with a median of seven days and a range of a minimum of 2 days to a maximum of 86 days. The relationship between the FS/DM instrument and the DCS with the children’s hospital length of stay was analyzed using the Spearman’s correlation coefficient. There was no significant relationship between hospital length of stay and the FS/DM instrument score (Spearman’s r<sub>2</sub> -0.09, p=0.40) and between hospital length of stay and the DCS (Spearman’s r<sub>2</sub> 0.11, p=0.32).
Parents’ satisfaction scores based on participation in the briefings

Parents’ satisfaction scores based on their participation in the parent briefings revealed very similar results. Mean total FS/DM instrument scores for parents who did not participate in the briefings was 79.9 (SD=17.0) and 76.1 (SD=20.3) for parents who did participate in the briefings (see Table 11). The difference between groups was not statistically significant ($\chi^2 = 0.92, p = 0.36$).

Table 11

Satisfaction Scores of Parents Who Did and Did Not Participate in the Parent Briefing

<table>
<thead>
<tr>
<th>Study</th>
<th>FS-DM total instrument scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subgroup</td>
<td>Mean</td>
</tr>
<tr>
<td>Parents who did not participate in the parent briefings$^a$</td>
<td>79.9</td>
</tr>
<tr>
<td>(i.e., psychometric component only)</td>
<td></td>
</tr>
<tr>
<td>Parents who participated in the parent briefings$^b$</td>
<td>76.1</td>
</tr>
</tbody>
</table>

Note. Maximum score = 100.

$^a$A total of 55 parents did not participate in the parent briefings and only participated in the psychometric component of the study. $^b$A total of 27 parents participated in the parent briefings.
Comparisons of number of parents who asked questions when physicians did and did not sit during briefings

Questions were posed by a parent (n=22) in 38 of the 68 briefings. The frequency of sitting (see Table 12) and presence of the attending physician (see Table 13) at the briefings was slightly higher for briefings during which parents asked questions.

Table 12

*Frequency of Parent Questions during 68 Parent Briefings: All Providers were Seated*

<table>
<thead>
<tr>
<th>Parent asked a question when providers were seated</th>
<th>Number of parents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>28 (73.7)</td>
</tr>
<tr>
<td>No</td>
<td>19 (63.3)</td>
</tr>
</tbody>
</table>

Table 13

*Frequency of Parent Questions during 68 Parent Briefings: Attending Physician was Present*

<table>
<thead>
<tr>
<th>Parent asked a question when attending physician was present</th>
<th>Number of parents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13 (34.2)</td>
</tr>
<tr>
<td>No</td>
<td>8 (26.7)</td>
</tr>
</tbody>
</table>
Feasibility of a Randomized Controlled Trial (RCT)

The study results were examined, using the criteria stated, to assess the feasibility for a randomized controlled trial:

1. The FS/DM was determined to be a suitable primary outcome measure for a RCT design given:
   a) Sixty-nine out of 82 parents (84.2%) rated the FS/DM instrument as suitable measure to ask parents to complete about their child’s hospital stay.
   b) a moderate inverse correlation (Spearman’s $r_2 \approx -0.635$, $p<0.0001$) with the DCS was obtained.
   c) The internal consistency reliability of the FS/DM instrument, measured with the Cronbach’s alpha coefficient, was 0.87.
   d) variability in respondents’ range of scores for each item of the FS/DM instrument was evident, given the spread of responses across all response domains. However the majority of responses were excellent or very good, ranging from 67.0% to 83.0% of the total number of responses for each item on the instrument. (See Appendix R for individual item scores and total instrument scores for the FS/DM.)

2. Acceptability and feasibility of the study intervention were as follows:
   a) The training session and OSCE provided a sufficient amount of time for all 29 study nurses (100.0%) to be competent in carrying out the study intervention, which is greater than the 85.0% criterion.
b) Twenty-nine nurses out of 76 nurses (38.2%) and 18 out of 18 (100.0%) physicians participated in the study. Nurses’ participation was less than the 48 % (N=36/75) anticipated that would be needed to carry out the intervention.

c) Thirty-one out of 50 eligible parents (62.0%) participated in the study intervention, which is greater than the 50.0% criterion.

d) Physicians and nurses carried out the parent briefing intervention as per protocol 68 times out of the expected 93 (73.1%), which is lower than the 85.0% criterion. Only 12 out of 31 parents got the recommended “dose” of the intervention. On 12 of the 25 occasions (48.0%) when the briefing was not carried out as scheduled, it was due to the fact that a study nurse was not working (n=7) or a physician was not available (n=5). Parents participated 68 times out of 70 (97.1%), which is higher than the 85.0% criterion.

e) Eleven out of 25 nurses (44.0%) reported that the time it took to complete the briefing was reasonable. However, only 1 out of 8 physicians reported the same.

Between 23 to 25 out of 27 parents and 22 to 25 out of 25 nurses rated their experience participating in the intervention as a 4 or higher (using a 5 point Likert scale) on all 5 questions related to the parent briefing experience in the Feasibility questionnaire (Table 10). Using the same criteria (scores of 4 or 5), physicians’ responses were more mixed.

While all 8 physicians agreed that the briefing was easy to carry out,
and 6 felt it enhanced communication, only 4 of 8 recommended its use in the future, and only 3 of 8 thought the time required was reasonable and it was helpful to their clinical practice (Table 10).
CHAPTER 5: DISCUSSION

In this chapter, strengths and limitations of the study will be presented. In addition, each research objective will be addressed and discussed individually in relation to current relevant literature. Where applicable, the conceptual orientation for the study, that is, Bourdieu’s Logic of Practice, specifically his concepts – fields, capital, and habitus – as they relate to cultural and symbolic capital within the field of pediatric medicine, will provide a context from which to analyze study results.

Strengths and Limitations of the Study

Strengths

The psychometric component of the study used two instruments to measure aspects of decision making. Although the instruments had not been used in this population before, both had been previously validated in prior studies in other clinical settings. In order to promote honest responses by parents, the principal investigator (who was not involved in the care of the children) collected the completed coded instruments from parents in a sealed, opaque envelope prior to discharge from the hospital. The sample of 86 children represented a heterogeneous group with varying diagnoses and lengths of stay. This variability is important when evaluating the psychometric properties of a measure.

Bourdieu’s concepts -- specifically, habitus, capital, and fields -- were used as central ideas for the design of the parent briefing intervention. Habitus, which is a concept that allows for the understanding of behaviour in the social fields in which it occurs, was reflected in the use of chairs during the briefings. The act of sitting to conduct the briefings required clinicians to change their usual manner and style of
communicating with parents. The concept of capital refers to resources that individuals draw on to maintain and enhance their position. This concept was reflected in the kind of information that was seen as valuable and how it was communicated during physician/nurse-parent communication practices. Field was reflected in the relative positions each player, that is, physicians, nurses, and parents, held within the paediatric in-patient unit hierarchical structure. This conceptual orientation to the study intervention created a unique and insightful perspective from which to understand clinician and parent behaviours that has not been previously explored in this manner.

All of the 18 eligible physicians participated in the phase I component of the study. Meetings were held with physicians as a group and on an individual basis to review the study, the study intervention, and expectations of them as participants. The training sessions and OSCEs ensured consistency in the knowledge and skills of all nurses involved in delivering the study intervention. The study PI was available on a regular basis during the data collection period to provide extra support to study nurses was needed.

Limitations

This study was conducted from a single hospital site with a small sample size of only English speaking parents. Therefore, results should not be generalized beyond the patient population or the hospital medical units.

The eligibility criteria required the attending physician to anticipate the child’s hospital LOS from the point of enrollment. This was, in reality, very challenging for the attending physicians and the care team. As a result, six children initially enrolled in the psychometric study had a LOS < 3 days and thus their parents could not complete the
instruments. In addition, anticipating time of discharge to have parents complete study surveys was also at times difficult. Six children in the psychometric study and two children in the phase I single group post-test study were discharged unexpectedly, and there was no post-discharge follow-up to ask them to complete the instruments.

Although nurses participated in education sessions and modified OSCEs to ensure competency in the study intervention, physicians did not complete a similar process before being required to carry out the study intervention. This approach to clinicians’ preparation may have partially contributed to some of the issues related to compliance that were described earlier, such as rate of completion of the briefings and use of chairs.

Due to the nature of the intervention, many factors needed to take place in order for the briefing to be carried out. A study nurse needed to be assigned to a study family at the start of the day shift. The nurse needed to let the physician know of parents enrolled in the study at the beginning of the rounds, and the physician needed to page the nurse when s/he was ready to conduct the briefing for enrolled parents. This multi-step process at times was vulnerable to clinicians’ workload, unit activity, patient acuity, and nursing assignments. As a result, compliance rates were affected. The nurses’ ability to follow through with the study intervention for parents enrolled in the study was largely dependent upon the number of nurses trained in the study intervention. Although 25 nurses participated in the study, this number was not large enough to ensure a study family was assigned to a study nurse 100.0% of the time.

For a majority of the briefings (n=43/68), the attending physician delegated the briefing to a junior member of his/her staff. If the attending physician delegated the briefing to a junior staff person, it was their responsibility to instruct him/her on how to
carry it out. It was anticipated that the attending physician would conduct the majority of the briefings. Delegation between the attending physician and junior staff was tracked during the data collection period by study nurses using an audit form. The study PI did meet with junior medical staff persons as needed, depending on their involvement in the briefings. The study PI did not directly observe the briefings as this would have introduced potential confounding variables to the communication process and would not reflect how the briefing would be carried out in a large RCT or in practice. Attending physicians were responsible for completing the feasibility questionnaires at end of data collection, and as a result only 8 out of the 13 physicians who completed questionnaires (out of the 18 that consented) had experienced the briefing process and could comment on it. Therefore, a future study should include a systematic process for training junior staff in the parent briefing intervention and for follow-up with regards to questionnaire completion.

Study Objective #1

Decision about the primary outcome measure for a proposed trial

The first objective was to make a decision about a primary outcome measure for a future randomized controlled trial based on two instruments designed to measure aspects of the decision making process that were used in this study. The FS/DM instrument was the main instrument of interest for this study, and, therefore, each outcome measure will be discussed separately.

Family Satisfaction with Decision Making Instrument

The psychometric data indicated that the FS/DM instrument showed evidence of good reliability and validity as a primary outcome measure for a future randomized
controlled trial. This conclusion was based on an evaluation of the psychometric properties of the instrument which included content validity, construct validity, reliability and distribution of scores. Each will be discussed separately in further detail comparing study results with previous research evaluating the FS/DM instrument. As well, the issue of patient satisfaction measurement and its importance as an outcome measure will be discussed in relation to the above.

*Content Validity.* Content validity of the FS/DM instrument for this study was assessed by end users of the instrument, namely parents of children who had a child admitted to hospital who were enrolled in the study (Nevo, 1985; Streiner & Norman, 2003). Sixty-nine out of 82 parents felt the FS/DM instrument was suitable to ask parents to complete about their child’s hospital stay.

A similar approach was used by Heyland & Tranmer (2001) to create the original instrument items. Heyland & Tranmer (2001) sought feedback from family members of critically ill patients to pre-test the questions for clarity and completeness of content. Although the Heyland & Tranmer instrument was developed for use by family members of critically ill patients and tested within an adult ICU setting, the results of the psychometric component of this study indicate that this instrument is suitable for other populations in other settings where communication and decision making are integral to patient care.

*Construct Validity.* Construct validity of the instrument for this study was evident as there was a moderate inverse correlation between the FS/DM and the DCS (Spearman $r^2 \sim 0.635$, $p<0.0001$). The study hypothesis was supported. This is similar to previous construct validity testing of the FS/DM, where scores on the FS/DM were found to have a
positive moderate correlation (Spearman $r^2 0.562$, $p<0.001$) with scores on family perceptions of quality of care in the ICU (Wall et al., 2007).

Reliability. An estimate of reliability, as measured by the Cronbach’s alpha coefficient, for the FS/DM was 0.87, indicating an acceptable coefficient for an internal consistency reliability measure. This result is virtually identical to previous reliability testing of the instrument in studies in adult ICUs in both Canada and the United States where the Cronbach’s alpha coefficients were 0.87 (Heyalnd & Tranmer, 2001) and 0.88 respectively (Wall et al., 2007).

Measure of Patient/Parent Satisfaction as a Quality Care Outcome

This is the first time this instrument has been used with parents of ill children, and, as a result there are no previous scores to provide a reference point for comparison. Thirty-eight out of 82 parents in this study scored their satisfaction with decision making to be “excellent”, and the mean total score was 78.6 ($SD = 18.4$, $Mdn = 82.5$, $IQR = 65.0$, 92.5). The FS/DM mean total score in this study is similar to mean total scores in previous studies conducted by Heyland and colleagues with family members of adult patients in an ICU (Heyland et al, 2002; Wall et al, 2007), in which the mean total scores were 76.1 (Heyland & Tranmer, 2001), 75.9 (Heyland et al., 2002) and 82.5 (Wall et al., 2007) respectively. These findings are also similar to previous reports regarding patient/parent satisfaction with their hospital care (Charles et al., 1994; Haines & Child, 2005; Malacrida, et al., 1998; Schaffer et al., 2000; Ygge & Arnetz, 2001). In addition, these findings are consistent with previous research of parents’ experiences during a child’s hospitalization where they express dissatisfaction with their involvement in decisions related to their child’s care (Brown & Ritchie, 1990; Callery & Smith, 1991,
Carnevale et al., 2007; Mello et al., 2004; Meyer et al, 2002; Studdert, Burns et al. 2003; Studdert, Mello et al., 2003; Thorne & Robinson, 1988).

A critique of patient and/or parent satisfaction survey research is that generally results are negatively skewed, that is, typically 80.0% of respondents report high levels of satisfaction (Fitzpatrick, 1991; Fitzpatrick & Hopkins, 1983). The distribution of parents’ responses to the 10 item FS/DM instrument for this study indicated that while there was variability in the range of scores across all response domains, a large percentage of responses were negatively skewed. Typical of satisfaction scores, the majority of responses in this study were categorized as “excellent” or “very good”, representing approximately 77.0% of the total number of responses for each item on the subscale.

Therefore, approximately 23.0% of parents’ responses were categorized as “good”, “fair”, and “poor”. This is keeping with previous studies by Heyland and colleagues, in which 20.0 to 25.0 percent of family members of ICU patients responses were categorized as “good”, “fair”, and “poor” (Heyland & Tranmer, 2001; Heyland et al., 2002).

Thus, in this study, the FS/DM instrument demonstrated excellent evidence of reliability and validity, and the negative skewness commonly associated with patient satisfaction measures. The phase I single group post-test design did not have a comparison group. It is therefore impossible to determine if the briefing intervention improved satisfaction scores. Therefore, in keeping with the satisfaction literature (Fitzpatrick, 1991; Fitzpatrick & Hopkins, 1983; Heyland & Tranmer, 2001; Heyland et
al., 2002, 2003), the most appropriate way to use the instrument in a future trial would be to compare the number of participants who are less than very satisfied in the two groups.

Study Objective #2

Feasibility and acceptability of a parent briefing intervention

This feasibility study took place within a medicine in-patient unit in a large metropolitan paediatric tertiary care academic health sciences centre with parents of children with complex health care needs. The curative approach to care in acute care hospitals is out of sync with the substantial and unique needs of hospitalized children with medical complexity, whose chronic condition will not be cured, and who will require frequent hospital admissions over the course of their life-time (Burke & Alverson, 2010; Cohen et al., 2011). Although a family-centered care philosophy has been adopted by paediatric hospitals to guide care practices, parents’ reports of their experiences have chronicled the challenges they face in having their needs met for information and participation in decisions related to their children’s care (Brown & Ritchie, 1990; Burke et al., 1991; Callery & Smith, 1991; Carnevale, 1990; Robinson, 1987; Thorne & Robinson, 1988).

The following discussion will highlight study results according to Bourdieu’s key concepts such as positioning of physicians, nurses, and parents within the field of paediatric medicine, habitus and the use of chairs, and linguistic practices related to cultural and symbolic capitol as it relates to children with complex health care needs and their parents within a paediatric acute care setting.
Positioning of Clinicians and Parents within the Field of Paediatric Medicine

Fields have structural properties that are important to consider when discussing the study findings (Swartz, 1997, p. 122-6; Wacquant, 1998, p.6-7). Physicians’, nurses’, and parents’ engagement in the study and their evaluation of the parent briefing intervention reflected their respective positions within the field. The disparity in experiences by physicians compared with nurses and parents regarding the briefing could be viewed as reflecting the different strategies that individuals will use to obtain capital most favourable to their own position and situation (Swartz, 1997, p.122-6; Wacquant, 1998, p.7).

Physicians. Given the nature of the study intervention within the context of inter-professional practice, physician support and participation was integral to the feasibility and acceptability of the study intervention. The inclusion of physicians in the study was an acknowledgement of their position on the inter-professional team, their powerful position within the field of paediatric medicine, and of the control they have over the structure of daily linguistic practices with parents (Dracup & Bryan-Brown, 2006; Hawryluck, Espin, Garwood, Evans, & Lingard, 2002; Lingard, Espin, Evans, & Hawryluck, 2004).

This study was originally intended to be conducted within a paediatric intensive care unit (PICU). However, the medical staff objected to this study taking place within their setting. The reasons for their objections were not fully explored, but appeared to relate to the time the intervention would take and its perceived lack of value. The fact that all eligible physicians from the paediatric medicine in-patient unit agreed to participate in the study is important to note. Physicians whose primary responsibility is to care for
children with medical complexity on a busy acute care in-patient hospital unit may find their roles somewhat out of step with their counterparts in other parts of the hospital. The goal of care for this special population of children is not curative, but rather the management of symptoms for an optimal quality of life for the child and family. The physicians’ positioning within the hierarchy of medical specialists is determined by the type and amount of medical and technological knowledge that they possess relative to the population that they serve. They provide high quality care to a complex population of children. This expertise is sought after when these children require frequent and/or extended hospitalizations and multiple ambulatory care visits over the space of many years. Consequently, in many cases they are able to form long-term relationships with parents of these children.

Although all physicians consented to participate in the study, their involvement was constrained by the fact that they followed an on-call rotation that limited their participation to a month at a time. For example, a three month schedule would place a physician on-call for one month then off service for two months. During the month that they were on-call, physicians actually delegated the briefing to a junior member of the staff 63.2% (n=43/68) of the time. This pattern of behaviour may have many explanations depending on the view of “capital” that the physician held. One possibility is that the attending physicians who consented to participate in the study and eventually carry out the study interventions did not perceive the briefings to be a direct threat to their position in the field and therefore delegated the briefings to junior staff to complete. Another, not necessarily conflicting possibility, is that the attending physician did not view the briefings as “capital” or as a valuable activity that would add to her/is position in the field
and thereby did not feel the need to personally conduct the briefing. An equally plausible explanation is that the briefing was perceived as a threat to the attending physician and therefore delegation to a junior staff member prevented loss of capital.

Given the relative positioning of physicians within the field, the approach to recruit and train physicians was different from the approach taken with nurses. Attempts were made by the study PI to provide physicians with the necessary information regarding the parent briefing during regularly scheduled program and departmental meetings to minimize demands on their time and maximize their knowledge/awareness of the study. Physicians were not asked to attend an education session. Persuading physicians to give up their time for an educational session would mean convincing them of the benefits to them for conducting the briefings with enrolled families. However, given that the briefings had not been evaluated as yet, no promises about benefits could be made.

*Nurses.* The number of nurses who agreed to participate in the study (n=29/76, 38.2%) did not meet the initial estimate of 36 nurses projected to complete the study intervention. Reasons stated by nurses for non-participation included not able to participate in education session, anticipation of LOA from the hospital during the study period, and general lack of interest in participating.

Nurses’ positioning relative to physicians in the unit could have played a factor in their ability and/or desire to participate in the study. Nurses occupy a lower position in the field relative to physicians based upon the amount and type of cultural (i.e. medical and technological knowledge) and symbolic capital (i.e. linguistic practices) that they have obtained through education and training experiences. Nurses with more paediatric experience than others will have had more opportunities to acquire capital and engage in
linguistic practices with physicians to secure their higher position in the nursing hierarchy. Their participation in the briefing could be viewed as an opportunity to enhance their capital and ultimately their position with physicians and parents. Nurses may have used the briefings as an opportunity to demonstrate their medical and technological knowledge to the physician and the parent simultaneously thereby enhancing their positioning with both the physician and the parent. This perspective may explain some of the nurses’ favourable responses to their evaluation of the parent briefings.

In addition, the constraints posed by nurses’ defined roles within the health care system may have contributed to their ability to participate in the study intervention. Nurses’ workload is largely determined by patient census, acuity, and the complexity of patient care in combination with the skill mix of the nurses providing care. They are directly responsible for caring out the patient’s plan of care in collaboration with the inter-professional team. These factors may have affected their ability to participate in opportunities to enhance their cultural and symbolic capital and as a result their position.

*Parents.* Thirty-one out of 50 eligible parents agreed to participate in the study. Parents’ participation in the study could be viewed as an attempt to gain important medical and technological knowledge from the physicians and the nurses caring for their child. Acquiring this knowledge could enable them to become active participants in decisions related to their child’s care. This perspective could explain their favourable responses. Parents have previously reported wanting a more active role in decisions related to their children’s care (Brown & Ritchie, 1990; Burke et al, 1991; Callery & Smith, 1991; Carnevale, 2007; Dudley & Carr, 2004; Gatrell et al., 2004; Kerr, 2002;
Kleiber et al., 2006; Mello et al., 2004; Robinson, 1987; Thorne & Robinson, 1988).
However, only 31 out of 50 eligible parents agreed to take part in the briefing study. Eight parents could not attend the briefings as scheduled. It is not clear whether the remaining 11 parents wished to acquire the medical and technological knowledge being shared during the briefings. It may be that they were already knowledgeable about their child’s chronic condition and did not perceive the intervention to provide them with any new knowledge to facilitate their involvement in decisions related to their child’s care. Another plausible explanation could be that they preferred that the physician make all medical decisions related to their child’s care and therefore did not perceive the briefing to be helpful to them.

**Compliance: Parent Briefing Intervention**

Compliance of clinicians and parents with the parent briefings was evaluated by examining attendance (practice), use of chairs (habitus), content of briefing (capital), and clinician and parent evaluation of the intervention (field). Attendance at the parent briefings by a physician or delegate, nurse, and parent was necessary in order for the parent briefings to occur. Only 12 out of 31 parents received a minimum of 3 briefings during the first week of the child’s hospitalization, i.e. a full “dose” of the study intervention. For 11 of 25 briefings, the physician (n=6) and the nurse (n=5) did not complete the briefing. As a result, only 68 out of an expected 93 (73.1%) briefings were conducted.

A majority of the time the physician participating in the briefing was a resident or fellow. Having residents and fellows involved in the parent briefing process could be seen as a natural extension of their education and training in an academic health sciences
centre. However, from a Bourdieusian perspective, it could also be a reflection of the medical students’ position in the field relative to physicians. Attending physicians may have viewed expert knowledge and decision making as “capital” rather than the act of sharing information with parents through communication practices and therefore had the junior staff complete the briefing.

The positioning of nurses relative to physicians in the field of pediatric medicine impacted upon their ability to participate in the study intervention. Nurses were expected to have sufficient medical and technological knowledge to carry out medical care and therapies to be able to manage a 1:2 or 1:3 nurse-patient assignment. This workload can affect their ability to be involved in important discussions with the medical team as patient rounds are carried out according to the physician’s schedule and not the nurse’s availability. As a result, nurses needed to maintain an active role in the study protocol to ensure their presence at the briefings. They had to notify the attending physician of enrolled families when he/she began the rounds process, instruct the attending physician to page them when they were about to begin the briefings, and ask for assistance from their nursing colleagues as needed to be able to attend the briefings. Therefore, for these reasons 85.0% completion was probably an unrealistic goal, given the realities of this highly complex and hierarchical pediatric hospital setting and the positioning of key players within the in-patient unit who were asked to participate in the briefing.

On all but two occasions, a parent was present for the planned briefing. The commitment of parents in this study to be present in the hospital during the time of the briefing probably highlights the value they placed on receiving up to date information from members of the health care team. This behaviour by parents could be viewed as an
attempt to gain important medical and technological knowledge to enhance their position with physicians and nurses (Lahire, 2003; Marcoulatos, 2001; McKeever & Miller, 2004; Swartz, 1997).

Habitus: The Use of Chairs

The act of sitting down to engage in the parent briefing process was an integral component of the study intervention. Three chairs were placed in the hospital room of each child enrolled in the study, that is, a chair for the physician, nurse, and parent. All parties were aware that the chairs were to be used for the parent briefing. Although physicians and nurses indicated their support of using the chairs, the fact that the chairs were not used by clinicians in 21 of the 68 briefings is worthy of discussion.

Bourdieu’s concept of habitus as it relates to the use of the chairs necessitates further critical reflection. Health care providers have been socialized into acquiring a certain habitus that has shaped their interactions with parents. The act of sitting to engage in the parent briefing would have required physicians and nurses to change their habitual ways of interacting with parents. This may have been more difficult for some to do than they had originally anticipated. According to Bourdieu, their position in the field, which is based on capital, has influenced their habitus or behaviours. Therefore, a change in behaviour may have required more sustained interactions with parents over a longer period of time than the study protocol allowed. Consequently, a friendly reminder for clinicians regarding chair usage could have been built into the study protocol to provide continued reinforcement of their use during the briefings over the course of the study. In addition, training for junior medical staff about the parent briefing intervention could
have been added to the study protocol to ensure that all medical representatives who would have had an opportunity to participate in the briefings were properly trained.

An alternate way of viewing the use of chairs is that they were used in 47 of 68 briefings, which suggests that change in practice is possible when situations offer different structural conditions in which the practice was originally formed (Berger, 1986; Gartmen, 1991; Kontos, 2006; Lau, 2004; Sewell, 1992; Swartz, 1997, p.212-213, 289).

Anecdotal comments from physicians who used the chairs during the parent briefings highlighted the fact that the physical act of sitting had an effect on the dynamics of the interaction. However, as these comments are from a few physician participants in the study, further research is required to examine the manner and style of health care provider-parent communication practices that include the use of chairs, and if the sustained use of chairs during communication practices can bring about change in clinicians’ habitus.

*Linguistic Practices: Cultural & Symbolic Capital*

In the field of pediatric medicine, the discourse of the medical model and knowledge of disease and technology functions as cultural and symbolic capital in the care of children with complex health care needs. As a result, the briefing was designed to incorporate Bourdieu’s concepts of cultural (i.e. medical and technological knowledge) and symbolic capital (i.e. linguistic style).

According to the checklist data provided by the nurses, physicians and nurses were 100.0% compliant with the content of the briefing. However, these are self-reported data; briefings were not directly observed. Twenty-two parents asked questions during 38 briefings. This behaviour by parents may be viewed as them taking advantage of an
opportunity to engage in linguistic practices with physicians and nurses to receive important information and have their question(s) answered. Nine parents did not ask questions. This may be because they had no questions or that the briefing did not help them feel comfortable in stating their questions at that specific time with the team members present.

While there were times when the intervention was as little as 5 minutes and as long as 40 minutes, the length of time needed to complete the parent briefing was found to last a mean of 11.9 minutes (SD = 6.9). Previous research by Lingard et al. (2005) that examined situational briefing processes (Lingard et al., 2005) found 3.5 minutes (range 1-6 minutes) to be the average length of time needed to complete a Team Briefing process. However, in all instances in the Lingard study, the team briefings were completed between members of the inter-professional team in an OR setting with physicians, anesthesiologists, and nurses.

This study is the first study of its kind to include parents in a situational briefing process, and, therefore, there are no previously established benchmarks available to provide context of the findings from this study. Although the briefings took place during the usual patient rounds process, the feasibility of this length of time for each briefing from physicians and nurses perspective got mixed reviews. All 25 nurses completed the feasibility questionnaire. However, only 13 out of 18 physicians completed the questionnaire, even after repeated email reminders to do so. Twenty-two out of 25 nurses and 3 out of 8 physicians reported that the time it took to complete the briefing was reasonable. Such differences would be influenced by nurses’ and physicians’ respective positions in the field. The fact that 5 out of the 18 physicians did not complete the
questionnaires raises questions about the intervention’s importance and relevance to their clinical practice.

Feasibility of a Future Randomized Controlled Trial

This study addressed important methodological issues for a future randomized controlled trial that included an evaluation of a primary outcome measure and the feasibility of the study intervention. This study provided evidence to support the use of the FS/DM instrument as an outcome measure of a future RCT. However, given the low compliance rate and the mixed responses from clinicians regarding the briefing, the feasibility of the parent briefing intervention for a future RCT was not supported. It is premature to propose an RCT at this time, as further research needs to be done before a RCT is feasible and warranted. Specific recommendations for further research are listed in the next chapter.
CHAPTER 6: SUMMARY, IMPLICATIONS, AND CONCLUSIONS

Summary

Advances in medical knowledge and technology have lengthened the life-death trajectory for children with complex chronic conditions. As a result, increasing numbers of children dependent upon technology require frequent hospitalizations (Goldson, et al., 2006; Gordon, et al., 2007; Horn et al., 1995; Newacheck & Halfon, 1998; Perrin et al., 1993; Sieben-Hein & Steinmiller, 2005; van der Lee et al., 2007). Communication problems and conflict between parents, physicians, and nurses regarding the child’s care delay treatment and decision making and prolong hospital stays. Qualitative studies report parents’ dissatisfaction with communication and decision making processes. However, few intervention studies, especially RCTs, have addressed these issues within a paediatric context. Bourdieu’s theory, as the conceptual orientation for the study, offers a perspective on human behaviour that provides insight into the present state of affairs in parent-professional relations.

The purpose of this study was to address important methodological issues to determine if an RCT of a Bourdieu-informed parent briefing intervention was warranted and feasible. The objectives of the study were: 1) to inform the decision about the primary outcome measure for a proposed trial by assessing the psychometric properties and distribution of scores of two instruments designed to measure aspects of communication and decision making processes; and 2) to assess the feasibility and acceptability of the Parent Briefing study intervention, from the perspective of both clinicians and parents.
In this single-site study, the feasibility study involved two components: a psychometric study that was conducted concurrently with a phase I single group post-test study. Eighty-six parents of children admitted to a pediatric medicine in-patient unit with a LOS $\geq 3$ days participated in the psychometric component of the study and completed the Family Satisfaction with Decision Making (FS/DM) instrument and the Decisional Conflict Scale (DCS) prior to their child’s discharge from hospital. A small subgroup of these parents (n=31) who had children admitted to hospital, who met criteria of the complex care service, participated in the Phase I single group post-test component of the study. These 31 parents participated in a number of parent briefings over the course of their child’s admission.

The primary instrument of interest for the study, the FS/DM instrument, was determined to be a suitable, reliable, and valid instrument to measure parents’ satisfaction with communication and decision making during a child’s hospitalization. Psychometric properties of the instrument in this study were found to be within acceptable ranges. For example, construct validity testing revealed a moderate inverse correlation was established using the DCS (Spearman’s correlation coefficient $r_2 -0.64$, $p<0.0001$), internal consistency reliability, as measured by the Cronbach’s alpha coefficient, was 0.87, and variability in respondents’ range of scores for each item within the instrument was evident. Therefore, the FS/DM instrument would be an acceptable primary outcome measure for a future randomized controlled trial and/or other quasi-experimental and quality improvement studies in which parents’ satisfaction with decision making is an outcome.
The feasibility and acceptability of the parent briefing intervention by clinicians who carried out the study intervention and by parents who participated in the study intervention was evaluated. The feasibility of the study intervention for a future RCT was evaluated. One hundred percent of eligible physicians, 62.0% of eligible parents, and 38.2% of eligible nurses participated in the study. Physicians and nurses carried out the study intervention on 68 out of an expected 93 occasions. Chairs were used for 47 of the 68 briefings. The average length of time to complete the briefing was 12 minutes (SD=6.9). Twenty-five of 27 parents, 23 of 25 nurses, and 4 of 8 physicians reported that the parent briefing was easy to carry out. All 25 nurses and 6 of 8 physicians reported that the briefing enhanced parent-physician/nurse communication, and 22 of 27 parents found the briefings helpful.

Implications for a Future Randomized Controlled Trial

Before a future trial is feasible, a number of issues related to the integrity of the study intervention need to be addressed, such as competence of nurses and physicians with carrying out the study intervention, consistent application of the study intervention by physicians and nurses that include the use of chairs, and an effective “dose” of the study intervention.

The phase I single group post-test component of the study required physicians and nurses to work together to conduct the briefing for parents enrolled in the study. Nurses participated in an education session prior to the start of the study to ensure competency with the intervention. However, physicians were not required to do the same. As their individual manner and style of communicating with parents varied, participation in the education session would have provided a consistent application of the study intervention.
and protocol. Therefore, future research that examines physician/nurse-parent communication practices as part of a study intervention would benefit from coordinating a joint inter-professional education session for physicians and nurses. Incentives such as remuneration would also be needed to increase the likelihood of physicians’ participation in the session.

The study intervention was not applied consistently. Twelve of the 31 parents received the full dose of the intervention, i.e. participated in 3 briefings during their child’s first 5 days in their PMIU hospital admission. Several factors within the clinical setting infringed on the ability of clinicians to carry out the parent briefing intervention. The number of nurses who agreed to participate was insufficient to ensure that all briefings were conducted. Nursing scheduling and assignments did not allow for a study nurse to be assigned to a study family 100% of the time that it was required. Therefore, further consideration would need to be given to the number of clinicians needed to carry out the intervention and strategies that would address scheduling and assignment processes to ensure maximum compliance. In addition, strategies and/or other incentives to encourage and support nurses to participate in the study would need to be considered to ensure maximum participation by nursing unit staff.

An important element of the study intervention that was not consistent throughout the study period was the use of chairs for the briefings. Although clinicians were instructed to use the chairs for the briefings, increased, ongoing emphasis on the importance of the chairs might have increased compliance. Such emphasis might include careful monitoring and post-briefing feedback, and email reminders during the study period.
Implications for Future Research

Although the findings from the phase I component of this study do not indicate that a randomized controlled trial would be feasible at this point, there are a number of implications for future research.

The Next Study

This study is the first of its kind to include parents in a briefing intervention in an acute care setting. Observation of clinician-parent interactions was not possible during this study. A qualitative study would be helpful to examine the manner and style of health care provider-parent communication practices that include the use of chairs. The study would involve video-taping parent briefings and interviewing each participant post briefing using Bourdieu’s key concepts, specifically -- habitus, capital, and fields -- as the framework for analysis of the interactions. This could provide insightful information about clinician and parent behaviours during communication and decision making practices that could lead to refinement of the intervention for a future pilot RCT.

Strengthening Methods for Pilot RCT

Training Physicians. Future research should address the issue of physician and resident engagement and competence in the parent briefing intervention. A systematic approach to training physicians and junior staff such as residents would need to be conducted as part of the preparation stage prior to the start of the study data collection period. Similar to the approach taken with nursing staff who were involved in the study, physicians/residents would attend a joint education session to clearly outline expectations of clinicians participating in the study and to ensure that all clinicians engaged in the parent briefing intervention were competent to do so. This would promote a consistent
Recruiting Nurses. A future study would need to reassess the number of nurses needed to carry out the study intervention as per protocol. This would require a sufficient number of study nurses to be available to be assigned to a parent enrolled in the study at all times. Training 10% more nurses than the number required would be a useful strategy to consider due to attrition. In addition, employing creative strategies to encourage staff nurses to participate in the study such as incorporating their participation into the hospital based nursing professional development program may enhance recruitment efforts.

Monitoring Use of Chairs. The use of chairs for the parent briefing intervention was an integral component of the study. The usual practice was to stand while engaging in daily discussions with parents. Therefore, asking them to sit while conducting the briefing required clinicians to change their manner and style of interactions with parents. According to Bourdieu, changing a person’s behaviour or “habitus” is dependent upon the opportunities available to them in the environment to behave differently. Therefore, future studies would need to build into the study preparation stage sufficient time and opportunity for clinicians to sit to engage in discussions with parents before they are expected to engage in this behaviour for the study.

Having chairs available for sitting is the preferred option rather than using the bed that is available in the patient’s room. Clinicians and parents may not see the bed as an available option for sitting as it could be perceived as the parent’s personal space and therefore not appropriate for important physician/nurse-parent discussions.
Implications for Practice

Given the preliminary nature of this study, that is, a two-part study involving a psychometric component and a phase I single group post-test component, and based on the study findings, there are no direct implications for practice at this time. However, as parents, nurses, and physicians reported that the briefings enhanced physician/nurse-parent communication, it might be important to consider key components of the parent briefing intervention for future health care provider-parent communication and decision making practices in acute care settings. The manner and style of health care provider-parent interactions and behaviours, structures within the physical environment of an acute care hospital setting that promote and/or restrict the use of chairs and the exchange of medical and technological knowledge, and strategies to engage parents that would enhance their position within the inter-professional team would be important communication practices to consider for future clinical practice.

As a first step, orientation and continuing education programs could sensitize staff to the hierarchical power structure of acute care hospitals and engender discussions about ways to improve timely access for parents to relevant information regarding their child’s care. In addition, nurses and physicians and other members of the inter-professional team could be encouraged to sit while regularly engaging in important communication and decision making practices with parents. The use of chairs during these important interactions between physicians, nurses, and parents could bring about long-lasting changes in health care provider-parent behaviours and subsequently their relationships.
Conclusion

Parents’ satisfaction with elements of their child’s hospital care is seen as an important indicator of quality of care. However, our ability to measure aspects of communication and decision making for parents of hospitalized children with complex health care needs was limited. This study provided evidence of the suitability, reliability and validity of the Family Satisfaction with Decision Making instrument (FS/DM) as a primary outcome measure for a future trial or other research studies. Further research is required to explore its use with parents of acutely ill children in various other programs and/or in other acute care settings.

Enhanced communication practices is one strategy that may be used to address communication problems and conflict that can arise between physicians, nurses, and parents regarding decisions related to their child’s hospitalized care. The evidence from this study suggests that a parent briefing intervention may have benefits for parents of children with complex health care needs and for physicians and nurses providing their care. Physicians, nurses, and parents who participated in the parent briefing perceived the briefings to be easy to participate in and/or carry out and perceived that the briefings enhanced physician/nurse-parent communication. In addition, anecdotal comments from clinicians and parents about the use of chairs during the briefings hinted at their effect on the interaction. Physicians however also reported that the briefings were not helpful to their practice and the time it took to complete the briefings was not reasonable.

Further research is therefore required to further explore the utility of the briefings in clinical practice from physicians’, nurses’, and parents’ perspectives. In addition, the use of chairs during structured communication practices warrants further study to
determine if their use has an effect on clinicians’ attitudes and behaviours and on parents’ satisfaction and behaviours.

Bourdieu’s theory as a general science of human behaviour proved to be useful as a framework from which to view clinician-parent behaviours within an acute care hospital setting that is different than the rhetoric of family-centered care. Further research is required to explore his concepts, specifically -- capital, habitus, and fields -- and their application to hierarchical structures within a variety of health care settings.
Reference List


Appendix A: Confirmation of Entry Form

**Patient Study No.**

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**Confirmation of Entry Form**

Study identifying code:  
Patient Study Number: (from above)

Child’s Date of Birth: (from above)  
Year:  
Month:  
Day:  

Date & Time of Entry:  
Year:  
Month:  
Day:  
24 hour:  

---
Appendix B: Parent Consent Form I (Psychometric Study)

Title of Research Project:
A communication intervention to improve parents’ satisfaction with decision making for children with complex health care needs during a hospitalization: A feasibility study

Investigator(s):

Principal Investigator:
Karen LeGrow
416-250-6525

Co-Investigators:
Dr. Ellen Hodnett
416-946-8676
Dr. Eyal Cohen
416-813-7654, ext. 2626
Dr. Robyn Stremler
416-978-6925
Dr. Pat McKeever
416-978-2855
Sherri Adams
416-813-5787

Contact Information:

Purpose of the Research:
This study seeks to describe parents’ satisfaction with communication and the decision making process during their child’s admission to hospital.

Description of the Research:
All parents agreeing to participate in the study will be required to complete two surveys the day before your child’s discharge from the hospital. Both surveys will ask you to rate your satisfaction with aspects of your child’s care. The surveys will take approximately 10 minutes each to complete for a total of 20 minutes. You will be required to complete the surveys and hand them to the Clinical Research Project Assistant before you leave the hospital.

Medical information about your child’s care while in hospital, i.e. diagnosis on admission, length of stay, etc., will be gathered from your child’s chart for use in the study.

Potential Harms:
There are no known harms associated with participation in this study.

Potential Discomforts or Inconvenience:
The time commitment required to participate in the study and complete the two surveys prior to discharge from the hospital may be a minor inconvenience for you or your family.

Potential Benefits to individual subjects:
You and your child will not benefit directly from participating in this study.

You will receive a letter describing the results of the study once it is completed.
Potential Benefits to Society:
The enhancement of knowledge and skill related to parent-professional communication may benefit hospitalized children with complex care needs at large.

Confidentiality:
Confidentiality will be respected and no information that discloses the identity of you, your child, or your family will be released or published without consent unless required by law. This legal obligation includes a number of circumstances, such as suspected child abuse and infectious disease, expression of suicidal ideas where research documents are ordered to be produced by a court of law and where researchers are obliged to report to the appropriate authorities. For your information, the research consent form will be inserted in to your child’s health record. Health records identifying the patient may be given to and inspected by the HSC Clinical Research Office Monitor.
The data produced from this study will be stored in a secure, locked location. Following completion of the research study, data will be kept as long as required then destroyed as required by Sick Kids policy.

Reimbursement:
You will receive a parking pass for completing the study surveys.

Participation:
Participation in research is voluntary. If you choose not to participate, you will continue to have access to quality care at HSC. New findings developed during the course of the research, which may impact on your willingness to continue, will be provided to you and your consent will be requested again, if necessary. You will be given a copy of this consent form for your records.
In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

Sponsorship:
The sponsor/funder of this research is the Canadian Institute of Health Research (CIHR).

Conflict of Interest:
I, and the other research team members have no conflict of interest to declare.

Consent:
By signing this form, I agree that:
1) The study has been explained to me. All my questions were answered.
2) The possible harms and discomforts and the possible benefits (if any) of this study have been explained to me.
3) I know about the alternatives to taking part in this study. I understand that I have the right not to participate and the right to stop at any time. The decision about whether or not to participate will not affect my health care at The Hospital for Sick Children.
4) I am free now, and in the future, to ask any questions about the study.
5) I have been told that my medical records will be kept confidential, except where release of information is required by law, e.g., suspected child abuse, public health.
6) I understand that no information that would identify me, will be released or printed without asking me first.”

I hereby consent to participate.

_________________________________________
Name of Parent

_________________________________________
Signature & Date

_________________________________________
Name of person who obtained consent

_________________________________________
Signature & Date

The Person who may be contacted about the research is:

_________________________________________
who may be reached at telephone #:

_________________________________________

The person who may be contacted about this research is: Karen LeGrow, who may be reached at telephone #: 416-250-6525

For answers to questions about research subjects’ rights and research-related injury, please contact the Research Ethics Board Manager at (416) 813-5718.
Appendix C: Parent Consent Form II (Phase I Study)

Research Consent Form – Parent (Phase I Study)

Title of Research Project:
A communication intervention to improve parents’ satisfaction with decision making for children with complex health care needs during a hospitalization: A feasibility study

Investigator(s): Contact Information:
Principal Investigator:
Karen LeGrow 416-250-6525
Co-Investigators:
Dr. Ellen Hodnett 416-946-8676
Dr. Eyal Cohen 416-813-7654, ext. 2626
Dr. Robyn Stremler 416-978-6925
Dr. Pat McKeever 416-978-2855
Sherri Adams 416-813-5787

Purpose of the Research:
This study seeks to determine if a communication intervention has an effect on parents’ satisfaction with communication and the decision making process for children with complex health care needs during a hospitalization.
This research also seeks to examine the experiences of nurses when a structured communication approach is used to guide daily parent/nurse/physician communication regarding the child’s care during the patient rounds process.

Description of the Research:
Parents who agree to participate will take part in the patient rounds process in the mornings during the time in which the doctors and nurses meet to discuss your child’s care. These discussions will take place on hospital day 2 – day 4. You will be asked to complete two surveys the day before your child’s discharge from hospital. Both surveys will ask you to rate your satisfaction with aspects of your child’s care. The surveys will take approximately 10 minutes each to complete for a total of 20 minutes. You will be required to complete the surveys and hand them to the Clinical Research Project Assistant prior to you leaving the hospital.

Potential Harms:
There are no known harms associated with participation in this study.

Potential Discomforts or Inconvenience:
The time commitment required to participate in the study and complete the two surveys prior to discharge from the hospital may be a minor inconvenience to you and your family.
Potential Benefits to individual subjects:
You and your child may benefit from participating in this study. You will participate in a formalized discussion with your child’s physician and nurse about your child’s care to have your questions answered and your concerns addressed. You will receive a letter describing the results of the study once it is completed.

Potential Benefits to society:
The enhancement of knowledge and skill related to parent-professional communication may benefit hospitalized children with complex care needs at large.

Confidentiality:
Confidentiality will be respected and no information that discloses the identity of you, your child, or your family will be released or published without consent unless required by law. This legal obligation includes a number of circumstances, such as suspected child abuse and infectious disease, expression of suicidal ideas where research documents are ordered to be produced by a court of law and where researchers are obliged to report to the appropriate authorities. For your information, the research consent form will be inserted in to your child’s health record. Health records identifying the patient may be given to and inspected by the HSC Clinical Research Office Monitor.
The data produced from this study will be stored in a secure, locked location. Following completion of the research study, data will be kept as long as required then destroyed as required by Sick Kids policy.

Reimbursement:
You will receive a parking pass (i.e. a minimum of 3 parking passes @ $11.00 each) for the days that you participate in the study intervention.

Participation:
Participation in research is voluntary. If you choose not to participate, you will continue to have access to quality care at HSC. New findings developed during the course of the research, which may impact on your willingness to continue, will be provided to you and your consent will be requested again, if necessary. You will be given a copy of this consent form for your records.
In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

Sponsorship:
The sponsor/funder of this research is the Canadian Institute of Health Research (CIHR).

Conflict of Interest:
I, and the other research team members have no conflict of interest to declare.
Consent:
By signing this form, I agree that:
1) The study has been explained to me. All my questions were answered.
2) The possible harms and discomforts and the possible benefits (if any) of this study have been explained to me.
3) I know about the alternatives to taking part in this study. I understand that I have the right not to participate and the right to stop at any time. The decision about whether or not to participate will not affect my health care at The Hospital for Sick Children.
4) I am free now, and in the future, to ask any questions about the study.
5) I have been told that my medical records will be kept confidential, except where release of information is required by law, e.g., suspected child abuse, public health.
6) I understand that no information that would identify me, will be released or printed without asking me first.”

I hereby consent to participate.

______________________________ ________________________________
Name of Parent The Person who may be contacted about the research is:

______________________________
Signature & Date who may be reached at telephone #:

______________________________
Name of person who obtained consent

______________________________
Signature & Date

The person who may be reached about the research is: Karen LeGrow, who may be reached at telephone #: 416-250-6525

For answers to questions about research subjects’ rights and research-related injury, please contact the Research Ethics Board Manager at (416) 813-5718.
Appendix D: Family Form

Patient Study No. 

Family Form
BASELINE INFORMATION

Instructions: Please fill in bubbles like this ● Not like this Ø

1. Parent 1: sex 
   Male    Female

2. Parent 1: age 
   Years

3. Parent 1: Highest level of education completed: (mark one only)
   ○ less than high school
   ○ high school
   ○ community college
   ○ university
   ○ post-graduate

4. Parent 2: sex 
   Male    Female

5. Parent 2: age 
   Years

6. Parent 2: Highest level of education completed: (mark one only)
   ○ less than high school
   ○ high school
   ○ community college
   ○ university
   ○ post-graduate
7. Marital Status: (mark one only)
   - married / common law
   - Single

8. Other siblings in the family: (mark one only)
   - none
   - 1
   - 2
   - 3 or more

9. Ethnic origins: (mark all that apply)
   - Canadian
   - English
   - Scottish
   - Irish
   - Chinese
   - Italian
   - East Indian
   - French
   - German
   - Portuguese
   - Polish
   - Jewish
   - Jamaican
   - Greek
   - Spanish
   - Vietnamese
   - Other

10. Language spoken in the home: (mark all that apply)
    - English
    - Chinese
    - Italian
    - Cantonese
    - Portuguese
    - Punjabi
    - Spanish
    - Polish
    - Tamil
    - Greek
    - Vietnamese
    - Other
11. Current Place of Residence: (mark one only)
   ○ in the GTA (includes: Toronto, York, Durham, Halton and Peel regions)
   ○ outside the GTA but in Ontario (excluding: Toronto, York, Durham, Halton, and Peel regions)
   ○ outside the province of Ontario

12. Length of time living in Canada: (mark one only)
   ○ less than one year
   ○ 1 – 2 years
   ○ 3 – 5 years
   ○ 6 – 10 years
   ○ 11 – 15 years
   ○ greater than 15 years
Appendix E: Child Form

Patient Study No.

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**Child Form**

**BASELINE INFORMATION**

1. Admission date to PMIU

   Year:   Month:   Day:   24 hour clock

2. 1st admission to PMIU: (mark one only)
   - Yes
   - No

3. GRASP score on admission:

4. RIW score on discharge:

5. Hospital length of stay (LOS) upon discharge:

6. Diagnosis on discharge from PMIU:

   ____________________________________________________________
   ____________________________________________________________
NURSE FORM
(Baseline Information to be collected prior to start of study)

1. Highest level of nursing education completed: (mark one only)
   - Diploma
   - Bachelor of Nursing
   - Master of Nursing
   - Doctorate of Nursing

2. Years of pediatric nursing experience in an acute care hospital:
   - 1-3
   - 4-7
   - 8-10
   - over 10
Appendix G: Nurse Consent Form

Research Consent Form - Nurses

Title of Research Project:
A structured communication intervention on parents’ satisfaction with decision making for medically complex children during a hospitalization: A feasibility study.

Investigator(s):

Principal Investigator:          Contact Information:
Karen LeGrow                    416-250-6525

Co-Investigators:
  Dr. Ellen Hodnett             416-946-8676
  Dr. Eyal Cohen               416-813-7654, ext. 2626
  Dr. Robyn Stremler           416-978-6925
  Dr. Pat McKeever             416-978-2855
  Sherri Adams                 416-813-5787

Purpose of the Research:
This research seeks to inform the decision about primary outcome measure for a proposed future trial and to assess the feasibility and acceptability of a structured communication intervention from the perspective of clinicians carrying out the intervention and parents participating in the intervention.

This research also seeks to examine the experiences of nurses when a structured communication approach is used to guide daily parent - nurse/physician communication regarding the child’s care

Description of the Research:
All nurses agreeing to participate in the study will be asked to attend a 4 hour training session about the study and the study intervention. The training session will be offered 4 times over the course of 4 weeks which will allow flexibility for nurses to plan to attend the seminars on days that they are not scheduled to work. Within two weeks post education session each nurse will participate in an OSCE related to the study intervention. A nurse must pass the OSCE to participate in the study.
At completion of the data collection period each nurse will complete a survey about her experience in the study. The survey will take approximately 10 minutes to complete.
If changes are made to the study or new information that might affect your willingness to continue to participate in the research becomes available, you will be informed.

Potential Harms:
There are no known harms associated with participation in this study. Participation in this study does not place you at additional risk.
Potential Discomforts or Inconvenience:
The time required to attend the educational session, participate in an OSCE, and complete the feasibility survey may be a minor inconvenience.

Potential Benefits:
It is anticipated that each nurse who completes the training session and OSCE successfully will acquire enhanced knowledge and skill development related to parent-nurse communication

To individual subjects:
Nurses participating in the training session will benefit directly from participating in this study. They will receive an educational session and OSCE that will enhance their communication and interactions with parents of medically complex children during a pediatric hospitalization.

To society:
The enhancement of knowledge and skill related to parent-professional communication may benefit hospitalized children with complex care needs at large. The results of this study will be presented at departmental leadership and research rounds, and hospital nursing grand rounds.

Confidentiality:
Confidentiality will be respected and no information that discloses the identity of the subject will be released or published without consent unless required by law. This legal obligation includes a number of circumstances, such as suspected child abuse and infectious disease, expression of suicidal ideas where research documents are ordered to be produced by a court of law and where researchers are obliged to report to the appropriate authorities. For your information, the research consent form will be inserted in the patient health record. Health records identifying the patient may be given to and inspected by the HSC Clinical Research Office Monitor. The data produced from this study will be stored in a secure, locked location. Following completion of the research study, data will be kept as long as required then destroyed as required by Sick Kids policy.

Reimbursement:
Nurses participating in the education sessions will be paid for education time (i.e. 4 hours for the training session and 1 hour for the OSCE; Total of 5 hrs paid time). In addition, each nurse will receive a certificate of participation and a small token of appreciation.

Participation:
Participation in research is voluntary. If you choose not to participate, you will continue to have an unchanged relationship with the Hospital for Sick Children. New findings developed during the course of the research which may impact on your willingness to continue will be provided to you and your consent will be requested again, if necessary.
Your participation may contribute to the creation of new diagnostic tests, new medicines or other events that may have commercial value. However, your participation in this study will not entitle you to a share in any future economic benefits. You will be given a copy of this consent form for your records. If you become ill or are injured as a result of participation in this study, medical treatment will be available at no additional cost to you. In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

Sponsorship:
The sponsor/funder of this research is the Canadian Institute of Health Research (CIHR)

Conflict of Interest:
I, and the other research team members have no conflict of interest to declare.

Consent:
By signing this form, I agree that:
1) The study has been explained to me. All my questions were answered.
2) The possible harms and discomforts and the possible benefits (if any) of this study have been explained to me.
3) I know about the alternatives to taking part in this study. I understand that I have the right not to participate and the right to stop at any time. The decision about whether or not to participate will not affect my health care at The Hospital for Sick Children.
4) I am free now, and in the future, to ask any questions about the study.
5) I have been told that my medical records will be kept confidential, except where release of information is required by law, e.g., suspected child abuse, public health.
6) I understand that no information that would identify me, will be released or printed without asking me first.”

I hereby consent to participate.

________________________________________
Name

________________________________________
Signature & Date

________________________________________
Name of person who obtained consent

________________________________________
Signature & Date
The person who may be contacted about the research is: Karen LeGrow, who may be reached at telephone #: 416-250-6525.

For answers to questions about research subjects’ rights and research-related injury, please contact the Research Ethics Board Manager at (416) 813-5718.
Appendix H: Family Satisfaction with Decision Making Instrument (FS/DM)

Patient Study No

The questionnaire is being completed by the child’s parent: (mark one only)
- Parent 1
- Parent 2
- Other, please specify: ____________________

Date of Completion: ____________ ____________ ____________
Year Month Day

Your participation in this study is very important and appreciated.

Thank you for your involvement.
FAMILY SATISFACTION WITH DECISION MAKING AROUND CARE OF YOUR CHILD

INSTRUCTIONS FOR PARENTS OF SICK CHILDREN

This questionnaire is designed to measure how you feel about YOUR involvement in decisions related to your child’s health care. In the Hospital, your child may have received care from different people. We would like you to think about all the care your child received when you are answering the questions.

**PLEASE CHECK ONE BOX THAT BEST DESCRIBES YOUR FEELINGS**

**INFORMATION NEEDS**

**Frequency of Communication with Doctors:** How often doctors communicated to you about your child’s condition
- □ Excellent
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ N/A

**Ease of Getting Information:** Willingness of doctors and nurses to answer your questions
- □ Excellent
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ N/A

**Understanding of Information:** How well doctors and nurses provided you with explanations that you understood
- □ Excellent
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ N/A

**Honesty of Information:** The honesty of information provided to you about your child’s condition
- □ Excellent
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ N/A

**Completeness of Information:** How well doctors and nurses informed you what was happening to your child and why things were being done
- □ Excellent
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ N/A

**Consistency of Information:** The consistency of information provided to you about your child’s condition (Did you get a similar story from the doctor and nurses)
- □ Excellent
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ N/A
How are we doing?
Your opinions about your child’s Hospital stay

PROCESS OF MAKING DECISIONS:

During your child’s stay in the Hospital, many important decisions were made regarding the health care she or he received. From the following questions, pick one answer from each of the following set of ideas that best matches your views:

Did you feel included in the decision making process?
☐ 1 I felt very excluded
☐ 2 I felt somewhat excluded
☐ 3 I felt neither included nor excluded from the decision making process
☐ 4 I felt somewhat included
☐ 5 I felt included

Did you feel supported during the decision making process?
☐ 1 I felt totally overwhelmed
☐ 2 I felt slightly overwhelmed
☐ 3 I felt neither overwhelmed nor supported
☐ 4 I felt supported
☐ 5 I felt very supported

Did you feel you had control over the care of your child?
☐ 1 I felt really out of control and that the health care system took over and dictated the care my child received
☐ 2 I felt somewhat out of control and that the health care system took over and dictated the care my child received
☐ 3 I felt neither in control or out of control
☐ 4 I felt I had some control over the care my child received
☐ 5 I felt that I had good control over the care my child received

When making decisions, did you have adequate time to have your concerns addressed and questions answered?
☐ 1 I could have used more time
☐ 2 I had adequate time
How are we doing?
Your opinions about your child’s Hospital stay

Do you have any suggestions on how to make care provided in the Hospital better?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Do you have any comments on things we did well?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Please add any comments or suggestions that you feel may be helpful to the staff of this hospital ward.
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Please rate whether you think this survey is a suitable one to ask parents to complete about their child’s hospital stay.

1 2 3 4 5
agree disagree

We would like to thank you very much for your participation and your opinions. Please return your completed survey to the Research Nurse for this study or to your child’s assigned nurse.

THANK YOU

Appendix I: Decisional Conflict Scale (DCS)

Please think about the decisions you have made while your child has been in the hospital and look at the following comments some people make when deciding about care for their child in the hospital. Please show how strongly you agree or disagree with these comments by CIRCLING THE NUMBER from 1 (strongly agree) to 5 (strongly disagree) that best shows how you feel about the decisions you have made.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree Or Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I know which options are available to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>I know the benefits of each option.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>I know the risks and side effects of each option.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>I am clear about which benefits matter most to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>I am clear about which risks and side effects matter most.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>I am clear about which is more important to me (the benefits or the risks and side effects).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>I have enough support from others to make choices.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>I am choosing without pressure from others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>I have enough advice to make choices for my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10.</td>
<td>I am clear about the best choices for my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11.</td>
<td>I feel sure about the best choices for my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12.</td>
<td>Decisions are easy for me to make about my child's care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>I feel I have made informed choices about my child's care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14.</td>
<td>My decisions show what is important to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15.</td>
<td>I expect to stick to my decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16.</td>
<td>I am satisfied with my decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix J: Parent Feasibility Questionnaire

Parent ID Study No.

Questionnaire for Parent(s) in the ‘Parent Briefing’ Group
Feasibility Survey

The questions are about your experience as a participant in the “Parent Briefing’ Study.

1. What I liked about being in the study (check all that apply):
   - Contacts with study nurse(s)
   - Being in this study helped me feel reassured
   - There were few or no extra demands on my time and energy
   - Helped to find answer to an important research question
   - Liked nothing
   - Other

2. What I disliked about being in the study (check all that apply):
   - Contacts with study nurse(s)
   - Being in this study caused me to feel worried
   - Disliked the extra demands on my time and energy
   - Disliked nothing
   - Other

3. If you had the decision to make again, would you choose to be in the study?
   (Choose one):
   - Definitely yes
   - Probably yes
   - Probably not
   - Definitely not
   - Not sure
‘Parent Briefing’ Experience

Based upon your experience participating in the ‘Parent Briefing’ sessions over the past few days and/or weeks, please rate each of these statements on a scale of 1 to 5, where 1 is ‘not at all’ and 5 is ‘very much so’.

4. The Parent Briefing process was easily to participate in.
   Not at all 0 1 2 3 4 5 very much so

5. I found the Parent Briefing sessions helpful.
   Not at all 0 1 2 3 4 5 very much so

6. I would recommend the parent briefing sessions to other parents with a child admitted to hospital.
   Not at all 0 1 2 3 4 5 very much so

7. I would recommend the use of parent briefing sessions in the future.
   Not at all 0 1 2 3 4 5 very much so

Please add any other comments:
________________________________________________________________________
________________________________________________________________________
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We would like to thank you for your participation and your opinions. Please return your completed survey to the Research Nurse for this study or to your child’s assigned nurse.

THANK YOU
Appendix K: Physician/Nurse Feasibility Questionnaire

Physician/Nurse ID Study No. 

Questionnaire for Physicians & Nurses in the ‘Parent Briefing’ Group
Feasibility Survey

The questions are about your experience as a participant in the “Parent Briefing” Study.

1. What I liked about being in the study (check all that apply):

   O Daily contact with study parent(s)
   O Time set aside for parent-physician/nurse communication was reasonable
   O There were few or no extra demands on my time and energy
   O Helped to find answer to an important research question
   O Liked nothing
   O Other

Comments: ________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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________________________________________________________________________

2. What I disliked about being in the study (check all that apply):

   O Daily contact with study parent(s)
   O Time set aside for parent-physician/nurse communication was not reasonable
   O Disliked the extra demands on my time and energy
   O Research question is not important
   O Disliked nothing
   O Other

Comments: ________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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________________________________________________________________________
‘Parent Briefing’ Experience

Based upon your experience participating in the ‘Parent Briefing’ sessions over the past week, please rate each of these statements on a scale of 1 to 5, where 1 is ‘not at all’ and 5 is ‘very much so’.

3. The Parent Briefing process was easy to carry out.
   Not at all 0 1 2 3 4 5 very much so

4. I found the Parent Briefing sessions enhanced parent-physician/nurse communication.
   Not at all 0 1 2 3 4 5 very much so

5. Engaging in the parent briefing checklist sessions was helpful to my clinical practice.
   Not at all 0 1 2 3 4 5 very much so

6. The time it took to complete the parent briefing checklist was reasonable.
   Not at all 0 1 2 3 4 5 very much so

7. I would recommend the use of parent briefing sessions in the PICU in the future.
   Not at all 0 1 2 3 4 5 very much so

Please add any other comments:
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

We would like to thank you for your participation and your opinions. Please return your completed survey to the Research Nurse for this study.
THANK YOU
Appendix L: Nurse Education Session Outline

Competency:
Each nurse will be able to successfully complete the ‘Parent Briefing’ process with parents entered into the intervention group of the feasibility study.

Objectives:
After completion of the training session the study nurse will be able to:
1. state the purpose of the parent briefing
2. describe strategies to engage parents in the briefing process
3. describe the 4 key elements of the parent briefing process.
4. identify when it is appropriate to use therapeutic questions throughout the briefing process.
5. demonstrate documentation of the briefing process, highlighting relevant information for the IPP care team.
6. successfully complete an OSCE of the parent briefing process in a simulated clinical setting.

Prerequisites:
1. At least 1 year of pediatric nursing experience in an acute care hospital.
2. Interest in participating in the session and becoming a study nurse

Length of session:
Formal education session: 4 hours
Clinical Training: participate in an OSCE within 2 weeks post education session

Suggested teaching methods and learning activities:
Lecture, case study, small group discussion, role playing and objective structured competency evaluation (OSCE)

Resources:
Laptop, LCD, Flipchart, markers, and session handouts.

Evaluation:
Objective Structured Competency Evaluation (OSCE)

Important information to teach and demonstrate
The following teaching plan will be implemented by an APN (i.e. study PI) and an ANPE with expertise in interpersonal practices between families and the health care team
1. Introduction & Outline of Session (5 min)
2. Overview of Study (15 min)
3. Summary of Literature: parent-professional communication & parent satisfaction with care during a child’s hospitalization (15 min)
4. Theoretical perspective guiding the study
   i. Symbolic/Cultural Capital
   ii. Social Positioning of Parents
5. Study Intervention – Parent Briefing (2:15 hrs)
   - Description of Parent Briefing
   - Process for engaging parents in parent briefing process
     i. Act of sitting down
   - Key Elements of the Briefing
     i. Update
     ii. Plan of Care
     iii. Questions
     iv. Concerns
   - Use of key questions & probes
   - Documentation
   - Patient Bedside Rounds
   - Clinical Application:
     i. ‘Dose’ of the study intervention
     ii. Case Study & Group Discussion
     iii. Role Play Activity

6. Scheduling & Process for Completion of OSCE (30 min)

7. APN/ANPE Clinical Support during study intervention period (15 min)

8. Wrap Up (15 min)

References


### CLINICAL SCENARIO:
Using present clinical caseload to apply parent briefing.

<table>
<thead>
<tr>
<th>Assessment Checklist</th>
<th>Needed Prompting</th>
<th>Forgot</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Engagement with child’s parent</strong></td>
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<tr>
<td>❑ Sit down to be at the same level as the parent</td>
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<tr>
<td>❑ Introduce yourself</td>
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<tr>
<td>❑ Establish and maintain eye contact</td>
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<tr>
<td>❑ Explain purpose of discussion</td>
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<td>❑ Minimize distractions and interruptions</td>
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<td><strong>2. Informational update re: child’s health status</strong></td>
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<tr>
<td>❑ Review/update information related to child’s diagnosis, prognosis, test, procedures, treatments and cares</td>
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<tr>
<td>❑ Translate medical terminology</td>
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<tr>
<td>❑ Use of probe: <em>Is there anything the doctor or nurse has said that you would like more information about?</em></td>
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<tr>
<td>❑ Use active listening techniques: repeating, providing, and clarifying information</td>
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<tr>
<td>❑ Use of probe: <em>Is there anything the doctor/nurse has said that is concerning you about your child?</em></td>
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<td><strong>3. Review plan of care for next 12-124 hours</strong></td>
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<tr>
<td>❑ Review only those systems that are significant at time of briefing: Neurological, Cardiovascular, Respiratory, GI/GU, Skin Integrity, Pain &amp; Sedation, Medications &amp; Fluids, Treatments/Procedures/Diagnostics, and General Care Requirements</td>
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<tr>
<td>❑ Use active listening techniques: repeating, providing, and clarifying information</td>
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<tr>
<td>❑ Translate medical terminology, i.e. <em>jargon, short forms, acronyms, abbreviations, etc.</em></td>
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<tr>
<td>❑ Use of probe: <em>Is there anything about your child’s plan of care that you would like more information about?</em></td>
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<tr>
<td><strong>4. Identify &amp; answer questions</strong></td>
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<tr>
<td>1. Use of probe: What other aspects of your child’s care do you need/wish to discuss at this time?</td>
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<tr>
<td>2. Use of probe: What would be most helpful for you to know right now?</td>
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<tr>
<td>3. Document in child’s health record</td>
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<tr>
<td><strong>5. Identify &amp; address concerns</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Use of probe: What is concerning you the most right now about your child?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Use of active listening techniques: repeating, providing, and clarifying information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Document in child’s health record</td>
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<tr>
<td><strong>6. Acknowledge emotional responses</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1. Recognize their emotional responses</td>
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</tr>
<tr>
<td><strong>7. Use of key questions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. What would be most helpful for you to know right now?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. What additional information would help you the most at this time?</td>
<td></td>
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</tbody>
</table>
Appendix N: Physician Consent Form

Research Consent Form - Physicians

Title of Research Project:
A structured communication intervention on parents’ satisfaction with decision making for medically complex children during a hospitalization: A feasibility study.

Investigator(s):
Principal Investigator: Karen LeGrow
Contact Information: 416-250-6525

Co-Investigators:
Dr. Ellen Hodnett 416-946-8676
Dr. Eyal Cohen 416-813-7654, ext. 2626
Dr. Robyn Stremler 416-978-6925
Dr. Pat McKeever 416-978-2855
Sherri Adams 416-813-5787

Purpose of the Research:
This research seeks to inform the decision about primary outcome measure for a proposed future trial and to assess the feasibility and acceptability of a structured communication intervention from the perspective of clinicians carrying out the intervention and parents participating in the intervention.

This research also seeks to examine the experiences of physicians when a structured communication approach is used to guide daily parent/nurse/physician communication regarding the child’s care

Description of the Research:
All physicians agreeing to participate in the study will be asked to attend a 30 minute information session about the study and the study intervention. The information session will be offered 6 times over the course of 3 weeks which will allow flexibility for physicians to attend a session during their regular work week.

Once physicians have participated in an information session and completed a consent form, they will be expected to carry out the study intervention with families entered into the study. The physician will be expected to carry out the parent briefing process as per study protocol. At completion of the data collection period each physician will complete a survey about his/her experience in the study. The survey will take approximately 10 minutes to complete.

If changes are made to the study or new information that might affect your willingness to continue to participate in the research becomes available, you will be informed.

Potential Harms:
There are no known harms associated with participation in this study. Participation in this study does not place you at additional risk.
Potential Discomforts or Inconvenience:
The time required to participate in an information session and complete the feasibility survey may be a minor inconvenience.

Potential Benefits:
Physicians who participate in the study intervention may not benefit directly. However, if improved communication and decision making processes result, there may be fewer demands on physicians' time for additional meetings with parents outside of the rounds process.

To individual subjects:
It is anticipated that the parent briefing process will provide a formal process for important communication to take place between parents of children with complex needs and physicians during a pediatric hospitalization.

To society:
The enhancement of knowledge and skill related to parent-professional communication may benefit hospitalized children with complex care needs at large.
The results of this study will be presented at departmental leadership and research rounds, and hospital nursing grand rounds.

Confidentiality:
Confidentiality will be respected and no information that discloses the identity of the subject will be released or published without consent unless required by law. This legal obligation includes a number of circumstances, such as suspected child abuse and infectious disease, expression of suicidal ideas where research documents are ordered to be produced by a court of law and where researchers are obliged to report to the appropriate authorities. For your information, the research consent form will be inserted in the patient health record. Health records identifying the patient may be given to and inspected by the HSC Clinical Research Office Monitor.
The data produced from this study will be stored in a secure, locked location. Following completion of the research study, data will be kept as long as required then destroyed as required by Sick Kids policy.

Reimbursement:
Physicians participating in the intervention will receive a certificate of participation and a token of appreciation.

Participation:
Participation in research is voluntary. If you choose not to participate, you will continue to have an unchanged relationship with the Hospital for Sick Children.
New findings developed during the course of the research which may impact on your willingness to continue will be provided to you and your consent will be requested again, if necessary.
Your participation may contribute to the creation of new diagnostic tests, new medicines or other events that may have commercial value. However, your participation in this study will not entitle you to a share in any future economic benefits.
You will be given a copy of this consent form for your records. If you become ill or are injured as a result of participation in this study, medical treatment will be available at no additional cost to you. In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

Sponsorship:
The sponsor/funder of this research is the Canadian Institute of Health Research (CIHR)

Conflict of Interest:
I, and the other research team members have no conflict of interest to declare.

Consent:
By signing this form, I agree that:
1) The study has been explained to me. All my questions were answered.
2) The possible harms and discomforts and the possible benefits (if any) of this study have been explained to me.
3) I know about the alternatives to taking part in this study. I understand that I have the right not to participate and the right to stop at any time. The decision about whether or not to participate will not affect my health care at The Hospital for Sick Children.
4) I am free now, and in the future, to ask any questions about the study.
5) I have been told that my medical records will be kept confidential, except where release of information is required by law, e.g., suspected child abuse, public health.
6) I understand that no information that would identify me, will be released or printed without asking me first.”

I hereby consent to participate.

________________________________________________________
Name

________________________________________________________
Signature & Date

________________________________________________________
Name of person who obtained consent

________________________________________________________
Signature & Date

The person who may be contacted about the research is: Karen LeGrow, who may be reached at telephone #: 416-250-6525.

For answers to questions about research subjects’ rights and research-related injury, please contact the Research Ethics Board Manager at (416) 813-5718.
Appendix O: Compliance Data Collection Form

PLEASE NOTE: FORM TO BE COMPLETED BY STUDY NURSE

Patient Study

Date: ____________________________

Time to complete: ________ minutes

Attendance for completion of checklist:

Physician:  □ Staff  □ Resident  □ Fellow

Nursing:  □ Staff  □ CSN

Family:  □ Parent

Sitting down for briefing:  □ Yes  □ No

Please check box to indicate the areas that were discussed with parent:

□ Understanding of what is happening to their child

□ Child Health Issues Updated and/or Reviewed

□ Plan of Care for the Day

□ Questions identified & answered
  □ Yes, documented in the IDCS
  □ No questions/concerns stated at this time

□ Concerns identified & addressed
  □ Yes, documented in the IDCS
  □ No questions/concerns stated at this time

Please indicate if the following has occurred:

Additional meeting requested by parent(s)
  □ Yes  □ No

Complaint by parent(s) made to the CHS Manager
  □ Yes  □ No
Appendix P: Data Management & Data Validation

Data Collection Forms

Data collection forms specifically designed for this feasibility study or used in previous studies and chosen for this study all collected information relevant to the outcome measures of interest. All forms contained a unique patient study number and a secondary identifier. Instructions to respondents for completing the forms are clear and concise. Copies of all data collection forms are provided in the appendices: Confirmation of Entry Form (Appendix A), Family Form (Appendix D), Child Form (Appendix E), Nurse Form (Appendix F), the Family Satisfaction with Decision Making subscale (FS-ICU/DM) (Appendix H), the Decisional Conflict Scale (Appendix I), Compliance Data Monitoring Form (Appendix O), Physician/Nurse Feasibility Survey (Appendix K), and the Parent Feasibility Survey (Appendix J).

Computer Database

All data collected for the trial was entered and organized into computerized database programs. A relational database programs, Microsoft Access, was used for data management for the trial. This database program contained all important and relevant information related to data collection for the trial. For example, this program contained administrative data for key persons involved with the operation of the trial and lists of tables in the database as well as list of variables of the tables. All files created in the computerized data base in relation to the trial was password protected and regularly backed up on a rotating basis on hard drive and encrypted USB port drives.
Data Received

Keeping track of data received and data that was outstanding or unavailable was carried out. Date stamping the forms as they are being received was one strategy used to assisting the tracking of information. A file folder was made and initiated for each family entered into the study. Confirmation of enrolment was the first document placed in the folder along with the Confirmation of Entry Form (Appendix A). Other documents added were demographic information forms and all outcome measure instruments. A Document Checklist (Appendix Q) was placed on the cover of the file folder to keep track of data forms completed and contained within the file. In addition, an Access program record was created to replicate the document checklist electronically to show awaiting data to be received. All paper forms collected throughout the data collection period for the study and other important documents was be stored in a locked filing cabinet within The Hospital for Sick Children.

Data Checking & Accuracy

All data received from the start of the study through to the completion of the data collection period was checked for completeness of the case, identifiers between pages of a case, logic of the data, and protocol compliance. Data checking was an on-going process that began when study recruitment started and continued throughout the recruitment period until all cases were received and completed. The process began early once a complete set of data was received for a case. A hand double data entry (DDE) strategy was carried out after both data entries were entered into the computer and compared. During this process, the data from each form was entered by two different people into two separate data bases. Discrepancies in data were corrected by a third party
so that both data bases are identical. In addition, visual checking was done in conjunction with the computer printout however this will not catch all errors.

Another step in the process of checking data is checking the accuracy of the data. Accuracy of data was checked by examining the range, sequence, and duration for responses recorded for items contained in the data collection forms. Examples of accuracy checks for range included all dates recorded on the forms relating to hospitalized events will need to fall within the duration of the trial period. An example of this is the date of admission of the hospitalized child to PMIU contained within the Child Form (Appendix E). This date was checked to see that it occurred during the time of data collection. In addition, the hospitalized child’s date of birth, recorded on the demographic Family Form (Appendix D), would need to be no greater than 18 years from the year that the study starts as the maximum age of pediatric patients is 18 years of age.

Examples of accuracy checks for sequence included the logical sequence of events related to study protocol. Examples of sequence checks include the admission date of the child to PMIU as recorded on the demographic Child Form (Appendix E) that would need to logically follow the start date for the study, the date and time recorded on the Confirmation of Entry Form (Appendix A) will need to logically follow the date of admission of the child to PICU as recorded on the Child Form (Appendix E) and the date documentation of the study intervention recorded on the Compliance Data Monitoring Collection Form (Appendix O).
## Appendix Q: Document Checklist

<table>
<thead>
<tr>
<th>Patient Study No.</th>
<th>Baseline Information</th>
<th>Enrolment Date</th>
<th>FS-ICU/DM</th>
<th>DCS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family □</td>
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<td>Child □</td>
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<td>Contact Information □</td>
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</table>
## Appendix R

### Parents’ Responses to Items on the FS/DM Instrument ($N = 82$)

<table>
<thead>
<tr>
<th>FS/DM instrument items</th>
<th>Excellent no. (%)</th>
<th>Very good no. (%)</th>
<th>Good no. (%)</th>
<th>Fair no. (%)</th>
<th>Poor no. (%)</th>
<th>Item Mean score (%)</th>
<th>Item SD (%)</th>
<th>Item Mdn score</th>
<th>Item IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency of communication</strong></td>
<td>30 (37)</td>
<td>27 (33)</td>
<td>16 (20)</td>
<td>7 (9)</td>
<td>1 (1)</td>
<td>74.07</td>
<td>25.45</td>
<td>75.00</td>
<td>50, 100</td>
</tr>
<tr>
<td><strong>Ease of getting information</strong></td>
<td>41 (50)</td>
<td>24 (29)</td>
<td>14 (17)</td>
<td>3 (4)</td>
<td>0 (0)</td>
<td>81.40</td>
<td>21.81</td>
<td>87.50</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Understanding of information</strong></td>
<td>38 (46)</td>
<td>30 (37)</td>
<td>12 (15)</td>
<td>2 (2)</td>
<td>0 (0)</td>
<td>81.71</td>
<td>20.05</td>
<td>75.00</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Honesty of information</strong></td>
<td>43 (52)</td>
<td>22 (27)</td>
<td>15 (18)</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>82.01</td>
<td>22.32</td>
<td>100.00</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Completeness of information</strong></td>
<td>37 (46)</td>
<td>26 (32)</td>
<td>13 (16)</td>
<td>4 (5)</td>
<td>1 (1)</td>
<td>79.01</td>
<td>23.87</td>
<td>75.00</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Consistency of information</strong></td>
<td>37 (45)</td>
<td>18 (22)</td>
<td>17 (21)</td>
<td>9 (11)</td>
<td>1 (1)</td>
<td>74.70</td>
<td>27.64</td>
<td>75.00</td>
<td>50, 100</td>
</tr>
<tr>
<td><strong>Included in decision making process</strong></td>
<td>49 (60)</td>
<td>15 (18)</td>
<td>8 (10)</td>
<td>5 (6)</td>
<td>5 (6)</td>
<td>79.88</td>
<td>30.29</td>
<td>100.00</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Supported during the decision making process</strong></td>
<td>30 (37)</td>
<td>36 (44)</td>
<td>10 (12)</td>
<td>4 (5)</td>
<td>2 (2)</td>
<td>76.83</td>
<td>23.82</td>
<td>75.00</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Control over their child’s care</strong></td>
<td>32 (39)</td>
<td>31 (38)</td>
<td>7 (9)</td>
<td>10 (12)</td>
<td>2 (2)</td>
<td>74.70</td>
<td>27.36</td>
<td>75.00</td>
<td>75, 100</td>
</tr>
<tr>
<td><strong>Adequate time to have concerns addressed &amp; questions answered</strong></td>
<td>67 (82)</td>
<td>_a</td>
<td>_a</td>
<td>_a</td>
<td>15 (18)</td>
<td>81.71</td>
<td>38.90</td>
<td>100.00</td>
<td>100,100</td>
</tr>
<tr>
<td><strong>Total subscale score</strong></td>
<td>46</td>
<td>31</td>
<td>15</td>
<td>6</td>
<td>2</td>
<td>78.64</td>
<td>18.14</td>
<td>82.50</td>
<td>65, 92.5</td>
</tr>
</tbody>
</table>

*Note.* Calculation of scores: excellent = 100; very good = 75; good = 50; fair = 25; poor = 0; yes = 100; no = 0.  

*a only yes =100 or no = 0 responses for this question.*
## Appendix S

### Parents’ Responses to Items on the DCS (N = 80)

<table>
<thead>
<tr>
<th>Decisional Conflict Scale items</th>
<th>Item mean scores</th>
<th>Standard deviation</th>
<th>Item median score</th>
<th>Inter-quartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Uncertainty</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am clear about the best choices for my child.</td>
<td>19.62</td>
<td>20.28</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I feel sure about what to choose.</td>
<td>21.20</td>
<td>20.84</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>The decisions are easy for me to make.</td>
<td>25.96</td>
<td>23.99</td>
<td>25.00</td>
<td>0, 50</td>
</tr>
<tr>
<td><strong>Factors contributing to uncertainty</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what options are available to me.</td>
<td>21.25</td>
<td>19.93</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I know the benefits of each option.</td>
<td>21.88</td>
<td>18.39</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I know the risks and side effects of each option.</td>
<td>26.56</td>
<td>21.55</td>
<td>25.00</td>
<td>0, 50</td>
</tr>
<tr>
<td>I am clear about which benefits matter most to me.</td>
<td>18.44</td>
<td>18.55</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I am clear about which risks and side effects matter most.</td>
<td>24.06</td>
<td>22.31</td>
<td>25.00</td>
<td>0, 37.5</td>
</tr>
<tr>
<td>I am clear about which is more important to me.</td>
<td>22.19</td>
<td>22.15</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I have enough support from others to make a choice.</td>
<td>21.15</td>
<td>20.18</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I am choosing without pressure from others.</td>
<td>19.23</td>
<td>18.43</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I have enough advice to make a choice.</td>
<td>21.20</td>
<td>20.45</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td><strong>Effective decision making</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I have made informed choices.</td>
<td>18.67</td>
<td>20.98</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>My decisions show what is important for my child.</td>
<td>16.25</td>
<td>18.27</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I expect to stick to my decision.</td>
<td>20.00</td>
<td>20.82</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td>I am satisfied with my decisions.</td>
<td>18.75</td>
<td>20.48</td>
<td>25.00</td>
<td>0, 25</td>
</tr>
<tr>
<td><strong>Total scale score</strong></td>
<td>21.64</td>
<td>21.88</td>
<td>17.02</td>
<td>9.38, 30.47</td>
</tr>
</tbody>
</table>

*Note.* Maximum score = 100.